Edwin B. Fisher *Editor*
Linda D. Cameron · Alan J. Christensen
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Associate Editors

Principles and Concepts of Behavioral Medicine

A Global Handbook

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Editor's Dedication

This work is dedicated to Rebecka Rutledge Fisher, whose encouragement was essential throughout its development.

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Contents

Part 1 The Ecological Range of Relationships Between Behavior and Health

Part II Knowing in Behavioral Medicine: Epistemic Foundations

Part III Key Influences on Behavior and the Relationships Among Behavior, Health and Illness

Part IV Approaches to Changing Behavior Related to Health

Part V Key Areas of Application in Prevention and Disease Management

Part VI Interventions to Enhance Quality of Life

Part VII The Contexts of Behavioral Medicine Science and Practice

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Part 1

The Ecological Range of Relationships Between Behavior and Health

Introduction

1

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As defined by the International Society of Behavioral Medicine (http://www.isbm.info/about-isbm/charter/), behavioral medicine is:

> … the interdisciplinary field concerned with the development and integration of psychosocial, behavioral and biomedical knowledge relevant to health and illness and the application of this knowledge to prevention, etiology, diagnosis, treatment and rehabilitation. The scope of "behavioral medicine" extends from research efforts to understand fundamental biobehavioral mechanisms; to clinical diagnosis and intervention; to disease prevention and health promotion.

This volume embraces the breadth of that definition and emphasizes a very wide range of subjects including fundamental aspects of learning, emotion, cognition, genetics and epigenetics, and brain-behavior relationships as well as our still emerging understanding of how natural and built environments, sociocultural factors, and public policies influence behavior and behavior change. The interventions behavioral medicine includes are correspondingly broad, from individual interventions to improved stress management to policy approaches to designing communities that promote physical activity and implementing national health plans that encourage healthy behaviors. In short, behavioral medicine encompasses the entirety of the range of relationships between behavior and health. It is this breadth of both conceptual perspectives and application that this volume seeks to convey.

The contributions of behavior to health and health care have often been limited by failure to

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identify and assert the roles of behavior and to articulate fully a view of *health as behavior*, how we live our lives. This is in sharp contrast to construing health status as some aggregate of clinical risks and clinical problems. For example, we may think about health as years of quality of life and the behaviors that comprise a life of quality, rather than as years of survival. Similarly, from a behavioral perspective, we can approach health not as managing this, that, or another clinical problem, but rather as promoting and guiding the core behaviors that comprise health across most all diseases and their risks:

- Eating a healthy diet, engaging in regular physical activity, sufficient and restful sleep
- Avoiding dangerous behaviors like smoking and excessive alcohol use
- Cultivating healthy relationships to give and receive social support
- Avoiding/minimizing perceived stress and subjective burden
- Getting screening appropriate to age, sex, family history, and genotype
- Taking appropriate medications

In emphasizing the range of influences on behaviors related to health, this book takes what has come to be termed a *socio-ecological perspective.* This is explained in more detail later in this chapter, but central to this perspective is attention to influences at multiple levels – biological, psychological, family, social, community, cultural, organizational, system, policy – and the relations among these levels, e.g., influences of community and cultural forces on family and individual behavior.

Scope of Behavior and Health

Behavior is central to the development, prevention, treatment, and management of a number of primary diseases and health conditions, including heart disease, cancer, stroke, pulmonary diseases, unintentional injuries, communicable diseases, diabetes, suicide, kidney diseases, liver diseases, and HIV/AIDS. According to the World Health Organization (World Health Organization, 2015a):

- Tobacco accounts for around six million deaths every year (including from the effects of exposure to second-hand smoke) and is projected to increase to eight million by 2030.
- About 3.2 million deaths annually can be attributed to insufficient physical activity.
- More than half of the 3.3 million annual deaths from harmful drinking are from non-communicable or chronic diseases.
- In 2010, 1.7 million annual deaths from cardiovascular causes have been attributed to excess salt/sodium intake.

The United States Centers for Disease Control and Prevention has estimated that 14 of the top 15 causes of death in the United States are attributable to modifiable behaviors, including physical inactivity, poor diet, smoking, alcohol and other drug use, poor injury control, inadequate sun protective behaviors, inappropriate use of medicines, insufficient immunization, unsafe sexual and reproductive practices, poor oral hygiene, and mental health problems (Heron, Hoyert, et al., 2009). Other countries report similar impacts. In Switzerland, for example, costs of stress management are estimated at 4.2 billion Swiss francs per year (Grebner, Berlowitz, et al., 2010).

The breadth of connections between behavior and health is formidable. In addition to the commonly recognized role of behaviors such as smoking, diet, and physical activity, other behaviors are also fundamental to the development of a number of diseases. For example, stress and stress management play important roles in the development and management of cardiovascular and other diseases, and unsafe sex practices increase the likelihood of contracting infectious diseases such as HIV/AIDs. Chronic conditions like diabetes require self-management of interlinked behaviors through careful monitoring of diet, physical activity, stress management, and complex disease-specific tasks such as blood glucose monitoring linked with adjustment of medication, diet, and activity. Behavioral and psychological interventions have been shown to enhance not only quality of life, but also survival through improved psychological adjustment as well as changes in risk behavior (Andersen, Yang, et al., 2008). Cutting across a number of these effects of behavior on health are interactions between behavioral and biological factors such as in cigarette smoking (True, Xian, et al., 1999) and behavioral and environmental influences on expression of genetic propensities for diabetes (Pratley, 1998) or excessive alcohol use (Ducci, Enoch, et al., 2008).

Behavior Matters[1] The broad roles of behavior in health and disease (Nater, Gaab, et al., 2006) were documented in a 2011 review (Fisher, Fitzgibbon, et al., 2011) that examined three major diseases (cardiovascular disease, cancer, and HIV/AIDS) and four major risk factors (tobacco use, poor diet, physical inactivity, and excessive alcohol consumption). Together, these account for great health impacts around the world. For example, the four risk factors account for an estimated 36.8% of all deaths in the USA (Mokdad, Marks, et al., 2004, 2005).

For each of these three major diseases and four major risk factors, the 2011 review examined six types of behavioral influence. The first was how behavioral, environmental, and genetic influences moderate one another. Five additional types of influence focused on the roles of behavior in the development of health problems, prevention, disease management, quality of life, and population approaches to health promotion.

Table 1.1 has been adapted from the 2011 review. It provides examples from published research of each of the six types of behavioral influence for each of the three major diseases as well as the four risk factors. As an example of the many ways in which behavior matters, alcohol use has impacts on health ranging from birth defects to accidents and injuries to alcohol-related liver disease and pancreatitis (Healthy People 2010, 2000). Genetic predispositions may incline the individual to excessive use but these are also moderated by psychosocial factors such as childhood maltreatment (Ducci, Enoch, et al., 2008). Although often difficult to treat, brief interventions can reduce drinking (U.S. Preventive Services Task Force (USPSTF), 2004; Whitlock, Polen, et al., 2004) and problems associated with alcohol (O'Connor & Whaley, 2007), while more intensive psychological treatments can improve quality of life among those recovering from excessive use (Arnedt, Conroy, et al., 2007). Along with tobacco use and physical activity, alcohol use stands as an area in which environmental modifications, such as reducing density of retail outlets, can be effective (The Guide to Community Preventive Services).

Another set of examples of how behavior matters surround cardiovascular disease, with which the roles of behavior range from the effects of stress on expression of the serotonin transporter gene (Williams, 2007) through the roles of diet, physical activity, smoking, and stress in the development (Eckel & Krauss for the AHA Nutrition Committee, 1998), prevention (Goldberg, Temprosa, et al., 2009), and management of disease (Fonarow, Gawlinski, et al., 2001; Ornish, Scherwitz, et al., 1998). Comprehensive, multi-sector community and population approaches to cardiovascular risk reduction have also documented reduced risk (Vartiainen, Puska, et al., 1994) and mortality (Puska, Vartiainen, et al., 1998).

Table 1.1 provides many additional examples across cancer, HIV/AIDS, tobacco use, poor diet, and physical inactivity. Chapters 2 and 3, *infra* on "Types of Diseases and their Causes" and "Risky Behaviors," provide far greater details of the roles of behavior in major diseases and health challenges around the world.

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[1] This section is drawn from a paper co-authored by Fisher and his colleagues, Marian Fitzgibbon, Russell Glasgow, Debra Haire-Joshu, Laura Hayman, Robert Kaplan, Marilyn Nanney, and Judith Ockene. We are indebted to them for providing permission to draw at length from their paper, the full citation of which is, Fisher, E. B., Fitzgibbon, M. L., Glasgow, R. E., Haire-Joshu, D., Hayman, L. L., Kaplan, R. M., Nanney, M.S., & Ockene, J. K. (2011). Behavior matters. *American Journal of Preventive Medicine, 40*(5), e15–30.

Table 1.1 Behavior – health linkages among major "actual causes" of death and major diseases

Linkage 1 – behavioral, environmental, and genetic influences moderate one another
Tobacco use: Both environmental and genetic factors influence onset and persistence of smoking (Agrawal, Madden, et al., 2005; Heath, Kirk, et al., 1999; Madden, Heath, et al., 1999; Maes, Neale, et al., 2006)
Poor diet: Studies of food preferences indicate genetic influences are smaller than environmental influences (Perusse, Tremblay, et al., 1988; Reed, Bachmanov, et al., 1997)
Physical activity: In twin studies, greater physical activity levels are associated with lower rates of obesity in genetically high-risk individuals (Samaras, Kelly, et al., 1999)
Alcohol use: Childhood maltreatment exacerbates genetic influences on adult alcohol use and anti-social personality among women and men (Ducci, Enoch, et al., 2008)
Cardiovascular disease and diabetes Influence of serotonin transporter gene on cardiovascular risk is moderated by stress and environmental factors (Williams, 2007)
Cancer: Nutrition and lifestyle intervention reduces prostate gene expression and tumorigenesis in men (Ornish, Magbanua, et al., 2008)
HIV/AIDS: In monkey models of HIV, individual characteristics (sociability), stable versus unstable social conditions, and genotype for the serotonin transporter gene interact in their effects on disease progression (Capitanio, Abel, et al., 2008)
Linkage 2 – behavior influences health
Tobacco use: Numerous Surgeon General's reports have concluded that smoking is a leading cause of cancer, cardiovascular, and pulmonary disease and premature death (Centers for Disease Control and Prevention, 2004)
Poor diet: Systematic reviews conclude that obesity contributes to hypertension, hyperlipidemia, diabetes, CVD, and some cancers (Calle & Thun, 2004; Goldberg & King, 2007; Must, Spadano, et al., 1999; National Heart Lung and Blood Institute and National Institute of Diabetes and Digestive and Kidney Disease, 1998; Schulze & Hu, 2005; Sharma, 2007; United States Department of Health and Human Services, 2001)
Physical activity: Randomized trials and systematic reviews conclude that physical activity is associated with decreased all-cause mortality, (Blair, Kohl, et al., 1989) reduced risk for chronic diseases, reduced risk of breast cancer (Berlin & Colditz, 1990; Haskell, Lee, et al., 2007; Powell, Thompson, et al., 1987)
Alcohol use: "Alcohol abuse alone is associated with motor vehicle crashes, homicides, suicides, and drowning…. Long-term heavy drinking can lead to heart disease, cancer, alcohol-related liver disease, and pancreatitis. Alcohol use during pregnancy is known to cause fetal alcohol syndrome, a leading cause of preventable mental retardation" (Healthy People 2010, 2000)
Cardiovascular disease and diabetes Diet and obesity are risk factors for diabetes and cardiovascular disease (Eckel, Krauss, & for the AHA Nutrition Committee, 1998)
Cancer: Findings from systematic reviews, meta-analyses, large prospective studies, and randomized trials link risk for cancer with poor diet, physical inactivity, smoking, stress, and social involvement (Office of Behavioral and Social Sciences Research, 2007; Greenwald, Clifford, & Milner, 2001; Kuller, 1997; Matthews, Shu, et al., 2001; Rockhill, Willett, et al., 1999; Thune, Brenn, et al., 1997)
HIV/AIDS: There is "substantial and consistent evidence that chronic depression, stressful events, and trauma may negatively affect HIV disease progression" (Reiche, Nunes, & Morimoto, 2004; Leserman, 2008)

(continued)

Table 1.1 (continued)

Linkage 3 – behavior change interventions prevent disease
Tobacco use: A major multi-site trial demonstrated that smoking cessation programs substantially reduce mortality even when only a minority of patients stop smoking (Anthonisen, Skeans, et al., 2005)
Poor diet: Systematic reviews and randomized trials of interventions for childhood obesity show positive impacts on diet, weight gain trajectory, and weight loss maintenance, (Campbell & Hesketh, 2007; Connelly, Duaso, & Butler, 2007; DeMattia, Lemont, & Meurer, 2007; Epstein, Valoski, et al., 1994; Fitzgibbon, Stolley, et al., 2005; Summerbell, Waters, et al., 2005) and on insulin resistance (Savoye, Shaw, et al., 2007)
Physical activity: Among overweight, previously inactive women at risk for type 2 diabetes, accumulating 10,000 steps/day for 8 weeks improved glucose tolerance and reduced both systolic and diastolic blood pressure (Swartz, Strath, et al., 2003)
Alcohol use: A 15-min counseling for pregnant women increased abstinence from drinking 5X relative to controls and resulted in higher birth weights, birth lengths, and 3X reduction in fetal mortality (0.9% vs 2.9%.) (O'Connor & Whaley, 2007)
Cardiovascular disease and diabetes Lifestyle interventions focusing on diet, weight loss, and exercise can reduce the incidence of diabetes in persons at risk for the disease (Diabetes Prevention Program Research Group, 2002; Tuomilehto, Lindstrom, et al., 2001; Lindstrom, Ilanne-Parikka, et al., 2006)
Cancer: In a number of large prospective longitudinal studies and meta-analyses, physical activity has been linked to reduced risk of colon cancer (Albanes, Blair, & Taylor, 1989; Ballard-Barbash, Schatzkin, et al., 1990; Lee, Paffenbarger, & Hsieh, 1991; Martinez, Giovannucci, et al., 1997; Meyerhardt, Heseltine, et al., 2006; Samad, Taylor, et al., 2005; Thun, Calle, et al., 1992)
HIV/AIDS: The US Preventive Services Task Force recommends high-intensity behavioral counseling to prevent sexually transmitted infections for all sexually active adolescents and for adults at heightened risk (U.S. Preventive Services Task Force (USPSTF), 2008)
Linkage 4 – behavior change interventions improve disease management
Tobacco use: Self-management skills (e.g., setting quit date, planning for coping with temptations to relapse) help individuals quit smoking (Fiore, Bailey, et al., 2000)
Poor diet: Randomized behavioral interventions show that peer nutrition education positively influences diabetes self-management in Latinos (Perez-Escamilla, Hromi-Fiedler, et al., 2008)
Physical activity: Randomized clinical trials show that exercise training reduces HbA1c among those with diabetes (Boule, Haddad, et al., 2001)
Alcohol use: Brief behavioral counseling interventions with follow-up produce small to moderate reductions in alcohol consumption that are sustained over 6- to 12-month periods or longer.(US Preventive Services Task Force (USPSTF), 2004; Whitlock, Polen, et al., 2004)
Cardiovascular disease and diabetes Diabetes self-management programs improve disease management (Norris, Engelgau, & Narayan, 2001) and metabolic control (Anderson, Funnell, et al., 1991, 1995; Aubert, Herman, et al., 1998; Clement, 1995; Greenfield, Kaplan, et al., 1988; Muhlhauser & Berger, 1993; Norris, Lau, et al., 2002; Pieber, Brunner, et al., 1995; Rubin, Peyrot, & Saudek, 1989, 1993) including among older adults and ethnic minorities, (Anderson, Herman, et al., 1991; Glasgow, Toobert, & Hampson, 1991; Glasgow, Toobert, et al., 1992) and reduce complications (The Diabetes Control and Complications Trial Research Group, 1993, 1995) as well as myocardial infarction, stroke, or death from cardiovascular disease (The Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications (DCCT/EDIC) Study Research Group, 2005)

(continued)

Table 1.1 (continued)

Interventions promoting comprehensive lifestyle changes for patients with coronary artery disease can reduce progression of coronary atherosclerosis and cardiac events (Ornish, Scherwitz, et al., 1998) and increase smoking cessation, improve functional capacity, lower LDL cholesterol, and reduce all-cause mortality (Fonarow, Gawlinski, et al., 2001)
Cancer: Randomized trials of patients with cancer indicate that physical activity increases functional capacity during chemotherapy, (MacVicar, Winningham, & Nickel, 1989) improves marrow recovery and decreases complications during peripheral blood stem transplantation, (Dimeo, Fetscher, et al., 1997) and decreases fatigue and other symptoms associated with radiation therapy and chemotherapy (Mock, Dow, et al., 1997)
HIV/AIDS: Behavioral medicine interventions have improved adherence and helped individuals cope with the disease and its impacts, in turn improving their general disease management and quality of life (Office of Behavioral and Social Sciences Research, 2007)
Linkage 5 – psychosocial and behavioral interventions improve quality of life (QOL)
Tobacco use: Improved health-related QOL is a significant health outcome for ex-smokers compared to current smokers (Crothers, Griffith, et al., 2005; Garces, Yang, et al., 2004; Ostbye & Taylor, 2004; Wilson, Parsons, & Wakefield, 1999)
Poor diet: In randomized trials, lifestyle interventions show improved nutritional status and quality of life and less depressive symptoms and improved physical functioning (Drewnowski & Evans, 2001; Scheier, Helgeson, et al., 2005; Fontaine & Barofsky, 2001)
Physical activity: Randomized trials show physical activity improves quality of life in older adults (Drewnowski & Evans, 2001; Rejeski, Brawley, & Shumaker, 1996) and improves quality of life and fatigue in breast cancer survivors (Courneya, 2003)
Alcohol use: Cognitive-behavioral treatment of insomnia among those recovering from excessive alcohol use improved measures of sleep as well as depression, anxiety, and quality of life (Arnedt, Conroy, et al., 2007)
Cardiovascular disease and diabetes Comprehensive behavioral disease management interventions among patients with cardiovascular disease or diabetes show benefits for a variety of clinical indicators as well as reduced general distress and depressive symptoms, (Blumenthal, Sherwood, et al., 2005) emotional and social functioning, (Castaldo & Reed, 2008) reduced anxiety and depressed mood, (Vale, Jelinek, et al., 2003) general quality of life (Ades, Pashkow, et al., 2000; Cochran & Conn, 2008; Lalonde, Gray-Donald, et al., 2002; Yu, Sheung-Wai Li, et al., 2003)
Cancer: Randomized psychosocial interventions show decreased psychological distress, pain and nausea secondary to treatment, and improve quality of life and immune system modulation (Antoni, Lehman, et al., 2001; Lepore, Helgeson, et al., 2003; Lieberman, Golant, et al., 2003; Penedo, Dahn, et al., 2004)
HIV/AIDS: Stress-management interventions enhance emotional status and quality of life (Antoni, Caricco, et al., 2006; Scott-Sheldon, Kalichman, et al., 2008)
Linkage 6 – health promotion programs improve health of populations
Tobacco use: Antismoking campaign in California that includes counter-media, youth prevention programs, cessation services, and tax increases reduced smoking and accompanying rates of cardiovascular disease (Fichtenberg & Glantz, 2000) and death rates from lung cancer (Jemal, Thun, et al., 2008)
Poor diet: Mass-media health education campaigns (Stern, Farquhar, et al., 1976) and policy and environmental supports (McAlister, Puska, et al., 1982; Puska, Nissinen, et al., 1985) can lead to significant improvements in fruit, vegetable, and fat consumption in general populations.
Physical activity: Community-wide walk to school programs increase walking and biking to school (Staunton, Hubsmith, & Kallins, 2003), and walking and fitness trails increased physical activity in a rural African-American population (Brownson, Housemann, et al., 2000)

(continued)

Table 1.1 (continued)

Alcohol use:
Guide to Community Preventive Services reports that regulating density of outlets for alcohol reduces consumption and that enforcing laws prohibiting the sale of alcohol to minors reduces underage consumption (The Guide to Community Preventive Services)
Cardiovascular disease and diabetes
Working with mass media, food producers, community-level campaigns, diverse professionals, informal opinion leaders, and the health system, a regional program in North Karelia, Finland, reduced cardiovascular risk factors (Vartiainen, Puska, et al., 1994) and mortality (Puska, Vartiainen, et al., 1998) as well as cancer risk factors (Luostarinen, Hakulinen, & Pukkala, 1995)
Cancer:
In 2006, overall cancer death rates declined because of 50% reduction in male smoking from 47% in the 1960s to less than 23% (Thun & Jemal, 2006)
HIV/AIDS:
Behavioral medicine programs have made major contributions to slowing the spread of HIV/AIDS; from 150,000 cases per year in the early 1980s to approximately 40,000 today (Centers for Disease Control and Prevention, 2005)

Global Trends in Health and Behavior[2]

Life expectancy has increased markedly over the past 50 years, with an ever increasing proportion of the world's population expected to live until late adulthood. Between 1950 and 1990, life expectancy at birth increased from 40 years to 63 years in developing countries (World Bank, 1993). More recently still, average life expectancy increased to 68 years globally in 2007, with a disproportionately large portion of that increase occurring in countries in Asia, including China (WHO, 2009).

Despite the global increases in average life expectancy, recent decades have witnessed a marked increase in non-communicable diseases (NCDs). The global prevalence of non-communicable diseases is expected to rise from 43% in 1998 to 66% in 2030 (WHO, 2008). Key growth will include cardiovascular and respiratory diseases with their behavioral risk factors of unhealthy diet and alcohol consumption, physical inactivity, and tobacco use (WHO, 2005). Among risk factors, tobacco use itself is projected to cause more premature death and disability than any other single disease, with mortality attributed to tobacco use projected to increase from 5.4 million deaths in 2004 to 8.3 million deaths in 2030 (WHO, 2008). A major contributor to this is the increased uptake of tobacco use in very populous countries such as China.

Amidst significant improvements in health, both social and economic disparities remain a major cause of poor health and disease. Attention to disparities and to the social determinants of health has grown dramatically, spurred in large measure by the leadership of the United Nations. It has placed health in the context of human equity and human rights dating back to the UN Universal Declaration of Human Rights (1948) and the Alma Ata Declaration, which advocated achievement of 'Health for All' (1978). A major initiative included the Commission on Social Determinants of Health, chaired by Sir Michael Marmot. The Commission reviewed the evidence surrounding global health inequalities and the "causes of the causes," culminating in the final report, *Closing the Gap in a Generation* (Commission on the Social Determinants of Health, 2008). The three main recommendations in the report proposed to reduce ill health and disadvantage are (1) improving daily living conditions; (2) redressing the inequitable distribution of power, money, and resources; and (3) improving measurement and

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[2] This section is adapted and updated from Oldenburg B, De Courten M, Frean E. The contribution of health psychology to the advancement of global health. In Suls, J., Davidson, K. W., Kaplan, R. K. (eds) Handbook of Health Psychology Guilford Press, 2010.

understanding of the problem and assessing the impact of action. The pertinence of behavior to the first two is clear and great. These issues of social determinants of health, non-health policy and health, and equity/inequity are discussed at length in numerous chapters, especially those by Sherlaw et al. and by Siddiqi et al., *infra*.

Characterizing Overall Burden of Disease The Global Burden of Disease (GBD) framework, developed in 1992 with the support of the World Bank and World Health Organization, summarizes the wide-ranging and sometimes seemingly contradictory information available on morbidity, mortality, and other health outcomes. Prior to the GBD framework, evidence for policy-making was limited primarily to disease-specific mortality statistics. The initial and subsequent GBD studies provide a more comprehensive measure that aggregates and standardizes measures of mortality, disability, impairment, and illness that arise from disease, injury, and risk factors. GBD studies combine the years of life lost due to premature mortality and healthy years of life lost due to disability in a "Disability-Adjusted-Life-Year" (DALY) (Lopez, Mathers, et al., 2006). One DALY, therefore, is equal to 1 year of full health lost, whether by death or by disability. This allows direct comparison of impacts of diseases that cause early death with impacts of those that cause prolonged suffering or disability.

An analysis of global DALYs and life expectancy between 1990 and 2013 (DALYs Collaborators, Murray, et al., 2015) noted interesting differences in changes in life expectancy and DALYs. Worldwide life expectancy at birth rose by 6.2 years from 1990 to 2013, from an average of 65.3 years to 71.5 years. A more complex picture emerges in considering DALYs, and, a key component of DALYs, years of life lived with disability, YLDs. With increased numbers living longer, the worldwide total YLDs have increased and the total DALYs have increased for non-communicable diseases. The authors conclude that an epidemiological transition is occurring in which global health is improving but population growth, aging, and increased non-communicable diseases have increased the numbers of DALYs and YLDs.

Global Goals and Health In 2000, the United Nations set a group of eight Millennium Development Goals (MDGs) for achievement by 2015. Four were directly related to health: reduce child mortality, improve maternal health, combat HIV/AIDS, malaria and tuberculosis, and increase access to safe drinking water and sanitation (UN, 2008). In May of 2015, the WHO reported on progress toward the health-related goals in each of the 194 countries for which data were available (World Health Organization, 2015b). Drawn from the WHO's description, this section summarizes the "mixed" results to date:

- **Child deaths halved** – Since 1990, child deaths have been reduced almost by half – falling from an estimated 90 deaths per 1000 live births to 46 deaths per 1000 live births in 2013. This progress, however, has not achieved the goal of reducing the death rate by two-thirds. Less than one-third of all countries achieved or were on track to meet this target by the end of 2015. The top killers of children aged less than 5 years are now: preterm birth complications, pneumonia, birth asphyxia, and diarrhoea.
- **Saving more mothers** – The number of women who died due to complications during pregnancy and childbirth has almost halved between 1990 and 2013. This however is also insufficient to reach the goal of 75% reduction by the end of 2015. The maternal mortality ratio has fallen in every region. However, 13 countries with some of the world's highest rates have made little progress in reducing these largely preventable deaths. In the WHO African Region, 1 in 4 women wanting to prevent or delay childbearing does not have access to contraceptives, and only 1 in 2 women gives birth with the support of a skilled birth attendant. Less than two-thirds (64%) of women worldwide receive the recommended minimum of 4 antenatal care visits during pregnancy.
- **Reversing the spread of HIV** – In 2013, 2.1 million people were diagnosed with new infections, down 38% from 3.4 million in 2001. At the same time, expansion of WHO recommendations regarding who is eligible for treatment have increased the numbers who

will need to be reached in order to achieve the goal of universal access to treatment for HIV. The world was projected to have exceeded the target of placing 15 million people in low- and middle-income countries on antiretroviral therapy (ARTs) by the end of 2015. By the end of 2013, almost 13 million people received ARTs globally. Of these, 11.7 million lived in low- and middle-income countries, representing 37% of people living with HIV in those countries.

- **Increasing access to safe drinking water and sanitation** – Although the global target for increasing access to safe drinking water was met in 2010, the WHO African and Eastern Mediterranean Regions fall far short, particularly for people living in rural areas or with income poverty. Almost one billion people still have minimal access to basic sanitation and are forced to defecate in open spaces such as fields and near water sources. Lack of sanitation facilities puts these people at high risk of diarrheal diseases (including cholera), trachoma and hepatitis.

Other key indicators of health noted in the appraisal of progress toward Millennium Development Goals make clear the broad role of behavior in health worldwide:

- Life expectancy at birth has increased 6 years for both men and women since 1990.
- Two-thirds of deaths worldwide are due to non-communicable diseases.
- In some countries, more than one-third of births are delivered by cesarean section.
- In low- and middle-income countries, only two-thirds of pregnant women with HIV receive antiretroviral therapy to prevent transmission to their baby.
- Over one-third of adult men smoke tobacco.
- Only 1 in 3 African children with suspected pneumonia receives antibiotics.
- 15% of women worldwide are obese.
- The median age of people living in low-income countries is 20 years, while it is 40 years in high-income countries.
- One quarter of men have elevated blood pressure.

Following the 2015 appraisal of progress toward the *Millennium Development Goals*, members of the United Nations adopted the *Sustainable Development Goals: 17 Goals to Transform our World*. Their broad objectives, to be achieved over the next 15 years, are “to end poverty, protect the planet, and ensure prosperity for all as part of a new sustainable development agenda” (United Nations, 2015). The 17 goals range widely including, for example, “climate action” and “responsible production and consumption.” Under the overarching health goal to “Ensure healthy lives and promote well-being for all at all ages,” specific targets are:

- By 2030, reduce the global maternal mortality ratio to less than 70 per 100,000 live births
- By 2030, end preventable deaths of newborns and children under 5 years of age, with all countries aiming to reduce neonatal mortality to at least as low as 12 per 1000 live births and under-5 mortality to at least as low as 25 per 1000 live births
- By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases
- By 2030, reduce by one third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well-being
- Strengthen the prevention and treatment of substance abuse, including narcotic drug abuse and harmful use of alcohol
- By 2020, halve the number of global deaths and injuries from road traffic accidents
- By 2030, ensure universal access to sexual and reproductive health-care services, including for family planning, information and education, and the integration of reproductive health into national strategies and programs
- Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all
- By 2030, substantially reduce the number of deaths and illnesses from hazardous chemicals and air, water and soil pollution and contamination

- Strengthen the implementation of the World Health Organization Framework Convention on Tobacco Control in all countries, as appropriate
- Support the research and development of vaccines and medicines for the communicable and noncommunicable diseases that primarily affect developing countries, provide access to affordable essential medicines and vaccines, in accordance with the Doha Declaration on the TRIPS Agreement and Public Health, which affirms the right of developing countries to use to the full the provisions in the Agreement on Trade Related Aspects of Intellectual Property Rights regarding flexibilities to protect public health, and, in particular, provide access to medicines for all
- Substantially increase health financing and the recruitment, development, training and retention of the health workforce in developing countries, especially in least developed countries and small island developing States
- Strengthen the capacity of all countries, in particular developing countries, for early warning, risk reduction and management of national and global health risks

As with the previous Millennium Development Goals, these Sustainable Development Goals make clear the critically important contribution of behavior to health around the globe.

Historical and Conceptual Roots of Behavioral Medicine

Behaviorism

An important foundation for the development of behavioral medicine has been the intellectual tradition and empirical approaches of behaviorism in western psychology of the twentieth century. Neil Miller, a major figure in twentieth-century behaviorism and in the application of behaviorism to complex behavior and psychotherapy (Dollard & Miller, 1950), contributed greatly in the development of behavioral medicine. Many important areas of behavioral medicine have their roots in behavior therapy and its application to mental health and psychotherapy of behaviorism and the "laws of learning" (Wolpe, 1969). For example, biofeedback (Cox, Sutphen, et al., 1998), stress-management interventions featuring relaxation and active coping with stressors (Bishop, Kaur, et al., 2005; Levenkron, Cohen, et al., 1983; Nater, Gaab, et al., 2006; Penedo, Dahn, et al., 2004; Surwit, van Tilburg, et al., 2002), group and individual interventions for weight management or smoking cessation (Lichtenstein, Harris, et al., 1973; Stuart, 1967), all are based in behavior therapy and were integral to the early development of self-control and self-management interventions in the 1960s (Bandura, 1969; Goldfried & Merbaum, 1973; Kanfer, 1970).

The connections between behavioral medicine and behaviorism were also social and organizational. The first meeting of the US Society of Behavioral Medicine (SBM) in 1979 was held in conjunction with a meeting of the Association for the Advancement of Behavior Therapy (AABT, now called the Association for Behavioral and Cognitive Therapies). W. Stewart Agras, the founding president of SBM (1979–80) was also president of AABT (1985), and a number of major contributors to behavioral medicine and obesity research have been presidents of AABT (Richard Stuart, 1974–75, G. Terrence Wilson, 1980–81, and Kelly Brownell, president of both AABT and SBM in 1988–89) as was Gerald C. Davison (1973–74), the senior author of this volume's chapter on Values in Behavioral Medicine.

Behaviorism has evolved considerably over recent decades to encompass and explain complex patterns of behavior, including "self control," addictions, and even community approaches to substance use disorders. This evolution has included articulation of the linkages among complex behaviors, including through the growing field of behavioral economics. It has also expanded in scope to include a broad range of social, organizational, and economic determinants of behavior, sharing much with socio-ecological models in community and public health. Approaches to alcohol abuse, for example, may emphasize economic substitutability of alcohol and positive addictions and promote alternatives to drinking rather than focusing on reducing alcohol consumption itself (Vuchinich & Tucker, 1996).

Behaviorism, behavioral economics, and their evolution as a foundation of behavioral medicine are more fully explored in the present chapter by Rachlin and colleagues, *infra*.

Cognitive Psychology and Decision Making

As behaviorism has grown to address complex patterns of behavior, so too the "cognitive revolution" led much of psychology toward explorations of attention, perception, problem-solving, and memory processes shaping behavior (Mandler, 2002). With this, many behavioral medicine researchers increasingly turned their attention to cognitive and decision-making processes directing health behavior. Applications of cognitive psychology to behavioral medicine have included research on illness schemata and their roles in shaping health information processing, health behaviors, adjustment to illnesses, health outcomes, and even survival (Cameron, Durazo, & Rus, 2015; Crawshaw, Rimington, et al., 2015). Public health emphases on disease prevention fueled research on risk perception and its influence on decisions to engage in protective behaviors such as vaccinations (Weinstein, Kwitel, et al., 2007) and risky behaviors such as cigarette smoking (Slovic, 2001). Economic models of rational decision making gave rise to models of health decision making such as the Health Belief Model (Janz & Becker, 1984), with decisions being viewed as calculations made by weighing the health risks with the benefits versus costs of the health behavior. Advances in social cognition and affective science fostered the development of increasingly sophisticated theories of health cognition that incorporated social influences (e.g., norms and social learning), emotions (e.g., fear), and dual-coding (deliberative and automatic thought) processes (Ajzen, 1985; Bandura, 1977; Leventhal, 1970). Self-regulation theories of health behavior evolved to incorporate these processes into models of the dynamic processes through which individuals set health goals, engage in actions to attain them, and evaluate their progress in goal attainment (Carver & Scheier, 1998; Leventhal, Bodnar-Deren, et al., 2012).

Cognitive theory and research inform an array of behavioral medicine interventions. For example, health communications commonly reflect the application of social learning theory with model characters displaying healthy behaviors. Cognitive behavior therapy is used to treat numerous health conditions, including depression and anxiety disorders (Hollon, Stewart, & Strunk, 2006), as well as substance abuse (McHugh, Hearon, & Otto, 2010) and binge eating (Painot, Jotterand, et al., 2001). Mindfulness interventions have proliferated, with mounting evidence of their benefits for individuals with chronic pain, cancer, epilepsy, and numerous other conditions (Carlson, 2012). Decision aids designed to assist individuals facing complex medical decisions (e.g., choices of cancer treatment) are increasingly commonplace, and they have been shown to improve knowledge, increase participation in "shared decision making," and reduce decisional conflict (Stacey, Légaré, et al., 2014). Research revealing the automaticity of many health behaviors is guiding the development of "nudge" and other strategies to encourage healthy choices through priming, such as by using small plates to reduce food consumption or narrow glasses to reduce alcohol intake (Marteau, Hollands, & Fletcher, 2012).

Psychosomatic Medicine

Psychosomatic medicine and behavioral medicine have much in common. According to the journal *Psychosomatic Medicine*, the field includes "experimental and clinical studies dealing with various aspects of the relationships among social, psychological, and behavioral factors and bodily processes in humans and animals" (http://journals.lww.com/psychosomaticmedicine/pages/aboutthejournal.aspx). Nevertheless, there are differences in emphasis and tradition between the two, including:

1. The significantly longer tradition of psychosomatic medicine and its clear dedication to and establishment in medicine
2. The relative lack of research concerning prevention in psychosomatics

3. The strong orientation of behavioral medicine toward neuroscience and experimentally based methodologies
4. The clear dedication of behavioral medicine toward inclusion of a very broad range of disciplines relative to the greater emphasis in psychosomatics on medicine, psychiatry, and psychology
5. The fact that psychosomatics has its origins in psychoanalysis such as in the work of Franz Alexander (Alexander & Benedek, 1950). In 1950, Mitscherlich implemented the first department for psychosomatic medicine at the University Hospital Heidelberg, Germany (Mitscherlich, 1995). He was strongly engaged in implementing a psychoanalytically driven holistic bio-psycho-social view for diagnosis and treatment of medically ill patients. In German-speaking countries this psychoanalytic tradition is still very much alive and present at university institutions. In contrast, the roots of behavioral medicine come from learning theories, behavior therapy, and psychophysiology. Therefore research and teaching is present in psychology, neuroscience, and medicine such as internal medicine and psychiatry.

Decades ago, these fields showed large differences in their research methods with an emphasis on case studies in psychosomatics and experimental studies in behavior medicine. Recent research methodologies in psychosomatics and behavior medicine are more similar, especially in the USA where the differences and the separation between both research fields are much less than was the case in the past. Both psychosomatic and behavioral medicine engage in research on mind-body-interactions. Therefore in both disciplines psychological and somatic aspects and their interaction are studied. Both disciplines have also come to draw on a broad set of variables to explain a variety of diseases and disorders. These substantive similarities are reflected in the American Psychosomatic Society being member of the International Society of Behavioral Medicine since the 1990s. Indeed, many behavioral medicine research groups publish their findings in journals such as *Psychosomatic Medicine* or the *Journal of Psychosomatic Research*.

Public Health and the Ecological Perspective

Within public health and much literature seeking to address population approaches to health, an "ecological model" of health has gained substantial popularity (McLeroy, Bibeau, & Steckler, 1988; Sallis & Owen, 2015). In ecological or socio-ecological approaches, the behavior of the individual is viewed as guided by layers of influences including the family, proximal social influences such as social networks or neighborhoods, organizational influences such as worksite or community systems or health-care systems, and larger social influences such as government, policy, and large economic structures. Different models may identify different numbers of layers of influence and different components of each, but they share two important emphases: (1) that the behavior of the individual reflects the influence of all the layers; and (2) that the layers interact in their influence so that, e.g., communities may influence families but families may also influence communities.

Many applications and research initiatives in behavioral medicine embrace the multi-layered influences of the socio-ecological model. For example, research in India extending the findings of the Diabetes Prevention Program (described in the chapter on obesity by Johnston et al., *infra*) examines cultural and community factors surrounding healthy diet, physical activity, and diabetes; recruits the influence of the family; and promotes key behaviors of the individual. Similarly, cognitive behavior therapy for postpartum depression in Pakistan is delivered through the primary care system by peer "Lady Health Workers" and is presented and described in ways that take into consideration cultural views and stigma surrounding mental health in rural Pakistan (Rahman, 2007).

In addition to breadth of influence, the socio-ecological model moves attention "upstream" to focus on how policy, organizational, cultural, social, and community characteristics influence family and individual practices that in turn can significantly impact on prevention and care. This then leads to greater attention to upstream determinants in prevention and their influence on populations that share the same upstream determinants. This supports substantial interest in primary prevention and populations in behavioral medicine and provides a conceptual link with public health in which the population and prevention emphases are especially paramount.

There is a fundamental congruence between behaviorism's emphasis on individual history and experience guiding behavior, and socio-ecological perspectives' articulation of the social and organizational layers that are the architecture of that history and experience. Although experimental psychology and behaviorism focused on the behavior of individuals through much of their history, Skinner extended these principles to the behavior of groups and organizations in 1953 with *Science and Human Behavior* (Skinner, 1953) and behavioral economics has further extended the behavioral perspective to include broad policies and incentives (see Rachlin et al., *infra*). Both socio-ecological perspectives and contemporary behaviorism share then an emphasis on individual behavior as being shaped by experience across a wide array of settings and, as highlighted in the ecological perspective, the organizational and policy level structures of the settings the individual experiences. Both also share the assumption that these same approaches to analyzing individual behavior can be applied to the behavior of larger social units such as groups or organizations and the influences of their environments – including individuals within them.

Interestingly, both behaviorism and socio-ecological perspectives share a sensitivity to blaming the victim in analyses of individual behavior or behavior problems. Both would look to socioeconomic, cultural, family, and individual experiences among other background factors in seeking to explain important health behaviors such as smoking, obesity, physical inactivity, type A behavior, and impulsiveness.

Key, Cross-Cutting Concepts

There are a number of concepts and perspectives that underlie behavioral medicine in all the breadth of its discovery and application. Among them are the following.

Principles of Behavior Change Are Not Necessarily Consistent with Perspectives of Clinical Medicine

What makes most sense in behavior change may make little sense from the perspective of medical priorities. Consider shaping self-management skills. One might begin by working in areas in which individuals have skill and confidence and are most likely to succeed (Bodenheimer, Lorig, et al., 2002; Lorig & Holman, 2003), even if that is not the area that is most important for their health. Thus, an individual who smokes and is only a little overweight might begin by focusing on physical activity, even though their smoking is a greater concern. This is not just an academic concern. Among those with diabetes who smoke, a major barrier to quitting smoking may be concern about weight gain, a concern reinforced by clinical emphasis on bodyweight in diabetes. Strongly discouraging weight gain is likely to provoke relapses to cigarettes as a familiar anorexic agent. Instead, it is important to encourage individuals to accept modest weight gain following smoking cessation. This principle may lead to a path to behavior change that seem circuitous or unnecessarily prolonged to clinicians who are focused on "fixing the problem." Appreciation of the wisdom of the behavioral approach, that emphasizes building on strengths and small successes, should not be assumed among patients or clients as well as clinical colleagues.

Distinctions Among Behaviors Do Not Follow Distinctions Among Clinical Diseases

The classifications of diseases into those that are infectious or non-communicable or into categories such as cancers, lung diseases, or cardiovascular diseases do not correspond to meaningful distinctions among behaviors. A number of behavioral influences cut across all of these. Further, many determinants of these behaviors and general principles for changing them extend across clinical categories. That is, for example, the determinants of smoking and nicotine addiction are quite independent of whether smoking ends up causing heart disease or cancer. Instead, distinctions among behaviors need to be articulated in behavioral terms. Quitting smoking is very different than losing weight, adhering to a regimen of antihypertensive medication, or managing stress. They all entail very different behaviors. As obvious as this may seem, consider how often "adherence" is used in an undifferentiated way as if adherence to a diet were the same as adherence to taking a pill two times a day or adherence to recommended physical activity.

Because research related to health is often organized in terms of disease categories, lessons about behavior change in one area may not be received in others. Key lessons from adherence to medication regimens, for example, include the value of prompts and linking medication-taking to other behaviors (Conn, Ruppar, et al., 2016). These are likely to extend across different medications and different risk factors or diseases for which they are intended. Occam's razor, the law of parsimony, encourages scientists to conclude the simplest relationship among events until data prove otherwise. Following this well-respected principle of science, we should assume that strategies like prompts and linking medication to other behaviors will extend, for example, from adherence to antihypoglycemic medication to adherence to antidepressants, rather than waiting for evidence in the one before applying evidence from the other.

Diseases Pose Distinct *Behavioral* Challenges

Notwithstanding the point just made that important behavioral processes transcend categories of disease, it is also the case that different diseases do pose distinct challenges to those they affect. For example, individuals may be more likely to achieve sustained abstinence from smoking following a myocardial infarction than following a diagnosis of chronic obstructive pulmonary disease. This difference in abstinence rates probably reflects likelihoods of survival with each disease and the consequently different incentives for smoking cessation with each one (Fisher, Brownson, et al., 2004; Gritz, Kristeller, & Burns, 1993). Similarly, ketoacidosis or hyperglycemia in diabetes, sudden inability to breath in asthma, the shame attached to obesity in some cultures, the blame attached to cigarette smoking in others, the compromises of daily activities and intimacy that come with many diseases, all of these pose very different patterns of threat, annoyance, and distress. In terms of treatments, adherence to insulin injections in diabetes or to use of controller and responder medicines in asthma may entail many differences from adherence to an antihypertensive medication or to a statin for cholesterol. The psychological and behavioral peculiarities of different diseases and health challenges need to be understood if interventions are to address them effectively.

As discussed in the chapter on psychological factors in health by Snoek et al., *infra*, diabetes distress reflects both distinctive features of diabetes and the burdens it provides and is often linked with depression, which is more prevalent among those with diabetes. For those who are both depressed and appreciably distressed by diabetes, treatment needs to be integrated and to reflect an understanding of the specific demands of diabetes as well as depression (Snoek, Bremmer, & Hermanns, 2015). For other diseases in which depression is often a factor such as coronary heart disease and heart failure or chronic obstructive pulmonary disease, the relative roles of disease-specific distress and depression probably need to be explored.

Behavior and Health Behaviors Are Fundamentally Contextual

Variability by setting and context is not just "noise" but true variance reflecting important influences that need to be understood and considered. As noted previously and in a number of chapters, the socio-ecological perspective that integrates individual-level influences with family, social, community, organizational, and policy influences has been widely adopted and used in behavioral medicine and public health (Christensen, 2000; McLeroy, Bibeau, & Steckler, 1988; Sallis & Owen, 2015). A key emphasis of a socio-ecological perspective is that layers of influence interact as, e.g., families may influence communities just as communities may influence families. The role of a specific influence, then, will depend on the contexts in which it is provided. Success of a worksite chronic disease management program, for example, may depend in large measure on other features of the workplace. For example, success could depend on whether employees are provided release from duties to attend program meetings, whether human resources policies are supportive of chronic disease management, the quality of employee health benefits (in countries in which employer-provided health insurance is common), and the leadership of company executives in setting an organizational climate that encourages those with chronic diseases to use the program. Across all of these, "are worksite chronic disease management programs effective" might not be the correct question to ask. The answer will be determined by a variety of factors outside the program itself.

Interaction of Genes and Behavior Is the Norm, Not the Exception

With very few exceptions, there is no gene expression without environmental and behavioral moderation and very little behavior without genetic moderation or propensity. See chapter by Strahler, Mueller-Alcazar, and Nater, *infra.* A classic example of this is with diabetes among Pima Indians. Pima Indians in the USA show "the highest reported prevalence of type 2 diabetes mellitus … of any population in the world" (Pratley, 1998, p. 175). Yet, Pimas living in Mexico have relatively low levels of diabetes. Ample evidence links genetics to diabetes *within* the Pima population (Pratley, 1998). Thus, the expression of a genetic propensity for diabetes is dependent on exposure to a food environment sufficient to trigger it. The interaction of genes and environment around nutrition and metabolism extends to the intrauterine environment in which adverse nutritional status including over- or undernutrition may lead to epigenetic effects that program the fetus for metabolic problems in adult life (El Hajj, Schneider, et al., 2014).

Expression of the serotonin transporter gene provides an interesting example of the complexities of gene X environment interaction. It turns out that the same genotype can have both advantageous and disadvantageous effects. The work of Williams and his colleagues (2001, 2008) initially pointed to the long alleles of the serotonin transporter gene as the "bad actors"; individuals with one or two long alleles seemed to have significantly greater blood pressure responses to stress and greater CVD risk. However, in a longitudinal study of depression among young adults, the number of *short* alleles (either one or two) was related to greater likelihoods of depression and suicidality (Caspi, Sugden, et al., 2003). In other studies of Williams and his group (2003), whether the bad actor is the long or short allele appears to vary by sex and group origin, e.g., Sub-Saharan Africa, Asia, etc.

We tend to think of these and other genetic effects as conferring a vulnerability to some disease or condition. From this perspective, it is confusing that, in some studies, a particular genotype is associated with a benefit while in other studies the same genotype is associated with a risk or harm. Williams and his colleagues have suggested another way of framing these influences, as conferring a greater or lesser sensitivity to environmental influences (Belsky, Jonassaint, et al., 2009). Thus, in a study of depression among young adults, those with two short alleles of the serotonin transporter gene reported greater depression than those with other genotypes *if* they had been exposed to early adversity in childhood or recent negative life events. However, among those exposed to positive early environment or recent positive events, those with two short alleles reported the least depression (Taylor, Way, et al., 2006). It seems that the two short alleles confer not advantage or disadvantage, *per se*, but greater responsiveness to the environment, for good or ill.

Other studies have also noted a similar pattern of greater or lesser sensitivity to environment conferred by genetics. In one study, observers' measures of poor home and neighborhood quality during adolescence predicted lower self-esteem in young adulthood among those with short alleles of the serotonin transporter gene. In contrast, there were no effects of home and neighborhood quality among those with two long alleles (Jonassaint, Ashley-Koch, et al., 2012). In a study of those exposed to a series of hurricanes in the US state of Florida during 2004, county-level indices of joblessness and crime moderated the effects of the serotonin transporter gene in a remarkable interaction. In counties with low crime/low unemployment, the short allele was associated with lower levels of post-traumatic stress disorder, but in counties with high crime/high unemployment, the short allele was associated with greater risk of post-traumatic stress (Koenen, Aiello, et al., 2009). Putting these findings together, sensitivity to environment may be, itself, influenced by genetic variation. Thus, genotype is far from destiny, independent of context. Rather, sensitivity to context is itself embedded in some genotypes – no doubt further influenced by other contexts in the external, phenotypic, and intracellular environments. Also, as detailed in the chapter by Strahler, Mueller-Alcazar, and Nater, *infra*, epigenetic effects of environment and behavior add further complexity.

Reciprocal Determinism Is Very Important

The ways in which environments may moderate the effects of interventions delivered to the individual, and the complex interactions among genes and environments run parallel to what others have called "reciprocal determinism" (Bandura, 2001). This refers to the complex interrelationships between human behavior and the environment. The environment influences our actions but our actions also influence the environment. For example, a family may teach a daughter to recognize her talents and express them proudly. The daughter may then influence her community to be more supportive of women's talents. Continuing up the ladder of complexity, one can see the same kind of reciprocity in the influence of:

- the group on the individual and the individual on the group;
- the organization on the division and the division on the organization; and
- policies on organizations and organizations on policies.

This pattern of reciprocal influence of the environment on the agent and of the agent on the environment is a very important dynamic across all living systems. It poses an important counterpoint to more primitive models such as those which get lost in debate over whether genes *or* environment are important, models that seek a single cause and in which a single thing can be only a cause or an effect, but not both.

It is worth noting that, statistically, interactions are even handed. They do not confer greater influence or reality to one or the other components of the statistical interaction. Whether we graph the influence of A as dependent on the presence/absence of B or the influence of B as dependent on the presence/absence of A, it is the same interaction. Consider the work of Meaney and colleagues on how maternal rearing and gene expression interact in their influence on adult stress response (Meaney & Szyf, 2005; Zhang, Labonte, et al., 2013). One could say that the expression of genes in adult stress response is dependent on maternal rearing, or one could say that the impact of maternal rearing on adult stress response is dependent on particular genes. Both refer to the same data. Similarly, the relationships among genes, environment, and diabetes among the Pimas can be stated in either of two ways:

- Genetic factors associated with membership in the Pima population have a strong influence on prevalence of diabetes among a population exposed to the obesigenic environment of US diet and food distribution
- The obesigenic environment of the USA has a strong influence on prevalence of diabetes among a population genetically predisposed to high rates of diabetes

Both accurately describe the same data. What is "figure" and what is "ground," that is, what is moderating what, can be a matter of perspective. The constant, however, is that multiple levels interact.

Individual Responsibility Versus It Takes a Village[3]

The concept of individual responsibility has been used to denote the importance of individual behavior in health and health care, for example, in Knowles' influential 1977 editorial in *Science,* "Responsibility for Health" (Knowles, 1977). However, the appeal to individual responsibility can be used as an argument to minimize attention to behavior. In the clinical setting, we often hear "…there's nothing I can do if the patient doesn't want to help himself." At the policy level, the parallel argument suggests that investment in programs to help individuals improve health behaviors is wasted because those behaviors will ultimately be decided by the individuals themselves.

"Responsibility" is shaped by the contexts of people's lives. Socioeconomic status, social isolation, and associated stress (Adler & Matthews, 1994; Glanz, Basil, et al., 1998; Parmenter, Waller, & Wardle, 2000; Steptoe & Wardle, 1999; Wardle & Steptoe, 2003) have great influence on health behaviors. Cultural influences are also profound (Kumanyika, 2005; Steptoe & Wardle, 1999) especially with eating behaviors and feeding practices such as in the valuing of meat and other high-fat foods in cultures in which they were unavailable in the past (Kumanyika, Obarzanek, et al., 2008). Inconsistent and changing health recommendations may also cause skepticism that further encourages retention of unhealthy practices (Wasserman, Flannery, & Clair, 2007) especially in communities that are marginalized from mainstream culture (Corbie-Smith, Thomas, & St. George, 2002). Heavy marketing of high-fat and high-sugar foods (Barr-Anderson, Larson, et al., 2009), alcohol (Anderson, Bruijn, et al., 2009), and cigarettes (Lovato, Linn, et al., 2003) especially targeting children is commonplace and effective. In low-income neighborhoods, disproportionate outdoor advertisements (Kwate, Jernigan, & Lee, 2007; Kwate & Lee, 2007; Kwate & Meyer, 2009) and limited access to stores selling healthy foods are well documented (Block, Scribner, & DeSalvo, 2004; Powell, Chaloupka, & Bao, 2007). These influences are substantial, e.g., a 1.46 odds ratio of being obese associated with living in neighborhood with fast-food outlets but without supermarkets *after controlling* for education, income, and other individual characteristics (Morland, Diez Roux, & Wing, 2006). Economic, social, environmental, and cultural factors account for substantial portions of individual and group differences in health behaviors.

Striking a balance between individuals and their environment is critical (Minkler, 1999). Behavioral interventions are clearly effective (Fisher, Fitzgibbon, et al., 2011), including those implemented at the community and population level. The balance among individual, community, environmental, and policy influences and an emphasis on behavior cutting across all of them will make substantial contributions to both improving health and well-being and reducing health-care costs.

Global Perspective

Behavioral medicine as a field has been developing in and across many countries around the world. This is reflected in the increasing membership of the International Society of Behavioral Medicine that includes member societies from Australasia, Chile, China, Hong Kong, Hungary, Japan, Korea, Mexico, Romania, Slovakia, Thailand, Venezuela, Western, Central, and Eastern Europe, and the USA. Across these countries and societies, emphases have varied, depending on different historical traditions such as in the strong tradition of psychosomatic medicine in Europe, noted above, but the contributions to the field now come from every continent of the world.

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[3] This section is drawn from a paper co-authored by Fisher and his colleagues, Marian Fitzgibbon, Russell Glasgow, Debra Haire-Joshu, Laura Hayman, Robert Kaplan, Marilyn Nanney, and Judith Ockene. We are indebted to them for providing permission to draw at length from their paper, the full citation of which is, Fisher, E. B., Fitzgibbon, M. L., Glasgow, R. E., Haire-Joshu, D., Hayman, L. L., Kaplan, R. M., Nanney, M. S., & Ockene, J. K. (2011). Behavior matters. *American Journal of Preventive Medicine, 40*(5), e15–30.

These differences notwithstanding, the underpinning health issues and challenges to be addressed by the field of behavioral medicine are now very global in nature. While the fundamental principles of behavior and biology are considered universal, the moderation of their expression by the environment and other influences, as discussed above, varies across populations, nations, and regions of the world. How behavioral medicine interventions can be appropriate and effectively disseminated given this incredible diversity is a major challenge to the field. A good example of this lies in the rapid increase and uptake of digital technologies across the world. This is both an incredible opportunity for the field of behavioral medicine and also a major challenge. Designers of digital programs and platforms, for example, need to recognize and plan for the fact that the applications they design are likely to be used by people worldwide, in very different cultures, settings, and health settings.

Noteworthy successes of international spread of behavioral medicine include the Chronic Disease Self Management Program that was developed by Kate Lorig and her colleagues at Stanford University in the USA (Lorig & Holman, 1993; Lorig, Ritter, & Plant, 2005). It has now been implemented in many countries (e.g., Fu, Fu, et al., 2003) and is licensed in 26 countries outside the USA (http://patienteducation.stanford.edu/programs/cdsmp.html). Williams' Lifeskills program has integrated cognitive-behavioral interventions for anger and stress management and cardiovascular risk reduction and shown these effective in varied countries (Williams & Williams, 2011). Both of these successful programs have emphasized a well standardized intervention and protocol that is implemented in a similar way in different settings but with, of course, modifications such as for food choices or culturally specific ways of discussing stressors or anger-inducing interactions.

Another approach to global dissemination places more emphasis on adapting interventions to the needs and strengths of intended audiences as well as system, cultural, organizational, and setting characteristics. Interventions are defined by their key components or the functions they fulfill while encouraging local planning of how they are operationalized (Aro, Smith, & Dekker, 2008; Fisher, Ballesteros, et al., 2015; Fisher, Earp, et al., 2010; Hawe, Shiell, & Riley, 2004). In this approach, a program may look very different in different settings while still being guided by the key functions or characteristics that identify it. An example of success in this is the spread of diabetes prevention programs. It is striking – as well as a key example of the effectiveness of behavioral interventions – that in China (Li, Zhang, et al., 2008), Finland (Tuomilehto, Lindstrom, et al., 2001), and the USA (Diabetes Prevention Program Research Group, 2002), remarkably similar initiatives were successful in preventing diabetes through diet, physical activity, and weight loss. At the same time this intervention approach requires considerable tailoring to cultural and other characteristics of a variety of international settings (Aziz, Absetz, et al., 2015), including in India as described in detail in the chapter by Johnston, Foreyt, and colleagues, *infra.*

The challenge of thinking globally, examining what continuities exist across, and what specific features distinguish, varied countries, groups, and cultures, provides behavioral medicine a valuable stimulus to a better understanding of its principles and constitutive elements. This book is intended to reflect this interplay among fundamental and global continuities, distinctions among peoples and settings, challenges in global dissemination, and intellectual efforts to forge a coherent set of ideas and principles that can embody behavioral medicine while keeping it a vibrant, dynamic approach that is capable of embracing and adapting to new challenges and insights.

What Is Global?

Across much of this introductory chapter and most all of the chapters in the book, concern for global applicability and dissemination is common. This raises questions about what is meant by "global." In contrast to "international" which is generally applied to things intended to span national and cultural differences (e.g., "international" organizations), global is often used to refer to both distinctive features of cultures as well as to features that transcend cultures, and to their interweaving. In the previous illustration of the key features of diabetes prevention, physical activity and weight management need to be adapted to cultural, population, organizational, and system characteristics of the settings in which they are applied, such as in an emphasis on family and group influences in India. Similarly, the chapter on peer support (Fisher et al., *infra*) describes how expressions similar to "It wasn't anything she did or said, it was knowing she was there" are common in many different cultures, pointing to a universal value of social connection. Specific ways in which social support is provided or exchanged (e.g., Dutton, 2012), however, include the importance of implicit and explicit support in cultures emphasizing collectivist versus individualist values. These point to the importance of cultural differences in how possibly universal influences are manifest (e.g., Kim, Sherman, & Taylor, 2008). Similarly, the approach to interventions described previously as emphasizing tailoring to implementation settings of core features or functions (Aro, Smith, & Dekker, 2008; Fisher, Ballesteros, et al., 2015; Fisher, Earp, et al., 2010; Hawe, Shiell, & Riley, 2004) entails a consideration of both what is universal and what is particular.

As a working model, we encourage the expectation that there are core characteristics of processes or influences which are universal. How they are implemented or manifest, on the other hand, may be very culture- and setting-specific. This reflects the interweaving of the universal and the particular in "global."

Plan for the Book

This book is organized to provide basic knowledge about behavioral medicine, how it may be applied, who does it, how it develops evidence and knowledge, and important bodies of knowledge that underlie it, including genetics, behaviorism itself, stress, social and cultural influences, and the social determinants of health and health disparities, including the broad range of influences from outside health care and health policy. It then provides chapters detailing a number of approaches to behavioral medicine, including health education, early detection and screening, promoting adherence to treatments, patient-provider interaction, and approaches broader than the individual including peer or social support, communities, and policies. The following section of the book examines the application of behavioral medicine to key areas of risk, prevention, and health care. Topics in this section are cigarette smoking, physical activity, weight management and obesity, violence and injury, chronic disease management, interventions for communicable diseases, including for HIV/AIDS and among high-risk groups, psychological factors in health and disease, and the growing application of genetics in prevention, decision making, and health. A subsequent section examines behavioral medicine approaches to enhancing quality of life including among children and families and at the end of life. The book then closes with a series of chapters examining cross-cutting issues – values and behavioral medicine and a behavioral medicine perspective on health care and the value it adds, or sometimes fails to add – and, then, a chapter that looks toward the future in emerging fundamental science including information technology, and the editors' closing chapter identifying important future trends and directions.

The focus of the book is on the very broad range of concepts in behavioral medicine and how they can be applied globally. Because of that range, comprehensive review of evidence in all areas would necessitate either a book far too lengthy to be of broad use or one that foregoes explication and exploration of concepts in order to catalog specific findings. Additionally, the field grows at such velocity that any such broad evidence review would be out of date before it were published, let alone read. Consequently, the present volume is written to sample broadly from the evidence supporting the many relationships between behavior and health discussed in the book. It is planned to sample wisely so as to include those major areas of evidence (e.g., the roles of behavioral risks in development of diseases that pose major population burden). But it does not include all evidence that may support the topics it addresses. Thus, the individual chapters are not systematic reviews or evidence reviews or meta-analyses, but presentations of key concepts and exemplary evidence to support them. They are intended to be useful both to the student first exploring behavioral medicine and to those experienced in the field but perhaps wanting to learn about previously unexplored areas or the evolution of favorite topics. For both, they provide a conceptual base from which to begin work in an area, to understand its topography and key concepts, and to be familiar with seminal and enduring patterns of findings.

Additional Sources of Interest

The *Encyclopedia of Behavioral Medicine* edited by Marc Gellman and Rick Turner (Springer, 2013) includes over 1200 entries on specific topics in behavioral medicine. As such, it provides an authoritative and comprehensive complement to the current volume's emphasis on concepts and broad principles.

Behavioral medicine is addressed in many journals representing the fields of medicine, public health, psychology, nursing, social work, etc. Journals that have been closely associated with the field and which readers might consult to expand their familiarity with it include:

Addictive Behaviors	*American Journal of Public Health*
Annals of Behavioral Medicine	*Health Psychology*
International Journal of Behavioral Medicine	*Journal of Behavioral Medicine*
Journal of Consulting & Clinical Psychology	*Patient Education and Counseling*
Psychosomatic Medicine	

Presentation of the range of behavioral influences on health as well as the range of influences on those behaviors that in turn influence health entails a variety of perspectives. For example, depression is, at once, a major risk for cardiovascular disease, a contributing and complicating factor in smoking and smoking cessation, a frequent accompaniment to (and perhaps antecedent of) diabetes, and a central factor in quality of life. In a book such as this, it is desirable that each chapter stands on its own. Consequently, the discussion of depression in a number of chapters in the book will be somewhat overlapping. We have not sought to eliminate this overlap in order to maximize convenience to the reader and the desired presentation of topics in integrated, comprehensive manners as opposed to piecemeal with multiple references to key information in varied sections of the book.

Because of the breadth and range of topics covered by the chapters, there is no single outline or format that would suit all of them. By design, the chapters pursue varied organizational approaches as judged by their authors to fit best the topics they address. We have also encouraged the authors to include their own perspectives in their chapters. As a result, we hope the book represents the field as well as the diversity of perspectives of individuals and groups within it. It should be noted that the opinions or perspectives articulated in the chapters are not necessarily those of the editors or endorsed by them. Behavioral medicine is a vibrant and sometimes contentious field, so we hope the book captures this.

For those who already identify themselves as being part of behavioral medicine, we hope the book enhances your appreciation of our field, its collegiality, and the satisfaction of working in a field that has so much potential to improve global health. For those new to behavioral medicine, we hope the book welcomes you and encourages you to join in!

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2

Overview of Types of Disease, Their Epidemiology, and Treatments

Shajahan Yasin, Carina K. Y. Chan, and Kaitlyn E. Brodar

Behavioral medicine addresses the full range of diseases that affect humans. Fully describing these, their causes, and treatments would require a book of its own. For the reader's convenience, we summarize here some of the major types of diseases and health problems with which those in behavioral medicine frequently deal.

Much of the material in the text is drawn from general descriptions of diseases and health problems from the World Health Organization and other organizations. To avoid multiple references to these within the text, we have cited them at the beginning of each section to which they are pertinent. For more detailed coverage of diseases on which a reader may wish to focus her or his work, good starting places are major texts in medicine such as *Cecil's Textbook of Medicine* (Goldman & Schafer, 2016) and *Harrison's Principles of Internal Medicine* (Kasper, Fauci, et al., 2015) or major texts in other fields of behavioral medicine, such as *Primary Care: A Collaborative Practice* in nursing (Buttaro, Trybulski, et al., 2013).

Obesity

General reference: *Obesity and overweight* (World Health Organization, 2015d).

Obesity is often defined by body mass index (BMI), which is calculated by the formula: weight in kg divided by height in meters squared. A BMI that exceeds 30 kg/m^2 is generally considered indicative of obesity. BMI between 25 and 29 is considered overweight. This is not absolute, however. For people of Asian origin lower cutoff values for obesity has been recommended (Zeng, He, et al., 2014).

There are some limitations in the use of BMI as it may be elevated by muscular mass. Excess body fat, especially central and visceral fat, may be a more precise characterization of disease risk. Body fat may be assessed by diameter at the level of the waist. A ratio of waist-to-hip circumference that is equal to or greater than 0.9 in men and 0.85 in women has been used to assess risks associated with obesity (World Health Organization, 1999).

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Epidemiology

The prevalence of overweight and obesity has been increasing in both adults and children in the United States as well as around the world. The World Health Organization reports that in 2014, 1.9 billion adults and 42 million children worldwide were overweight or obese (World Health Organization, 2015d). Obesity appears to be increasing 30% faster in low- and middle-income countries than in higher-income countries. This results in a "double burden" of disease for lower-income countries. While they still struggle with infectious diseases, noncommunicable diseases are now also on the rise, primarily due to the rising obesity rates.

The genes and environment of an individual combine to promote obesity. In genetically prone individuals, a sedentary lifestyle and excess food, especially carbohydrates with a high glycemic index, combine to increase risk. Individuals from a lower socioeconomic status (SES) and/or with lower education levels bear a disproportionate burden of the prevalence of obesity. Part of the reason for this is that obesity has been associated with limited access to healthy food, and individuals from a lower SES background are less likely to have access to grocery stores or markets with a full range of food options (Pechey & Monsivais, 2015). Instead, they may obtain food from "convenience stores," tiendas, or other stores emphasizing high fat, high carbohydrate, or "fast" food (Morland, Diez Roux, & Wing, 2006).

Obesity and overweight are risks for multiple health problems. A *partial* list includes coronary heart disease, hypertension (high blood pressure), stroke, type 2 diabetes mellitus, abnormal blood lipids, cancer (especially colon, breast, and endometrial cancer), osteoarthritis, sleep apnea, gallstones, and reproductive problems, including menstrual irregularities and infertility (World Health Organization, 2015d). Medical costs related to obesity are estimated to exceed $200 billion annually in the United States alone (Spieker & Pyzocha, 2016). Obesity also has a significant impact on an individual's day-to-day activities; for example, one study found that obesity was associated with a significant increase in days absent from work (Cawley, Rizzo, & Haas, 2007).

Prevention, Management, and Treatment

Managing obesity requires a multidisciplinary approach that involves modifying the lifestyle of the affected individual. The two key aspects of most interventions include structured dietary interventions and a strategy to increase physical activity.

Dietary interventions, which can be complex, include reduction of caloric intake, with increased intake of foods with low glycemic index and increased consumption of soluble fiber (from fresh fruits and vegetables). Consultation with a dietitian is often recommended.

Similarly, patients benefit from a balanced exercise plan, ideally developed in consultation with an exercise physiologist. This includes a mix of aerobic, stretching, and strength exercises gradually increasing in intensity. It is important to incorporate exercise into daily activities, like using stairs as opposed to elevators and increasing walking activities.

With the help of a psychologist or similarly trained professional, cognitive behavioral intervention strategies like goal setting, stimulus control, assertive communication skills, stress management, and managing relapse are important components of interventions that are often neglected.

A number of anti-obesity drugs are available and have been shown to be effective. These should be used in combination with behavioral modification strategies. Surgical options are also available and are reserved for patients with severe obesity or those with comorbid conditions. Two common procedures are bypass surgery and laparoscopic placement of an adjustable gastric band. Importantly these procedures need to be complemented with dietary advice and counselling.

Cardiovascular Disease

General reference: *Cardiovascular diseases* (World Health Organization, 2015a).

Cardiovascular disease (CVD) may be defined as all the diseases of the heart and circulation and includes coronary heart disease (which may present as angina and heart attack), arrhythmia, heart failure, congenital heart disease, as well as cerebrovascular disease and stroke.

Many people with underlying disease of the blood vessels have no symptoms, so that a heart attack or stroke may be the first symptom of disease. However, many individuals with coronary artery disease have early symptoms which may include chest pain or discomfort and breathlessness, especially on exertion such as when running or on climbing stairs. Pain may also be precipitated by stress and anxiety.

Heart attack symptoms include pain or discomfort in the center of the chest which may radiate to the arms, left shoulder, jaw, or back (National Heart Lung and Blood Institute, 2015a). The individual may develop difficulty in breathing, vomit, or break into a cold sweat.

Heart attacks, or myocardial infarction, and strokes are usually acute events and are mainly caused by an abrupt blockage in blood vessels that prevents blood from flowing to the heart or brain. This is due to buildup of fatty deposits or plaques on the walls of the blood vessels that supply the heart or brain. Rupture of these plaques can result in sudden block to the blood flow. Strokes can also be caused by rupture and bleeding from blood vessels in the brain or from blood clots.

A stroke most commonly manifests as sudden weakness of the face, arm, or leg, usually on one side of the body (National Stroke Association, 2016). Confusion, difficulty speaking or understanding speech, visual disturbances in one or both eyes, difficulty walking, dizziness, and loss of balance or coordination may also occur. Some forms of stroke may present with severe headache and loss of consciousness, indicating a brain bleed.

Three major categories of stroke are recognized by the CDC: ischemic, transient ischemic, and hemorrhagic (Centers for Disease Control and Prevention, 2013b). Ischemic strokes are the most common and are caused by a blockage in an artery that inhibits blood flow to the brain. Transient ischemic strokes are also caused by artery blockage, but are much shorter, with the blockage generally lasting less than 5 min. Finally, hemorrhagic strokes result from leakage or bursting of an artery, which damages surrounding brain cells. They are generally caused by high blood pressure or an aneurysm.

Arrhythmias are abnormal beats of the heart or abnormal heart rhythm (American Heart Association, 2015a). Rhythm abnormalities may result in slowing of the heartbeat (bradycardia), speeding of the beat (tachycardia), and irregularity of the heart rhythm. The effects of these arrhythmias are related to what impact they have on cardiac output or the ability of the heart to pump blood. When the abnormal rhythm is of short duration, the individual may tolerate this quite well. However, an individual can go into a cardiac arrest when the ventricles go into a severe tachycardia or go into fibrillation as no blood is pumped into the rest of the body, including the brain. A common form of arrhythmia is atrial fibrillation in which the atria go into very rapid and uncoordinated beats. In such instances the atria are ineffective in pumping blood, and the blood in the atria may form a thrombus or clot. Such thrombus can dislodge and enter the circulation, blocking blood flow to the organs. If this happens to the brain, it can cause a stroke. The risk of arrhythmias tends to increase with age. Damage to the heart by myocardial infarction or heart failure is often a trigger for arrhythmias. Other factors that can provoke arrhythmias include alcohol, cigarettes, recreational drugs, and some prescribed medications.

Heart failure occurs when the heart is unable to pump enough blood to meet the needs of the body (American Heart Association, 2016a). Heart failure occurs gradually; as the heart fails, blood backs up in the veins and causes fluid to build up in the tissues. The symptoms of heart failure include edema (due to excess fluid in body tissues), shortness of breath, coughing and wheezing, tiredness, and fatigue. Most cases of heart failure result from damage to the heart from coronary artery disease or previous heart attack and hypertension.

Epidemiology

According to the World Health Organization, CVDs are the leading cause of death globally; every year more people die from CVDs than from any other cause (Alwan, 2010). An estimated

17.5 million people died from CVDs in 2012, which constituted 31% of all deaths (World Health Organization, 2015a). Low- and middle-income countries are disproportionately affected; over 80% of CVD deaths take place in low- and middle-income countries. They occur almost equally in men and women. As great as the toll of CVD is, the WHO also notes that "most cardiovascular diseases can be prevented by addressing behavioral risk factors such as tobacco use, unhealthy diet and obesity, physical inactivity and harmful use of alcohol using population-wide strategies" (World Health Organization, 2015a). It has been estimated that behavioral risk factors are responsible for about 80% of coronary heart disease and strokes (Alwan, 2010). Smoking is an especially strong risk factor for heart disease, increasing the likelihood of dying from coronary heart disease and cerebrovascular disease by two- to threefold. Among people who stop smoking, risk of cardiac events can fall by 50%. Risk of heart attacks, stroke, and peripheral vascular disease decreases significantly over the first 2 years after stopping smoking.

Prevention, Management, and Treatment

In addition to smoking cessation, other behavioral modifications such as reducing salt intake, increasing intake of fruits and vegetables, regular physical activity, and avoiding harmful use of alcohol have been shown to reduce the risk of cardiovascular disease (World Health Organization, 2015a). Cardiovascular risk can also be reduced by preventing or managing hypertension, diabetes, and elevated blood lipids, all of which are powerful risk factors for heart disease and stroke. In addition to individual-level interventions, these objectives can be accomplished at the community level, with the aim to reduce cardiovascular mortality. An exemplar of primary prevention was conducted in North Karelia, Finland (Puska, Vartiainen, et al., 1998). It took a comprehensive approach that included working through primary care such as to improve blood pressure screening and control but also with food producers to create more health alternatives to traditional high-fat foods and with communities and media to promote healthier lifestyles including smoking cessation. Over time, lifestyles became healthier (e.g., reduction in dietary fat intake, salt consumption, smoking), risk factor levels were lower (e.g., decreased serum cholesterol, blood pressure), and, associated with these risk reductions, mortality from CVD declined markedly relative to other areas of Finland (Jousilahti, Laatikainen, et al., 2016; Puska, Vartiainen, et al., 2009).

Underlying behavioral risks for CVDs are some of the major forces driving social, economic, and cultural changes of modern life that include globalization, urbanization, and ageing of the population. These are often considered "the causes of the causes." These forces have been recognized, for example, as contributing to substantial CVD in Central and Eastern Europe in the years following the breakup of the Soviet Union (Kopp & Réthelyi, 2004). On the basis of such evidence, the WHO (Alwan, 2010) suggests that governments should enact policies that create conducive environments for making healthy choices affordable and available to motivate people to adopt and sustain healthy behavior.

Treatment of Acute Events Heart attacks and strokes are typically acute events. In both cases, prompt treatment can halt or reverse damage and is therefore of great importance. Therefore, health professionals should be familiar with the signs and symptoms of heart attack and stroke and encourage immediate medical assistance when they are noted. As identified by the US Centers for Disease Control, the signs and symptoms of these two conditions are described in Table 2.1.

For immediate treatment of a heart attack, thrombolytic medications are used to dissolve blood clots in the coronary arteries, in combination with nitroglycerin to improve blood flow and aspirin to prevent additional clotting (National Heart Lung and Blood Institute, 2015b). Coronary angioplasty is also employed to open blocked arteries.

Acute treatment for ischemic strokes involves administering tissue plasminogen activator (tPA), which can dissolve the blood clot blocking the

Table 2.1 Major signs and symptoms of heart attack and of stroke (Centers for Disease Control and Prevention, 2015a, b)

Major symptoms of a heart attack	Signs and symptoms of stroke
Pain or discomfort in the jaw, neck, or back	Sudden numbness or weakness in the face, arm, or leg, especially on one side of the body
Feeling weak, light-headed, or faint	Sudden confusion, trouble speaking, or difficulty understanding speech
Chest pain or discomfort	Sudden trouble seeing in one or both eyes
Pain or discomfort in arms or shoulder	Sudden trouble walking, dizziness, loss of balance, or lack of coordination
Shortness of breath	Sudden severe headache with no known cause
Additional symptoms, *more common among women:* Unusual or unexplained tiredness Nausea or vomiting	

artery (American Heart Association, 2016c). Endovascular treatment, which utilizes a stent retriever to capture and remove the clot in the artery, may also be used after tPA has been administered. Hemorrhagic strokes are typically treated with the endovascular procedure described above or with surgery, which involves placing a metal clip on the burst or leaking artery.

Long-Term Treatment and Management of CVD Individuals with CVD must adhere to a long-term disease treatment and management plan, which will most certainly include behavioral changes and may also involve medication and/or various medical and surgical procedures (American Heart Association, 2016d).

Lifestyle Changes Treatment varies across different types of cardiovascular problems, but common to each is the primary role of lifestyle changes. Following a nutritious, heart-healthy diet that includes fruits, vegetables, whole grains, and fish and limits on sodium, trans fats, sugar, alcohol, and red meat is essential (National Heart Lung and Blood Institute, 2015b). Stress management and regular physical activity are also important, and it is strongly suggested that individuals with CVD quit smoking.

Medication Medication can also be utilized to treat and manage cardiovascular conditions. In the case of myocardial infarction, ACE inhibitors are often prescribed to reduce blood pressure (National Heart Lung and Blood Institute, 2015b). Blood thinners and anticlotting medications may also be used to prevent blood clots from forming. Beta-blockers are prescribed to relieve pain and reduce the heart's workload, and statins are used to lower cholesterol levels.

Many of the same medications used to treat myocardial infarctions are also used to treat heart failure, in addition to angiotensin II receptor blockers (ARBs), aldosterone antagonists, and diuretics, each of which acts in different ways to reduce blood pressure (American Heart Association, 2016b). To treat arrhythmias, antiarrhythmic medication is used to encourage a normal heart rhythm by preventing pacemaker cells from firing abnormally (American Heart Association, 2016c). Calcium channel blockers and beta-blockers may also be prescribed.

Medical and Surgical Procedures In some cases, surgical treatment may be necessary. Coronary artery bypass grafting, which involves grafting a healthy artery or vein to go around a site of blockage to create a new path for blood flow to the heart, is frequently used as a treatment option for a myocardial infarction (National Heart Lung and Blood Institute, 2015b). This procedure may also be used for heart failure (American Heart Association, 2016c). Other options include coronary angioplasty, in which a stent is placed to keep an artery open; valve replacement; and, in more drastic situations, a heart transplant. Pacemakers may be implanted to treat arrhythmias. Other devices include implantable cardioverter-defibrillators which are surgically inserted devices which counteracts abnormal firing of pacemaker cells (American Heart Association, 2015b). Left ventricular assist device may also be used to help the failing heart pump blood (American Heart Association, 2016c).

Other procedures for treating arrhythmia include ablation, in which heart tissue with abnormal firing is targeted and destroyed so that surrounding tissue can grow and function normally, and defibrillation, which involves shocking the heart in order to establish a normal rhythm (American Heart Association, 2016b, c).

Cancer

General reference: *Cancer* (World Health Organization, 2016c).

Cancer, which may also be called malignant tumors and neoplasms, is a term used for a group of diseases in which cells in the body divide uncontrollably and invade other tissues. This is due to damage of genetic material of the cell producing mutations which cause unrestrained growth and spread of cells. Cancer cells can spread to other parts of the body through the blood and lymph systems. This process is referred to as metastasis and is the major cause of death from cancer. There are more than 100 different types of cancer. Most cancers are named for the organ or type of cell in which they start. For example, cancer that begins in the lung is called lung cancer; cancer that begins in melanocytes of the skin is called melanoma.

The transformation from a normal cell into a tumor cell is not fully understood but is thought to be a multistage process. Initially, precancerous lesions may form which then turn into malignant cancers. These changes are thought to be due to interaction between a person's genetic factors and external agents or carcinogens, which may include physical carcinogens, such as ionizing radiation, chemical carcinogens, such as asbestos as well as components of tobacco smoke, and biological carcinogens, such as infections from certain viruses and bacteria.

Epidemiology

The WHO estimates that after CVD, cancer is the next leading cause of death worldwide (Alwan, 2010), accounting for 8.2 million deaths in 2013, 62% of which occurred in low- and middle-income countries (Global Burden of Disease Cancer Collaboration, 2015). The most common causes of cancer death are due to cancers of the lung, breast, colon, stomach, and liver. In countries with high income, the leading causes of deaths due to cancer are lung cancer among men and breast cancer among women (Alwan, 2010). The incidence of cancer rises dramatically with age and is thought to be due to a buildup of risks for specific cancers that increase with age as well as a decline in cellular repair mechanisms that counteract the uncontrolled division of cells in carcinogenesis.

Risk Factors for Cancer

The National Cancer Institute (www.cancer.gov) lists four major behavioral factors that may be considered major risk factors for cancer. These include use of tobacco, unhealthy diet, inadequate physical activity, and alcohol misuse. These often occur together. An in-depth discussion of these behavioral risk factors can be found in Chap. 3 by Chan and Yasin, *infra*.

Among infective agents, hepatitis B and hepatitis C are implicated in liver cancer, human papillomavirus (HPV) in cervical cancer, *Helicobacter pylori* in stomach cancer, and Epstein-Barr virus in Burkitt lymphoma. Together, these infective agents are estimated to cause up to 18% of cancer burden (Parkin, 2006). There are now effective vaccines against hepatitis B and HPV that are effective in the prevention of liver cancers and cervical cancers.

Many cancers of the hematological system, breast, lung, and thyroid are also caused by exposure to ionizing radiation, including medical radiation through x-rays, computed tomography (CT), and fluoroscopy. Reducing radiation exposure is an important strategy to prevent cancers (National Research Council, 1990).

Prevention, Management, and Treatment

Early detection and treatment of cancer are key strategies in reducing its incidence. There are two components in the early detection efforts, screening, and early diagnosis.

Early Detection, Screening, and Diagnosis Early diagnosis is particularly relevant for cancers of the breast, cervix, mouth, larynx, colon and rectum, and skin (World Health Organization, 2016h). For diagnosis to occur, individuals must be identified as eligible for diagnostic evaluation. Education and awareness of early signs and symptoms of cancers may help identify those who may benefit from diagnosis. The World Health Organization notes that some early signs of cancer include lumps, sores that fail to heal, abnormal bleeding, persistent indigestion, and chronic hoarseness.

Screening is defined as the systematic application of a test in a population without symptoms. The aim of screening is also to identify persons who have abnormalities that are suggestive of a specific cancer, to refer them for further tests that can lead to a diagnosis, and to facilitate prompt treatment. For a screening program to be efficacious, it should be cost-effective, affordable, acceptable, and accessible. The screening test should be available to the majority of the at-risk population.

Evidence supports especially early detection and/or population screening for breast cancer, ideally by mammography; for colorectal cancer, by fecal samples, sigmoidoscopy, or, ideally, colonoscopy; for cervical cancer, by the "Pap test" (developed by Georgios Papanikolaou, also called "cervical smear"); for oral cancer, by inspection of the mouth; for melanoma or cancer of the skin, by visual inspection by the individual, relationship partners, or health workers (Curiel-Lewandrowski, Chen, & Swetter, 2012); and, supported by recent evidence, lung cancer. Screening for prostate cancer is controversial with patients advised to discuss options with their physician.

The advisability of screening varies by age, family history, other demographic characteristics, and presence of other risk factors (e.g., smoking history). Details for who should be tested and when are available through the websites of the American Cancer Society (American Cancer Society, 2015) and the US Preventive Services Task Force (US Preventive Services Task Force, 2016).

Although screening can be an effective preventive approach when it is part of a public health program, it is important to realize that indiscriminate testing which is not evidence based can be harmful both through false-positive test results or unnecessary treatment, which can result in unnecessary distress, and by increasing costs due to unnecessary tests and treatments (see Kaplan et al., Behavioral Medicine and the Benefits of Health Care: A Critical Appraisal and the Need for Exnovation, *infra*.).

Management Treatments for cancer vary widely and include surgery, chemotherapy, and radiation therapy. Each of these can be curative, but this depends on the particular cancer and the stage at which treatment is initiated. Two important changes in cancer treatment include chemotherapy guided by pharmacogenetics and immunotherapy. Recent advances in genetics have led to the ability to select chemotherapeutic agents according to individual genotypes (National Cancer Institute, 2014). This is expected to improve the precision and effectiveness of treatment over that guided purely by clinical characteristics, stage, and progression of cancer. Immunotherapies are developing that stimulate and enhance the body's own immunologic processes to combat cancers.

Because of advances in treatment as well as timely detection and diagnosis, many cancers are becoming chronic diseases (Hewitt, Greenfield, et al., 2006). Thus, ongoing "survivorship" is an important area of cancer care that includes management similar to that of other chronic diseases. As cancer survivors age and develop other chronic diseases, the care of their cancer and those other diseases needs also to be addressed. Survivors of cancer including, for example, childhood cancer, may be at risk for developing other cancers, further complicating their care.

Palliative care including psychosocial support is an important but too often neglected dimension of cancer care. Ideally, it should be initiated from the time of diagnosis, not necessarily as a major emphasis but as a dimension of comprehensive care. The continuum from survivorship through palliative and end-of-life care includes the importance of psychosocial support, pain management, and support for the families of those with cancer, both before and after death should it occur. Psychosocial supportive services enhance quality of life even among those with noncurable cancer (Spiegel, 2012) and may extend survival (Andersen, Yang, et al., 2008; Spiegel, 2001).

Diabetes Mellitus

General reference: *Diabetes* (World Health Organization, 2016f).

Diabetes is a chronic disease that is characterized by chronic elevation of blood glucose levels (hyperglycemia). It is a result of the pancreas not producing enough insulin (insulin insufficiency) and/or the tissues in the body lacking the ability to use insulin effectively (insulin insensitivity). Insulin is a hormone that regulates blood sugar levels. Hyperglycemia, or raised blood sugar, over time leads to serious damage to many of the body's systems, especially the nerves and blood vessels.

Diabetes mellitus is diagnosed by measuring the level of plasma glucose either in the fasting state or 2 h after a meal. The current WHO diagnostic criterion for diabetes is fasting plasma glucose equal to or above 126 mg/dl (7.0 mmol/l) or 2 h postprandial plasma glucose of equal or above 200 mg/dl (11.1 mmol/l) (World Health Organization, 2006).

Epidemiology

WHO estimates that the global prevalence of diabetes in 2008 was 10% in adults aged 25 years and over (Alwan, 2010). The International Diabetes Federation estimates the current number of individuals with diabetes worldwide at 415 million and estimates this will grow to 642 million by 2040 (International Diabetes Federation, 2015).

Diabetes is classified into several categories (American Diabetes Association, 2014):

Type 1 Diabetes Type 1 diabetes, which previously was known as insulin-dependent diabetes and juvenile-onset diabetes, results from immune destruction of the insulin-producing beta cells of the pancreas. In the majority of cases, type 1 diabetes develops before the 40th year, with a peak in puberty. Those with type 1 diabetes require daily administration of insulin for survival. Individuals present with polyuria (excessive passing of urine), polydipsia (excessive thirst), weight loss, and often with constant hunger and fatigue. The presentation can be quite sudden.

Type 2 Diabetes Previously known as non-insulin-dependent or adult-onset diabetes, type 2 diabetes results from resistance to the effects of insulin. Type 2 diabetes accounts for 90% of diabetes cases around the world. Symptoms are usually gradual in onset, but may be similar to those of type 1 diabetes. Due to the gradual onset, many individuals may not be diagnosed until several years after onset. In some instances, complications due to long-standing diabetes may be the occasion for initial diagnosis.

Until recently, type 2 diabetes was seen only in adults, but with increasing childhood obesity around the world, it is now also occurring in children. The risk of developing type 2 diabetes increases with age, obesity, and lack of physical exercise.

Gestational Diabetes This condition involves hyperglycemia with onset or first symptoms during pregnancy. Symptoms are similar to those experienced in type 2 diabetes. It is generally diagnosed through screening during pregnancy. Most cases resolve upon delivery, but a history of gestational diabetes is a risk factor for subsequent type 2 diabetes.

Impaired Glucose Tolerance (IGT) and Impaired Fasting Glycemia (IFG) Impaired glucose tolerance (IGT) and impaired fasting glycemia (IFG) are intermediate conditions in which glucose levels are elevated, but do not meet criteria for diabetes. People with IGT or IFG, which is also referred to as prediabetes, are at a higher risk of developing diabetes.

Impacts and Complications

Diabetes is a cause of significant morbidity. It is the leading cause of renal failure. In developed countries, it is a major cause of visual impairment and blindness (Resnikoff, Pascolini, et al., 2004). Lower limb amputations are ten times more common among those with diabetes (Icks, Haastert, et al., 2009). Most of the complications of diabetes develop gradually. They can be disabling or even life-threatening. Some of the major complications of diabetes include:

Heart and blood vessel disease. Diabetes significantly increases the risk of cardiovascular problems, including coronary artery disease, stroke, narrowing of arteries due to plaques (atherosclerosis), and high blood pressure. For men, erectile dysfunction often results from compromised blood flow.

Nerve damage (neuropathy). Excess sugar can damage the capillaries that supply the nerves, especially in the legs. This can result in symptoms like tingling, numbness, burning, or pain that usually begins distally in the toes or fingers and spreads proximally. This eventually leads to loss of all sensation in the limbs. Healing of cuts and blisters can be delayed, and these can become infected. Severe damage to nerves and vessels may require amputation of the toe, foot, or even leg.

Kidney damage (nephropathy). Diabetes can damage the tiny capillaries that are part of the filtering system in the kidneys. Over time this can lead to kidney failure or irreversible end-stage kidney disease, requiring dialysis or a kidney transplant.

Eye damage. Diabetes is the leading cause of blindness among adults resulting from damage to the blood vessels of the retina (diabetic retinopathy). Diabetes increases the risk of cataracts and glaucoma.

Skin and mouth conditions. Individuals with diabetes are prone to bacterial and fungal skin infections. Gum infections can also occur especially when associated with poor dental hygiene.

Other health complications. Diabetes may also increase the risk of osteoporosis and has also been associated with increased risk of Alzheimer's disease and vascular dementia.

Prevention, Management, and Treatment

The risk of developing type 2 diabetes increases with age, obesity, and when there is a family history of diabetes. Certain racial groups including those of African origin, Hispanic Americans, American Indians, and Asians of Indian origin seem to be at heightened likelihood of developing diabetes (Spanakis & Golden, 2013). But these group propensities are highly influenced by the environment. The classic example of this is among the Pima Indians, who have one of the highest rates of diabetes in the world if they live in the United States, indicative of a strong genetic propensity for the disease, but a low prevalence if they live in traditional settings in Mexico, indicative of the role of environment in moderating that genetic propensity (Pratley, 1998).

The most important modifiable risk factors for the prevention of diabetes are being overweight and physically inactive. Even among those at high risk because of insulin insensitivity and abnormally high blood sugar levels, behavioral interventions can prevent and delay diabetes (Diabetes Prevention Program Research Group, 2002).

Diabetes entails many of the issues encountered in chronic diseases, including lifestyle approaches to prevention and management; sophisticated medical treatments; diverse complications, affecting individuals from childhood to old age; and challenges to individuals and their families; diabetes is an important model of chronic disease in general. It also is a model of interventions that can achieve appreciable benefits in terms of reducing risks of complications and progress.

The Diabetes Control and Complications Trial was a landmark that showed convincingly that good blood glucose control in those with type 1 diabetes reduces complications of the disease (The Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications (DCCT/EDIC) Study Research Group, 2005). Interpretation of that finding extends also to type 2 diabetes. Studies of care of type 2 diabetes through the UK Prospective Diabetes Study (UKPDS) have shown relationships between chronic elevated glucose levels, complications of diabetes, and mortality and benefits of improved glucose control (UK Prospective Diabetes Study Group (UKPDS), 1998a, b). This leads to glucose control being a major objective in diabetes management. This is often measured by glycosylated hemoglobin, a measure of the proportion of hemoglobin cells in the bloodstream that have a glucose molecule attached to them. The more the average level of glucose in the blood, the greater the percentage of hemoglobin molecules that are glycosylated. Good glucose control is generally viewed as a glycosylated hemoglobin (or "HbA1c") value of less than 7% or 53 mmol/mol, but this objective is moderated clinically by other factors, especially age (American Diabetes Association, 2014). A number of medications have been developed to improve blood glucose control. These operate through varied pathways including altering digestion and processing of carbohydrates that are major sources of glucose as well as enhancing insulin function and glucose metabolism (American Diabetes Association, 2015).

Management of diabetes is best accomplished through a collaborative relationship among the health-care team, the patient, and her or his family. The aim of management is to keep blood glucose levels close to normal so as to prevent acute, extreme excursions and to delay and prevent long-term complications. Recent guidelines, however, have endorsed moderating blood glucose goals to individual characteristics, including age and other clinical features such as history of severe hypoglycemic episodes, advanced microvascular or macrovascular complications, or extensive comorbid conditions (American Diabetes Association, 2015). Treatment involves healthy diet and weight management, regular physical activity, monitoring of blood sugar, various medications to enhance glucose metabolism, and, often, insulin therapy. Additionally, it is important for those with diabetes to avoid tobacco use, as smoking greatly increases the risk of cardiovascular diseases among those with diabetes (Jia, 2013). The following paragraphs provide an overview of key components of diabetes management (American Diabetes Association, 2016).

Monitoring Blood Glucose In type 1 diabetes, self-monitoring of blood glucose is an integral part of the treatment plan. Frequency of self-monitoring may vary across situations but is generally recommended before meals and before going to sleep. With insulin treatment of type 2 diabetes, as well, frequent daily self-monitoring of blood glucose is recommended.

HbA1c is assessed periodically and provides a measure of average blood glucose level over the previous 2–3 months and serves as an indicator of diabetes control. HbA1c however provides no information on glucose variability.

Dietary recommendations are generally in line with those for the general population, with increased intake of fruit and vegetables, whole grains, and fish and with moderate calorie restriction. Fiber intake should be increased. On the other hand, foods which are absorbed rapidly and converted to sugar in the blood (referred to as foods with a "high glycemic index") should be avoided. Salt intake should be reduced and alcohol should be consumed only in moderation.

Regular exercise, especially aerobic exercise, is important in maintaining weight and improving glucose control as it improves insulin sensitivity. It also reduces blood pressure and cholesterol levels.

Weight Management Overweight (body mass index of 25.0 to 29.9 kg/m^2) and obesity ($BMI > 29.9\ kg/m^2$) are major risk factors for type 2 diabetes and cardiovascular disease. Even a small reduction in weight of 5–10% can reduce the risk for diabetes or improve blood glucose control among those with the disease.

Medication Because it is defined as an inability to produce insulin, all patients with type 1 diabetes require insulin and careful monitoring to avoid hypoglycemic as well as hyperglycemic events. In type 1 diabetes, the use of pump therapy and continuous glucose monitoring (CGM) sensors are becoming increasingly popular.

Most patients with type 2 diabetes eventually require medications. These may be oral medications like metformin, which is often a first-line therapy, or a whole range of newer medications to enhance glucose metabolism. Worldwide, there is a tendency to "undertreat" diabetes by continuing diet and exercise recommendations or insufficient medication in spite of persistent obesity and poor glucose control rather than moving patients to insulin therapy. The expanded range of medications available and the evidence especially for cardiovascular benefits of good blood glucose control argue for more proactive treatment of diabetes early in the course of the disease (Skyler, Bergenstal, et al., 2009).

An important feature of diabetes is that it is *fundamentally progressive*. That is, it tends to worsen. This has several important implications. While it is eventually necessary for many, patients may see the recommendation of insulin therapy as indicating a failure on their part (Funnell, Kruger, & Spencer, 2004). Instead, the advisability of insulin should be understood as part of the natural course of diabetes amidst understandable difficulty in managing blood sugar – many lean and fit adults with type 2 diabetes take insulin. Additionally, the fundamentally progressive nature of diabetes means that individuals can manage their disease assiduously, but still experience complications and worsening clinical status. This of course can be very discouraging for the individual. Management of diabetes needs to balance (a) determined efforts for a healthy lifestyle and appropriate use of medications with (b) recognition that although diabetes may be managed, it is progressive and unpredictable, so that outcomes cannot be assured, and with (c) support from the clinical team, family, and friends, for the patient in coping with the many challenges diabetes presents. Behavioral medicine programs can help patients and families cope with the psychological and behavioral demands of living with diabetes, both in youth and adults.

Chronic Obstructive Pulmonary Disease

General references: *Chronic obstructive pulmonary disease* (COPD) (World Health Organization, 2016b) and *Burden of COPD* (World Health Organization, 2016d).

Chronic obstructive pulmonary disease (COPD) is a life-threatening lung disease resulting from irreversible damage to the airways and the lung tissue due to inhaled irritants, usually cigarette smoke. COPD is confirmed by pulmonary function tests that assess the ability of the lungs to inhale and exhale air. For example, "FEV1" or "forced expiratory volume 1" is the amount of air the individual is able to exhale in 1 s. These tests are used for assessing severity as well as response to treatment.

COPD consists of two conditions: emphysema and chronic bronchitis. In emphysema, the alveoli and alveolar walls in the lungs are damaged, resulting in reduction of the amount of gas exchange. In chronic bronchitis, the bronchi and bronchioles which line the airways are inflamed due to chronic irritation. This results in mucus formation and thickening of the bronchioles. Chronic bronchitis may be diagnosed if an individual coughs with sputum 3 months in a year for two consecutive years. People with COPD usually have varying degrees of both emphysema and chronic bronchitis.

Patients with COPD complain of progressive breathlessness with periodic acute episodes often brought about by respiratory infections, air pollution, or cardiac failure. Initially breathlessness is only evident on exertion, but eventually it is evident at rest as well. Cough often in the mornings with excess of clear or yellow sputum is often a feature. In late stages, patients tend to lose considerable weight. Generally, if due to smoking, symptoms become evident after the age of 40.

Epidemiology

The WHO estimates that more than 65 million individuals worldwide have COPD. COPD was the cause of over 3 million deaths in 2005, 90% of which were in low- and middle-income countries (World Health Organization, 2016b). The main cause of COPD is smoke from tobacco use either directly from smoking or secondhand smoke (Alwan, 2010). As tobacco use among women in high-income countries has increased, the prevalence of the disease is now becoming equal in men and women. Individuals with asthma (see next section) and who smoke are at even higher risk for COPD. A rare cause for COPD is a genetic disorder called alpha-1-antitrypsin deficiency.

People with COPD are at increased risk of respiratory infections including the common colds and pneumonia that can be quite severe and life-threatening (Mayo Clinic, 2015b). Risk of cardiac disease is also increased, partly because of the shared and strong risk factor of cigarette smoking. Hypertension is also associated with COPD. Lung cancer is more common among those with chronic bronchitis even when the effect of smoking is taken into account. Individuals with COPD are also at higher risk of coronary artery disease and lung cancers due to all three conditions having common risk factors.

Prevention, Management, and Treatment

The vast majority of cases of COPD are due to smoking cigarettes. Therefore, emphasis has to be on preventing smoking and on programs for smoking cessation (see Chap. 24 by Borland, *infra*).

As noted, COPD is not curable, and the best approach is in prevention and slowing the rate of progression. Patients should be encouraged to stop smoking at every opportunity and should be referred to smoking cessation programs. Most patients who succeed in stopping smoking fail to do so on the first few attempts (Fisher, Brownson, et al., 2004). Smoking cessation efforts should be framed to encourage individuals to view failure not as a sign of inability to quit but as part of a common path to cessation.

Once COPD is diagnosed, treatment is directed at preventing exacerbations and improving airway flow with the use of bronchodilators. Flu vaccination annually and pneumococcal pneumonia vaccination can help to reduce respiratory exacerbations. Examinations to regularly screen for hypertension, coronary artery disease, and lung cancer are essential for proper disease management. Supplemental oxygen may also be used in severe cases. The damage caused by COPD is irreversible, but individuals can learn ways of utilizing their remaining lung capacity as efficiently as possible. Inhaled or oral steroids as well as antibiotics when required are also common to assist with disease management. Additionally, pulmonary rehabilitation is a behavioral medicine intervention that promotes exercise, effective breathing, and appropriate medication usage and can increase both length and quality of life for people with COPD (Nguyen, Harrington, et al., 2015; Sahn, Nett, & Petty, 1980).

Bronchial Asthma

General reference: *Bronchial asthma* (World Health Organization, 2016a).

Asthma is a chronic pulmonary disease that is characterized by reversible airflow obstruction. The airways tend to be hyperactive to inhaled substances that cause an allergic reaction in the airways. Airway inflammation is considered to be the fundamental process underlying these features of the disease.

A good history and physical examination are all that is usually required for diagnosis, but in some instances lung function tests may be needed. These include spirometry to assess the narrowing of the bronchi and peak flow meter measurements. Occasionally, diagnosis can only be made by demonstrating hypersensitive airways by provoking the airways to constrict by administering drugs like histamine or methacholine to provoke a reaction in the airway.

Asthma can develop at any age, but typically begins during childhood. Although a common myth is that people outgrow their asthma as they become adults, reoccurrence in later years is common, suggesting persistence of the underlying condition with variation in expression. The classic symptoms of asthma are recurrent wheezing, episodic breathlessness, and chronic cough. Symptoms can be mild and intermittent to severe and life-threatening. A wheeze that occurs when exhaling is especially common in children. Many people with asthma only present with a chronic cough. Symptoms are often worse at night and in the early hours of the morning.

Epidemiology

Asthma is the most common chronic disease among children. The WHO estimates that approximately 150 million individuals around the globe suffer from asthma, and rates appear to be rising by about 50% each decade. Deaths from asthma exceed 180,000 annually and occur much more frequently in low- and middle-income countries and in low-income populations within countries in part due to underdiagnosis and undertreatment as well as air pollution and other environmental factors that are often more pronounced in low-income communities. Asthma creates a substantial burden to individuals and families and restricts an individual's activities for a lifetime. In the United States alone, approximately $6 billion is spent on health-care costs related to asthma each year.

Asthma is likely to have genetic as well as environmental causes. It has been postulated that home construction limiting ventilation, urban living, and/or parental emphases on germ avoidance have led to a lack of exposure of the immune system to infectious antigenic stimuli in childhood. According to this "hygiene hypothesis," this may be a factor in the growing incidence of asthma and other autoimmune and allergic diseases in the developed world (Weiss, 2002). Environmental exposures, however, may also play a role in rising asthma rates; in particular, individuals who live near controlled animal feeding operations that generate high levels of exposures to bacteria are significantly more likely to develop asthma (Heederik, Sigsgaard, et al., 2007; Sigurdarson & Kline, 2006). Parental smoking during pregnancy has also been associated with a significant increase in the likelihood that a child will become asthmatic (Harju, Keski-Nisula, et al., 2016). Additionally, asthma has been linked with obesity, also increasing globally (Beuther, Weiss, & Sutherland, 2006; Chih, Chen, et al., 2016).

Exercise can trigger an attack especially in a cold and dry environment. Irritants in the air, especially those encountered in the workplace like chemical fumes and gases, can also trigger asthma. In many cases, individuals with asthma are allergic to environmental allergens like dander from pets, cockroaches, dust mites, and pollen. Other more general triggers include smoke, drugs like aspirin and beta-blockers, and strong emotions.

Milder forms of asthma disturb sleep, which can impact work productivity including time being away from school or work. Children with milder forms of asthma that have not been diagnosed may only manifest as underperforming academically at school (Mayo Clinic, 2015a). Asthma, however, is a serious disease and is a frequent cause of hospitalizations and avoidable death, especially in low-income groups and families with considerable psychosocial stress in which access to medications and adherence to care may be compromised (Miller & Strunk, 1989).

Prevention, Treatment, and Management

While asthma itself may not be preventable, there are many ways of preventing asthma attacks and managing the disease to live a full life with it (National Asthma Education and Prevention Program Third Expert Panel on the Diagnosis and Management of Asthma, 2007). A noted expert and colleague, Robert Strunk, emphasized in his work that people should not restrict their activities to manage their asthma but should manage their asthma to live full lives. Identifying and avoiding allergens and triggers are important. Flu and pneumonia vaccinations can help in reducing the likelihood that these conditions will trigger an asthma attack. Monitoring and identifying flare-ups and taking the appropriate medications early can also help abort an attack. Management of asthma requires education and patient involvement. A stepwise approach to the management of asthma is now recommended. An asthma action plan, developed in partnership with the patient, can be very useful in monitoring symptoms (Asthma UK, 2016; National Heart Lung and Blood Institute, 2007). In particular, it helps the patient to understand what medications are needed and when and identifies worsening asthma so that help can be obtained early.

Peak expiratory flow meters are portable devices that can be used at home to monitor airflow obstruction, similar to pulmonary function testing discussed under COPD. The mainstay of treatment is inhaled corticosteroids – "controller" medications – which reduce the hypersensitivity of the airways and also reduce inflammation. Short-acting agonists – "responders" – are drugs that dilate the airways to relieve attacks and are generally given through an inhaler, but may also be given orally or intravenously.

Behavioral medicine programs training parents and/or youth with asthma in proper use of medications and medication adherence and avoidance of triggers can reduce symptoms and associated hospital and emergency care (Fisher, Strunk, et al., 2009; Krieger, Takaro, et al., 2009; National Asthma Education and Prevention Program Third Expert Panel on the Diagnosis and Management of Asthma, 2007).

Human Immunodeficiency Virus Infection and Acquired Immunodeficiency Syndrome

General references: *HIV/AIDS* (World Health Organization, 2015c) and *Guideline on when to start ART and on PrEP for HIV* (World Health Organization, 2015b).

The human immunodeficiency virus (HIV) affects and weakens the immune system, which results in reduction in the surveillance and defense systems against infections and some types of cancer. As the virus destroys immune cells, infected individuals gradually become immunodeficient.

Diagnosis of HIV infection occurs through blood tests detecting the presence or absence of HIV antibodies. After infection there may be a latent period of up to 2 weeks before tests become positive. About 50% of infected persons develop symptoms of viral infection about 2–6 weeks after infection. This is called acute retroviral syndrome and may consist of fever, sore throat, rash, and joint pains. Patients then go into an asymptomatic phase in which there is a slow progression to severe immunodeficiency.

Epidemiology

HIV has claimed more than 25 million lives over the past three decades. There were approximately 36.9 million people living with HIV in 2014. Sub-Saharan Africa is the most affected region, with nearly 1 in every 20 adults living with HIV. In 2014, 2 million people were newly infected with HIV. That same year, HIV was responsible for 1.2 million deaths, 150,000 of which were children under 15 years of age (World Health Organization, 2015c).

HIV Transmission Transmission occurs through blood-to-blood contact between infected and non-infected individuals. Most often this occurs through sexual intercourse. Heterosexual intercourse is now the dominant mode of spread around the world. The presence of other sexually transmitted diseases, especially those that are associated with genital ulcers, facilitates sexual transmission of HIV. Intravenous drug use that involves needle sharing is another common form of transmission. A third path of transmission is from an infected mother to child in utero, during labor, or through breastfeeding. The final mode of transmission is through blood products. Fortunately, this has become extremely rare with screening of blood products.

About 50% of untreated individuals develop AIDS within 10 years of HIV infection, 30% develop milder symptoms, and 20% will still be entirely symptom-free after 10 years. Initial manifestation may occur in skin and mucous membranes and manifest as shingles, genital herpes, and oral and vaginal candida infections. As more severe immunodeficiency develops, patients start developing opportunistic infections.

Prevention, Management, and Treatment

Prevention The mainstay of reducing risk of HIV infection is by limiting exposure to the virus and to the risk factors. Key approaches recommended by the WHO for HIV prevention include:

Male and female condom use. Consistent use of male and female condoms during vaginal or anal penetration can be effective against the spread of HIV. Male condoms have an 85% or greater protective effect against the sexual transmission of HIV and other sexually transmitted infections (STIs).

Voluntary medical male circumcision. Medical male circumcision reduces the risk of heterosexually acquired HIV infection in men by approximately 60% and may also be beneficial in preventing HIV transmission in women and lowering sexually transmitted infections in both sexes (Quinn, 2007).

Harm reduction for injecting drug users. People injecting drugs should use sterile injecting equipment, needles, and syringes. The WHO recommends a comprehensive package of interventions for HIV prevention and treatment (World Health Organization, 2014) that includes:

- Programs offering free needles and syringes to discourage sharing these
- Opioid substitution therapy for those dependent on opioids
- Evidence-based interventions, including brief psychosocial interventions for those with harmful alcohol or other substance use
- HIV testing and counselling
- HIV treatment and care
- Low-cost or free access to condoms
- Management of STIs, tuberculosis, and viral hepatitis

Testing and Counselling All people exposed to risk factors should be tested for HIV and other STIs, and if positive they should be encouraged to access necessary prevention and treatment services without delay. The WHO also recommends offering testing for partners or couples.

All testing and counselling services should include the five Cs recommended by WHO (World Health Organization, 2015c): informed consent, confidentiality, counselling, correct test results, and linkage to care, treatment, and other services. Mandatory or coerced testing by health-care providers, government or other authorities, or from partners or family members is generally not advised as it infringes on human rights and discourages high-risk individuals from seeking care and may drive the problem underground. The US Centers for Disease Control and Prevention recommends that “everyone between the ages of 13 and 64 get tested for HIV at least once as part of routine health care” and that those at heightened risk be tested more frequently, including every 3–6 months for sexually active gay and bisexual men (Centers for Disease Control and Prevention, 2016).

Elimination of Mother-to-Child Transmission of HIV HIV transmission from an HIV-positive mother to her child during pregnancy, labor, delivery, or breastfeeding is called vertical or mother-to-child transmission (AIDS info, 2016). If no treatment is instituted, HIV transmission rates are between 15% and 45%. However, if the mother and child are provided with antiretroviral drugs, mother-to-child transmission can be nearly fully prevented. The WHO recommends lifelong treatment should be offered to HIV-positive pregnant women regardless of their CD4 counts.

Management The WHO now recommends that antiretroviral therapy should be initiated in everyone living with HIV at any CD4 cell count (World Health Organization, 2015e). In addition, the use of daily oral preexposure prophylaxis is recommended as a prevention choice for people at substantial risk of HIV infection as part of combination prevention approaches. This expanded use of antiretroviral therapy keeps people living with HIV alive and healthier and reduces their risk of transmitting the virus to partners.

The current antiretroviral drugs do not cure but suppress the HIV infection. These drugs have essentially made HIV/AIDS into a complex chronic disease requiring long-term and continuing management. To monitor their benefit, CD4 (which is a measure of the degree of immunodeficiency) and plasma viral load (which is an indication of degree of viral replication) should be assessed every 3–4 months to assess the progression of the disease.

Antiretroviral therapy has also been used for prevention. If an HIV-positive person adheres to an effective antiretroviral therapy regimen, the risk of transmitting the virus to their uninfected sexual partner can be reduced by 96%. For couples in which one partner is HIV-positive and the other HIV-negative, the WHO recommends offering antiretroviral therapy to the HIV-positive partner regardless of her/his CD4 count. Additionally, antiretroviral drugs taken by the HIV-negative partner can be effective in preventing HIV transmission from the HIV-positive partner.

Following exposure to HIV, the use of antiretroviral drugs within 72 h of exposure can prevent infection. This is often recommended for healthcare workers following needlestick injuries in the workplace.

Tuberculosis

General reference: *Tuberculosis (TB)* (World Health Organization, 2015e).

Tuberculosis (TB) is caused by the bacteria, *Mycobacterium tuberculosis*, and most often affects the lungs. TB is spread from person to person through air droplets. Active TB manifests as cough, fever, night sweats, and weight loss. Symptoms may be mild for weeks, which may lead to delayed care-seeking as well as increased time for transmission to other people. Tuberculosis often affects young adults, in their most productive years. TB has a high mortality rate without treatment.

Epidemiology

According to the WHO (World Health Organization, 2015e), TB is second only to HIV/AIDS as the greatest worldwide killer caused by a single infectious agent. In 2011, 8.7 million people fell ill with TB and 1.4 million died from it. Over 95% of TB deaths occur in low- and middle-income countries, and it is among the top three causes of death for women aged 15 to 44. Because HIV weakens immune protection, TB is a leading killer of people living with HIV, causing one-quarter of all deaths among them.

Tuberculosis is closely linked with poverty. Overcrowding and malnutrition are common predisposing factors. Diabetes, smoking, and alcoholism are also significant risk factors for tuberculosis.

Many people have latent TB. Although infected with TB, they remain asymptomatic. People who are co-infected with HIV and TB are 20 to 30 times more likely to become sick with active or symptomatic TB. Risk of active TB is also greater in persons suffering from other conditions that impair the immune system.

Prevention, Management, and Treatment

TB is a treatable and curable condition. Active, drug-sensitive TB is treated with a standard 6-month course of four antimicrobial drugs. It is recommended that the drugs are given under direct supervision by a health worker to ensure adherence, also called directly observed therapy or DOT. This is in the interest both of the infected individual and of the broader community in order to avoid partially completed treatment, which can provide the opportunity for development of drug-resistant strains of TB.

Multidrug-resistant tuberculosis (MDR-TB) is a form of TB caused by bacteria that do not respond to isoniazid and rifampicin, the two most powerful, first-line (or standard) anti-TB drugs. It is becoming more common. This is attributable to several factors, including the increasing prevalence of TB linked with the worldwide HIV/AIDS problem and frequent poor adherence, providing suboptimally treated bacteria the opportunity for mutations to drug-resistant forms. Patients with multidrug-resistant TB require more toxic second-line drugs that need to be given for longer periods.

Mental Disorders

General reference: *Mental health action plan 2013–2020* (World Health Organization, 2013).

Mental disorders are changes in thoughts, feelings, and behaviors that produce significant distress or affect the person's ability to function effectively. Mental health is an integral part of health and well-being. This is reflected in the definition of health in the Constitution of the World Health Organization: "health is a state of complete physical, *mental and social well-being* and not merely the absence of disease or infirmity" (emphasis added) (World Health Organization, 1946).

The Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association, 2013) is widely used as the standard diagnostic manual for diagnosing mental disorders. It is now in its fifth edition (DSM-5), which provides a better framework to guide accurate and consistent diagnoses and the study of associations between disorders. Categories of mental disorders included in DSM-5 (American Psychiatric Association, 2013) are presented in Table 2.2.

Table 2.2 Categories of mental disorders included in DSM-5

Classification of mental disorders (DSM-5)
Neurodevelopmental disorders
Schizophrenia spectrum and other psychotic disorders
Bipolar and related disorders
Depressive disorders
Anxiety disorders
Obsessive-compulsive and related disorders
Trauma- and stressor-related disorders
Dissociative disorders
Somatic symptom disorders
Feeding and eating disorders
Elimination disorders
Sleep-wake disorders
Sexual dysfunctions
Gender dysphoria
Disruptive, impulse control, and conduct disorders
Substance use and addictive disorders
Neurocognitive disorders
Personality disorders
Paraphilic disorders
Other disorders

Mental problems can also be understood using the perspective of lifespan development with some specific mental disorders typically diagnosed in childhood (e.g., autism spectrum disorder), adolescence (e.g., eating disorders), early adulthood (e.g., schizophrenia), adulthood (e.g., depressive and anxiety disorders), and late adulthood (e.g., neurocognitive disorders).

Epidemiology

According to the WHO (World Health Organization, 2013), certain individuals and groups may be at a higher risk of developing mental health problems. In addition to genetic predispositions, exposure to adversity at a young age is an established preventable risk factor for mental disorders. Other causes of vulnerability include economic poverty, other chronic diseases, membership in ethnic groups that are subject to discrimination, human rights violations, discrimination based on sexual identity, living in war zones, exposure to natural disasters, and exposure to domestic violence and abuse.

Mental disorders frequently lead to poverty and homelessness. Stigmatization and discrimination may result in restriction of the right to work or obtain an education. In many countries, health insurance coverage or available services for mental problems are less comprehensive than for physical health problems.

Mental health problems are associated with elevated risk of disability and mortality (Sartorius, Holt, & Maj, 2015). Reviews indicate the odds ratio for the effect of depression on all-cause mortality is 1.7 and the relative risk for schizophrenia is 2.59 (Prince, Patel, et al., 2007). Mental disorders are also strongly associated with suicide risk, suicide being the second most common cause of death among young people worldwide.

Comorbidity Mental disorders may affect and in turn be affected by many other diseases. Diseases like cancer, cardiovascular disease, diabetes, and HIV/AIDS are associated with elevated levels of depression and anxiety disorders. Conversely, anxiety and depression predispose people to myocardial infarction and diabetes (see Snook, et al., *infra*). Many risk factors such as low socioeconomic status, alcohol use, cigarette smoking, and stress are common to both mental disorders and noncommunicable diseases.

Mental health problems are discussed in further detail in Chap. 30 by Snoek et al., *infra.* Here we focus on three broad areas of frequent concern in behavioral medicine: depression, anxiety disorders, and schizophrenia.

Depression (World Health Organization, 2016e)

Depression is characterized by sadness or depressed mood and loss of interest or pleasure. Depression should be distinguished from day-to-day emotional responses to challenges in daily living. Moderate to severe depression can result in great suffering and can lead to suicide.

Depression is a common illness worldwide; it accounts for 4.3% of the global burden of disease and is among the largest single causes of disability worldwide at 11% of all years lived with disability globally. It is more common in women. While depression is very common, much of it goes unrecognized, and even when recognized, it may be untreated or inadequately treated. Social stigma associated with depression is a major barrier in treatment.

Diagnosis and Symptoms The cardinal symptoms of depression are a depressed mood with loss of interest, an inability to experience pleasure in normally enjoyable acts (anhedonia), and a reduced energy. In addition to poor self-esteem, guilt and disturbed sleep and appetite are common. Thoughts about self-harm may also occur. The more of these clinical features the patient displays, the more severe depression is judged to be. Anxiety symptoms like irrational worry, fear, and feeling tense often coexist with depression.

It is important to distinguish people with depression who have manic episodes. Bipolar disorder typically consists of both manic and depressive episodes separated by periods of normal mood. Manic episodes involve elevated or irritable mood, hyperactivity, rapid or pressured speech, inflated self-esteem, and a decreased need for sleep with increased energy. Poor judgment may lead to financial or other decisions harmful to the self.

Contributing Factors and Prevention Depression is often caused by the interaction of social, psychological, and biological factors. There are interrelationships between depression and physical health. For example, both cardiovascular disease and type 2 diabetes can lead to depression and vice versa.

Prevention programs can reduce depression. These include community approaches like prevention of child abuse and domestic abuse and/or measures that enhance cognitive, problem-solving, and social skills of children and adolescents (Gladstone, Beardslee, & O'Connor, 2011). Exercise programs also help to prevent or manage depression (Stanton & Reaburn, 2014).

Management Depression can be reliably diagnosed and effectively treated. Treatment options for moderate to severe depression include psychosocial support and psychotherapy, which may include cognitive behavior therapy, interpersonal psychotherapy, or problem-solving treatment. Medications are often beneficial in severe, recurrent depression and should be considered along with psychological treatments.

Suicide and Suicide Prevention According to the WHO (World Health Organization, 2015e), almost 1 million people die from suicide every year, a global mortality rate of 16 per 100,000, or one death every 40 s. Suicide is among the three leading causes of death among those aged 15–44 years in some countries and the second leading cause of death in the 10–24 years age group. In addition to these, suicide attempts are up to 20 times more frequent than completed suicide.

In addition to depression, alcohol use disorders and impulsivity are major risk factors for suicide. Suicide prevention involves multiple strategies (Mann, Apter, & Bertolote, 2005). Managing depression and alcohol and substance abuse effectively as well as follow-up with those who have attempted suicide can reduce suicide rates. Strategies restricting access to common methods of suicide like firearms or pesticides have also been shown to be effective in reducing suicide rates.

As many as two-thirds of those who commit suicide will have had contact with a primary care physician within the previous month. Thus, vigilance by health-care providers to identify vulnerable individuals may be an important preventive strategy (Luoma, Martin, & Pearson, 2002).

Anxiety and Stress-Related Disorders

From the perspective of the evolution of *Homo sapiens*, anxiety is an important adaptive response to a threat (National Institute of Mental Health, 2016b). In many circumstances of contemporary life, however, it can become maladaptive. Features of maladaptive anxiety include the response being disproportionate to the level of threat, persistence or worsening, disruption of normal functioning, or association with appreciable physical symptoms. Such features may become associated with enduring changes in behavior, cognition, and patterns of behavior such as in phobias or other patterns of avoidance or in obsessive or compulsive patterns.

The DSM-5 groups together generalized anxiety disorder, social phobia, specific phobia, and panic disorder in the general category of "anxiety disorders." It distinguishes them from other conditions generally viewed as also related to anxiety and stress, including obsessive-compulsive disorders and post-traumatic stress disorder.

Genetic predispositions contribute to some anxiety and stress disorders, including those characterized by panic, generalized anxiety, or agoraphobia as well as phobias about specific objects, like insects or some animals. Environmental stressors, however, play an important role. Nearly all of the anxiety disorders are affected in some way by external prompts and the way the individual processes or reacts to them.

Diagnosis Patients with anxiety and stress disorders experience emotional distress with troubling thoughts and somatic symptoms that may be accompanied by disturbances of sleep, concentration, or social or occupational functioning. The various disorders, however, differ in presentation and treatment.

In generalized anxiety disorder, the patient experiences consistent worry over multiple areas of his or her life for at least 6 months (National Institute of Mental Health, 2016b).

Panic attacks are characterized by a transient episode of intense fear and a sense of impending doom (e.g., fear of dying, losing control), with accompanying physical symptoms, such as chest pain, dizziness, and shortness of breath. If such acute anxiety episodes occur in predictable response to external stimuli, the disorder is called phobia. Examples include phobia induced by animals, heights, and interpersonal situations (social phobia).

Post-traumatic stress disorder (PTSD) has gained considerable attention in recent years as it has been widely recognized among veterans of combat as well as victims of a number of other traumatic stressors, including sexual violence and discrimination related to ethnic and sexual identity and, especially in community samples, loss of a loved one (Breslau, Kessler, et al., 1998). Additionally, DSM-IV identified acute stress disorder (ASD) as a disorder which also follows a severely stressful event like the near loss of life or limbs. The symptoms of both these conditions are the same and include re-experiencing thoughts and memories including nightmares and flashbacks, avoiding situations that remind the individual of the event and symptoms that increase arousal like irritability, outbursts of anger, irritability, and sleep difficulties (American Psychiatric Association, 1994). PTSD and ASD differ primarily in terms of whether diagnosis is made within or after 4 weeks following an instigating traumatic event, although some controversy surrounds their differentiation (Bryant, Friedman, et al., 2011).

Obsessive-compulsive disorder (OCD) manifests as recurrent obsessions (thoughts and impulses that are difficult to suppress) and compulsions (repetitive behaviors) that serve to reduce anxiety (National Institute of Mental Health, 2016a).

Management Anxiety and stress disorders can often be treated effectively with psychological therapy (National Institute of Mental Health, 2016b). Key strategies include the behavioral and cognitive approaches of encouraging positive behavior, exposure-based interventions that extinguish anxiety responses to feared stimuli, and changing dysfunctional patterns of thinking that often surround anxiety and responses to stimuli that evoke it. Anxiolytic medications and, increasingly, antidepressant drugs are often prescribed in moderate and severe anxiety disorders.

Psychotic Disorders and Schizophrenia

Psychotic disorders are mental disorders in which thoughts and emotions are so impaired that there is a loss of contact with external reality. The prototypical psychotic disorder is schizophrenia, a chronic and severe mental disorder that affects how a person thinks, feels, and behaves (National Institute of Mental Health, 2016a; World Health Organization, 2016g). Manifestations of schizophrenia include hallucinations (false sensory perceptions), delusions (fixed false beliefs), and thought process disturbances. The split referred to in the name, “schizophrenia” (as in “schism”) does not refer to multiple personalities, but an inferred splitting off from reality. Over time, individuals with schizophrenia experience a progressive decline in function marked with apathy, social withdrawal, lack of will or motivation, and blunted affect (lack of emotional expressiveness).

Symptoms of schizophrenia may be characterized as positive or negative. Among the positive are active hallucinations, delusions, thought disturbances, and inappropriate verbal and overt behavior. Among the negative symptoms are withdrawal, flat affect, and diminished feelings or pleasure disturbance. Compared to positive symptoms, negative symptoms have been linked to worse outcomes and poorer functioning (Rabinowitz, Levine, et al., 2012).

Schizophrenia has been estimated to affect between 0.5% and 1% of the world’s population with an onset in late adolescence and early adulthood (Centers for Disease Control and Prevention, 2013a). Onset tends to be later in women. It accounts for more days of hospitalization worldwide than any other health problem. Approximately one-third of individuals with schizophrenia attempt suicide. The exact etiology of schizophrenia is unknown, but it is clearly multifactorial with strong genetic factors interacting with psychosocial and developmental factors (National Institute of Mental Health, 2016b). Heritability includes propensity for a range of related problems referred to as schizophrenia spectrum disorders, schizoid tendencies, or schizo-affective disorder.

As with other chronic conditions, management of schizophrenia focuses on maintaining social roles and quality of life, not cure. Psychosocial programs help patients manage interpersonal stressors and facilitate maintenance of key social roles such as employment. Family interventions (Goldstein, 1992) have been shown to be successful in reducing families’ reactions to their family member with schizophrenia; for example, criticality and emotional overinvolvement are understandable, but nevertheless exacerbate disturbance. These interventions have been shown to reduce hospitalization (Falloon, Boyd, et al., 1982). Programs that provide structured living and work environments may enable those with schizophrenia to live relatively independently and enjoy satisfying lives. Most will require antipsychotic medications especially to treat acute psychotic episodes. However, these medications may have side effects like movement disorders and may contribute to obesity and, thereby, diabetes and cardiovascular disease.

Conclusion

Our understanding of disease and illness over the past decades has included a growing recognition of multifactorial causes including genetic, psychological, and social factors, all of which contribute to our risks of morbidity and mortality. Our lifestyles and behaviors are strongly influenced by the family, community, economic, and physical environments in which we live, and as such these environments contribute substantially to many of the diseases we suffer. As our understanding of disease development has come to recognize the interactions among these many influences, so our understanding of diseases has come to recognize interactions among them. These include the influences of mental health and physical diseases on each other and the fact that, especially among chronic conditions, co-occurrence of several or "comorbidity" is normative.

Behavioral medicine of the future will focus much attention on the interactions among influences and among conditions detailed here. Health, prevention, and health care of the twenty-first century will increasingly recognize the interplay of biology, behavior, and environment in leading to illness and in helping to prevent, cure, and manage it. In these, the behaviors and lifestyles of individuals and groups will play central roles.

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Risky Behaviours

3

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Behaviours and Health

Human behaviours play significant roles in health promotion and disease prevention. As discussed in this chapter, the aetiology of many diseases is influenced by a combination of non-modifiable, medical and psychosocial factors, but certain behaviours are highly associated with increased mortality and morbidity. Although physiological predictors are important, many chronic (communicable and noncommunicable) diseases can also be understood in terms of modifiable lifestyle or behavioural risk factors. Undoubtedly, understanding and changing behaviours pose great challenges as they can never be explained by one simple process (e.g. one gene or one virus). Instead, the interplay between biological, psychological, social, organizational and system/policy-related factors within cultural contexts needs to be considered. As some risk factors (e.g. age, family history and race/ethnicity) and health are often unchangeable, strategies that focus on modifying maladaptive behaviours or adopting health-protective ones may be especially effective means for promoting health and preventing diseases.

People in all walks of life engage in various types of behaviours that are directly or indirectly affecting their health status and/or future health outcomes. "Health behaviour" can be defined as any activity undertaken for the purpose of preventing or detecting disease or for improving health and well-being (see Conner & Norman, 1995 for a review). However, it must be noted that although health behaviours do have health implications, individuals are not necessarily driven by health goals when they engage in those behaviours. For example, exercise may be performed for different reasons such as personal enjoyment, social engagement and/or weight management. Health behaviours, in general, can be categorized into two groups: health enhancing or health impairing. Behaviours such as physical activity, healthy dietary intake, weight control, sun protection and cancer screening are health protective and can enhance health or facilitate early detection of diseases. Risky behaviours, by contrast, are any activities that will increase the likelihood of disease onset and injury. More specifically, they are risk factors that can raise the

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probability of adverse health outcomes (World Health Organization, 2009a). Behaviours such as sedentary lifestyle, low fruit and vegetable consumption, smoking, excessive alcohol consumption, unsafe sexual practices and non-compliance to medical recommendations are likely to put one at risk of developing future illnesses and/or accelerating disease progression. Intuitively, individuals should opt for health-enhancing rather than health-impairing behaviours; however, the decision to adopt health-enhancing behaviours and quit the risky ones is not always a straightforward process.

As people travel through the lifespan, they face different health risks and problems. As a result, their preventive needs and goals change with age. For example, adolescents have become more sedentary due to increased screen-based behaviours (e.g. television and computer use). Young adults may consume alcohol more often because of the social groups they belong to. Working class individuals may develop unhealthy eating habits due to more convenient access to fast food, and the middle-aged to older populations may not have adhered to their medical regimens and/or regular screening recommendation. Even though people are sometimes fully aware of their risky behaviours, knowledge alone is often insufficient to stop people from doing them. For some chronic diseases, education was found to have only small to moderate effects on disease outcomes and patient empowerment (see Warsi, Wang, et al., 2004 for a review). Moreover, some risky behaviours may be enjoyable and addictive, while the adverse effects of which can be too long delayed to be perceived. All these make behaviour change an even more challenging task.

Rising cost in lives lost and medical costs due to risky lifestyle behaviours have posed health and economic burdens to both developed and developing countries (e.g. Dans, Ng, et al., 2011; Pratt, Macera, Wang, 2000). In 2005, the World Health Organization (WHO) reported that 60% of worldwide deaths are related to noncommunicable diseases such as cardiovascular disease, stroke, cancer, diabetes and chronic respiratory diseases, with over 80% of these deaths occurring in low- and middle-income countries (World Health Organization, 2005). Scientific evidence has shown that some key behavioural determinants and lifestyle factors are related to these health conditions.

Health Risk Behaviours

The WHO identified the leading risk factors for mortality around the globe in 2008. They were high blood pressure (responsible for 13% of world deaths), tobacco use (9%), high blood glucose (6%), physical inactivity (6%), overweight and obesity (5%), high cholesterol (5%), unsafe sex (4%) and alcohol use (4%) (World Health Organization, 2009a). Of these, the four that are not themselves behaviours, high blood pressure, high blood glucose, overweight and obesity and high cholesterol, are nevertheless strongly influenced by diet, physical activity and other risk behaviours (Brown & Siahpush, 2007; Bullen, 2008). The global spread of these health risks is also transiting to low- and middle-income countries where the burden of chronic and noncommunicable diseases may be in multiples of that in high-income ones. For burden of diseases (measured in terms of disability-adjusted life years (DALYs)), the leading risks were underweight (6% of global DALYs), unsafe sex (5%), alcohol use (5%) and unsafe water, sanitation and hygiene (4%), followed closely by high blood pressure (4%) and tobacco use (4%) (World Health Organization, 2009a).

There are unique demographic and geographic patterns in the distribution of these health risks. For example, in many underdeveloped countries, undernutrition continues to be a primary concern related to unhealthy diet. People consume insufficient protein, vitamins and minerals which potentially affect the development of children. Among the developed and developing countries, rising body mass index increases people's risk of developing noncommunicable diseases. The transition of risk factors (e.g. from underweight to obesity) and the double burden of diseases (coexistence of infectious and noncommunicable diseases) in developing countries (e.g. India) highlight more serious health, social and economic implications affecting developing regions (Gupta, Joshi, et al., 2008).

It is critical to understand why some individuals are more exposed to certain health risks and are more vulnerable to developing some kind of diseases than others. The initiation and maintenance of risky behaviours can be attributed to individual health choices, sociocultural values and the environment in which one is situated. The determinants of engaging in these health risk behaviours work at different levels, and some may be more impactful than others for certain subgroups in the population. Besides, some individuals may be more at risk to engage in certain types of behaviours depending on their developmental phases in the lifespan. An ecological approach to understanding the contributions of these factors takes into account the multilevel influence of individual, social, community, organization, environment and policy (Sallis & Owen, 2015).

Figure 3.1 illustrates the ecological model of the determinants of health behaviours across the human lifespan. At an individual level, evidence has demonstrated that health behaviours are underpinned by complex decision-making and goal-setting processes influenced by cognitive, affective and social variables (Ajzen, 1985; Cameron & Leventhal, 2003; Conner & Norman, 2005). In addition, a range of environmental and contextual factors are related to health behaviours in youths (e.g. Brown, Pfeiffer, et al., 2009; De Wit, Stok, et al., 2014; Lawman & Wilson, 2012) and adults (e.g. Giskes, van Lenthe, et al., 2011; Wendel-Vos, Droomers, et al., 2007).

Family influence is powerful especially early in individuals' developmental phases. For children and adolescents, the family plays a primary role in shaping cultural and social values, beliefs and tradition behaviours (DiClemente, Santelli, & Crosby, 2009). This can include transfer of health knowledge, facilitation of adopting healthy habits and discouraging health risk behaviours. Familial support for health behaviours may be social, emotional, tangible or instrumental and may be transmitted through modelling. As people develop through the lifespan, school, community, neighbourhood and workplace also provide additional settings to facilitate the adoption and maintenance of health (risk) behaviours.

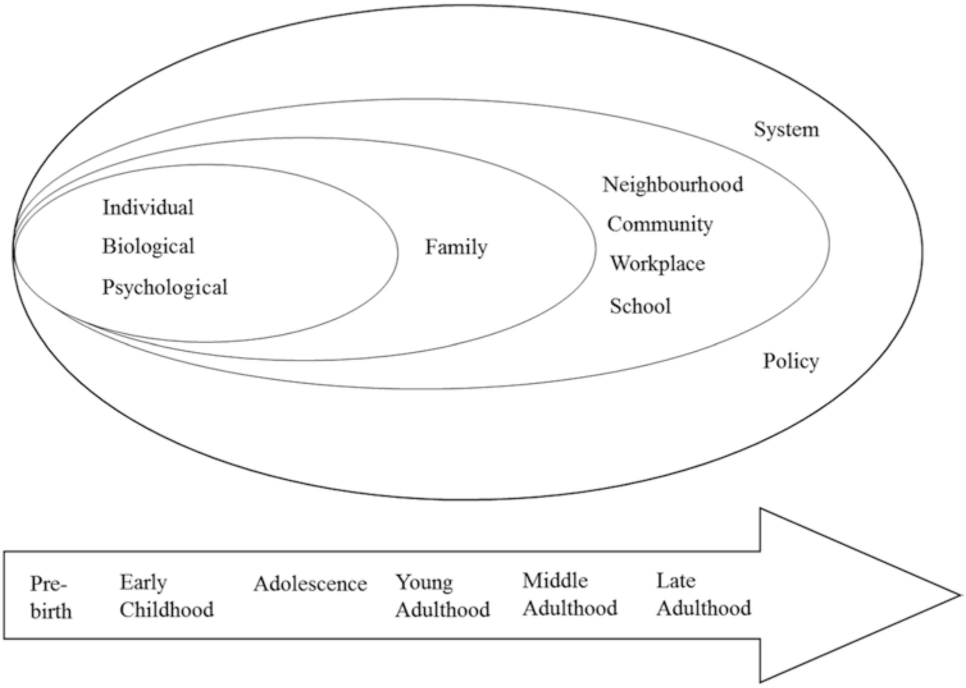

Fig. 3.1 An adapted ecological model of the determinants of health behaviours throughout the life course

Last but not the least, the involvement of the society at a health system or policy level can reduce certain risky behaviours. Policies and health systems can have great impact on whole populations over a long period of time. Policy initiatives can provide directives for investing in relevant and appropriate resources as well as collaborating with public and private stakeholders in supporting individuals to take health-protective actions. These directives and collaborations can foster opportunities (e.g. urban planning with the presence of safe walking trails), facilitate support (e.g. access to affordable healthy food) and provide cues (e.g. economic and labelling disincentives for unhealthy choices) to help people adopt healthy or reduce unhealthy behaviours. Modifying the environment and changing policies may lead to more permanent behaviour change than conducting individual-based health promotion programmes although the time lag between scientific discovery and policy uptake and adoption remains very long. The translation of research evidence to policy and healthcare delivery is particularly important in high-risk populations and resource-poor and developing countries because chronic diseases and health risk behaviours are likely to be more prevalent among these peoples and regions (Chan, Oldenburg, & Viswanath, 2015).

In general, policy approaches can influence behaviours via three major pathways: physical environment and access, economic environment and communication environment (Brownson, Haire-Joshu, & Luke, 2006; Novak & Pelaez, 2004) (see also chapter by Sherlaw et al. in this volume). The orientation of health systems towards preventing and controlling chronic diseases may promote the reduction of risk behaviours. Many healthcare systems have a focus on managing acute health problems such as infectious diseases and maternal and child health. Gradually shifting the healthcare system to address the chronicity of many diseases at this new age is an ongoing challenge but may be a more feasible and sustainable strategy to address the shift in health risks, especially for developing countries (Allotey, Reidpath, et al., 2011; Yasin, Chan, et al., 2012).

Identifying the ecological determinants of risky behaviours at different points in the lifespan is crucial for designing effective intervention strategies. Additionally, understanding the characteristics and distributions of these modifiable risky behaviours can help target specific subgroups in the population who are at greater risk of developing and maintaining unhealthy behaviours.

Table 3.1 summarizes the associations of some common risk behaviours and their diseases.

Table 3.1 Common health risk behaviours and their associations with chronic diseases

	Some common chronic diseases						
Risk factors	CVD	Diabetes	Cancer	Stroke	Chronic respiratory diseases	Hypertension	HIV/AIDS
Overweight/obesity	X	X	X	X		X	
Sedentary behaviour	X	X	X	X		X	
Physical inactivity	X	X	X		X	X	
Elevated cholesterol	X	X	X	X		X	
Low fruit and vegetable intake	X	X	X	X		X	
Energy-dense diet	X	X	X	X		X	
Tobacco use	X	X	X	X	X	X	
Excessive alcohol consumption	X		X	X			
Unsafe sexual practices			X				X
Omission of appropriate medical screening and vaccination		X	X		X	X	

Many health risk behaviours including sedentary and physically inactive lifestyle, unhealthy diet, tobacco and alcohol abuse, unsafe sexual practices and omission of recommended screening and vaccination programmes are preventable and modifiable. They can also be specifically defined to be addressed in health promotion programmes. This chapter describes a sample of these common risky behaviours that are associated with increased burden of diseases across the lifespan. It also reviews risk factors that are closely related to behaviours, such as obesity. The determinants related to the development and maintenance of these behaviours are addressed within various contexts. The multiple levels at which determinants operate will be considered globally using the ecological approach and with reference to different populations.

Gene-environment interactions are important determinants of several behavioural risks, including obesity (Bouchard, 2008; Qi & Cho, 2008), alcohol consumption and tobacco use (Heath, Madden, et al., 2003). These are not covered in the present chapter but are addressed extensively in the chapter on genetics, behaviour and behaviour-genetic interactions by Nater and colleagues (*infra*).

Overweight and Obesity

Although obesity is not, itself, a behaviour, it is so closely related to behaviours and such a growing, worldwide health problem that it deserves inclusion in its own section of a chapter on *risky behaviours*. At its base, obesity is a result of imbalance of energy expenditure and intake over time. When one's energy expenditure cannot compensate with one's energy intake, the gradual positive shift of caloric intake can result in obesity. Among adults, obesity and overweight have been defined through the use of the body mass index (BMI), a measure of weight relative to height (kg/m^2). It is generally recommended that adults maintain their BMI within the range between 18.5 and 24.9. A BMI of 25 or above and 30 or above indicates overweight and obese status, respectively. While this is a general guideline for assessing obesity risk across all age groups of adults and both genders, some adjustment for population differences may be needed to take into account the variability in normative weight and general body-build. For example, individuals who come from cultures of smaller body-built (e.g. Asia) may be overweight even when their BMI has not reached the general guideline. For groups of Chinese origin, BMI values of 24.0 (for men) and 23.0 kg/m^2 (women) have been recommended as cutoffs for obesity (Zeng, He, et al., 2014). A waist-to-hip ratio has been suggested to be more indicative and be more accurate in defining overweight and obesity in Asia. Waist circumference is another measure to identify those at risk by virtue of overweight (men, greater than or equal to 102 cm; women, greater than or equal to 88 cm) (Han, Lean, & Morrison, 1995).

Obesity and Health Outcomes

Energy imbalance, overweight and obesity pose significant health, social and economic burdens to individuals and societies. The burden of overweight and obesity accounts for approximately 10% of direct medical costs of countries globally (Withrow & Alter, 2011). In 2010, overweight and obesity have caused 3.4 million deaths worldwide (Ng, Fleming, et al., 2014), some as a result of chronic conditions associated with overweight and obesity (e.g. diabetes). Elevated BMI has multiple adverse metabolic effects on blood pressure, cholesterol and insulin resistance. The burden of some common chronic conditions can be attributed to overweight and obesity. These include 44% of diabetes, 23% of ischaemic heart disease and between 7 and 14% of certain types of cancer (World Health Organization, 2000, 2009a). Evidence has documented the relationship between obesity and cardiovascular disease (Pérez Pérez, Ybarra Muñoz, et al., 2007) and pancreatic cancer (Michaud, Giovannucci, et al., 2001). Excessive body weight is also a risk factor of osteoarthritis (Grotle, Hagen, et al., 2008) and lower back pain (Shiri, Karppinen, et al., 2010).

Early onset of obesity will have lifelong impact on health and well-being. Consistent evidence has shown that overweight and obesity during childhood and adolescence can lead to premature mortality and physical morbidity such as diabetes, hypertension and ischaemic heart diseases in adulthood (e.g. Reilly & Kelly, 2011). Apart from physical consequences, other adverse psychological and behavioural issues associated with increasing BMI among children include poorer self-esteem (Mirza, Davis, & Yanovski, 2005; Strauss, 2000), lower peer esteem (Mirza, Davis, & Yanovski, 2005), higher levels of sadness and loneliness and development of other risk behaviours, e.g. smoking and alcohol consumption (Strauss, 2000).

Who Is Overweight or Obese?

According to data from the WHO, more than 1.9 billion adults, 18 years and older, were overweight in 2014, among whom 600 million were obese. This amounted to a global adult prevalence of 39% for overweight and 13% for obesity (World Health Organization, 2015b).

The current prevalences of overweight and obesity reflect sharp increases in recent decades. The prevalence of obesity, for example, had nearly doubled between 1980 and 2008 (World Health Organization, 2014f). Similarly, the prevalence of those who were overweight had increased from 29 to 37% for men and from 30 to 38% for women between 1980 and 2013 (Ng, Fleming, et al., 2014). It is estimated that by 2030, the global prevalence of overweight may be 38% and that for obesity may rise to 19.7%. With projected population growth, this would result in 2.16 billion overweight and 1.12 billion obese adults worldwide (Kelly, Yang, et al., 2008).

Overweight and obesity among children have drawn increasing alarm and have become public health concerns worldwide. The global prevalence of overweight and obesity among children had grown from around 5% in 1990 to 7% in 2012 (World Health Organization, 2014f). For 2013, the WHO estimated that 42 million children under the age of 5 were overweight or obese (World Health Organization, 2015b). This rise of infant and childhood obesity is not confined to high-income groups but has been observed in low- and middle-income countries (World Health Organization, 2011b).

There is considerable difference in the distribution of obesity around the globe. Certain groups of people are more likely to be obese than others. According to the World Health Statistics, in 2008, the prevalence of obesity among adults was the highest in the WHO region of the Americas (23.5% for men, 29.7% for women), followed by the WHO region for Europe (20.4% for men, 23.1% for women) and the WHO region for the Eastern Mediterranean (13% for men, 24.5% for women). By contrast, the WHO region for Africa (5.3% for men, 11.1% for women) and WHO region for Western Pacific (5.1% for men, 6.8% for women) had much lower prevalence, with the WHO region for Southeast Asia (1.7% for men, 3.7% for women) the lowest (World Health Organization, 2014f). These regional differences, however, need to be considered in light of the use of Western BMI norms for obesity.

Some clear patterns of gender differences emerged. In the top three WHO regions, over half of the women were overweight, and among the overweight, half were obese. In all WHO regions, women were more likely to be obese than men. For example, teenage Iranian girls showed a higher prevalence of overweight and obesity than boys (Kelishadi, Pour, et al., 2003). Other factors must interact with gender, however, to explain overweight and obesity risk. Among adolescents in the United States, for example, males have been found to have higher intakes of energy and fat, and females are more likely to meet healthy eating recommendations (Xie, Gilliland, et al., 2003).

Obesity was once considered a problem in high-income countries due to economic growth, urbanization and westernization. Indeed, statistics still show that the prevalence of raised BMI increases as a function of countries' income level (Neuman, Finlay, et al., 2011). Although the prevalence may seem low relative to the high- and middle-income countries, among low- and middle-income countries, there is a trend of rapid increase in overweight and obesity prevalence (e.g. in the Middle East, North Africa, Latin

America and the Caribbean) (Popkin & Gordon-Larsen, 2004; Prentice, 2006), upward shift in BMI levels for the overweight and obese and rising waist circumference across age groups (e.g. in China) (Popkin & Slining, 2013). Asia may seemingly have a lower prevalence in overweight and obesity relative to other regions; however, the fast rate of increase and the early onset among younger populations and in those with lower BMI have posed serious concerns (Yoon, Lee, et al., 2006). All these imply that these regions will be hit by more chronic diseases in upcoming years.

Overweight and obesity seem to be unequally distributed within countries with racial/ethnic minorities having the highest obesity risk across different socioeconomic status (SES) groups (Scharoun-Lee, Kaufman, et al., 2009). In the United States, for example, ethnic disparities in BMI and waist circumference are apparent and have become wider between non-Hispanic blacks and non-Hispanic whites (Beydoun & Wang, 2008). This may be explained, in part, by differences in dietary intake among these groups. In the United States, blacks have been found to have the highest intake of energy and total fat (Xie, Gilliland, et al., 2003). Minority populations, especially minority women, are disproportionately affected (Rosenberg, Kipping-Ruane, et al., 2013).

More important than ethnicity, there is a relationship between SES and obesity patterns (Scharoun-Lee, Kaufman, et al., 2009). These relationships are moderated in complex ways, however, by the income level of the country. Within more affluent or industrialized countries, the relationship between obesity and income tends to be inverse. Socioeconomic status (e.g. income, education and occupation) and associated factors such as food insecurity help explain disparities in prevalence of overweight and obesity (Ali & Lindström, 2006). Income is influential in determining dietary intake (e.g. fat, protein, vegetable and carbohydrate and sugar intake) and subsequently body weight. By contrast, within some developing countries such as China and the Philippines, increase in income is associated with higher dietary fat consumption (Popkin & Gordon-Larsen, 2004; Popkin, Paeratakul, et al., 1995). While childhood obesity remains largely a problem of the more affluent low- and middle-income countries, the pattern for adults is somewhat mixed. There is emerging evidence to suggest, however, that the burden of obesity is shifting towards the poor in middle-income countries. In low-income countries, obesity increases with SES for both genders, but this association is mixed for men and is largely inverse for women in middle-income countries (Dinsa, Goryakin, et al., 2012).

Education is another major SES factor associated with diet and obesity. Higher education level is associated with lower body weight in developed countries. For children, parental education is a strong predictor of childhood obesity (Lamerz, Kuepper-Nybelen, et al., 2005). More educated adults and parents are probably more likely to follow dietary recommendations and adopt less risky behaviours than their less educated counterparts. Furthermore, evidence has shown that adolescents from lower SES backgrounds tended to have poorer diets, more fat and refined sugar intake and less consumption of fruits and vegetables (Hanson & Chen, 2007; Xie, Gilliland, et al., 2003).

What Explains Excessive Weight?

The search for biological determinants of obesity has included examination of genetic composition and family history. Scientific advances have suggested some evidence that obesity may be related to genetic defects with several candidate genes identified playing significant roles in its pathogenesis (Boutin & Froguel, 2001). Genetic variations may affect the physiological regulation of hunger, satiety and food intake (Bell, Walley, & Froguel, 2005). Although a biological explanation for the development of obesity seems plausible, the surge in obesity in the past few decades, far more rapid than population genetic shifts can explain, points to the importance of environmental factors and lifestyle changes towards more caloric intake and less energy expenditure.

The two most proximal risk factors for maintaining long-term energy imbalance, overweight and obesity are sedentary lifestyle and/or insufficient physical activity and unhealthy eating habits (particularly the consumption of energy-dense diet). In addition to their impact on obesity, they influence a number of other health conditions. Sedentary lifestyle and fruit and vegetable consumption are discussed in separate sections of this chapter. More general unhealthy eating is discussed in the following.

Determinants of Unhealthy Eating

Sociocultural Factors

For children and youths, the physical and sociocultural environments influence children's eating patterns and diet quality, mostly at the individual and household levels. Physical factors include availability and accessibility of food options and portion sizes. What is readily available at home, easily accessible and ready to be eaten determine children's eating behaviours. Children are also more likely to eat more when larger portion size is offered. Sociocultural factors that are especially relevant for youth's dietary behaviours are primarily parental influence and family processes. More specifically, there are associations among a range of parent, child and family factors, e.g. parental intake with children's fat and soft drink consumption, parent and sibling intakes with adolescents' fat intake, less encouragement and prompts given with energy intake and less parental education with fat intake (see Patrick & Nicklas, 2005; van der Horst, Oenema, et al., 2007 for reviews).

Similarly, parental involvement and family cohesion are associated with eating behaviours (Moore & Harre, 2007). Having a supportive home food environment (e.g. joint meals and communal meals) can facilitate more healthy eating (De Wit, Stok, et al., 2014) and less fast-food intake among young people (Burgess-Champoux, Larson, et al., 2009). Having adolescents involved in food preparation is associated with lower fat intake, less carbonated beverages consumption among girls and lower intakes of fried food among teenage boys (Larson, Story, et al., 2006). The family context may be a good channel to facilitate healthy eating among youth. It is also important to note that the changing role of women may have also adversely affected eating and physical activity patterns which are critical determinants of body weight, especially in developing countries (Martorell, Kettel Khan, et al., 2000).

Built Environment

Studies have shown associations between environmental factors and dietary behaviours (e.g. Giskes, van Lenthe, et al., 2011) in adults. Globalization of food markets has made food very convenient to access. The local food environment can influence food choices easily within communities. Some evidence has suggested that the presence of supermarkets and fast-food stores is related to obesity prevalence in the United States, with lower obesity prevalence in areas having at least one supermarket whereas areas with at least one franchised fast-food restaurant had a higher prevalence (e.g. Morland & Evenson, 2009).

High intake of energy-dense food (e.g. consumption of high-sugar food, sweetened beverages and saturated fat) is a problem in many countries with urbanization and modernization. This shift in eating climate also affects young people much earlier and has implications for early onset of overweight and obesity. Living in an urban environment is related to a range of behavioural patterns that can impact on diet and body weight. The transition to urbanization especially in developing countries also explains the distinct difference in BMI and physical activity between rural and urban residents. For example, the BMI of urban teens in Iran was significantly higher than that of their rural counterparts (Kelishadi, Pour, et al., 2003). In India, the prevalence of obesity was highest for urban population, followed by urban slum and then rural populations among both men and women, with those living in rural reporting higher activity levels (Yadav & Krishnan, 2008). The difference in obesity risk between urban and rural residence may be related to the distinctly different characteristics in the environment, e.g. transportation, food marketing, availability of food, etc.

Similar rural versus urban difference in obesity prevalence, however, may not necessarily exist in other regions, e.g. Europe (Peytremann-

Bridevaux, Faeh, & Santos-Eggimann, 2007). It should be noted that the definition of rural and urban areas can vary between different countries and for many developed countries; residents may not be confined to either urban or rural areas for working and living purposes. Furthermore, access to and the availability of fast food and restaurants, for example, are also reasonably convenient in rural as well as urban districts in developed regions.

Sedentariness and Physical Inactivity

In 2011, physical inactivity was identified as the fourth leading risk factor for global mortality, causing 6% of all deaths (Frank, Andresen, & Schmid, 2004). Sedentary behaviour (typically defined as prolonged sitting) was also seen as an important contributor to the development of many noncommunicable diseases. Sedentary behaviour is defined as any waking activity characterized by an energy expenditure of less than 1.5 metabolic equivalents and a sitting or reclining posture (World Health Organization, 2011b). These may include television watching, computer usage and travelling in vehicles to name a few examples. By contrast, physical activity is "bodily movement that is produced by skeletal muscles which requires energy expenditure" (World Health Organization, 2014d) and can be carried out in various domains such as recreational (e.g. playing sports, gardening), transport (e.g. walking or cycling to school and work), household and occupational (e.g. construction) activities. Sedentary behaviours and physical activity are related to each other, but they are also distinct concepts. Research has shown that sedentariness may not always be associated with physical inactivity and vice versa (Salmon, Owen, et al., 2003).

Physical Inactivity, Sedentariness and Health Outcomes

Physical activity is an essential component of a healthy lifestyle. Research in the past decades has established that regular physical activity is linked to many physical and mental health benefits for males and females of all ages and conditions (Sedentary Behaviour Research Network, 2012). The benefits of regular physical activity vary across individual's health conditions and age. In general, evidence has shown that regular physical activity is associated with reduced risk of all-cause mortality (Gupta, Goel, et al., 2012), longevity (Lee & Paffenbarger, 2000; Paffenbarger & Lee, 1999) and the prevention of several chronic diseases. Physical activity can influence bodily mechanisms via blood lipids, body weight, blood pressure, metabolic changes, glucose tolerance, insulin resistance, immunologic functions and hormonal regulation. Individuals who are more active were found to have lowered risk of type 2 diabetes (Boyle, Keegel, et al., 2012), colon cancers (Hu, Willett, et al., 2004; Myers, Atwood, & Froelicher, 2003), breast cancer (Sesso, Paffenbarger, & Lee, 1998; Thune, Brenn, et al., 1997), pancreatic cancer among those who are overweight (Michaud, Giovannucci, et al., 2001) and prostate cancer (see Warburton, Nicol, & Bredin, 2006 for a review). Besides, there is also evidence to support routine, weight-bearing exercise across all age groups of people for better bone health (e.g. Berard, Bravo, & Gauthier, 1997) and reduction of fall risk among adults (Gregg, Pereira, & Caspersen, 2000).

Physical inactivity, by contrast, increases the risk of many noncommunicable diseases (Lee, Shiroma, et al., 2012) and can be attributed for approximately 21–25% of breast and colon cancers, 27% of diabetes and 30% of ischaemic heart disease (World Health Organization, 2014d). Furthermore, time spent in sedentary activities may result in decreased overall energy expenditure and has been found to associate with weight gain in children and youth (Hu, Manson, et al., 2001) and with overweight and obesity in children (Mitchell, Mattocks, et al., 2009) and adults (Brown & Siahpush, 2007).

While the physical health aspects have been emphasized, there is also compelling evidence to show that physical inactivity is related to mental health and cognitive functioning. Physical activity can help to alleviate stress and fatigue (Proctor, Moore, et al., 2003) and enhance self-confidence, satisfaction and general well-being (Liu, Hu, et al., 2011). Recent evidence suggests that physical activity can counteract depression (Eriksen & Bruusgaard, 2004; Van Uffelen, van Gellecum, et al., 2013), reduce psychological distress (Hassmen, Koivula, & Uutela, 2000; King, Taylor, et al., 1989; Netz, Wu, et al., 2005) and enhance quality of life via positive psychological outcomes such as positive affect, self-efficacy and self-esteem in older populations (Perales, del Pozo-Cruz, & del Pozo-Cruz, 2014). Physical fitness has also been demonstrated to beneficially influence cognitive processing among older adults (Strawbridge, Deleger, et al., 2002). Regular physical activity may also reduce poor cognitive functioning in middle age (Elavsky, McAuley, et al., 2005) and cognitive decline and dementia in the elderly (Colcombe & Kramer, 2003).

Globally, the recommended level of physical activity for adults (18–64 years old) is 150 min of moderate-intensity activity per week or 75 min of vigorous activity per week or an equivalent combination of both. For children and youth under 18 years old, an accumulation of at least 60 min of moderate- to vigorous-intensity activity daily is recommended. Increasing the duration to 300 min of moderate- and 150 min of vigorous-intensity activity is suggested to have additional health benefits for adults (Singh-Manoux, Hillsdon, et al., 2005). Accumulating even short bouts (10-min bouts, three times per day) of moderate physical activity throughout the day can produce similar training effects as those of a single, longer (30-min) bout (World Health Organization, 2010).

Who Is (In)active?

In 2010, the global prevalence of physical inactivity (fewer than five instances of 30 min of moderate activity per week or fewer than three instances of 20 min of vigorous activity per week) among adults 18 years old or above is estimated to be 23% (20% men and 27% women) (World Health Organization, 2015a). Physical activity level varies across the human lifespan, but in general, it decreases with age and during adulthood. Physical inactivity is also more prevalent in older adults. While one might expect that children and adolescents are in the developmental phase where they have the most amount of energy and are usually highly active (e.g. in sports and other general activities), statistics have shown alarming evidence that many young people are living a predominantly sedentary lifestyle. About 81% of schoolgoing adolescents are physically inactive (World Health Organization, 2015a), and sedentary behaviour has been found to increase during puberty (Brodersen, Steptoe, et al., 2007; van Sluijs, Page, et al., 2010). Approximately 34% of young people spend more than 2 h watching TV per day (Marshall, Gorely, & Biddle, 2006). In general, young people between 2 and 18 years old spend 2–4 h on screen-based activities and 5–10 h sedentary daily (Salmon, Tremblay, et al., 2011). For adults, the median reported sitting time per day was around 5 h in a 20-country international study. Adults between 18 and 39 years old and with post-school education had higher sitting times (Bauman, Ainsworth, et al., 2011). Over 40% of men and women watched two or more hours of television each day (Clark, Sugiyama, et al., 2010).

The prevalence of regular physical activity also differs across several demographic characteristics. Overall, participation in physical activity decreases as people grow older (King, Castro, et al., 2000; van Stralen, De Vries, et al., 2009), with women experiencing greater decline in older age groups than men (Brownson, Boehmer, & Luke, 2005). Gender is a consistent demographic correlate of physical inactivity. This difference is more distinct in earlier than later stages in the lifespan. Male youths are less inactive than their female counterparts (Brodersen, Steptoe, et al., 2007; Caspersen, Pereira, & Curran, 2000; Sallis, Prochaska, & Taylor, 2000; Telama & Yang, 2000). In general, women and girls tend to be less active than men and boys (e.g. Caspersen, Pereira, & Curran, 2000; Moore & Harre, 2007; Trost, Owen, et al., 2002). Women are also more inactive than men in adulthood (Dumith, Hallal, et al., 2011; World Health Organization, 2002, 2006) with young women being slightly less active than middle-aged women (World Health Organization, 2015a). Middle-aged (45–64 years) and older-aged (65 years or above) people are more sedentary than their younger counterparts (25–44 years) (Clark, Sugiyama, et al., 2010).

Some ethnic groups are also more sedentary than others. Among students in the United Kingdom, for example, Asians are less active than whites and blacks are more sedentary than whites (Brodersen, Steptoe, et al., 2007). However, when geographic regions are compared, adolescents in the WHO Southeast Asia regions show lower prevalence of insufficient physical activity (74%) than those in the WHO East Mediterranean (88%), African (85%) and Western Pacific regions (85%) (World Health Organization, 2015a). Differences in activity levels also exist among countries of varying economic development (Dumith, Hallal, et al., 2011). In high-income countries, the prevalence of physical inactivity (41% men and 48% women) has doubled that in low-income countries (18% men and 21% women) (World Health Organization, 2015a).

Determinants of Sedentary and Inactive Behaviours

Apart from demographic factors, other correlates that explain physical activity generally include psychological and sociocultural factors, behavioural attributes and skills and the physical environment (Ford, Merritt, et al., 1991). In general, there has been a decline in work-related, transportation and home activities and increase in sedentary activity (see Bauman, Sallis, et al., 2002 for a review). The determinants summarized below can work alone or in combination with one another to explain activity levels.

Sociocultural Factors

Disparities in activity level exist between people of different socioeconomic status (SES) (Gidlow, Johnston, et al., 2006). Low SES is consistently found to be associated with less physical activity, among adolescents (Hanson & Chen, 2007; Stalsberg & Pedersen, 2010) and adults (King, Castro, et al., 2000; Trost, Owen, et al., 2002). Similarly, sedentariness also increases with low SES (Clark, Sugiyama, et al., 2010; van Sluijs, Page, et al., 2010). Furthermore, women of low SES and ethnic minority seem to have reported less activity (Caspersen & Merritt, 1992; Caspersen, Merritt, et al., 1990; Caspersen, Pereira, & Curran, 2000; Telama & Young, 2000). Some evidence has suggested that those coming from lower socioeconomic groups are less likely to use recreational facilities even if they have access to them, and they tend to perceive their environment as not very supportive for physical activity (Giles-Corti & Donovan, 2002). It is also likely that the disadvantaged group may have weaker social cohesion in the neighbourhood or friends with whom they can engage in activities. This may also partly explain the education inequalities in television viewing (Owen, Sugiyama, et al., 2011; Teychenne, Ball, & Salmon, 2012). Furthermore, the relationship between SES and physical activity may be dependent on the type of physical activity in developing countries (Bauman, Ma, et al., 2011); e.g. higher education and affluence are associated with more leisure-time activity, but less activity at work.

Social support has been suggested to be a consistent positive factor that is associated with physical activity for both adults and youths (see Bauman, Sallis, et al., 2002; Panter & Jones, 2010; Sallis, Prochaska, & Taylor, 2000; Sterdt, Liersch, & Walter, 2014; Trost, Owen, et al., 2002 for reviews). The range of social support may include physician's influence, support from friends and peers and support from spouse and family. For children, parental influence is quite instrumental for different types of activities including leisure-time physical activity and overall activity level through direct involvement, encouragement and modelling (Edwardson & Gorely, 2010). For youth in particular, peers and praise (Beets, Vogel, et al., 2006) and having fun with friends (Humbert, Chad, et al., 2008) affect activity levels. To encourage young people to be active, integrating different types of activities and having variety in the programmes are preferred (Humbert, Chad, et al., 2008). Encouraging children and youth to be active school commuters is associated with more physical activity (Faulkner, Buliung, et al., 2009). Parental influence is less clear, but parents' attitude, encouragement and transport are important determinants of activity (Edwardson & Gorely, 2010). Parental behaviours also correlate with television viewing, which is an important indicator of sedentary behaviour (Salmon, Tremblay, et al., 2011).

Environmental Factors

Industrialization has led many to join an urbanized and sedentary workforce. The overwhelming rise in technology use implies that screen-based activities have become a core part of most people's lives from young to old. Advances in technology have reduced daily physical activity substantially. The appeal of television and electronic games and the rising use of screen-based devices for study, work and recreation have substantially increased sedentary time among many adults and children. The built environment plays a big role in facilitating active and/or promoting sedentary behaviours (Giles-Corti & Donovan, 2002; Humpel, Owen, & Leslie, 2002; Panter & Jones, 2010; Sallis, Bowles, et al., 2009; Sterdt, Liersch, & Walter, 2014), and its characteristics can be understood in the following domains: availability/accessibility, infrastructure, safety and aesthetics (Brownson, Hoehner, et al., 2009; Humpel, Owen, & Leslie, 2002).

Living environments built to support physical activity are more likely to increase activity level. Having facilities available and accessible in the built environment is one of the important elements of a supportive environment (Bauman, Reis, et al., 2012). This applies to both the domestic environment and the larger neighbourhood. At home, evidence has shown relationships between home equipment and physical activity (Humpel, Owen, & Leslie, 2002). At work, employees' working occupations that demand long work hours and whose job nature requires low occupational physical activity are at risk of inactivity (Kirk & Rhodes, 2011).

In a study of 11 countries of broad geographic and socio-political diversity, neighbourhood characteristics associated with meeting physical activity guidelines included the presence of sidewalks and bicycle facilities, having shops and transit stops near home and the availability of low-cost recreation (Sallis, Bowles, et al., 2009). In fact, these attributes in the built environment can facilitate a few different domains (e.g. transportation, recreation) of physical activity and especially walking. Having convenient access to physical activity opportunities (e.g. close to their living area, good transportation facilities) has also been found to be important to increase activity levels in youths (Humbert, Chad, et al., 2008). The relationship between neighbourhood walkability and sedentary behaviour, however, seems inconsistent. People living in environments with lower levels of walkability have also reported more television viewing (Owen, Sugiyama, et al., 2011). On the contrary, others have found the opposite with high-walkable neighbourhood associated with higher levels of sedentary time (Van Dyck, Cardon, et al., 2010). Other additional factors may be interacting with the individual and/or the environment to affect sitting time.

While designing environments to support physical activity is an emerging international public health agenda, there are still very distinct differences between some developed and developing countries. For example, developed countries such as the Netherlands, Denmark, Australia and New Zealand have cities and roads planned to accommodate cyclists, and hence, active travel is more prevalent. By contrast, for developing countries such as Malaysia and India, similar built facilities may not be a national priority, and with high incidence of traffic accidents and injuries, this mode of physical activity is probably not encouraged, and hence, these behaviours are much less prevalent.

There is evidence to suggest that some safety-related attributes (e.g. light traffic, safe neighbourhood) in the environment are related to activity level (Casagrande, Whitt-Glover, et al., 2009; Humpel, Owen, & Leslie, 2002; Trost, Owen, et al., 2002). However, the relationship is shown to be weaker than the attributes described above (see Humpel, Owen, & Leslie, 2002 for a review). More recently, evidence of a relationship between neighbourhood safety and active travel has been mixed (Panter & Jones, 2010), and this could be due to the difference in interpretation and perception of safety which may vary between a minor (e.g. unstable weather, wetland, unattended dogs) to major concerns (e.g. crime rate in the area, busy roads and traffic). Some of these safety factors may be more significant in developing countries, e.g. Malaysia and India. Neighbourhood aesthetics are also important. Perceived neighbourhood characteristics such as pleasant scenery (e.g. connected to parks, beaches and/or nature) and attractive local areas are associated with activity level or walking. However, association between the actual quality of natural features in the neighbourhood and activity was not confirmed (Humpel, Owen, & Leslie, 2002; Panter & Jones, 2010).

Low Fruit and Vegetable Intake

Diet affects the physiology in our body including blood pressure, cholesterol level, blood glucose and body mass. A healthy diet is generally rich in fruits, vegetables, whole grains and fibre and low in saturated fats, sugar and sodium. The World Health Organization (2003) recommends a daily consumption of at least five servings of fruits and vegetables and fat that is less than 30% of total dietary energy with less than 10% from saturated fat and 1% from *trans* fat.

Low Fruit and Vegetable Consumption and Health Outcomes

Low fruit and vegetable consumption is an important risk factor for chronic diseases. In 2008, about 1.7 million (2.8%) of deaths are attributed to low consumption of fruits and vegetables globally (World Health Organization, 2009a). Approximately, 14% of gastrointestinal cancer death, 11% of ischaemic heart disease death and 9% of stroke death were attributable to an insufficient consumption of fruits and vegetables. Diet high in fat and/or sugar intake, resulting in low fruit and vegetable consumption, is associated with oral cancer (World Health Organization, 2009a). Fruits and vegetables play protective roles in preventing cancer (Block, Patterson, & Subar, 1992), stroke and coronary heart disease (Ness & Powles, 1997). Increasing the consumption of green leafy vegetables also reduces the risk of type 2 diabetes (Carter, Gray, et al., 2010), cancers (Boeing, Bechthold, et al., 2012; Lock, Pomerleau, et al., 2005) and heart disease and stroke (Lock, Pomerleau, et al., 2005).

Who Is at Risk?

Fruit and vegetable intake varies substantially among countries in different geographic regions as it depends a great deal on cultural, agricultural and economic environments. Although there is an increase in fruit and vegetable production worldwide, inadequate consumption remains. In the United States, between 1994 and 2005, the proportion of men and women eating fruits and/or vegetables five or more times per day was around 20 and 30%, respectively (Michels Blanck, Gillespie, et al., 2008). In 2011, only 8.2% of Australian adults had met the guidelines. The prevalence of inadequate fruit and vegetable intake has increased over time ranging from 47% (fruit) and 86% (vegetable) in 2001 to 52% (fruit) and 92% (vegetable) in 2012 (Heart Foundation, 2012). The prevalence of inadequate intake is also high among children and young people (Cooke, Wardle, et al., 2004; Kimmons, Gillespie, et al., 2009). Data on developing countries are very scarce. A World Health Survey conducted with 52 mainly low- and middle-income countries revealed that 77% of men and 78% of women consumed less than the minimum recommended level of fruits and vegetables in 2002–2003 (Hall, Moore, et al., 2009). The low fruit and vegetable consumption prevalence ranged from 37% (Ghana) to 99% (Pakistan). Other countries with high prevalence of low intake were China, Nepal, Ecuador and Mauritania.

Significant gender differences in the likelihood of low fruit and vegetable intake were reported, with males more likely to report low intakes in developed countries (Kimmons, Gillespie, et al., 2009; Story, Neumark-Sztainer, et al., 1998). In the United States, it was found that girls were more likely to meet the recommendations of fruit and vegetable intake, whereas boys had higher intakes of added sugar (Kelishadi, Pour, et al., 2003). Similar evidence has suggested that boys ate vegetables less frequently than girls in the United Kingdom and New Zealand (Cooke, Wardle, et al., 2004; Moore & Harre, 2007).

Determinants of Fruit and Vegetable Intake

Dietary behaviours can be explained by individual differences and sociocultural factors. The environment also plays a unique role in promoting and hindering healthy eating. Food choices are largely related to ecological factors in addition to personal preferences. Research has shown that healthy food choices are more likely to be facilitated and sustained if the environment provides availability and convenient access to these options (see Kamphuis, Giskes, et al., 2006 for a review).

Socioeconomic Status (SES)

There appears to be a SES gradient with respect to fruit and vegetable intake. Overall, consumption increases with increasing SES (Hall, Moore, et al., 2009; Hanson & Chen, 2007). Low SES was associated with poorer diets, i.e. inadequate consumption of fruits and vegetables and more fat and refined sugar intake (Petti, 2009). Some racial and ethnic minority groups are at greater risk (Cooke, Wardle, et al., 2004; Story, Neumark-Sztainer, et al., 1998). These observations may be explained partly by the availability, selection and accessibility of fresh fruits and vegetables at food stores in communities of different SES. Evidence has demonstrated that poorer quality of fresh produce and fewer grocery stores were present in communities of ethnic minority and low SES, suggesting a possible pathway of the disparities on this health risk behaviour (Zenk, Schulz, et al., 2006).

Sociocultural Norms

As noted in the discussion of unhealthy eating, the family is highly influential. Having regular family meals (Burgess-Champoux, Larson, et al., 2009), authoritative parenting style, parental modelling and peer normative beliefs (Cullen, Baranowski, et al., 2001) have been found to be associated with more fruit and vegetable consumption in children and adolescents.

Sociocultural norms include religious beliefs, especially among religions that emphasize particular dietary patterns. For example, Buddhism and Hinduism teach believers not to harm and encourage vegetarian diet, and Seventh-Day Adventists follow strict dietary guidelines and are mostly vegetarians. Religiosity can be understood in terms of believers' attachment to particular religions and adherence to specific teaching. Evidence has also shown that people who report higher religiosity and spirituality consume more fruits and vegetables (see Tan, Chan, & Reidpath, 2013 for a review). A religious neighbourhood can act, in part, like a community. Being affiliated with a strong religious community that discourages unhealthy eating may have neighbourhood effects on the believers' dietary qualities (Tan, Chan, & Reidpath, 2014).

Preferences, Availability and Accessibility

Socio-environmental factors can promote and inhibit healthy food intake. For youth, home availability of fruits and vegetables and taste preference are suggested to have direct associations with fruit and vegetable consumption for adolescent populations (Hanson & Chen, 2007; van der Horst, Oenema, et al., 2007). Determinants of home availability included social support for healthy eating, family meal patterns, family food security and socioeconomic status. The availability of fruits and vegetables at home is a powerful determinant of intake, predicting more consumption even when taste preferences are low. When availability was low, however, taste preference did not make a difference in intake among a group of adolescents in Minnesota (Ransdell & Wells, 1998). Similarly, the school food environment has also been shown to shape dietary behaviours. Having snack vending machines in schools is associated with lower daily consumption of fruit (Kubik, Lytle, et al., 2003).

At a population level, (un)healthy food choices depend, to a great extent, on the type of food stores and restaurants present in the neighbourhood. Evidence has shown that eating behaviours differ across neighbourhoods with different accessibility to grocery stores and supermarkets. The presence of supermarkets is related to more fruit and vegetable consumption by residents (Morland, Wing, & Roux, 2002) and meeting fruit and vegetable recommendations (Casagrande, Whitt-Glover, et al., 2009).

Tobacco Use

Since the beginning of the twentieth century, tobacco use has been rising steadily with the introduction of cigarette manufacturing. With the expansion of worldwide population, it is estimated that there are 1 billion smokers around the world (World Health Organization, 2014e). Tobacco smoking is a leading risk for mortality and contributes to an extremely heavy economic burden to societies and is undoubtedly a public health issue. The consumption of cigarettes has reached global epidemic proportions with an estimation of over 15 billion cigarettes smoked daily worldwide. The top five countries where the most number of cigarettes are consumed are China, the United States, Japan, Russia and Indonesia (World Lung Foundation, 2015). The following section will discuss tobacco use in the form of smoking and exposure to second-hand smoke.

Smoking and Health Outcomes

Tobacco kills approximately 6 million people each year. The WHO estimated that by 2020, 7.5 million will die from both direct tobacco use and second-hand smoke, accounting for almost 10% of global deaths with many deaths occurring prematurely (World Health Organization, 2011b). Almost one in eight deaths of adults over the age of 30 is due to smoking (Giskes, Kamphuis, et al., 2007). Tobacco smoke contains hundreds of dangerous substances including tar, nicotine and carbon monoxide. Adverse health effects of smoking are not limited to the smokers themselves, but also non-smokers who are exposed to passive smoking. Research has shown that cigarette smoking dramatically increases the risk of cancer (e.g. lung, oral and pharyngeal, pancreatic, colon and cervical) (World Health Organization, 2009a), chronic bronchitis and respiratory diseases, cardiovascular disease (Petti, 2009), cardiovascular disease and stroke (Bullen, 2008; Shah & Cole, 2010), chronic pancreatitis (Alexandre, Pandol, et al., 2011), osteoporosis (Ward & Klesges, 2001) and fracture (Kanis, Johnell, et al., 2005). It was estimated that tobacco smoking alone was responsible for 71% of lung cancer deaths around the world with 18% coming from high-income countries (Shah & Cole, 2010). Furthermore, attention should also be put on the high prevalence (about one-third of adults globally) of exposure to second-hand tobacco smoke among adults and children (World Health Organization, 2009b). Around 1% of worldwide mortality can be attributed to exposure to second-hand smoke (Öberg, Jaakkola, et al., 2011).

Who Smokes?

Globally, it is estimated that there are over 1 billion smokers and an estimated consumption of 6 trillion cigarettes annually (World Health Organization, 2011b) with 80% of these smokers living in low- and middle-income countries. Although there has been a decline in the prevalence of cigarette smoking in recent decades in some developed countries, the overwhelming majority of smokers begin tobacco use before they reach adulthood. In 2011, the global smoking prevalence among adults at the age of 15 or above was 36% for males and 8% for females. Between 2006 and 2012, the prevalence of current tobacco use among adolescents aged 13 to 15 years old was 20% for males and 10% for females worldwide (World Health Organization, 2009a). Older adolescents (15 years) are more likely to use tobacco than younger (13 years old) ones (World Health Organization, 2014f).

Boys are more likely to smoke than girls, and this gender difference is more distinct in some countries. In Cyprus, Nepal and Sri Lanka, for example, smoking is less common among girls (Christophi, Savvides, et al., 2009; Kabir & Goh, 2014). In general, men smoke more than women. In some regions, men are 10 (Southeast Asia region) to 15 (Western Pacific region) times more likely to be smokers than women (World Health Organization, 2011b). In some individual countries, including China and India, the gender gap is even greater (World Health Organization, 2011a). Cultural orientation of individual countries may explain distinct gender difference. The gender gap has narrowed substantially in recent times, especially in developed countries. Countries with a Western cultural orientation (e.g. the United States, the United Kingdom and New Zealand) have higher female smoking prevalence than other countries (Tyas & Pederson, 1998).

Smoking prevalence also varies across WHO regions, with the highest in the European region (29%) and lowest in the African region (8%). Although smoking prevalence is highest among upper-middle-income countries (World Health Organization, 2011b), low- and middle-income countries are where the burden of tobacco-related illness and death is heaviest (World Health Organization, 2014e).

Determinants of Tobacco Use

The determinants for tobacco use are multidimensional, and they include a combination of individual, sociocultural and environmental factors throughout the lifespan. This section focuses on the sociocultural precursors and environmental correlates associated with the initiation and maintenance of this risky behaviour.

Modelling and Social Learning

Parents, grandparents, siblings, peers, teachers and friends are likely to be the source of modelling smoking behaviours of young people. Peers' tobacco use is the most powerful determinant among youth smoking (Christophi, Savvides, et al., 2009; Peters, Wiefferink, et al., 2009; Tyas & Pederson, 1998). Parents and grandparents who smoke are also strong predictors of the likelihood of smoking among youth (Christophi, Savvides, et al., 2009; Peters, Wiefferink, et al., 2009) as is the sight of smokers at home and in public (Abraham & Sheeran, 2000). Exposure to smokers is also likely to influence individuals' attitudes and perception of social norms, especially among youths. Parental involvement (Harakeh, Scholte, et al., 2005), two-parent family (Tyas & Pederson, 1998) and parenting style (Tyas & Pederson, 1998; Wang, Ho, et al., 2015) have been suggested to be protective factors of youth smoking. Additional evidence has identified maternal care, control and authoritative (as opposed to authoritarian) parenting as associated with lower likelihood of adolescent smoking in Hong Kong (Wang, Ho, et al., 2015).

Socioeconomic Status and Education

Socioeconomic status (SES) and education are reliable determinants of smoking prevalence, smoking initiation and cessation (see Hiscock, Bauld, et al., 2012 for a review). In general, it has been suggested that low SES is associated with greater cigarette smoking (Hanson & Chen, 2007). The socioeconomic inequality also exists in low- and middle-income countries, and there is a differential relationship between SES and smoking for men and women. For men, smoking is disproportionately prevalent in the poor, whereas for women, the poorest and the richest are the most likely to smoke (Hosseinpoor, Parker, et al., 2012).

As might be expected, higher education and higher income are associated with better knowledge of smoking. Among some developed countries, evidence has shown that lower socioeconomic status is associated with lower awareness of smoking harms and nicotine misunderstanding (Siahpush, McNeill, et al., 2006). Furthermore, education is related to smoking frequency (Allison, Adlaf, et al., 1999), suggesting that disadvantaged groups may be more at risk. Some evidence has shown that those who had not completed high school were over three times more likely to smoke daily compared to their post-secondary counterparts in Canada (Allison et al., 1999). For youths, having parents with lower education increases the odds for smoking (Christophi, Savvides, et al., 2009). School curriculum and knowledge about the adverse effects that smoking can bring have been found to influence adolescents' attitudes and tobacco use (Kabir & Goh, 2014). Raising awareness and providing health information are important precursors for helping people make informed decision.

Marketing, Advertising, Accessibility and Availability of Cigarettes

Environmental factors beyond the family also affect the susceptibility to cigarette smoking. Strong evidence has shown tobacco marketing and advertising to be strong predictors of smoking initiation among adolescents. Those who are receptive to tobacco advertisement are more susceptible to smoke. This finding is consistent for students in both developed (Evans, Farkas, et al., 1995; Henriksen, Feighery, et al., 2004) and developing countries (Saito, Yasuoka, et al., 2013). Similarly, the density of retail cigarette advertising in school neighbourhood is also found to be related to high school smoking prevalence (Henriksen, Feighery, et al., 2008). Other evidence has also supported the effect of tobacco marketing on progression to established smoking (Biener & Siegel, 2000), with antismoking advertising having more positive effects on those in preadolescence and early adolescence by preventing smoking initiation (Wakefield, Flay, et al., 2003).

Access to and availability of cigarettes are highly significant predictors of smoking behaviour among youth (Tyas & Pederson, 1998; Woodruff, Candelaria, et al., 2003). The likelihood of smoking among adolescents is higher when the ease of buying cigarettes from a store increases (Christophi, Savvides, et al., 2009) or when they can have easy access at home (Woodruff, Candelaria, et al., 2003). The density of tobacco retailers near school areas is associated with students' access behaviours. The more the retailers, the more likely smokers were to buy their own cigarettes (Harakeh, Scholte, et al., 2005).

Policy and Society Influence

Legislation and policy change are influential determinants of behaviour, and this is evident in the case of smoking. In the past decades, the implementation of policies banning workplace smoking has witnessed a change in tobacco use among employees. More specifically, there has been a decline in cigarette consumptions or smoking prevalence in some developed countries, e.g. Australia, Canada, Germany and the United States (e.g. Brownson, Hopkins, & Wakefield, 2002; Chapman, Borland, et al., 1999; Fichtenberg & Glantz, 2002; Kabir & Goh, 2014; Sorensen, Barbeau, et al., 2004). This kind of environmental intervention not only reduces the frequency of smoking among smokers but also protects non-smokers from second-hand smoke. Similar efforts in developing countries are growing, but data on their enforcement and effectiveness are limited.

Tobacco taxes and cigarette prices are other system-level determinants of smoking. Increasing taxes has seen reduction in tobacco use, and raising cigarette prices can also reduce overall consumption (Brownson, Hopkins, & Wakefield, 2002; Chaloupka, Cummings, et al., 2002). These effects are likely to be stronger among those who are especially sensitive to the price of cigarettes such as youth and, in low- and middle-income countries, adults (Jha, 2009). However, most tax levy studies have been conducted in developed countries. Similar evidence in developing countries is very often unavailable. In particular, for countries where regulatory and enforcement capacity is low, policies may take time to be fully implemented, and they may be complicated by political and economic constraints. Furthermore, the implementation of health policies (e.g. taxation) in developing countries can sometimes be in competition with other political, economic and cultural conditions that should be taken into consideration.

Alcohol Consumption

Alcohol is a psychoactive substance that is commonly used as part of the modern lifestyle and is deemed a normative behaviour in some social contexts. In most Western cultures, alcohol beverage is an integral part of many occasional and communal events such as celebration of success, wedding, birthday and casual enjoyment. The majority of individuals in developed nations normally begin alcohol consumption some time during adolescence and young adulthood. However, excessive or hazardous alcohol consumption is a health risk factor and can lead to damaging or fatal consequences.

Health Impacts of Alcohol

Although some evidence suggests that some consumption can decrease the risk of coronary heart disease, stroke and diabetes (Corrao, Rubbiati, et al., 2000), heavy and prolonged drinking has been implicated in behavioural, social and health problems. In fact, harmful use of alcohol can become a serious public health burden and a cause to health inequalities (Beaglehole & Bonita, 2009). The harms associated with alcohol use very often outweigh its benefits, and the modest benefits are seemingly only applicable to a small segment of the populations (Jackson, Broad, et al., 2005). In 2012, about 5.9% of global deaths were attributed to alcohol use, and around 3.3 million people die from harmful use of alcohol each year (World Health Organization, 2014b). Heavy alcohol consumption can have adverse health and social effects on drinkers via three main pathways: (1) toxic effects on organs and tissues, (2) intoxication leading to cognitive and motor impairment, and (3) dependence. Both acute intoxication and chronic excessive drinking can have adverse effects on the brain, central nervous and muscular system, liver, heart and gastrointestinal system (Shield, Parry, & Rehm, 2013). Hepatic cirrhosis, cancer, injuries and alcohol dependence (Shield, Parry, & Rehm, 2013) are major consequences of harmful alcohol use which can have impacts beyond the individual. The alcohol-related burden of diseases is also much heavier for poor populations or lower-income countries.

In the age between 20 and 39 years old, about 25% of total deaths can be attributed to alcohol. Evidence from case-control studies has suggested that the risk of injury increases with increased alcohol consumption, with female being more at risk of injury (McLeod, Stockwell, et al., 1999). Not only does the quantity of drinking affect health, the pattern of drinking is also highly relevant to health outcomes. Approximately 20% of deaths in motor vehicle accidents can be attributed to excessive alcohol consumption, and very often the cases are due to heavy episodic drinking, also referred to as binge drinking (World Health Organization, 2014b). Teen alcohol use is also related to other health risk behaviours such as risky sexual behaviour and associated sexually transmitted diseases.

Distribution of Alcohol Consumption

The total volume and pattern of alcohol consumption are indicators of risky drinking behaviour. There is substantial variation in alcohol consumption across regions. According to the World Health Organization, developed and high-income countries have the most alcohol consumption. Globally, individuals above 15 years old drink on average 6.2 litres of pure alcohol per year. In 2010, the adult per capita consumption of alcohol was highest in the European region and lowest in the Eastern Mediterranean region (World Health Organization, 2014b). It is projected up until 2025 that alcohol consumption is expected to continue to increase. However, it is important to note that high consumption does not always equate to high alcohol-related problems.

There is a clear gender difference in drinking behaviour. Men drink more and tend to have more alcohol-related problems than women (Kerr-Corrêa, Igami, et al., 2007; Nolen-Hoeksema, 2004). In 2010, the average total alcohol per capita consumption was 21.2 litres and 8.9 litres for men and women, respectively. Women are more often lifetime abstainers than men (Wilsnack, Vogeltanz, et al., 2000). The difference may be explained, in part, by the differences in body composition and different rates of alcohol metabolism. In addition, social habits, customs and cultural expectation can also influence alcohol use in men and women. Age also influences alcohol consumption. Heavy drinking is more prevalent among young adults (Jackson, Sher, & Park, 2005) probably due to the change in social contexts associated with this stage of development. Among young adults between 20 and 24 years old, males were 2.4 times more likely than females to consume alcohol heavily (Allison, Adlaf, et al., 1999). About 11.5% of drinkers have heavy episodic drinking patterns (World Health Organization, 2014b).

The WHO European region and WHO region of the Americas have the highest proportions of current drinkers among adolescents, while the WHO Southeast Asia region and WHO Eastern Mediterranean region have the lowest. Heavy drinking rates are also highest among adolescents in the WHO European region but more prevalent in older age groups in the Southeast Asia region. The distribution of the levels and patterns of alcohol consumption can also be understood in terms of economic wealth. The prevalence of current drinkers and episodic heavy drinking is highest in high-income countries. Conversely, the number of abstainers decreases with economic wealth (World Health Organization, 2014b).

Determinants of Alcohol Consumption

Sociocultural Factors

Similar to smoking, research has consistently found that familial factors and peers play a critical role in predicting both youth and adult drinking (Jessor, Donnovan, & Costa, 1991; Weitzman, Folkman, et al., 2003). Peers are salient and available models especially during adolescence and young adulthood. The presence of peer drinkers contributes to high-risk alcohol use by direct influence, modelling and perceived norms (Borsari & Carey, 2001). Longitudinal studies have also supported the association between peer drinkers and subsequent alcohol use among adolescents (Leung, Toumbourou, & Hemphill, 2014). Furthermore, drinking with friends and the presence at an event of others who are intoxicated have been found to predict heavy episodic drinking among university students (Clapp & Shillington, 2001).

Parental influence plays a role in shaping attitudes towards and beliefs about drinking among youth (Borsari, Murphy, & Barnett, 2007). Living with parents appears to be protective against binge drinking (Bartoli, Carretta, et al., 2014), suggesting that parental control or the family environment may play a role in reducing this risky behaviour. The presence of family members at drinking events was also protective against heavy episodic drinking (Clapp & Shillington, 2001).

Socioeconomic status has complicated associations with drinking status, volume and patterns. People from lower SES tend to drink heavier, whereas those from higher SES drink more frequently (Grittner, Kuntsche, et al., 2013; Huckle, You, & Casswell, 2010), but SES does not always explain differences in alcohol-related consequences. However, some evidence has suggested that people with lower SES may be more vulnerable to alcohol-related problems (Grittner, Kuntsche, et al., 2012) which may be partially related to a lack of resources and access to care and supportive networks (World Health Organization, 2014b).

Contextual factors such as culture, religion and legal consequences are important determinants of abstention and drinking behaviours. In some countries, e.g. Brunei, Iran and Saudi Arabia, there can be serious legal consequences for drinking due to local laws and regulations. Other countries prohibit drinking among some subgroups in the populations due to social, cultural and/or religious norms (e.g. Muslims in Malaysia). Religion strongly predicts abstention (Michalak, Trocki, & Bond, 2007). Denominations such as the Seventh-Day Adventists, Mormons and Muslims prohibit alcohol, and drinking is therefore scarce among these religious groups.

Environmental Factors

The physical, economic and communication environments are all influential determinants of drinking behaviours. The built environment that has high density of alcohol outlets is found to be associated with the intensity and frequency of drinking (Weitzman, Folkman, et al., 2003). Alcohol promotional activity is associated with alcohol consumption among young people. Non-drinkers being exposed to alcohol advertising activities were more likely to become drinkers. Advertising also increased the likelihood of drinking for drinkers and non-drinkers (Smith & Foxcroft, 2009). Policies that regulate the environment are effective in reducing harm caused by alcohol. Interventions that address alcohol consumption through its pricing and availability, enforcement of legislation related to drinking-and-driving, increasing taxes and banning alcohol advertising have been identified as cost-effective means to reduce alcohol-related harm (Anderson, Chisholm, & Fuhr, 2009).

Risky Sexual Behaviours

Risky sexual behaviours contribute substantially to the burden of sexually transmitted infections (STIs) and the deadly human immunodeficiency virus (HIV). The predominant mode of transmission of HIV is sexual; however, there are other channels (e.g. sharing contaminated needles, receiving unsafe injections/blood transfusions, experiencing accidental needlestick injuries) through which HIV can be transmitted. Risky sexual behaviours can be defined as any sexual activity that increases the likelihood of contracting HIV or STIs or becoming pregnant. They often involve early initiation of sexual intercourse, unprotected sexual intercourse, inconsistent use of condoms (Taylor-Seehafer & Rew, 2000) and having multiple (and sometimes anonymous) sex partners. Early sexual experience is a risk as early initiation is more likely to be non-consensual, less likely to be protected against pregnancy and infection and predictive of a greater number of lifetime sexual partners (Wellings, Collumbien, et al., 2006). Each year there are about 333 million new cases of STIs worldwide with the highest rates in young adults (between 20 and 24 years old) and older adolescents (15 and 19 years old). At the end of 2013, there were approximately 35 million people living with HIV, 2.1 million of whom were newly infected (World Health Organization, 2014c).

Risky Sexual Behaviours and Health Consequences

Risky sexual behaviours are predictors of teenage pregnancy, serious sexually transmitted diseases and infections, e.g. HIV and human papillomavirus (HPV), which are also responsible for chronic diseases such as AIDS and cervical cancer, respectively (Danaei, Vander Hoorn, et al., 2005). In 2013, it was estimated that 1.5 million deaths were due to HIV/AIDS globally with over 1 million deaths in the WHO region of Africa (World Health Organization, 2014a). HIV targets the immune system, weakening the patients' defence systems against infections. Gradually, the virus impairs the immune functioning of the body, and individuals eventually become immunodeficient and are susceptible to infections and diseases that normal healthy immune systems can fight off (World Health Organization, 2014c). STIs are a major global cause of acute illness, infertility, long-term disability and death in men, women and infants. Over 30 bacterial and viral pathogens have been identified that can be transmitted sexually. The four common curable STIs are *Chlamydia trachomatis*, *Neisseria gonorrhoeae*, *syphilis* and *Trichomonas vaginalis* (World Health Organization, 2012).

Who Is at Risk?

Global data show that diversity in sexual behaviours and the prevalence of different risky sexual behaviours vary hugely among countries and by age and gender. Risky sexual behaviours may also be exacerbated at different stages of development (e.g. adolescence) and developmental vulnerabilities.

In general, sexual activity begins in late adolescence (15–19 years old), but there is enormous variability in this, and the trend seems to be shifting towards younger age. Across different samples, between 1 and 30% of men had their first sexual intercourse before the age of 15 and between 0.2 and 46% for women (Wellings, Collumbien, et al., 2006). Huge variation exists across regions. The age at which women have their first sexual experience is also dependent on the normative age of marriage in different countries, while the same may not be true for men (Wellings, Collumbien, et al., 2006). The trend of later marriage has been observed in many countries. This has increased premarital sexual relationships and the number of sexual partners. This is, however, more prevalent among industrialized countries than developing countries.

Among unmarried youth, between 29 and 63% of adolescent boys have had sexual experience in most countries, as compared to between 1 and 63% among adolescent girls. More boys than girls reported having two or more sexual partners in the previous year (Wellings, Collumbien, et al., 2006). For developed countries, the proportions of young men and women with sexual experience were fairly similar, about 46–59%.

Certain groups of people are more vulnerable than others, and they include sex workers, men who have sex with men and who have multiple sexual partners, bisexual men, women or men who experience sexual violence and children and young people who have been abused (World Health Organization, 2007). Evidence linking sexual activity with ethnicity has been mixed (Kotchick, Shaffer, et al., 2001).

Condom use is a key indicator of safe sex practice. National surveys in developed countries showed that condom use has increased over time and that its use by young people has also increased substantially in developed countries (Wellings, Collumbien, et al., 2006) and developing countries (Cleland & Ali, 2006). This increase is offset, however, by an increased number of sexual partners, which is another risk factor of sexual health (Clark, 2004; Johnson, Mercer, et al., 2001). In general, it is more common in men than in women to have had more than two sexual partners in the previous year, with reported rates higher in developed than in developing countries (Wellings, Collumbien, et al., 2006).

Determinants of Risky Sexual Behaviours

Broad social and environmental determinants contribute to risky sexual behaviours and interact with each other and individual characteristics to predict sexual health risk.

The family influences and shapes sexual values, sex roles and expected sexual behaviours, especially among youth. Some family structures and processes have been found to be protective against risky sexual behaviour. Parents play an important role in communicating sex-related topics, and evidence has suggested that gender-specific parenting plays a role in predicting risky sexual behaviours in adolescents. Parental monitoring has been found to be more protective against risky sexual behaviours for boys than girls, whereas parental warmth and emotional connections are more important for girls (Kincaid, Jones, et al., 2012).

Socioeconomic status in terms of family income and education has been found to correlate with initiation of sexual intercourse and teenage pregnancy, but no clear consistent relationships were reported between these SES indicators and consistency of condom use and number of sex partners (e.g. Santelli, Lowry, et al., 2000). It is probable that such relationships depend on other contextual variations, e.g. perception of the partner (Green, Fulop, & Kocsis, 2000), meaning of the relationship (Gebhardt, Kuyper, & Greunsven, 2003) and gender stereotypes (Marston & King, 2006).

Cultural norms associated with gender roles can also shape sexual behaviour patterns. Gender differences and relative power in sexual relationships (Matser, Heiligenberg, et al., 2014; Tschann, Adler, et al., 2002) as well as gender stereotypes (Tschann, Adler, et al., 2002) can influence the negotiation process of safe sex practice. Influences of gender role expectations and cultural norms can be quite complex. In sub-Saharan Africa, for example, married women found negotiation for safe sex practice more difficult than single women (Lagarde, Pison, & Enel, 1996), and lower condom use was prevalent among married couples (Clark, 2004).

The kind of relationship between the partners matters when understanding condom use (Marston & King, 2006; Parsons, Halkitis, et al., 2000). Partnership factors such as steadiness and duration of the relationship (Gebhardt, Kuyper, & Greunsven, 2003), perceived risk presented by sexual partner (Chapman, Borland, et al., 1999) and perceptions of benefits and costs (Green, Fulop, & Kocsis, 2000; Marston & King, 2006) are associated with inconsistent condom use. Men who use the Internet to look for sex partners are more likely to have unprotected sex (Liau, Millett, & Marks, 2006).

Religion and religious teaching often shape attitudes and normative beliefs of sexual behaviours. Some relationships exist between religiosity and sexual behaviours, attitudes towards sex and self-efficacy to negotiate safe sex. Evidence has demonstrated that high religiosity is associated with lower likelihood of engaging in sexual intercourse among adolescents (Kotchick, Shaffer, et al., 2001), later sex initiation, more condom use (Zaleski & Schiaffino, 2000) and greater likelihood of refusing unsafe sexual encounters among female adolescents (McCree, Wingood, et al., 2003). The association between religiosity and sexual behaviours, however, is stronger for adolescent females than males (Rostosky, Wilcox, et al., 2004).

Nonadherence to Recommended Cancer Screening and Vaccination Guidelines

Screening for disease and vaccinations are preventive behaviours of increasing importance as understanding of diseases and biological approaches to their prevention, early detection and treatment increase. The elimination of polio and smallpox during the twentieth century, for example, is a major public health victory directly attributable to biological discoveries but also to behavioural and public health campaigns to disseminate and implement the vaccines resulting from those discoveries. Childhood immunization and flu vaccination are common and successful strategies for improving public health (e.g. Colditz, Brewer, et al., 1994; Jordan, Connock, et al., 2006; Nichol, Lind, et al., 1995). At the same time, considerable controversy surrounds the use and promotion of screening in many areas. Here, we focus on several cancers for which there is strong evidence both regarding the value of screening and vaccination and evidence regarding the prevalence and factors influencing dissemination of screening and vaccination.

A considerable proportion of cancer burden can be prevented by early detection and treatment (Palli, del Turco, et al., 1986; Smith, 2014; World Health Organization, 2008). To date, prevention efforts worldwide have focused on cancers that are more prevalent and would have higher successes in the treatment and prognosis should they be detected earlier. Many developed countries have also issued cancer screening guidelines and practices or implemented national screening programmes targeting at-risk groups (e.g. Smith, Cokkinides, & Eyre, 2007). According to GLOBOCAN for 2008, breast cancer is the leading cause of cancer death in women (Ferlay, Shin, et al., 2010; Jemal, Bray, et al., 2011). Cervical cancer is also one of the common causes of cancer death for women in developing countries. While screening is one of the secondary preventive measures for cervical cancer, it is also preventable through vaccination against human papillomavirus (HPV) infection. This section discusses in more detail two common cancer screening behaviours (screening women via mammography for breast cancer and screening sexually active women using cytology smears for precancerous lesions) and an immunization behaviour (HPV vaccination).

A mammogram is an X-ray picture of the breast used to check for breast cancer (e.g. lumps or breast abnormality) in women who may have no signs or symptoms. Early detection of breast cancer symptoms means that treatment can be initiated earlier in the course of the disease and sometimes may prevent cancer spread. Mammography screening has been associated with a decline in (e.g. Andersson & Janzon, 1997) and risk reduction of (e.g. Palli, del Turco, et al., 1986) breast cancer. There was a reduced mortality among women between 40 and 74 years old, particularly for those over 50 years old (B. H. Marcus, Forsyth, et al., 2000). While there is evidence to show a reduced cancer mortality of 15%, the magnitude of this effect remains uncertain, and there is also a chance of overdiagnosis (Gøtzsche & Jørgensen, 2013).

A cervical smear test (the Papanicolaou smear, also known as Pap smear) is a screening test to detect abnormal changes in the cells of the cervix and human papillomavirus (HPV), which is responsible for over 99% of cervical cancer worldwide (Walboomers, Jacobs, et al., 1999). Evidence has shown associations between HPV testing and reduction in the number of advanced cervical cancers and deaths (Sankaranarayanan, Nene, et al., 2009). National screening programmes have been implemented in developed countries such as Australia, New Zealand and the United States. However, there are still substantial proportions of women who are nonadherent to the recommended screening guidelines, in particular, among women in developing countries (Sankaranarayanan, Budukh, & Rajkumar, 2001). In the last decade, the discovery, development and testing of the HPV vaccine have made the prevention of cervical cancer even more promising. The HPV vaccine approved for use in females aged between 9 and 26 years old was first introduced in 2006. The vaccine provides protection against infection of four types of HPV which are responsible for approximately 70% of all cervical cancers (Cutts, Franceschi, et al., 2007), HPV infections (Backes, Kurman, et al., 2009) and genital lesions in males (Giuliano, Palefsky, et al., 2011).

Who Does Not Screen or Vaccinate?

Prevalence data of cancer screening are more readily available among countries with screening programmes in place. In the United States, for example, 58% of women above 40 years old reported having had a mammogram in the last year, while 85% of adult women (above 18 years old) reported having had a Pap test in the preceding 3 years prior to 2004 (Smith, Cokkinides, & Eyre, 2007). In general, people of lower SES, lower education and ethnic minority are more likely to report inadequate screening (Claeys, Gonzalez, et al., 2002; Hsia, Kemper, et al., 2000; Kuitto, Pickel, et al., 2010). However, the reverse was true for HPV vaccine uptake. Those who are younger and with lower educational attainment and SES are more adherent (Brewer & Fazekas, 2007; Kuitto, Pickel, et al., 2010).

Other socio-demographic predictors have been associated with nonadherence. For example, unmarried women are less likely to report participation in mammography screening (Euler-Chelpin, Olsen, et al., 2008; Hsia, Kemper, et al., 2000), and ethnic minority groups are less likely to follow mammography and Pap test guidelines (Hsia, Kemper, et al., 2000; Williams-Brennan, Gastaldo, et al., 2012) and initiate and complete HPV vaccine doses (Kessels, Marshall, et al., 2012; Laz, Rahman, & Berenson, 2012). However, interactions between ethnic minority and other contextual variables (e.g. physician supply, rural and urban areas) have also been found (Coughlin, Leadbetter, et al., 2008). In developing countries specifically, women are very often uninformed, and their relatively lower education may have disempowered them to access healthcare or perform health-seeking behaviours (e.g. Denny, Quinn, & Sankaranarayanan, 2006).

Determinants of Nonadherence

Individual Factors

People's knowledge determines their awareness of cancers and related screening and vaccination issues (Kessels, Marshall, et al., 2012). In general, levels of knowledge about HPV, Pap test and cervical cancer in women have been poor, and this is worse for men (Klug, Hukelmann, & Blettner, 2008; Zimet, Liddon, et al., 2006). Unsurprisingly, knowledge is more inadequate among those in developing countries (Mutyaba, Mmiro, & Weiderpass, 2006; Wellensiek, Moodley, et al., 2002) and among minority groups (Gerend & Shepherd, 2011). Consistent evidence has suggested that individual's emotions and health cognitions can promote or inhibit cancer screening behaviours. Fear, anxiety and worry are the three most frequently reported emotions to predict screening (Consedine, Magai, et al., 2004), while perceived risk is the psychological and cognitive variable that has been found to affect individual's adherence to screening guidelines (Katapodi, Lee, et al., 2004; Vernon, 1999). Other individual psychosocial factors found to be associated with screening and vaccination acceptability and behaviours include perceived susceptibility, perceived benefits and barriers (Marlow, Waller, et al., 2009), perceived effectiveness (Brewer & Fazekas, 2007), cancer worry (Jung, Chan, & Viswanath, 2014) and exposure to mass media (Marcus & Crane, 1998).

Sociocultural Factors

Familial influence is an important determinant of screening and vaccination behaviours. For adolescents, parental awareness (Laz, Rahman, & Berenson, 2012), parental perception and perceived implication of sexual activities are associated with HPV vaccination (Brewer & Fazekas, 2007; Zimet, Liddon, et al., 2006). Family history of cancer influences the likelihood of following cancer screening guidelines (Hsia, Kemper, et al., 2000), and the absence of medical problems (Grosse Frie, Ramadas, et al., 2013) generally predicts inadequate screening.

Cultural and religious factors may interfere with or enhance protective and detective actions. Different cultural myths play significant roles in shaping cognitions among immigrants (Johnson, Mues, et al., 2008; Marlow, Waller, et al., 2009). Cultural norms, social values and implications of screening and vaccination (Williams-Brennan, Gastaldo, et al., 2012) are some of the predictors of nonadherence, especially among women in low- and middle-income countries. Religion has also emerged as a significant predictor, with Muslim or Hindu/Sikh females being less likely to accept HPV vaccination (Marlow, Waller, et al., 2009). Developing culturally appropriate education materials may be the way forward to enhance knowledge about cancer and screening guidelines (Farmer, Reddick, et al., 2007) and to narrow potential disparities in vaccine receipt in ethnic and religious groups.

Health Systems/Policy

The lack of resources and infrastructure in the health systems is one of the greatest barriers to screening and immunization in most developing countries (Denny, Quinn, & Sankaranarayanan, 2006). Healthcare systems in these countries generally emphasize acute health problems and are likely to have limited human and financial resources to target health risk behaviours associated with more chronic illness. In low-resource settings, the protocol used and logistics involved with screening and vaccination are likely to deviate from those used in more developed regions. For example, screening and vaccination sites need to be accessible to at-risk population to allow wide coverage. Screening needs to be of low cost and utilize low technology to provide prompt treatment of abnormalities (Denny, Quinn, & Sankaranarayanan, 2006).

Health insurance and the cost involved are key determinants to shape people's screening and vaccination intention and actual behaviours. Individuals without access to health insurance are less likely to comply with screening recommendations (Coughlin, Leadbetter, et al., 2008; Hsia, Kemper, et al., 2000; Sambamoorthi & McAlpine, 2003). The affordability of screening tests and accessibility to screening facilities have been suggested to be important determinants of screening behaviours (Bazargan, Bazargan, Bazargan, et al., 2004; Claeys, Gonzalez, et al., 2002; Williams-Brennan, Gastaldo, et al., 2012). New vaccines (e.g. for HPV infection) are usually more expensive and often more limited in developing countries than in developed ones. Hence, the relatively high cost to get vaccinated poses an extra burden in the developing world and may predict lower uptake (Kane, Sherris, et al., 2006).

Other Key Health Behaviours

In addition to those reviewed here, there are numerous other behaviours that have important influences on health. These include stress and stress management (see chapter by Siegrist, *infra*), adherence to treatments (Burke and colleagues, *infra*), satisfying relationships and social support (Uchino and colleagues, *infra*) and important areas of life that may not be thought of as health behaviours but which, nevertheless, have important impacts on health, such as work, recreation and relaxation, parenting and education (Sherlaw and colleagues, *infra*). Clearly, behaviour is not only a major contributor to health but a major component of it.

Summary

Health behaviours play critical roles in preventing a wide number of diseases and promoting long-term health. While the majority of infectious diseases can be prevented by practising good hygiene at the public health and individual levels, most common noncommunicable diseases require multiple health behaviour change for effective prevention and control.

This chapter has reviewed a selection of some major behavioural risks that contribute to the onset and maintenance of diseases, highlighting the specific subgroups of individuals by demographics and regions that are more susceptible to engaging in these risky behaviours. A combination of the health risk behaviours presented in this chapter is likely to accelerate the pace at which the chronic disease epidemic is emerging, specifically in developing countries. Identifying and understanding the distribution of these risk factors can help identify particular "at-risk" groups for health promotion "behaviour change" intervention. Compelling evidence has shown that the determinants of risky behaviours are multidimensional at multiple levels, and sometimes, they interact with individual differences on behavioural skills, health cognitions and motivation.

The risky behaviours described above do share some common ecological determinants at multiple levels. Physical, economic, political and sociocultural changes are important environmental factors to facilitate positive outcomes of behaviour change. One may ask how we can cure the environment to combat the high prevalence of risky behaviours. The built environment can provide opportunities for healthy and unhealthy choices, e.g. accessibility of food options, facilities and urban planning for physical activity. The costs associated with health risk behaviours is the major economic factor. Making healthy choices affordable is particularly relevant for bridging inequality in some behaviours. The same applies to making unhealthy choices more costly. The political environment is responsible for setting rules and regulations that may influence the adoption or cessation of health risk behaviours. However, the time lag between research discovery and translation to policy change and practice has been substantial. Smoking bans in public places and workplaces and nutrition and food marketing regulations have all taken many years to be implemented in real-life settings after research evidence became available. In the meantime, some of the determinants discussed in this chapter can be managed through individual and community actions. If risky behaviours could be discouraged through intervening at a greater number of ecological levels, the number of deaths and disabilities resulting from common preventable diseases could be greatly reduced.

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Behavioral Medicine: Who Does It and Where

4

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Behavior is a determinant in health and illness, affecting morbidity and mortality, disparities in health and care, medical errors, patient safety, primary care shortage, and physician discontent and burnout (Association of American Medical Colleges, 2011). Preventing and managing costly chronic disease depends heavily on reducing smoking and improving diet and exercise (McGinnis, Williams-Russo, & Knickman, 2002; Mokdad, Marks, et al., 2005). Behavioral medicine is increasingly being recognized as an important part of the solution to improving health-care problems by enhancing health and wellness, better explaining disease etiology, improving adherence rates to existing treatments, and contributing to the development of new interventions (Office of Behavioral and Social Sciences, 2007). Principles of behavioral medicine are also relevant for health professionals to understand and manage their own emotions, stress, and competing demands while staying empathically connected with those they serve.

Individuals with expertise in behavioral medicine are being called upon to meet the growing demand to incorporate more behavioral and social science in health-related research and practice. Clinicians, educators, and researchers in health-related areas, both today and in the future, are in need of developing behavioral medicine knowledge and skills (Allan, Barwick, et al., 2004). Unfortunately, there is an insufficient number of capable faculty in medical schools and other health professional training programs to integrate behavioral and social science content into the curricula (Association of American Medical Colleges, 2011).

This chapter reports how behavioral medicine and its training are occurring in some key disciplines and professions that are involved in addressing complex health problems. Two fields, psychology and public health, have been instrumental in the development of behavioral medicine and have behavioral medicine built into the fabric of their disciplines. They are at the forefront of helping to infuse behavioral medicine principles and practices throughout health-related areas. Other health fields, including medicine, nursing, pharmacy, and dentistry, are increasingly incorporating behavioral medicine into some combination of their education and training, practice, and research.

The scope and variety of behavioral medicine and of the disciplines and contexts through which it is studied and applied make a chapter such as this a substantial challenge. This challenge is greatly magnified by the ways the disciplines and

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settings of behavioral medicine also vary around the world. The framework of the chapter is primarily from the USA, but it is hoped that the inclusion of examples from other countries will help in the identification of principles and perspectives applicable worldwide.

Roots and Foundation of Behavioral Medicine

In 1977, behavioral medicine began to formally take hold in the USA when its definition was developed at the Yale Conference on Behavioral Medicine (Schwartz & Weiss, 1978). Within a year, both the Society of Behavioral Medicine and the *Journal of Behavioral Medicine* were created (Belar, 2008). At the time, relevant publications were coming out in the USA stressing the importance of health promotion and behavior, including the 1979 US Department of Health, Education, and Welfare report *Healthy People: The Surgeon General's Report on Health Promotion and Disease Prevention* and the 1982 Institute of Medicine report *Health and Behavior: Frontiers of Research in the Biobehavioral Sciences.* As a result, training programs specializing in behavioral medicine grew in number, while other health-related disciplines and professions began incorporating behavioral medicine training in their curricula. Internationally, the first International Congress of Behavioral Medicine was held in Uppsala, Sweden, in 1990, and the *International Journal of Behavioral Medicine* began publication in 1994.

The foundation of behavioral medicine rests upon and within a number of academic disciplines. Behavioral medicine is built not only on contributions from psychology and public health but also from anthropology, sociology, economics, communication, education, political science, social work, and, more recently, informatics. The unique and overlapping contributions of each discipline combine to create the interdisciplinary behavioral medicine endeavor, standing apart from while at the same time remaining inextricably part of its disciplinary origins.

Understanding behavioral medicine may fit with what the philosopher Gilbert Ryle (2009) describes as a category mistake: conceptualizing the category as something other than the elements that comprise it. In Ryle's example, a visitor to Oxford University who indicates appreciation of seeing the Bodleian Library, New College, Magdalen College, St. Catherine's College, and the Ashmolean Museum but then asks, "where is Oxford?" is committing the category error. The university, Oxford, is the libraries, the colleges, museums, etc. that comprise it, not something apart from them. In a similar way, behavioral medicine is a broad category that is made up of the work of health-care professionals such as dentists, epidemiologists, nurses, physicians, psychologists, public health professionals, and social workers. There is no "thing" of behavioral medicine apart from that work, but, as this chapter is intended to document, the breadth, excitement, and potential benefit of all that work – all that behavioral medicine – are great indeed.

Behavioral Medicine in Research

Behavioral medicine approaches that are used in the health professions are empirically derived and supported through research. A great number of academicians, from basic scientists to policy specialists and from many disciplines, have developed the principles, theories, and interventions used to modify behavior to improve health. The contributions from basic research to its application are illustrated in the work of one of the founders of behavioral medicine and one of its current leaders. Neil Miller, PhD, an eminent psychologist and founding member of the Academy of Behavioral Medicine Research, made important early conceptual and research contributions to the application of learning theory to complex human behavior (Dollard & Miller, 1950) and then extended that work to learned control over autonomic psychophysical processes. His groundbreaking laboratory research was applied by him and others to work in minimizing stress, treating disease, and promoting health (Miller, 1983). Edward Taub, PhD, then collaborated with Dr. Miller (Taub, Crago, et al., 1994) to develop constraint-induced movement therapy to promote neuroplastic changes in the brain that enhance motor recovery following stroke, traumatic brain injury, cerebral palsy in young children, multiple sclerosis, and other neurological injuries (Taub, Uswatte, & Mark, 2014).

Behavioral medicine research is increasingly being incorporated into larger research initiatives as the importance of behavior in health and illness is recognized internationally and in the USA. In the USA, the role of behavior is reflected in funding from the National Institutes of Health (NIH) and other agencies (e.g., Patient-Centered Outcomes Research Institute, Robert Wood Johnson Foundation, Agency for Healthcare Research and Quality). The National Institutes of Health in 2003 charted the "Roadmap for Medical Research" in the twenty-first century that recognizes the convergence of the biomedical and the socio-behavioral-cultural views of health and illness. The road map stimulated new ways of combining skills and disciplines in the physical, biological, and social sciences. Scientists extended beyond their individual disciplines to (a) more multilevel research from molecular biochemistry to individual behavior to social policy, (b) interdisciplinary research occurring in teams, and (c) patient-centered and relevant outcomes research. Other funding agencies similarly encouraged multilevel and interdisciplinary research including the behavioral determinants of morbidity and mortality, patient safety, and medical error reduction. Internationally, WHO calls for a stronger commitment to a multidisciplinary approach to research, including in the area of adherence, which is considered the primary determinant of treatment success (Sabaté, 2003).

Behavioral Medicine in the Health Professions

Behavioral medicine permeates many disciplines, professions, settings, roles, and activities in health. Behavioral medicine can occur as part of widely varying roles and activities, across different settings, and can be part of numerous professions. Those who engage in behavioral medicine activities do so in teaching, research, clinical, policy, or administrative capacities. Behavioral medicine professionals can conduct research, teach students, educate the public, intervene with individuals with chronic conditions, treat patients in clinics and hospitals, deliver community-based health program, or perform some other role.

The work can be conducted in academic institutions (e.g., teaching and research), community organizations (health, school), hospitals and clinics, fitness and wellness centers, businesses (e.g., employee health risk appraisal and health promotion), and government and nongovernment agencies, among other settings. Embracing the breadth of "cells to society," the target populations can involve the society or specific communities (e.g., health policy), patients in clinics and hospitals, individuals who are at risk (e.g., unsafe sex), children in schools or young adults in colleges, and healthy individuals (disease prevention), among others. The health-related issues addressed by those in behavioral medicine also vary widely but generally relate to the impact of behavior on health. The issues targeted can include disease prevention, physical and emotional health and well-being, sexual health, substance abuse prevention and management, physical activity engagement, addressing mental illness in patients with chronic disease, and nutrition and eating issues.

Describing a single model of the professional who does behavioral medicine is not possible. Few professionals identify themselves as doing behavioral medicine – they typically identify themselves within an established discipline or profession. For example, they do psychology, public health, nursing, or some other health-related professional work. Irrespective of their professional identity, there are some whose professional activities are primarily behavioral medicine in nature, while there are others who engage in behavioral medicine activities but in a more limited capacity. For example, a researcher may identify as a psychologist, or epidemiologist, or medical anthropologist, but the setting, role, and activities are primarily behavioral medicine in nature. Specialists in behavioral medicine, whose training and activities are focused on behavioral medicine, can come from a number of professions (e.g., anthropology researcher). Psychology, public health, and medicine are prominent among these.

An example of someone with more limited engagement in behavioral medicine is a nurse in an elementary school setting who is asked to help develop and implement a 6-month health promotion initiative to help students understand healthier food choices and identify opportunities for physical activity enhancement. In contrast to the behavioral medicine researcher, the school nurse's professional identity, setting, role, and activities are not specific to behavioral medicine. Behavioral medicine plays an important yet relatively limited role for the school nurse. Examples of professions in which the work involves behavioral medicine but not as the primary role can include medicine, nursing, dentistry, and pharmacy.

Given the broad range of professions and disciplines in behavioral medicine, describing the role of behavioral medicine in many of them is beyond the scope of a single chapter. Here, of necessity, is a selective describing of how psychology, public health, medicine, nursing, dentistry, and pharmacy incorporate and contribute to behavioral medicine.

Psychology

Psychology, as the science of behavior, has been instrumental in the formation of behavioral medicine and remains one of its core professions and disciplines. Psychologists continue to represent over 50% of the 2300 members of the US Society of Behavioral Medicine. Within psychology, the specialty of health psychology, with its focus on the promotion of health and prevention and management of disease, is most aligned with the objectives of behavioral medicine. The Society for Health Psychology, a division of the American Psychological Association (APA) currently has over 3500 members. In Europe, there is a separate organization of health psychologists, the European Health Psychology Society, with over 550 members.

William Schofield's landmark report in 1969 to the APA on "The Role of Psychology in the Delivery of Health Services" (Schofield, 1969) helped develop the eventual specialty of health psychology, as well as the formalization of behavioral medicine. In a 10-year span beginning in 1975, much occurred in the creation of health psychology. Two years before the 1977 Yale Conference on Behavioral Medicine, the Section on Health Research was created in the APA Division of Public Service. The Health Psychology Division of APA was subsequently formed within a year of the Yale Conference, and the journal *Health Psychology* was first published in 1982. The European Health Psychology Society was established in 1986 after an expert gathering in Tilburg, the Netherlands, and the Society's journal, *Psychology and Health*, began publishing a year later.

Training in health psychology was defined in 1983 at the Arden House National Working Conference on Education and Training in Health Psychology (Stone, 1983). At that time, a number of training programs in health psychology were developing at the doctoral, internship, and postdoctoral levels. As of 2015, the Association of Postdoctoral and Internship Centers website lists 423 internship programs providing supervised experience in health (behavioral medicine)-related areas.

Psychologists involved in behavioral medicine conduct research, professional practice, education and training, and advocacy across an array of community and health-care settings. As experts in human behavior, psychologists are grounded in psychological science and integrate knowledge from other areas such as biology, sociology, and public health as appropriate. Psychologists conducting behavioral medicine in health-care settings can engage in promoting health and preventing illness, addressing the needs of people with medical illness, assisting in stress and coping, and facilitating recovery, rehabilitation, and adjustment of health-related concerns (American Psychological Association, 2014). Common health issues addressed by psychologists include stress, adherence to medical regimens, pain, cardiovascular disease, cancer, tobacco and other substance use, eating and weight control, and physical activity (American Psychological Association, 2014). Psychologists in health-care settings can also contribute their behavioral medicine expertise in roles such as training and supervision, consultation, program development and evaluation, quality improvement, leadership and team coaching, and outcome evaluation (Belar, 2014; Nash, Khatri, et al., 2013; Nash, McKay, et al., 2012). Behavioral medicine psychologists often collaborate and sit on interprofessional teams with colleagues from medicine, nursing, sociology, anthropology, epidemiology, psychiatry, physical therapy, and public health. In the academic realm, psychologists are often at the forefront with their colleagues from other disciplines in developing theories and related interventions that are used by professionals in health-care settings to promote health and manage disease.

Public Health

Public health has long emphasized health of populations and especially prevention, as opposed to individual-level explanations or interventions. Sociology, political science, and health economics have always fit into public health and its training. Within these emphases, health education developed within public health but often with more of an emphasis on community health education and prevention than on the perspectives of psychology. To the extent it has focused on individual behavior, psychology and other behavioral sciences have lagged in their integration into public health (Schneiderman & Speers, 2001). Toward the end of the twentieth century, however, two conferences were held that marked a critical juncture in the role of behavioral and social science in public health (Coreil, 2009). The first, *Public Health in the 21st Century: Behavioral and Social Science Contributions*, was cosponsored by the US Centers for Disease Control and Prevention, the American Psychological Association, and other social science organizations and held in 1998. The second conference, *Towards Higher Levels of Analysis: Progress and Promise in Research on Social and Cultural Dimensions of Health*, was held in 2000 and organized by the National Institutes of Health. The theme in these meetings was the recognition that (a) knowledge about biological and genetic markers is important but limited in predicting who gets sick, who seeks treatment for health problems, and who recovers from illness and (b) behavioral and social sciences contribute to filling these gaps in our understanding of health. The relevance of behavioral and social science in public health has also increased as public health has expanded into new arenas of social welfare (including primary care services), reproductive health, child and family protection, injury prevention, and the health consequences of natural disasters, war, and political violence.

The social and behavioral sciences in public health address the behavioral, social, and cultural factors related to individual and population health and health disparities over the life course. More specifically, behavioral scientists provide insight into behavioral change occurring at different levels of analyses, and social scientists contribute to understanding organizational structure at the community level, including the utilization of community action, government, and health economic strategies (Schneiderman & Speers, 2001). Research and practice in this area contribute to the development, administration, and evaluation of programs and policies in public health and health services to promote and sustain healthy environments and healthy lives for individuals and populations (Coreil, 2009).

With the increased role of behavioral and social science in public health is the increased integration of behavioral and social science training in its curriculum. Coursework in social and behavioral sciences has become a mandated component of the core curriculum in all schools of public health in the USA seeking accreditation. The Association of Schools and Programs of Public Health (ASPPH) includes behavioral and social sciences as one of its core competency areas for the Master of Public Health (MPH) degree. The identified areas of learning within the behavioral and social science realm include, for example, (1) identifying the causes of social and behavioral factors that affect health of individuals and populations and (2) applying evidence-based approaches in the development and evaluation of social and behavioral science interventions.

Medicine

Physicians increasingly recognize that disease states cannot be prevented and managed without attention to the behavioral and social factors that are determinants of many health problems and serve as barriers to effective care. Physicians are expected to influence patients' behavior to promote health and prevent and manage chronic disease but in the past have often been ill-prepared in these areas. In the USA, there is now recognition of the importance of physician training in behavioral and social science. This now often begins prior to entering medical school as premedical students are expected to have an understanding of behavioral and social sciences. In its first change in 25 years, the Medical College Admission Test in the USA includes a new section, "Psychological, Social, and Biological Foundations of Behavior." The section tests students' understanding of behavior and behavior change, cultural and social differences that affect well-being, and the relationship among socioeconomic status, access to resources, and well-being.

Preparation in behavioral science continues in medical school, and not only in the USA but also in places such as Canada and Hungary as well. The Association of American Medical Colleges (2011) produced a report that provides a template for medical schools to incorporate behavioral and social sciences concepts in their curricula, as well as teaching methods for schools to implement the concepts. The report is built on other competency-based frameworks that help guide educators in designing medicine curricula. One framework from the US Institute of Medicine identifies six domains of behavioral and social science content and priority topics to be addressed in medical school (Cuff & Vanselow, 2004). Similarly, a report of the Royal College of Physicians and Surgeons of Canada (Frank, 2005) sets out specific roles which physicians must be trained to fulfill and the competencies that support fulfilling those roles. In Eastern Europe at Budapest, Hungary's Semmelweis University, the Institute of Behavioral Sciences, created in 1993, provides behavioral medicine courses to medical students (and dentistry and pharmacy students). Teaching behavioral and social sciences in medical school is not expected to produce specialists in behavior but to equip physicians with behavioral and social science-derived knowledge, skills, and attitudes required to practice medicine effectively (Cuff & Vanselow, 2004).

To redesign and enhance behavioral and social science curricula in medical school, the National Institutes of Health funded a mechanism (K07) and awarded nine grants to medical schools to develop medical education consistent with the Institute of Medicine recommendations (Cuff & Vanselow, 2004). The Indiana University School of Medicine, for example, used the funds to (a) infuse social and behavioral science into all for years for a total of 93 contact hours, (b) develop and use innovative interactive learning materials, including a simulation board game, to teach health policy and economics in a team-based learning context, and (c) create mechanisms to bring medical students in direct contact with community members and patients.

Nursing

Nurses are ideally positioned to use behavioral medicine to help improve health. In high- and middle-income and many low-income countries, nurses are located in virtually all patient care settings such as hospitals, long-term care, homes, schools, and the community (Institute of Medicine, 2011). Nurses, and in particular nurse leaders, have a growing focus on health promotion and risk reduction that extends beyond patient education and includes the facilitation of change. Clinical nurse leaders are being called upon to design and implement measures to modify risk factors and promote engagement in healthy lifestyles (American Association of Colleges of Nursing, 2013). The roles of clinical nurses remain in providing and coordinating care for the sick but are extending to include engagement with groups and communities around health promotion, secondary prevention, and risk reduction. For example, clinical nurses can develop clinical and health promotion and help patients access and interpret health information to identify healthy lifestyle behaviors. In addition, clinical nurses can evaluate the efficacy of health promotion and education modalities for use in a variety of settings and with diverse populations.

Diabetes care is one area in which nurses have long been actively involved, making major contributions in using behavioral medicine (Davidson, Ansari, & Karlan, 2007; Guthrie, Runyan, et al., 1964; Kahn, Fox, et al., 2009; Taylor, Miller, et al., 2003). In diabetes care, nurses can monitor patients between office visits, provide diabetes counseling, remind patients about appointments, and coordinate lab work and specialty care. In the USA, nurses and dietitians predominate among the ranks of Certified Diabetes Educators and their roles in ongoing diabetes management. The role of nurses is expanding to address other chronic conditions such as hypercholesterolemia, hypertension, and depression (Hiss, Armbruster, et al., 2007; Taylor, Miller, et al., 2003). In a care management role within an integrated care model, nurses are often at the nexus of care especially for those with complex problems, multiple morbidities, or frequent, avoidable hospital and acute care. This entails behavioral approaches to facilitate the patient's care and self-management of medical and behavioral health. Nurses in various specialty areas and at many educational levels are becoming competent in psychological interventions such as motivational interviewing and other health behavior enhancement approaches to improve patient health outcomes (Emmons & Rollnick, 2001; Maissi, Ridge, et al., 2011). All health settings can serve as a platform for health promotion interventions by nurses, including intensive care units, medical-surgical units, oncology units, emergency departments, and home health care.

The education of nurses is evolving to keep stride with the expanding role of nurses in addressing behavior and health. Nursing, along with other health disciplines, is developing a basic curriculum that includes the core competencies in health promotion and disease prevention (Allan, Barwick, et al., 2004; American Association of Colleges of Nursing, 2013; Institute of Medicine, 2011). Nursing education also seeks to create competencies in applying psychosocial, behavioral, and cultural approaches in practice (American Association of Colleges of Nursing, 2006). At the doctoral level, nursing education is also incorporating behavioral medicine principles, teaching concepts in public health, health promotion, evidence-based approaches, determinants of health, behavioral science, and cultural diversity. Advanced nursing graduates learn to analyze epidemiological and biostatistical data in the development, implementation, and evaluation of clinical prevention and population health (American Association of Colleges of Nursing, 2006). They are also competent in using assessment techniques at the organizational, systems, and community levels.

Dentistry

Oral health status can affect general health and quality of life. Among the pressing issues in oral health are those that involve behavior or psychological factors, including chronic facial pain, craniofacial birth defects and trauma, oral diseases related to behavior (e.g., tobacco use), and access to care for low-income and underserved minority groups (Mertz & O'Neil, 2002). The etiology of some oral diseases can include the modifiable lifestyle risk factors that are common to a number of chronic diseases: inadequate oral hygiene, tobacco use, diet, stress, and behaviors causing injuries. Dentists and other oral health providers (e.g., endodontists, periodontists, orthodontists, dental hygienists) are increasingly understanding the unhealthy effects of certain behaviors and the importance of enhancing health behaviors to prevent and control disease.

The structure of the dentistry practice in many ways is ideal to enhance health promotion. For some time, in many developed nations, people have visited the dental practice for routine visits more frequently than the medical practitioner (Ramseier, Suvan, et al., 2010). Continuity of care in dentistry allows unique opportunities for oral health providers to know their patients and therefore, become more involved in assessing and ensuring the overall health of their patients through screening, diagnosis, and referral (Wilder, O'Donnell, et al., 2008). These factors have led to broadening the role of dentistry to include, e.g., chronic disease management such as the important and insufficiently recognized relationship between periodontal disease and glycemic control in diabetes (Taylor, Burt, et al., 1996). The *British Dental Journal* has published a series of papers on a variety of preventive interventions, including dietary advice and smoking cessation (Watt, Daly, & Kay, 2003; Watt, McGlone, & Kay, 2003). Unfortunately, when oral health clinicians maintain conventional roles and their historical isolation from other health professionals, the opportunity to enhance health promotion is lost (Wilder, O'Donnell, et al., 2008).

In recognition of the opportunity for dental professionals to enhance health, the American Dental Education Association approved competencies for the new general dentist (American Dental Education Association, 2008). The competencies reflect that the general dentist addresses health-care issues beyond traditional oral health care with the goal of improving the health of society. Among the competency domains are those that reflect behavioral medicine. In particular, the "health promotion" domain includes the importance of applying prevention strategies (behavioral and educational in nature) and the need to contribute to improvement of oral health beyond those served in traditional practice settings. The "communication and interpersonal skills" domain includes the application of psychosocial and behavioral principles in patient-centered health care and communicating effectively with individuals from diverse populations. A part of the "patient care" domain is preventing, identifying, and addressing pain and anxiety in the dental patient and recognizing and managing substance abuse. Also among the competencies is participating with members of other health-care professions in the management and health promotion for all patients. Integrating dentistry with other health professions, including those in behavioral medicine, will help the effective implementation of health behavior change in the dental practice.

Pharmacy

Pharmacy has been long recognized as a profession that can address health promotion. Over 25 years ago, the World Health Organization held meetings on the role of the pharmacist in the health-care system, including the role of health promotion (World Health Organization, 1994). Before that the American Public Health Association had already outlined the public health role of the pharmacist in a pioneering statement (American Public Health Association, 2006). Pharmacists were declared an underutilized resource in promoting public health.

Pharmacies are considered the most accessible health-care entity in the community, and pharmacists are well recognized and highly credible health advisors (Kotecki, Elanjian, & Torabi, 2000). Pharmacies and pharmacists have access to a large proportion of the population, including those who are both healthy and ill and those who are not motivated to use other health services (Joyce, Sunderland, et al., 2007; World Health Organization, 1994). Community pharmacies are accessible sites to address key health behaviors through health screening (e.g., diabetes, cholesterol, osteoporosis) immunizations, pain control, participatory and clinical research, and counseling/health education (American Society of Health-System Pharmacists, 2008). Within these settings, pharmacists can actively engage in behavioral medicine activities including health education and disease prevention and control programs (American Society of Health-System Pharmacists, 2008; Maine, 2005). Within the health education realm, for example, pharmacists can develop patient education programs on safe and effective medication use or on topics such as tobacco cessation, exercise, and healthy nutrition (Crawford, 2005; Maine, 2005). Pharmacists can support the education and training of the population at an early age, such as through school health programs, to help children develop good health behaviors that can continue into adulthood. Furthermore, pharmacists can improve society's safe and effective use of medications by educating their health-care colleagues (American Society of Health-System Pharmacists, 2008; Crawford, 2005).

Education and training guidelines in pharmacy incorporate language related to pharmacists engaging in health promotion (Medina, Plaza, et al., 2013). Educational programs now train pharmacists to provide prevention, intervention, and educational strategies for individuals and communities to improve health and wellness and demonstrate a strong commitment to health promotion and illness prevention (e.g., provision of health screening, tobacco cessation counseling). In a Malaysian pharmacy school, for example, the curriculum includes a separate course on public health (Hassali, Shafie, et al., 2009).

While the long-standing interest in the public health role of pharmacists as health educators is considerable, the engagement and impact of pharmacists have been more limited, particularly in the USA (Kotecki, & Clayton, 2003; Kotecki, Elanjian, & Torabi, 2000). There are a few reports documenting pharmacist participation in health education and disease prevention. Challenges also exist, however, for pharmacists to counsel individuals on health behavior change. Pharmacists may feel health promotion is too far removed from the traditional role of dispensing medication, and they may lack interest and confidence in prevention activities targeting smoking, diet, and physical activity (O'Loughlin, Masson, et al., 1999; Watson & Hughes, 2012).

Australian pharmacists, in contrast, appear to be more active in health promotion and disease prevention and management (Joyce, Sunderland, et al., 2007). A variety of health promotion activities are currently conducted through community pharmacies as normal business, including smoking cessation, weight loss, sexual health, and alcohol awareness (Joyce, Sunderland, et al., 2007; Pharmacy Guild of Australia, n.d.). Activities in the USA may be catching up with such progressive models, however. For example, in a review out of Canada that includes studies from the USA, community pharmacists can be considered an important public health resource when providing clean needles to injection drug users as well as opioid substitution as part of a public health harm reduction model (Watson & Hughes, 2012).

There is a vision within the pharmacy profession to move beyond the manufacturing and selling of drugs and expand the role of community pharmacists to include more health education, health promotion, and disease prevention activities. The International Pharmaceutical Federation has taken up the concept of the "Seven Star Pharmacist," introduced by WHO, to engage pharmacists in activities like patient counseling for risk management and interventions to improve patient compliance (Habeeb Ibrahim, Jose, & Jegan, 2012). In the USA, as part of the health-care reform effort, there is a move for pharmacists to receive provider status (Clark, 2014). In a recent study reflecting the increasing scope of the pharmacist role, pharmacists directed a 12-week walking program in an employee health and wellness clinic (Fanous, Kier, et al., 2014). In addition, pharmacists in Asheville, North Carolina, used their accessibility and relationships with customers to enhance a diabetes management program that resulted in cost-effective clinical improvements (Cranor, Bunting, & Christensen, 2003).

Integrated Behavioral Medicine in Primary Care Settings

Around the world and in low- and middle-income as well as high-income countries, health care increasingly emphasizes the integration of treatment of individuals' health problems through medical settings, including primary care (Beaglehole, Epping-Jordan, et al., 2008). Behavioral medicine is becoming increasingly integrated into many medical specialty settings (e.g., rehabilitation units, transplant units), long-term care, and community-based health and social service sites. The integration of behavioral medicine into medical care is part of the evolving health-care system and its focus on improving the health of the population, providing better patient experience and outcomes, and lowering cost.

Primary Care

Among the medical settings in which behavioral medicine is taking a more active role is primary care. As many as a third of primary care patients meet diagnostic criteria for mental health problems that often go unrecognized and undertreated, and visits to primary care practitioners are driven by patients' psychological problems, such as anxiety, panic, depression, and stress (Wang, Lane, et al., 2005). Depression, for example, can go undetected in primary care both in the USA (Martin, Williams, et al., 2005) and other regions of the world including Hong Kong (Chin, Chan, et al., 2014), New Zealand (Carey, Jones, et al., 2014), and the UK (Mitchell, Vahabzadeh, & Magruder, 2011). Unaddressed mental illness is one factor accounting for poor control of high-risk and costly chronic illness. The preventable and modifiable unhealthy behaviors (e.g., smoking, sedentary lifestyle, poor diet) that are not being adequately addressed are also contributing to costly chronic disease (Mokdad, Marks, et al., 2005). Physicians in primary care, although expected to identify and manage their patients' behavioral health issues, are not necessarily interested or adequately prepared to do so.

Enhancing behavioral medicine services in primary care can address costly mental illness and chronic disease by targeting comorbid mental and physical illnesses and by enhancing health behavior. Services for behavioral issues can be more accessible for patients who would not normally seek such services (e.g., mental health related) because of stigma or difficulty overcoming other barriers (e.g., long wait lists, long commutes to services) (Croghan & Brown, 2010). Individuals from ethnic/racial minority backgrounds and underserved individuals, who may have the most difficulty in accessing services, may benefit most from behavioral medicine services being delivered in primary care settings (Gum, Iser, & Petkus, 2010; Pingitore, Snowden, et al., 2001).

Patient-Centered Medical Home

Within the USA, a strong emphasis is to transform primary care practices into patient-centered medical homes (PCMHs). The National Committee for Quality Assurance (NCQA) began a recognition program in 2008, which has led to 7000 primary care practices (about 10%) gaining the status of PCMH (www.ncqa.org/HomePage.aspx). Within the Veterans Administration Health Administration, a similar rollout in 2010 transformed its primary care services into Patient-Aligned Care Teams (PACT), another version of the PCMH, in recognition of its utility and efficiency (Kearney, Post, et al., 2014).

The PCMH concept is consistent with tenets of the Patient Protection and Affordable Care Act of 2010 (Runyan, 2011) in the USA and the Triple Aim framework of improving population health and patient experience at a reduced cost (Berwick, Nolan, & Whittington, 2008). The concept is also consistent with the proceedings from the 1978 World Health Organization's conference at Alma-Ata (World Health Organization, 2008), which highlighted the importance of addressing mental health in primary care using language that is incorporated into the PCMH model but did not use the term itself.

Fundamental to the PCMH is a recognition that is shared with behavioral medicine: most prevention and management occurs outside, not within the clinical setting – "nobody lives in a patient centered medial home."[1] Both behavioral medicine and the PCMH emphasize the influences of family, community, and social and eco-

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[1] George Rust, National Center for Primary Care and the Department of Family Medicine, Morehouse School of Medicine, Atlanta, Georgia, USA.

nomic determinant and seek to find ways to incorporate them in care and prevention. The PCMH incorporates elements of the Chronic Care Model that are designed in part to prevent costly illness (Coleman, Austin, et al., 2009). The model involves behavioral medicine principles and approaches that include, among other elements, informing and activating patients to engage in health behaviors and self-management of illness (Fromer, 2011).

In the PCMH, whole-person integrated care is delivered by an interprofessional team of healthcare providers. Care is comprehensive and focuses on quality and safety. Comprehensive, whole-person care addresses the behavioral as well as physical health needs of patients (Taylor, Lake, et al., 2011). In addressing behavioral health needs, components of behavioral medicine are understood and delivered by a range of healthcare providers in order to better prevent and manage chronic disease.

Within a strong emphasis on team-based care (Collins, Hewson, et al., 2010; Hogg, Lemelin, et al., 2009), behavioral medicine specialists are serving as important members of the PCMH team. They are valuable in providing patient care, guiding their health professional colleagues' use of behavioral medicine strategies and offering their expertise to enhance team functioning. Behavioral medicine specialists can provide much needed access to quality behavioral health care by treating mental and behavioral health-related conditions. They can also decrease the load on the medical providers and help improve coordination of care. As leaders in the practice with administration skills, they can assist in the development and evaluation of the behavioral medicine services that are integrated into the medical setting. With empirical abilities, they can help with quality improvement initiatives. Cost offset and fewer hospitalizations have been demonstrated for primary care patients who receive behavioral medicine services (Blount, Schoenbaum, et al., 2007). Clearly, there is a wide range of roles for behavioral medicine within the PCMH and primary care. The next section details several among these (Nash, McKay, et al., 2012; Nash, Khatri, et al., 2013).

Patient Care and Consultation

Health professionals with expertise in behavioral medicine can provide patient care directly, in face-to-face encounters, and indirectly, in serving as a consultant to other members of the treatment team. The behavioral medicine specialist can guide the medical team in routine screening of patients considering the number of patients in primary care who have unidentified or unaddressed behavioral health needs (Croghan & Brown, 2010). Once screened, evidence-based interventions are used to address mental illness (e.g., mood and anxiety disorders), enhance health behavior (e.g., related to obesity, sedentary lifestyle, and tobacco use), and manage chronic diseases and their comorbidities such as depression and comorbid diabetes (Katon, Von Korff, et al., 2004), coronary heart disease (Frasure-Smith & Lespérance, 2010), and chronic pain (Dobscha, Corson, et al., 2009; Kroenke, Bair, et al., 2009).

In the consultation role, the behavioral medicine specialist can provide expert guidance to primary care team members on patient-related and practice management issues. The consultation process can help the primary care team to know how best to use behavioral medicine resources, engage primary care team members in comanaging patients, support the decision-making or primary care team members, integrate a behavioral medicine component into the medical treatment of the patient, guide the physician and primary care team's use of behavioral medicine interventions such as motivational interviewing, and help physicians address behavioral health issues at early stages of development. Consultative roles can broaden the reach and influence of the behavioral medicine specialist's expertise across the practice (Robinson & Reiter, 2007).

Teaching and Supervision

Academic primary care centers serve as training ground for different health professionals (e.g., physicians, nurses, pharmacists). A specialist in behavioral medicine in the primary care setting has an opportunity to have an active role in formal training initiatives for health professionals, including physicians. For example, some primary care physician residency programs for decades have enlisted the expertise of behavioral scientists in the formal training of resident physicians (Fischetti & McCutchan, 2002; McDaniel, 1995). Psychologists in primary care are also increasingly creating opportunities for psychology training in primary care settings. Recognized training programs are established at the psychology doctoral, internship, and fellowship levels in integrated primary care (Bluestein & Cubic, 2009; Garcia-Shelton & Vogel, 2002).

Program Development and Evaluation

Many professionals with concentrated training in behavioral medicine are from academic disciplines (e.g., public health, psychology). The research skills that these professionals develop through their academic training are useful in primary care settings where performance assessment is increasingly required and technology is increasingly used in delivery of care. Research skills can be combined with understanding ways to meaningfully use health information technology to improve patient safety, satisfaction, and quality of care, particularly as it relates to behavioral health (Gardner, Kelleher, & Pajer, 2002). For example, behavioral medicine specialists can help with data management and tracking systems, including those that are web-based, for use in primary care settings (Grypma, Haverkamp, et al., 2006; Unützer, Choi, et al., 2002).

Integrated Behavioral Medicine Care in Worksite Settings

The workplace, where adults spend about half of their waking life, is a useful setting to reach and help people to engage in healthy behaviors. Worksite policies and programs can include some combination of delivering health-promoting educational programs at the worksite, creating incentives to use off-site facilities (e.g., fitness clubs), and offering employee health benefits (e.g., flu shots, hypertension screenings). Most worksite health promotion programs use behavioral medicine approaches to prevent chronic disease by promoting physical activity (Freak-Poli, Cumpston, et al., 2013) and reducing tobacco use (Cahill & Lancaster, 2014). It is in employers' interests to improve the health of their workforce, especially if employers are bearing the costs of health insurance.

The workplace is where large groups of smokers and sedentary adults are available to be reached and helped. Worksite smoking cessation programs in developed countries are encouraged by antismoking laws and use a variety of proven approaches, some policy related (e.g., not hiring smokers) and others medical (e.g., offering varenicline, nicotine replacement) and behavioral (e.g., counseling; (Cahill & Lancaster, 2014)). In developing countries, there remains a need to test and demonstrate the effectiveness of worksite smoking cessation programs. Physical activity is also emphasized in worksite health promotion programs, following WHO guidelines encouraging at least 30 min of moderate-intensity physical activity on most days (Freak-Poli, Cumpston, et al., 2013). To combat the increasing problem of positive energy imbalance in the Netherlands, health promotion strategies now extend beyond education or communication approaches to include environmental modifications. Environmental modifications are being tested in the worksite to increase movement for those workers who are spending a disproportionate amount of time either standing or sitting as part of work duties (Engbers, van Poppel, et al., 2005).

Behavioral Medicine by Community Members

Behavioral medicine health-care activities are not limited to licensed clinicians in professional settings. Individuals in the community can also play a critical role in promoting health using behavioral medicine. Individuals in a support capacity, referred to as "community health workers," "lay health advisors," "promotores," "peer support specialists," and other terms, make important contributions to health, health care, and prevention (Fisher, Coufal, et al., 2014). Based on foundations in behavioral medicine, peer supporters, under the guidance of licensed health professionals and in the communities and contexts of individuals they serve, link people who share knowledge and experience; provide emotional, social, and practical assistance for how to achieve and sustain health behaviors; help people cope with health-related stressors; and help with navigating the health-care system.

Peers from the community have been in a health-care support role all over the world for several decades (Bhutta, Lassi, et al., 2010). The services offered range widely, including provision of safe delivery; counseling on breastfeeding; management of uncomplicated childhood illnesses; preventive health education and treatment for malaria, TB, HIV/AIDS, STDs, and NCDs; and rehabilitation of people suffering from common mental health problems. Evidence demonstrates that community members add significantly to the efforts of improving the health of the population, particularly in those settings with the highest shortage of motivated and capable health professionals (Bhutta, Lassi, et al., 2010; Fisher, Coufal, et al., 2014). The services from community members in a support role have helped in the decline of maternal and child mortality rates and have also assisted in decreasing the burden and costs of TB and malaria (Bhutta, Lassi, et al., 2010). A measureable impact has been demonstrated in reducing disease burden in the management of hypertension, reduction of cardiovascular risk factors, control of diabetes, management of HIV infection, and screening in cancer (Fisher, Coufal, et al., 2014). Fisher and colleagues (2012) reported on programs in Cameroon, South Africa, Thailand, and Uganda that developed and evaluated peer support interventions for adults with diabetes. Assessments showed improvements in symptom management, diet, blood pressure, body mass index, and blood sugar levels for many of those taking part in the programs (see also Fisher et al., *infra*).

Thailand's success in promoting health through behavioral medicine is built on the vast network of community members, called Village Health Volunteers, who have been part of the Thai health system for over 35 years and have extended basic health care to remote areas of the country at relatively low cost. The role of volunteer corps is to assist in controlling and preventing disease. Among their many health promotion activities, they urge villagers to avoid smoking and alcohol and recommend regular exercise. They also assist pregnant women. The World Health Organization (Bhutta, Lassi, et al., 2010) reported evidence that the Village Health Volunteers helped curb infectious diseases and reduce infant mortality rates to one of the lowest in Asia.

Concluding Comments

Behavioral medicine is, in most places, not a profession or even a specialty area. It does not reside in one discipline or health-care profession and is not limited to health-care settings. Behavioral medicine is an area of interest or focus with a variety of professionals and even laypersons (e.g., peer coaches) who are interested in understanding and impacted health through behavior change. There is an increased emphasis on using behavioral medicine to improve the health of populations by incorporating behavioral change principles in policies and by delivering behavioral approaches in a number of settings (from health care specific to school to workplace). There is also an increased emphasis on understanding, researching, and teaching the role of behavior in health, whether it is in medical schools, in schools of public health, or in training programs of the allied health professions. Behavioral medicine, as an area of interest, is remarkably wide-ranging, whether the focus is at the cellular (e.g., neuroplasticity) or the societal level (e.g., policy). Behavioral medicine is also wide-ranging in covering the entire lifespan, from cradle to grave.

Behavioral medicine, with its variety and breadth, presents a challenge to define and grasp while bringing complex health problems a rich and useful set of perspectives and evidence.

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Part II

Knowing in Behavioral Medicine: Epistemic Foundations

5

Randomized Clinical Trials in Behavioral Medicine

Kenneth E. Freedland, Sara J. Becker,
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Introduction

Randomized controlled trials (RCTs) are the gold standard tests of interventions in many different areas of clinical research, and the core methodologies of RCTs cut across all of them. Nevertheless, each field tends to have its own distinctive methodological issues. This chapter discusses current issues in biobehavioral trial methodology, with an emphasis on interventions for the prevention or treatment of clinical problems in behavioral medicine. It is written from the perspective of researchers who are actively engaged in testing behavioral interventions for medically ill patients. The randomized controlled trial is a highly respected research paradigm in the medical community, and evidence of efficacy, effectiveness, and cost-effectiveness based on rigorous RCTs enhances the credibility of biobehavioral approaches in the medical settings that we seek to influence. This chapter highlights the many strengths of RCTs, how well suited they are to some of the most important objectives of clinical research, and their importance in behavioral medicine. Although other methods also play important roles in biobehavioral intervention research, the focus of this chapter is on randomized controlled trials.

Adapting to the Culture of Medical Trials

The disciplines that comprise the field of behavioral medicine share a commitment to conduct rigorous scientific research and to promote evidence-based practices, but their research cultures differ from one another in some respects. For example, nursing researchers usually ground their clinical trials in theories of nursing practice or health behavior change (Alligood, 2013). In contrast, physicians who conduct RCTs to test collaborative care interventions (Rollman, Belnap, LeMenager, Mazumdar, Houck, et al., 2009; Rollman, Belnap, LeMenager, Mazumdar, Schulberg, et al. 2009) or medications for psychiatric comorbidities in medically ill patients (Glassman, O'Connor, et al., 2002) tend to do so with little attention to any theoretical underpinnings of these approaches.

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Methodological traditions that do not meet mainstream medical research standards sometimes arise within particular disciplines or specific areas of clinical investigation. For example, psychotherapy trial reports often include extensive exploratory analyses of numerous potential moderators of treatment effects or post hoc searches for subgroups that either did or did not benefit from the intervention (Wolitzky-Taylor, Arch, et al., 2012; Hendriks, van der Schee, & Blanken, 2012; Grilo, Masheb, & Crosby, 2012). These kinds of exploratory and post hoc analyses tend to be received with resounding skepticism by biostatisticians and biomedical trialists, especially when numerous factors are examined or the primary outcomes are not significant (Sun, Briel, et al., 2011, 2012).

Persistent allegiance to traditions that are incompatible with more widely accepted methodological standards of clinical research can hurt our ability to compete for grant funding, publish our trials in high-impact medical journals, and influence clinical practices and policies. Thus, when planning a biobehavioral RCT, it can be helpful to review standard clinical trial methodology textbooks (e.g., Friedman, Furberg, & DeMets, 2010) and expert guidance published in high-impact medical journals (e.g., White, Horton, et al., 2011) and consider whether there are any ways in which the research plan needlessly departs from widely accepted biostatistical principles or other current methodological standards.

On the other hand, some of the differences between biobehavioral and biomedical trial methodologies would be difficult if not impossible to eliminate. For example, most behavioral intervention trials can be single-blinded but not double-blinded. This means that the outcome assessors are kept in the dark about which participants were randomly assigned to which group, but the interventionists and the participants themselves know the group to which they have been assigned. Because they are not double-blinded, the broader medical research community tends to question the methodological quality of even the most rigorously designed and scrupulously conducted behavioral trials (Relman & Angell, 2002). This may seem unfair, but it does little good to complain. It is better to find ways to measure and, when possible, to ameliorate the potential biases and other problems that these sorts of methodological limitations may impose on our trials. In single-blinded trials, for example, analyses of data derived from treatment credibility and outcome expectancy measures can be used to evaluate whether differential expectancies may have influenced the results (Smeets, Beelen, et al., 2008).

In typical biomedical RCTs, patients are randomly assigned in double-blind fashion to an active medication or to a seemingly identical but biologically inert placebo. It is difficult to maintain the double-blind in some drug trials. This can occur, for example, if pronounced side effects are common in the treatment arm but rare in the placebo arm. In most drug trials, however, no one knows which participants are taking the active medication and which ones are taking a placebo. This makes it possible to treat all participants in a nearly identical fashion, regardless of the group to which they have been assigned. For instance, neither group is likely to receive more clinical attention than the other group in a typical double-blinded RCT.

Single-blinding can open the door to a variety of unplanned differences between behavioral intervention and control groups. One of the most serious concerns is that the participants' propensity to seek other forms of treatment for the target condition may differ between the intervention and comparison arms of a behavioral trial (Freedland, Mohr, et al., 2011). For example, in an RCT of cognitive behavior therapy (CBT) for depression, the participants in the CBT arm may be more or less likely than those in the comparison arm to obtain antidepressants from their own nonstudy physician. This might occur in the comparison arm because the participants know that the investigators are not going to give them any treatment, and so they seek it on their own, outside of the study. On the other hand, it might occur in the intervention arm if the therapists tend to advise their patients to ask their nonstudy physician about antidepressant medications. These sorts of unplanned differences between treatment and comparison arms can make it more difficult for behavioral researchers to isolate the therapeutic effects of their interventions than it is for pharmaceutical trialists to do so with medications.

The boundaries of the experimental unit can also be more difficult to delineate in a biobehavioral than in a biomedical trial. In a typical drug trial, no one other than the study participant takes the study medication or placebo. In many behavioral trials, however, the target behaviors are imbedded in a social context. Dietary intervention trials, for example, can directly or indirectly influence the behaviors of family members in ways that can either enhance or diminish the efficacy of the intervention for the study participants (Quattrin, Roemmich, et al., 2012).

In short, clinically relevant RCTs in behavioral medicine are not pristine laboratory experiments. They are conducted within clinical and social environments that can affect trial outcomes in complex and sometimes unanticipated ways. These limitations and complexities do not diminish the importance and value of biobehavioral trials, but they increase the need for careful planning and monitoring. They also help to explain why other paradigms will also continue to play important roles in behavioral intervention research.

Defining the Purpose of the Trial

In any research endeavor, careful articulation of the purpose of the study should guide all other decisions. This includes such fundamental questions as whether to conduct an RCT or some other type of study and, if an RCT best fits the purpose of the research, how the trial should be designed.

An important consideration when defining the primary purpose of an RCT is whether its main aims are mechanistic, explanatory, or pragmatic. In medical research, *mechanistic* or *experimental* trials are usually conducted to investigate relationships among biological variables (Karanicolas, Montori, et al., 2009). In behavioral medicine, mechanistic or experimental trials are used to investigate behavioral or biobehavioral relationships. A recent RCT, for example, examined whether hostility reduction is associated with concomitant changes in blood pressure or other indicators of cardiovascular autonomic function (Sloan, Shapiro, et al., 2010). *Explanatory* (also known as *efficacy*) trials investigate whether or how well an intervention works under relatively optimal, tightly controlled conditions, whereas *pragmatic* (also known as *effectiveness*) trials evaluate interventions under more typical clinical practice conditions (Tunis, Stryer, & Clancy, 2003; Schwartz & Lellouch, 1967; MacRae, 1989; Thorpe, Zwarenstein, et al., 2009). Many studies blend the characteristics of two or three of these kinds of trials, although most RCTs can be described as being predominantly one kind or another.

Another important consideration when defining the primary purpose of an RCT in behavioral medicine is whether the primary outcome is a behavioral, an intermediate, or a clinically important medical variable. Many researchers in behavioral medicine aspire to improve major medical outcomes such as to reduce the incidence of asthma attacks, prevent cancer progression and metastasis, or prolong survival in heart failure. We aim to achieve these goals by targeting behavioral risk factors such as inadequate exercise or smoking or psychosocial problems such as stress or anxiety. We also aim to modify the biobehavioral or physiological pathways that mediate the effects of behavioral and psychosocial factors on medical outcomes. Consequently, trialists in behavioral medicine are concerned with at least three different kinds of outcomes: proximal behavioral targets, distal medical outcomes, and biobehavioral or physiological intermediate outcomes (also known as mechanisms or mediators).

In short, it is necessary to consider which types of trials to conduct, with which outcomes, and in which sequence, in order to have an impact on clinically important problems in behavioral medicine. For example, depression is a common psychiatric comorbidity in a heart condition known as atrial fibrillation (AF), and it is a risk factor for mortality in patients with AF (Frasure-Smith, Lesperance, et al., 2009). It is also associated with several biobehavioral factors, including elevated heart rate and medication nonadherence, which could plausibly mediate the effect of depression on mortality in AF. Little is known about how to treat depression in this particular patient population. Even less is known about whether potential mediators such as heart rate or nonadherence can be improved in these patients by treating their depression or whether doing so can reduce their mortality risk. Thus, there are several different reasons to conduct an RCT. However, it would not be feasible to simultaneously answer all of these questions in a single trial. A programmatic series of studies would be necessary, but where would be the best place to begin? Should mechanistic, explanatory, and pragmatic trials be conducted in any particular sequence, and if so, which one? And which primary outcomes should be chosen for these trials?

One could argue that the best place to begin would be with tightly controlled explanatory trials with depression (the behavioral target) as the primary outcome, in order to determine the best way to treat depression in these patients under relatively optimal conditions. It might be necessary to develop a novel, highly innovative treatment for these patients. However, rather than starting from scratch, most researchers would probably borrow interventions such as cognitive behavior therapy (CBT), problem-solving therapy (PST), or interpersonal therapy (IPT) that have already been well tested in other patient populations such as in depressed psychiatric patients. It might be necessary to modify these interventions to adapt them to the particular needs of patients with AF, but it might not be. For example, the behavioral activation component of CBT might have to be modified in order to ensure that it is medically safe (Skala, Freedland, & Carney, 2005), but in most other respects, CBT for depressed AF patients would probably be fairly similar to CBT for depressed psychiatric patients. Whether or not the interventions would have to be modified, these trials would help to identify the most efficacious treatments for depression in patients with AF.

However, it may not be possible to conduct a pristine efficacy study, even if it were the first behavioral intervention trial ever conducted in this patient population, because many of these patients will have access to antidepressant medications and perhaps to behavioral treatments for depression as well. The fact that there may have been little or no research on antidepressants or behavioral treatments for depression in this particular population does not necessarily prevent them from being used in clinical practice. Also, medications and surgical procedures for cardiac or other medical problems could affect some of the participants' psychiatric functioning during the trial. These variables might induce "noise" in the trial's outcomes or create unintended differences between the groups (i.e., biases). Both of these problems can make it difficult to conduct tightly controlled behavioral efficacy trials in medical patient populations. They can also make it difficult, from both ethical and clinical perspectives, to employ control groups that provide no treatment, a placebo, or a weak intervention for the condition of interest. If pure efficacy trials would be unrealistic, somewhat more pragmatic RCTs of treatments for depression would probably be the first stage in this line of research.

Relatively pragmatic trials could take a variety of different forms, none of which would involve comparing behavioral interventions to clinically irrelevant attention, placebo, or no-treatment control groups. A behavioral intervention might be compared to whatever treatment (if any) patients get as part of their usual medical care. Alternatively, if antidepressants are routinely prescribed for these patients, a trial might compare the effectiveness of a behavioral intervention plus antidepressant therapy to antidepressant therapy alone. This kind of pragmatic trial would help to determine whether it is possible to improve upon existing clinical practices and, if so, how much added clinical value interventions such as CBT, PST, or IPT might provide.

One could argue instead that the best place to start would be with a mechanistic trial, to determine whether treating depression improves intermediate biobehavioral or medical outcomes such as heart rate that influence the risk of mortality in AF. In this type of trial, heart rate would be the primary outcome and depression would be a secondary outcome. It is important to recognize, however, that improvement in an intermediate outcome such as heart rate provides no guarantee that a treatment will also improve clinically meaningful outcomes such as mortality, as the Cardiac Arrhythmia Suppression Trial (CAST) (Echt, Liebson, et al., 1991) and many subsequent trials have shown. Nevertheless, mechanistic trials that target intermediate biobehavioral or medical outcomes are usually smaller and less expensive than trials that target reductions in deaths, strokes, or other major clinical events, and positive findings can help build the case for conducting larger and more expensive trials that do target clinically important outcomes.

However, the success of this sort of mechanistic trial depends on achieving a wide differentiation between the groups in the psychosocial or behavioral target of interest. In the present example, it would be necessary to ensure that most cases of depression in the treatment arm would improve and that most cases in the control arm would persist. Improving depression may or may not decrease heart rate in patients with AF. Answering that question would be the purpose of the mechanistic trial, but it is a question that simply cannot be answered in a controlled, experimental fashion unless a large effect of treatment on depression can be achieved.

If the intermediate outcomes of interest are relatively inexpensive to obtain, and if they do not impose a substantial burden on the participants or the study staff, they could be included as secondary outcomes in efficacy or effectiveness trials of treatments for depression. In the present example, it would be neither difficult nor expensive to obtain heart rates on patients in a depression treatment trial. Thus, it might be possible to “kill two birds with one stone”, i.e., conduct a trial that has both explanatory and mechanistic aims. However, if the intermediate outcomes are relatively expensive or burdensome to obtain, it would be better to start with efficacy or effectiveness trials with the behavioral target as the primary outcome and postpone the mechanistic studies until highly efficacious or effective treatments for comorbid depression in AF have been identified.

If the ultimate goal is to improve survival in patients with AF and comorbid depression, the statistical power of this larger, more expensive trial will depend more on the number of clinical events (i.e., deaths) than it does on the number of participants. In studies that have relatively uncommon events as outcomes, large numbers of participants have to be enrolled to ensure that there will be enough events and hence adequate power (Friedman, Furberg, & DeMets, 2010). The target sample size in this example would be so large that a multicenter RCT would probably be necessary. A trial involving multiple sites and hundreds or thousands of participants is unlikely to be funded unless smaller trials and other preliminary studies have paved the way for it. Thus, it is necessary to think in terms of conducting an entire line of research rather than banking on a single behavioral trial to change the prevention or treatment of a major medical problem such as AF.

RCTs provide the best way to answer many treatment-related questions, but not all of them. For example, Scherrer, Svrakic, et al. (2013) conducted a retrospective cohort study of the psychiatric sequelae of prescription opioid use in 49,770 Veterans Administration (VA) health-care system patients. They found that long-term (>90 days) opioid use significantly increased the risk of developing major depression. It would not have been ethical to randomize patients to receive or not receive an opioid medication specifically to study whether exposure to opioids increases the risk of depression, and it would probably not have been feasible to conduct a sufficiently large RCT to investigate this question with adequate power. Also, a randomized trial would not have approximated the actual clinical practice patterns that were captured in this database study. Thus, a prospective RCT would not have been the best approach, given the purpose of this study.

If an investigator decides that an RCT would be the best way to address a particular question, he or she then has to make a variety of decisions about the design of the trial. Typical Phase II and III drug trials have to comply with widely accepted methodological standards and with Food and Drug Administration (FDA) rules and regulations

(Katz, 2004). Consequently, pharmaceutical researchers may have fewer decisions to make about how to design their trials than behavioral scientists have to make about theirs. Trial design can be quite challenging in behavioral medicine. Investigators often have to make difficult tradeoffs between competing demands and compromises between scientific objectives and ethical or practical constraints.

Some of the most important RCT design decisions depend on the trial's primary purpose (Freedland, 2013; Karanicolas, Montori, et al., 2009). If a design decision serves the primary purpose of the trial, it is probably a good one. If it is at odds with the trial's primary purpose, it is probably a bad one. For example, behavioral scientists often want to answer many secondary or exploratory questions in addition to testing their primary hypothesis. If this can be accomplished unobtrusively, the study's productivity is likely to increase accordingly. However, if a large battery of secondary or exploratory measures strains the budget or substantially increases respondent and staff burdens, the trial may fail to meet its main aims due to low recruitment, high attrition, or other serious difficulties. Relatively simple trials can be more productive than excessively complex trials (Yusuf, Collins, & Peto, 1984).

Defining the Population

Background

The impetus for conducting a clinical trial in behavioral medicine usually originates in the recognition of an important problem or unmet need in a particular group of patients or in a population at risk for the development of a particular medical condition. In fact, the problems and needs of specific populations define entire lines of clinical research. They are usually identified through epidemiological research and other kinds of observational studies. The rationale for conducting an RCT usually builds on these sorts of studies.

Representative Samples

A key challenge for a relatively pragmatic trial is to ensure that the enrolled sample is representative of the population of interest. The generalizability of the sample to the target population encompasses several different kinds of characteristics, including the participants' sociodemographic attributes, health status, and ability and willingness to adhere to the experimental intervention. Narrow selection criteria can minimize error variance in outcome variables, enhance internal validity, and make it easier to conduct tightly controlled efficacy trials, but these advantages may come at the expense of enrolling unrepresentative samples and diminishing external validity. Relatively pragmatic trials usually have more inclusive eligibility criteria, to ensure that the results can be generalized to typical patients or at-risk individuals. These issues are often articulated as a trade-off between internal validity (e.g., enrolling a homogeneous sample of patients who are likely to have high treatment adherence and study completion rates) and external validity (e.g., enrolling a sample that is more representative of problem as it exists in population at large, even if that means including participants who may not adhere to the entire treatment plan or who may not fully cooperate with the study protocol).

Timing

Behavioral medicine interventions may target individuals who are still healthy but at risk for a disease (primary prevention), patients who are in the early stages of a disease and at risk for adverse outcomes (secondary prevention), or patients in more advanced stages of a disease who are at risk for further morbidity, disability, or mortality (tertiary prevention). Whether to intervene early or late in the disease process is an important consideration that has many implications for research strategies, treatment delivery, and the benefits that might be expected.

Specification of the target population often focuses on a particular event or stage in the progression from being at risk for a medical illness, developing the illness, and experiencing its adverse consequences. Receptivity to behavioral medicine interventions can be increased by capitalizing on times when patients may be particularly interested in changing health-related cognitions and behaviors. "Teachable moments" (Hochbaum, 1958) often emerge from disruptive medical events such as an acute myocardial infarction or a serious, abnormal finding on a medical screening test. The positive benefits or negative consequences of relevant health-related behaviors tend to be more salient at such times. Intervening during teachable moments early in the course of a chronic condition may be a particularly effective way to motivate long-term behavior change (Keefe, Buffington, et al., 2002).

Matching Populations to Interventions and Vice Versa

The decision to focus on individuals with specific characteristics both influences and is influenced by the characteristics of the intervention. For instance, an intervention that targets an elderly and/or chronically ill population may have to accommodate a broader range of treatment settings and delivery options than one that targets a younger and healthier population. The INSPIRE trial (Blumenthal, Babyak, et al., 2006), for example, tested a stress management intervention for lung transplant candidates. The intervention was delivered via telephone rather than in person because the patients were severely medically ill and resided in widely dispersed communities around the United States. Face-to-face sessions would not have been feasible.

Behavioral medicine clinicians and researchers have traditionally focused on direct interventions with individual patients who have specific health conditions. However, growing awareness of the value of social support in health promotion has increased interest in indirect interventions involving spouses, parents, or other caregivers for many different conditions. In recent years, behavioral interventions have been extended to dyads and family systems, school and work communities, and entire neighborhoods.

Dyadic interventions target the patient along with a family member or other associate; examples include parent-child, husband-wife, patient-life partner, and patient-caregiver dyads. Similarly, interventions for families or for alternate support systems target the patient along with a network of individuals who serve important roles in the patient's life. Interventions targeting dyads and families aim to reduce vulnerability to physical illness by alleviating individual and shared stressors, promoting positive interactions between the patient and others, and teaching the skills that are needed to prevent and manage chronic disease. Recent studies provide evidence that including members of the patient's support network can help to promote health behavior change and to treat psychosocial problems in patients with chronic diseases (Keefe, Buffington, et al., 2002).

Social and Organizational Units

Behavioral RCT methodology has also been extended to interventions for classrooms, schools, or school systems; work environments; and even entire communities. For instance, an intervention trial might be conducted to test new ways to decrease cigarette smoking at school. Unlike typical clinical trials in which individual people are the units of randomization, this RCT would randomize entire organizational units (i.e., "clusters") to intervention or comparison conditions. These studies are therefore known as *cluster randomized trials.* The clusters have a hierarchical structure. In this example, entire classrooms at multiple schools might be randomly assigned to a smoking reduction intervention or to a control condition. The classrooms are the unit of randomization, the students are clustered within the classrooms, and the classrooms are clustered within schools. Special statistical techniques have to be used to account for the similarities (i.e., correlations) within the clusters. For example, the students' socioeconomic status may tend to be similar within the participating schools and different between the schools, and this could contribute to differences in smoking rates between schools.

The end result of cluster randomization is still a comparison of an intervention vs. a comparison condition. Since classrooms are the units of randomization, the statistical power to detect significant differences between the intervention and comparison conditions depends on the number of classrooms and on the similarity of students within classrooms (the intra-class correlation), not on the number of students. In other words, researchers planning such a trial would have to think in terms of enrolling a large number of classrooms rather than just a large number of students (Friedman, Furberg, & DeMets, 2010).

Large-scale interventions have the potential to reach numerous at-risk individuals in cost-effective ways (Glasgow, Vogt, & Boles, 1999; Gaglio, Shoup, & Glasgow, 2013), but testing them in randomized, controlled trials can be difficult, whether or not cluster randomization is employed. To some extent, the failure of RCTs to show widespread benefits of community smoking interventions may reflect the problems of fitting large-scale interventions into research methodologies that were originally designed for testing discrete, individual-level interventions. In the COMMIT trial (COMMIT Investigators, 1995), for example, standardization of the intervention constrained the freedom of community groups to guide the intervention according to their own judgment. Thus, the "community-based" nature of the intervention may have been compromised in the interest of conforming to a standardized, internally valid RCT design. This raises questions about whether alternative study designs might be needed to test these kinds of interventions (Fisher, 1995).

Defining the Outcomes

In many areas of medical research, "hard" clinical endpoints, i.e., death and objective measures of medical morbidity, are the gold standard for evaluating treatment efficacy. However, large, multicenter trials are usually required to study hard endpoints with adequate statistical power. These trials are expensive, and it is difficult to obtain funding for them. A less expensive alternative for testing behavioral interventions is to focus on patient-reported (subjective) outcomes, such as mood states, health behaviors, or health-related quality of life. The Patient Reported Outcomes Measurement Information System (PROMIS) covers many outcomes of interest to behavioral trialists, with state-of-the-art measures and assessment software (Barile, Reeve, et al., 2012; Gershon, Rothrock, et al., 2010; Riley, Pilkonis, & Cella, 2011). Further research is needed to evaluate the validity and sensitivity to treatment-related change of the PROMIS measures in a variety of patient populations. Thus, behavioral researchers should consider using PROMIS measures as secondary outcomes, along with better-established measures as primary outcomes.

Unfortunately, it is possible for an intervention to have little impact on objective clinical outcomes despite having positive effects on subjective outcomes. When hard clinical outcomes are too expensive to study, and patient-reported outcomes are insufficient, an alternative is to target surrogate or intermediate biological outcomes. In patients with type 2 diabetes, for example, poorly controlled blood glucose levels can result in painful and debilitating complications such as neuropathy and cardiovascular morbidity. An RCT was recently conducted in Northern Ireland to test a self-monitoring intervention for patients with newly diagnosed diabetes. The primary outcome measure was an intermediate or surrogate endpoint, glycated hemoglobin (HbA_{1c}), which is a laboratory test of how well blood glucose has been regulated in recent weeks.

However, there are well-known limitations to reliance on surrogate endpoints (DeMets & Califf, 2002). As important as HbA_{1c} is in the management of diabetes, it is not as important as the downstream clinical effects of poor glucose regulation, i.e., the hard clinical outcomes of diabetes such as neuropathy, blindness, and acute myocardial infarction. Also, treatments that have positive effects on surrogate outcomes can turn out to have either no effect or negative effects on hard clinical endpoints. The Cardiac Arrhythmia Suppression Trial (CAST), which was briefly discussed in a previous section, is the classic example of this all-too-common problem. A preliminary study showed that several drugs were effective in reducing the frequency of potentially lethal cardiac arrhythmias in patients with a recent myocardial infarction (Cardiac Arrhythmia Pilot Study (CAPS) Investigators, 1988). Based on these encouraging results, a larger, placebo-controlled, multicenter trial was conducted to determine whether these drugs could reduce the incidence of sudden cardiac deaths. Unfortunately, in the larger trial, patients who were randomly assigned to the anti-arrhythmic drugs were *more* likely to die than were those who were given a placebo (Echt, Liebson, et al., 1991).

Of course, there have been trials in which treatments of intermediate factors or surrogate medical outcomes have yielded clinically important benefits, including in diabetes. For example, the Diabetes Control and Complications Trial (DCCT) showed that intensive insulin management slows the development and progression of retinopathy and microalbuminuria in patients with insulin-dependent diabetes mellitus, relative to conventional therapy (DCCT Research Group, 1993). Still, there are many examples of trials in which treatments for intermediate factors or surrogate outcomes have either yielded no clinical benefit or have caused unexpected harm. Medical researchers are wary of surrogate endpoints because of their troubling experiences with trials such as CAST. Nevertheless, surrogate outcomes can be successfully employed in relatively small behavioral trials such as the recently completed Smart Heart Trial (Blumenthal, Sherwood, et al., 2005), and they can help to provide a basis for larger, multicenter trials with hard clinical endpoints (Rozanski, Blumenthal, et al., 2005).

The Enhancing Recovery in Coronary Heart Disease (ENRICHD) study was one of the largest clinical trials ever conducted in the field of behavioral medicine. Its purpose was to determine whether treatment of depression and low perceived social support (LPSS) can reduce the incidence of recurrent myocardial infarction or death in patients with a recent myocardial infarction. Unfortunately, the intervention had no effect on this hard clinical outcome (Berkman, Blumenthal, et al., 2003). In hindsight, many of the researchers who were involved in ENRICHD have wondered whether its design could have been improved and whether it might have yielded better results if it had been preceded by some smaller trials with surrogate endpoints. A proposed model for designing RCTs based on intermediate or surrogate endpoints is depicted in Fig. 5.1.

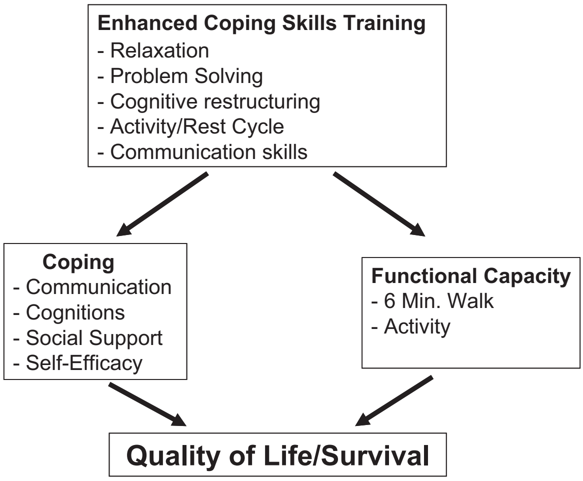

Fig. 5.1 A proposed model for designing randomized controlled trials using intermediate endpoints. Stage 1 consists of a single-center evaluation of a specific behavioral intervention. If successful, this intervention would be repeated at multiple centers, to assess the reproducibility of findings (stage 2). In both stages, intermediate endpoints, such as change in vascular function or plaque size during carotid ultrasonography, would be used to minimize necessary sample size and follow-up time. If reproducible results are obtained during stage 2, a multicenter intervention trial would be performed in stage 3, in which subjects would be observed for the occurrence of hard cardiac events such as cardiovascular mortality and morbidity (Adapted from Rozanski, Blumenthal, et al., 2005)

Defining the Intervention

Background

Defining and refining interventions for clinically significant problems in behavioral medicine can be challenging due to the multitude of factors that influence health-related behaviors. Behavioral medicine interventions fit the British Medical Research Council's definition of complex interventions: "*Complex interventions in health care, whether therapeutic or preventative, comprise a number of separate elements which seem essential to the proper functioning of the intervention although the active ingredient of the intervention that is effective is difficult to specify*" (MRC Health Services and Public Health Research Board, 2000, p. 1).

The process of defining complex interventions is iterative and includes multiple decision points (Craig, Dieppe, et al., 2008). Based on a literature review and our experience in conducting RCTs, we have identified several key dimensions of behavioral medicine interventions: type of treatment, target, modality, setting, delivery personnel, and intensity (see Table 5.1). Investigators have to make decisions about each dimension in planning the intervention for a behavioral RCT.

Table 5.1 Dimensions that represent critical decision points in the definition of an intervention

Dimension	Description
1. Content or type of intervention	Specific type of treatment selected to treat the target condition and target population
2. Target of treatment	The population that serves as the focus of treatment. This decision point includes (a) demographic and clinical characteristics of the identified patient population, including stage of disease progression, (b) decision whether to focus solely on the patient or to include members of the patient's clinical care and social support network
3. Treatment modality	How the treatment will be delivered to the patient
4. Treatment setting	Where the treatment will be physically delivered to the patient
5. Delivery personnel	Training background and pedigree of the health-care provider(s)
6. Intensity	Level of commitment required by the patient as determined by the frequency of treatment sessions, length of each session, and duration of the treatment program
7. Quality control	Use of procedures to ensure uniform delivery of the treatment protocol including therapist training, manuals or session outlines, and ratings of therapist adherence and competence

Type of Treatment

Educational, behavioral or cognitive-behavioral, self-regulatory, exercise or physical activity, and lifestyle interventions are common in behavioral medicine. Most of the RCTs in this field are tests of these types of interventions, either alone or in combination.

Educational interventions help patients acquire the knowledge and skills they need to prevent or manage disease. Health education interventions should do more than impart information to passive recipients; they should also provide opportunities to actively discuss questions and concerns and to receive personalized feedback (Goldman, 1988; Hatfield, 1988; Bisbee, 1991). Health education interventions typically include information about a particular medical condition and its prevention or treatment and about behavioral strategies for coping with it.

Behavioral treatments (BTs) refer to problem-focused behavioral and cognitive-behavioral interventions for stress, depression, anxiety, or other conditions that can affect physical health outcomes and that can also be distressing or disabling in themselves. Most BTs emphasize ongoing assessment of relevant cognitions and behaviors, explicit definition of treatment targets, and a collaborative relationship between the therapist and the patient. BTs often require a significant commitment of time for behavioral homework assignments.

Self-regulatory treatments (SRTs) help patients to become more aware of their physical symptoms and to control physiological parameters such as heart rate and muscle tension. Examples include biofeedback, relaxation, and mindfulness techniques. Biofeedback enables patients to learn how to control certain bodily states by amplifying physiological processes and using auditory, visual, or tactile signals to display them. Relaxation and mindfulness techniques focus the patient's attention on, and thereby increase control over, breathing, muscle tension, or other physiological processes.

Physical activity and exercise interventions help patients to increase physical activity and/or decrease sedentary behavior. The health benefits of these interventions depend upon sustained changes in daily activities.

Lifestyle or self-management interventions modify habits such as diet, physical activity, or medication adherence that influence risk for chronic health conditions and/or management of such conditions. They often include an emphasis on problem solving or similar approaches to addressing barriers to desired behaviors. Some target multiple health behaviors and involve frequent monitoring of treatment adherence.

The treatment approaches discussed above can also be combined. Treatments that blend elements of health education, BT, SRT, physical activity, and lifestyle modification, in various combinations, are becoming increasingly popular as evidence of their effectiveness accumulates. It can be difficult to precisely define the "active ingredients" of a single complex intervention (Craig, Dieppe, et al., 2008), and it becomes considerably more difficult when several treatment approaches are combined into a single package.

The challenge is not only that behavioral medicine interventions often contain multiple active ingredients but also that these ingredients may interact with one another to produce results that are not entirely predictable from the effects of the individual ingredients. In addition, combined interventions may have multiple targets, such as several different health-related behaviors (Prochaska, Spring, & Nigg, 2008; Spring, Moller, & Coons, 2012). It may not be feasible, in a single RCT or even in a series of RCTs, to pinpoint which ingredients of a complex, multitarget intervention are responsible for which outcomes. There is also the possibility that benefits rest on synergies among ingredients, so that there are no necessary and sufficient ingredients to be found. This is one of the reasons why many researchers are more interested in finding creative ways to improve the outcomes of complex interventions than in parsing their ingredients in minute detail. It is also one of the reasons for the growing interest in conducting trials that are more pragmatic than explanatory and in systematic approaches to behavioral intervention development such as the multiphase optimization strategy (MOST) (Collins, Baker, et al., 2011). In the MOST approach, different combinations of intervention components are tested and refined in early-phase treatment development studies. This paves the way for larger RCTs in which the efficacy or effectiveness of the entire complex intervention can be evaluated more definitively.

We recommend a three-tiered strategy for selecting the treatment when planning an RCT. First, treatments that have already been shown to be efficacious for the medical condition of interest should be considered. Second, if proven treatments are not available or appropriate for patients with that condition, investigators should consider ones that have been shown to be efficacious for similar conditions. Finally, if neither of these strategies identifies a promising intervention, investigators should consider devising a new treatment approach. If possible, a novel treatment should be based on a conceptual model of how it affects the mediators that are believed to link the disorder to adverse outcomes and of resiliency and vulnerability factors within the patient population. For example, Fig. 5.2 displays a conceptual model of coping skills training. It shows how this type of intervention could affect clinical outcomes by improving coping abilities and by increasing physical functioning in patients with chronic obstructive pulmonary disease (COPD).

Treatment Setting

Behavioral interventions have been tested in a wide variety of health service settings including outpatient clinics, inpatient units, emergency

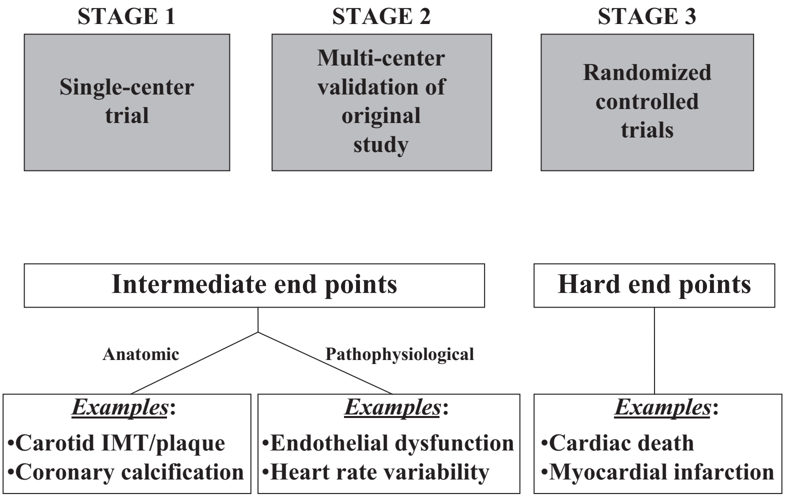

Fig. 5.2 Conceptual model of how a coping skills intervention affects treatment outcomes. In this proposed model, the coping skills intervention is hypothesized to improve quality of life and increase survival by improving coping abilities and increasing functional capacity

departments, and others. This is necessary in order to determine how to implement these interventions in health-care environments where they are both needed and deliverable. On the other hand, interventions that are delivered in settings such as outpatient clinics typically place the burden of transportation on the patient. This can pose a formidable barrier to treatment adherence for patients who are fragile, severely ill, mobility impaired, or unable to afford transportation.

Consequently, there is growing interest in providing interventions at more convenient locations, such as in the patient's home, school, place of employment, or residential treatment facility. In some cases, this may require some travel on the part of the interventionists. However, telehealth technologies (discussed in more detail below) are increasingly being used to facilitate *remote* interventions in natural environments (Reed, McLaughlin, & Milholland, 2000).

Treatment Modality

Historically, both intervention research and clinical practice in behavioral medicine have been confined to face-to-face individual or group treatment modalities. Although face-to-face interactions may offer therapeutic advantages in terms of the ability to focus attention on and emphasize key interactions or processes, these modalities have the disadvantage of requiring patients to make multiple, time-consuming clinic visits. Individual therapy is often considered to be the default modality for behavioral treatment, although there is some evidence that group therapy may be more effective for certain problems (Saab, Bang, et al., 2009). Moreover, technological advances have created new possibilities for the delivery of treatment services via novel channels that have the potential to reduce patient burden, facilitate the exchange of information between patient and provider, and ameliorate rising health-care costs.

Telehealth, which has been defined as "the use of telecommunications and information technology to provide access to health assessment, diagnosis, intervention, consultation, supervision, education, and information across distance" (Nickelson, 1998, p. 527), is becoming an accepted treatment delivery method in behavioral medicine. In one RCT, for example, a telephone-based intervention that included education about stress and health, instruction in specific coping skills, and information about relapse prevention was compared to usual care for patients awaiting lung transplantation (Napolitano, Babyak, et al., 2002). Patients who received the intervention reported superior outcomes on measures of perceived stress, depressive symptoms, general well-being and quality of life, and pulmonary-specific quality of life.

New telehealth technologies are emerging as viable options for the delivery of behavioral medicine interventions. Intervention delivery via video conferencing has been investigated in a number of areas including obesity management, smoking cessation, and biofeedback (Jerome & Zayor, 2000). Patients tend to report moderate to high levels of satisfaction with this modality (Nesbitt, Hilty, et al., 2000).

Internet-based treatments also have been developed and tested for a wide range of clinical problems in behavioral medicine. Examples include insomnia (Strom, Pettersson, & Andersson, 2004), chronic lower back pain (Buhrman, Faltenhag, et al., 2004), smoking cessation (Feil, Noell, et al., 2003), eating disorders (Zabinski, Wilfley, et al., 2001), and recovery from heart transplant (Dew, Goycoolea, et al., 2004).

Interactive technologies including computer programs, audio and video programs, and virtual reality (VR) systems also have considerable potential for the provision of remote behavioral health services. Handheld computers, smartphones, and portable devices that monitor various physiological parameters are increasingly being used to collect patient assessment data and remind patients to adhere to interventions (see Lynx, Brockmiller, et al., 2003). They can be designed to provide communication tailored to patient characteristics such as racial or ethnic group, risk factor status, behavioral history, or symptom severity (Noell & Glasgow, 1999). By combining real-time computer graphics with sensorimotor tracking devices, VR programs create realistic, treatment-relevant environments in which the patient can become fully immersed (Rothbaum, Hodges, et al., 1999). The evidence to date generally supports the efficacy of these interactive technologies (Noell & Glasgow, 1999), particularly as part of more comprehensive interventions. However, there have been few empirical comparisons of modalities and little research on their relative cost-effectiveness (Whitten, Mair, et al., 2002).

An important feature of these evolving technological modalities is that they introduce opportunities for new content of interventions. For example, the sort of monitoring of fluctuations in blood sugar as a function of variation in daily behaviors and diet that is possible with smartphone assembly and transfer of data and computer-based analysis and feedback is unimaginable with conventional paper records and clinician reviews.

It is important to recognize that standards of ethical and professional conduct governing RCTs in behavioral medicine are not altered by the use of novel technologies. Investigators considering novel treatment delivery methods must therefore take steps to ensure the same level of informed consent, patient confidentiality, quality assurance, and documentation of services that they would for trials of traditional treatment modalities (see Reed, McLaughlin, & Milholland, 2000).

In addition, the rapid pace of technological change makes it difficult to use standard trial designs, since RCTs can take years to plan, conduct, and analyze. Consequently, a new methodological framework, the Continuous Evaluation of Evolving Behavioral Intervention Technologies (CEEBIT), was recently proposed as an agile alternative to traditional approaches for evaluating innovative behavioral intervention technologies (Mohr, Cheung, et al., 2013). The CEEBIT framework relies on continuous evaluation of new technologies to refine ones that are promising and weed out ones that produce poor outcomes.

Treatment Intensity

The intensity of a behavioral intervention is usually characterized in terms of the frequency and length of treatment sessions and the duration of active treatment. Trade-offs between the duration and frequency of sessions are often made in order to minimize the participant burden, such that frequent sessions are relatively brief and infrequent sessions are longer. Most disease management interventions have had durations of less than 6 months, although some have used telehealth approaches to provide booster sessions over longer periods (Krumholz, Currie, et al., 2006).

Treatment intensity depends to a large extent on the type of treatment. For instance, physical exercise and lifestyle change interventions require frequent participation, with structured activities often scheduled on a daily basis. In contrast, educational and behavioral interventions often require fewer formal sessions, with many RCTs delivering weekly 50- or 60-min sessions. Decisions about intensity are also closely related to decisions about target populations, settings, and treatment modality. The respondent burden has to be acceptable for the target population. This is especially important when testing treatments for chronically ill or debilitated patients, which must take into account their severity of illness, medical or psychiatric comorbidities, and access to transportation, telehealth, or information technologies.

Dosage issues are systematically investigated in Phase I drug research, before the efficacy of a drug is evaluated in Phase II/III RCTs. There has been considerable methodological progress over the past decade in Phase I research (Jaki, Clive, & Weir, 2013). Consequently, pharmaceutical researchers can now use a variety of methodologically advanced strategies to determine optimal dosages before proceeding with larger trials. In contrast, treatment dosage or intensity decisions in behavioral medicine trials are seldom informed by systematic, early-phase dosage studies. Many dosage decisions are simply based on tradition, precedent, or estimates of the tolerance of the intended audience. For example, a researcher might decide to test a 6-session version of a behavioral intervention in an RCT simply because a 6-session version was used in previous studies. A shorter or longer version of the intervention might be more efficacious for the target problem or population, but the RCT will not shed any new light on this question because it will only evaluate a 6-session intervention.

Treatment intensity deserves more systematic attention in behavioral medicine research, for a number of reasons. Interventions that are too intensive may be too inefficient and burdensome, especially for very ill or debilitated patients, but ones that are not intensive enough may not be efficacious. Intensive interventions are more difficult to implement in clinical practice and more expensive to deliver than less intensive interventions, but patients with complex or treatment-resistant problems may need more intensive treatment than do other patients. Also, from a population perspective, a highly efficacious treatment that reaches only a small proportion of those for whom it is intended may achieve less than a modestly efficacious treatment that has broader reach. An optimal balance among these considerations can be difficult to achieve, but it is too consequential to ignore. It is as important to evaluate different dosages in early-stage clinical research on complex interventions as it is to investigate different combinations of treatment components.

However, larger studies may also be needed to investigate the effects of different dosages of an intervention on clinically relevant outcomes. Exercise interventions provide an informative example. An exercise prescription typically includes type of exercise (e.g., walking, biking, strength training), frequency (e.g., three times per week, daily), duration (e.g., 20, 30, or 60 min), and intensity (e.g., percentage of maximum heart rate or subjective rating of perceived exertion). However, there is uncertainty as to the optimal dosage of exercise for different medical conditions. Exercise promotes better health outcomes in a wide variety of medical conditions including colon cancer (Lee, Paffenbarger, & Hsieh, 1991), gallstones (Leitzmann, Rimm, et al., 1999), osteoporosis (Block, Smith, et al., 1987), and cardiovascular disease (Blair, Kohl, et al., 1995; Lee, Hsieh, & Paffenbarger, 1995; Leon, Connett, et al., 1987). Some exercise is better than none, but how much exercise is needed is unknown even for conditions such as coronary heart disease in which the health benefits of exercise are very well established (Jolliffe, Rees, et al., 2001; Oldridge, Guyatt, et al., 1988).

The issue of the optimal intensity of exercise is especially relevant for psychiatric conditions such as major depression. The SMILE trial (Blumenthal, Babyak, et al., 1999) demonstrated that the effects on depressive symptoms of aerobic exercise three times per week for 16 weeks are comparable to those produced by antidepressant medications. In SMILE, however, exercise was confounded with social support, and all patients randomized to exercise received the same exercise prescription (70–85% heart rate reserve, three times per week). In an effort to identify the optimal exercise prescription, the DOSE study (Dunn, Trivedi, et al.,

2005) randomized patients to one of four aerobic exercise groups that varied total energy expenditure and frequency or to an exercise placebo control condition. Approximately 80 min of moderate intensity aerobic exercise for a person who weighs 70 kg was more effective than a lower dose of exercise, although there was no difference in effectiveness as a function of the frequency of exercise training. These results confirm the value of well-designed RCTs in helping to establish the optimal intensity level of exercise. This approach could be extended to other interventions, such as relaxation or mindfulness training.

Treatment Delivery Personnel

Few interventions in behavioral medicine are the sole province of any single discipline. For example, disease management interventions for heart failure, diabetes, or depression have been delivered by nurses, case managers, physicians, pharmacists, social workers, dietitians, physical therapists, psychologists, information systems specialists, and even nonprofessional peers (Krumholz, Currie, et al., 2006). Within and across these professions, the levels of education, specialized training, and clinical experience required to deliver these interventions in the context of clinical trials have varied considerably. In a meta-analysis of psychotherapy outcome studies, Crits-Christoph and colleagues (1991) found that the use of experienced therapists reduces the proportion of variance in treatment outcomes that is attributable to therapist effects rather than to the intervention itself. However, reliance on highly trained and experienced therapists may limit the external validity and translational potential of a trial if the intervention is likely to be delivered in clinical practice settings by therapists with substantially less training or experience.

Multifactorial Intervention Research

The preceding sections addressed a variety of characteristics of behavioral interventions. In some cases, multiple studies may be needed to optimize and evaluate any one of these characteristics. Furthermore, optimizing *combinations* of these characteristics may not be a realistic goal for a single RCT, or even for a series of RCTs, because there may be too many combinations of interest to test in this fashion. In this circumstance, quality improvement (QI) research designs may provide more realistic alternatives for multimodal tweaking of complex interventions. Well-designed RCTs typically yield stronger evidence of efficacy or effectiveness than QI studies are able to produce, but QI studies are more feasible in some cases, and they can be very informative (Fan, Laupacis, et al., 2010).

Defining the Comparison Condition

The vast majority of pharmaceutical trials compare a single medication to a placebo that closely resembles the medication but that lacks its active ingredient. The decision to include a placebo arm in a standard efficacy drug trial is an easy one, because there are no better alternatives. In contrast, behavioral trialists have to choose from among a variety of comparison conditions. The choice is often difficult and sometimes controversial. In fact, it is not unusual for grant reviewers to raise more concerns about the comparator than about the intervention that a proposed trial is designed to evaluate.

The comparison conditions that are used in most behavioral RCTs can be divided into three categories. The *traditional* control groups are the familiar ones that are discussed in behavioral research methodology textbooks (e.g., Nock, Janis, & Wedig, 2008; Kazdin, 2003), including no treatment, wait list, attention, and nonspecific control conditions, as well as a variety of active comparators. *Existing practice* (EP) comparators have been given relatively little attention in standard methodology textbooks, yet they are playing an increasingly important role in behavioral intervention research in general and behavioral medicine research in particular. EP comparators include "usual care" (also known as "treatment as usual"), the current "standard of care," and others (Freedland, Mohr, et al., 2011). Finally, in at least three major trials, behavioral interventions have been compared to *pill placebo* control conditions (DeRubeis, Hollon, et al., 2005; Diabetes Prevention Program Research Group, 1999; Orchard, Temprosa, et al., 2005; Elkin, Shea, et al., 1989). Such trials have to include an active drug arm in addition to the pill placebo arm so that the participants can be blinded as to whether the pills they are taking are active drugs or placebos (assuming that they are randomized to a pill arm rather than to the behavioral intervention arm).

As emphasized throughout this chapter, major design decisions in behavioral intervention research depend on the study's primary purpose. This is especially apparent in decisions about comparators. For example, some investigators incorrectly assume that it is always necessary to control for attention when testing a behavioral intervention. If the main purpose of a trial is to determine whether a particular intervention is superior to an alternative intervention that exposes patients to the same amount of clinical attention, then it is indeed necessary to control for attention. If the main purpose of the trial is something else, it may be unnecessary to control for attention, and, in some cases, it would be counterproductive to do so (Freedland, 2013).

McDermott and colleagues (2011) tested a novel intervention for patients with peripheral arterial disease. It included eight telephone calls with a trained health counselor and focused on adherence to cholesterol-lowering medications and on encouraging patients to discuss cholesterol management issues with their physician. The pragmatic purpose of the trial was to determine whether cholesterol outcomes could be improved by adding this intervention to the patients' usual medical care. In order to answer this question, it was necessary to compare the intervention (plus usual care) to usual care alone. The investigators designed their trial accordingly. The usual care control condition was well suited to the primary aim of the trial.

However, the investigators also included an attention control condition. It is not clear why they decided to add this third arm to the trial, but it is likely that they did so in order to forestall any concerns about failing to control for attention. As it turned out, the attention control arm complicated the interpretation of the findings, and the intervention vs. usual care comparison was more informative than the intervention vs. attention control comparison. Routine medical care for peripheral artery disease usually does not include an ancillary counseling program that provides little more than diffuse clinical attention. Thus, the attention control condition did not help to answer the RCTs primary question, i.e., whether patients would have better outcomes if they were to receive a cholesterol counseling intervention than if they receive only their usual medical care for peripheral artery disease. Unexpectedly, the outcomes in the attention control condition were *worse* than those in the usual care arm. This created a situation in which the intervention was superior to the attention control condition, but not superior to usual care. Consequently, patients are no better off if given this intervention than if they simply receive standard medical care, even though the intervention could be called "efficacious" relative to a clinically artificial attention control condition. The authors themselves questioned the inclusion of the attention control arm in their trial (Pagoto, McDermott, et al., 2013), as did one of us (Freedland, 2013).

The primary purpose of a behavioral trial always depends, to some extent, on the stage of the research program of which it is a part. For example, in the initial test of a novel behavioral intervention, the investigator's goal may simply be to determine whether it has any detectable effect on an outcome of interest. This calls for a relatively small trial and hence a relatively lenient control condition. Comparison to a much more stringent condition, such as to an established treatment for the same problem, would require a much larger study and would be premature at such an early stage in the research program (Mohr, Spring, et al., 2009).

Establishing Quality Control Procedures

Rigorous quality control (QC) procedures are needed to ensure that the treatment protocol is implemented properly and consistently. Treatment-related QC activities include therapist training, use of a treatment manual, and assessments of treatment adherence and therapist competence. QC procedures should include a feedback loop in which assessments of adherence and competence inform revisions to the treatment protocol and therapist training.

The goal of therapist training is to ensure that the therapists have the skills and experience they need to deliver the intervention properly and familiarity with the clinical population that is the target of the intervention. The training should emphasize standardization of treatment procedures and promotion of adherence to them by all intervention staff. It should begin before the therapists start conducting their treatment sessions and should be led by supervisors with experience delivering the study intervention or similar treatments. Common training techniques include didactic instruction, role plays, and live or recorded demonstrations of model cases.

Treatment manuals or protocols serve to formalize treatment procedures and processes. The ones that are used in RCTs typically describe the rationale of the intervention, specific treatment procedures or processes, required materials, and recommended time allocations. If the intervention is highly structured, the manual may provide a session-by-session agenda. If the intervention is flexible or adaptive rather than tightly structured, it may instead provide guidelines for setting session agendas and for planning the course of treatment. A meta-analysis of psychotherapy outcome studies (Crits-Christoph, Baranackie, et al., 1991) found that the use of manuals reduced variability in therapist effects. Manuals also provide information that can be used for replication, and subsequently for clinical dissemination, if the RCT shows that the intervention is efficacious. Thus, treatment manuals can assist in enhancing both the internal and external validity of an intervention (Barber, Krakauer, et al., 1997).

Treatment adherence refers to the extent to which therapists deliver the intervention as prescribed by the treatment protocol. Therapist competence refers to the skillfulness with which the therapists deliver the intervention (Waltz, Addis, et al., 1993). It is possible for a therapist to be adherent yet unskilled or to be skillful but nonadherent. The goal of treatment supervision in an RCT is to optimize both adherence and competence. Adherence and competence are often assessed by reviews of audio or video session recordings, with systematic ratings by the supervisor, other therapists, and/or independent observers. Ratings may be completed for every session, or for a random sample of sessions, depending upon the time and resources available for this labor-intensive activity. QC reviews of clinical documentation (e.g., problem lists, intervention checklists, treatment plans, etc.) may also be performed.

When developing the treatment-related QC procedures for an RCT, the investigators should try to identify the specific elements of the intervention that have been empirically or theoretically linked to treatment outcomes. These elements should be emphasized in training, manuals, and evaluations of adherence and competence. The investigators should select strategies to monitor these specific elements that balance efficacy and effectiveness concerns. For example, although frequent supervision sessions may increase the integrity of treatment delivery, this strategy may be harder to disseminate than completion of brief QC checklists. Finally, the investigators should develop criteria to determine satisfactory adherence and competence based on precedents, empirical findings, or the theory underlying the approach.

Proactive quality control procedures are also needed for many other aspects of behavioral RCTs. The most demanding and time-consuming QC task in most trials is to ensure that the study data are as accurate and as complete as possible. Traditionally, much of the data in behavioral medicine trials has been collected on paper forms and then manually entered into research databases. This process presents many opportunities for errors and missing data, but it does have the advantage of supporting QC efforts in which the databases are compared against the original paper forms or questionnaires. However, there is an ongoing shift toward paperless data collection methods. For example, responses to structured interviews may be recorded on tablet computers instead of on paper forms. This is much more efficient than the traditional approach, but it can be difficult to tell whether an item was accurately entered. For example, if an interviewer mistakenly enters “25” instead of “35” as the age of a research participant, this error could easily slip through retrospective QC checks. Consequently, it is becoming increasingly important to build interactive data integrity checks and other proactive QC procedures into the data collection plan for behavioral RCTs.

Some Lessons Learned from ENRICHD

The ENRICHD trial (Berkman, Blumenthal, et al., 2003) provides an informative example of the development and implementation of a behavioral intervention for a complex, multicenter RCT. (Two of the present authors [Blumenthal, Freedland] were ENRICHD Investigators.) Patients who met the study’s criteria for depression and/or low perceived social support (LPSS) were enrolled within 1 month after hospitalization for an acute myocardial infarction (MI). When the trial was being planned, there was considerable evidence that both depression and low perceived social support placed post-MI patients at increased risk for recurrent MI or death (Berkman, Leo-Summers, & Horwitz, 1992; Frasure-Smith, Lespérance, & Talajic, 1993), but little evidence that either of these psychosocial risk factors could be modified with treatment or that modifying them could improve medical outcomes. Several previous RCTs had suggested that stress management interventions were not beneficial (Jones & West, 1996) and might even be harmful (Frasure-Smith, Lespérance, et al., 1997) for patients with coronary heart disease, and it seemed possible that treatment of depression and LPSS might also produce no benefit or unintended adverse effects. Under these circumstances, the best option was to look for an intervention that was already established as safe and effective for depression and social or interpersonal problems in adults, even if little was known about its effects on medical outcomes in cardiac patients.

Thus, the primary purpose of ENRICHD was not to test any particular intervention; it was to determine whether treatment of depression and LPSS can improve medical outcomes after an acute myocardial infarction. In other words, the primary research question of the trial was about the medical outcomes, not about the intervention. Several empirically supported therapies were considered. CBT was eventually selected because there was more empirical evidence supporting CBT for depression than any other form of psychotherapy, particularly in elderly and medically ill populations. CBT had also demonstrated superiority to IPT for depression in withdrawn and socially dysfunctional patients. However, although there were many social support interventions to choose from (Hogan, Linden, & Najarian, 2002), neither CBT nor any other psychosocial intervention had ever been shown to improve social support in socially isolated patients. Thus, no known evidence-based treatment could fulfill the criterion of having demonstrated effectiveness for *both* depression and LPSS. Consequently, the investigators decided to focus on cognitive therapy for depression but to expand it so that it could also be used to treat LPSS.

The core treatment manuals for the ENRICHD trial were *Cognitive Therapy of Depression* (Beck, Rush, et al., 1979) and *Cognitive Therapy: Basics and Beyond* (Beck, 1995). The investigators also developed a supplementary treatment manual for ENRICHD. It discussed the application of CBT to the treatment of LPSS and depression in post-MI patients, the details of how to deliver individual CBT for the trial, and the protocol for group CBT sessions. The supplementary manual drew both upon the extant empirical literature on behavioral interventions for cardiac patients and upon the clinical expertise of the investigators.

The characteristics of the patient population posed several barriers to the delivery of CBT. Prior RCTs of psychosocial treatments for cardiovascular patients had been conducted with demographically homogeneous populations. In contrast, the ENRICHD population was highly diverse, with 48% women, 34% racial or ethnic minorities, 40% over the age of 60, and 24% with less than a high school education (Berkman, Blumenthal, et al., 2003). The diversity of the population necessitated the use of novel strategies such as training in a range of cultural competencies, developing strategies to destigmatize the treatment, minimizing jargon in written materials, and using metaphors to communicate key concepts (ENRICHD Investigators, 2001). Furthermore, it was necessary to translate the assessment and treatment materials into Spanish and to hire both English- and Spanish-speaking therapists.

The timing of the intervention was a key decision point in planning the trial. Some of the impetus for the ENRICHD trial came from the study by Frasure-Smith and colleagues (1993) which showed that depression was a significant predictor of mortality during the first 6 months following an acute MI. These findings suggested that depression should be treated as soon as possible after the MI to minimize the mortality risk. A countervailing consideration was that medical problems might dominate course of recovery over the first 6 months after the MI and that they would dilute the impact of depression, LPSS, and their treatment on clinical outcomes. Moreover, because CBT usually requires weeks or even months of active participation to alleviate depression, some investigators argued that it would be more appropriate to provide treatment later in the disease process when the patient's medical condition was more stable.

Ultimately, the investigators decided to intervene as soon as possible after the acute MI in an attempt to reduce cardiac morbidity and mortality. In hindsight, this decision may have undermined the outcomes of the trial in two ways. First, the decision to treat earlier rather than later posed several barriers to initiating treatment. Because the mortality risk is highest in the first few months after an index event, patients had to be screened within 28 days after their index event to qualify for the study, and treatment had to begin as soon as possible. This often required the initial screening to occur in the hospital within days after the acute MI, a time when patients are typically preoccupied with their medical condition and are often unaware of or unconcerned about their depression or inadequate social support. Patients who consented to participate often felt less distressed after returning home and resuming familiar routines and consequently had some second thoughts about participating in the intervention. Consequently, early intervention sessions were often spent engaging the patient and building a therapeutic alliance, instead of focusing on techniques to alleviate depression and LPSS (ENRICHD Investigators, 2001).

Second, the decision to intervene early may have diminished the impact of CBT on clinical outcomes. A secondary analysis of ENRICHD data showed that depression was not related to mortality during the first 6 months, but was related to clinical outcomes 9–12 months post-MI (Carney, Blumenthal, et al., 2003). Thus, delaying patient enrollment for several months after the acute MI might have been a better strategy than intervening earlier, at least in terms of the goal of reducing morbidity and mortality by treating depression and LPSS in post-MI patients.

As discussed above, interventions in behavioral medicine are often timed to coincide with teachable moments. An acute MI may be a teachable moment in some ways, but as we learned from ENRICHD, many patients are too ill, debilitated, or preoccupied in the first few weeks after an MI to be able to use it as a teachable moment. Thus, the timing of interventions in behavioral medicine should not be decided only on the basis of the patients' cognitive or emotional readiness to learn; their medical and physical readiness must also be taken into account.

Decisions about the intensity and delivery of the intervention were not especially controversial during the planning stage of the trial, but in retrospect, they may have been less than optimal. The investigators decided to deliver the intervention in a flexible manner that would translate to community settings and that patients would receive a minimum of six sessions over a maximum period of 6 months. Unfortunately, the overall differences between the treated and control groups turned out to be fairly modest (2 points on the

Beck Depression Inventory [BDI] and 2 points on the ENRICHD Social Support Instrument [ESSI]). These differences were much smaller than needed for a strong test of the investigators' "causal and modifiable cardiac risk factor" hypotheses about depression and LPSS.

It is possible that more prolonged or intensive CBT, particularly for patients with severe depression, might have produced better clinical outcomes. The trial was not designed to answer this question. However, a secondary analysis revealed that patients in the intervention arm whose depressive symptoms did not improve had worse medical outcomes than those whose depression did improve (Carney, Blumenthal, et al., 2004), even though the primary analysis did not show a between-group difference in medical outcomes (Berkman, Blumenthal, et al., 2003). In addition, participants in the intervention arm who had severe depression (e.g., Hamilton Depression scores of >26) at baseline or who did not show a sufficient response to CBT within 6 weeks were offered an antidepressant in addition to CBT. Cumulative rates of antidepressant use by the end of follow-up in the usual care and CBT arms were 21% and 28%, respectively. A post hoc analysis revealed that patients who received antidepressants had better medical outcomes than patients who did not (Taylor, Youngblood, et al., 2005).

Another major decision concerned how to deliver the intervention in a manner that would foster participant retention. Some patients were too infirm to attend frequent outpatient sessions, incapable of driving themselves to clinic visits, or unable to find transportation. Moreover, some were discharged from the hospital to skilled nursing facilities for extended stays, and some were rehospitalized. To overcome these logistical barriers to study retention, it was necessary to conduct the intervention in a variety of settings and to use several different treatment modalities. For patients who were unwilling or unable to have face-to-face sessions, CBT sessions were delivered by telephone. In some cases, the therapists had to take the treatment to patient instead of asking the patient to come to them. This meant delivering the intervention at the patient's home or at bedside in the hospital. Some patients were offered transportation to the clinic in order to help overcome real and perceived logistical barriers. The investigators realized that these outreach strategies would not translate very well into clinical practice, but understood that they were necessary to maximize therapy engagement and participant retention for the trial. This is an example of the difficult trade-offs that often have to be made in planning a biobehavioral RCT.

A complementary strategy to enhance retention was to offer a combination of individual and group CBT sessions. Although participation in group CBT sessions was encouraged, the challenges of recruiting participants (only one patient was enrolled for every 14 screened) made it difficult to enroll enough patients during the same period in the same locale to fill a treatment group with a minimum of three to four patients. For example, at the Duke University site in Durham, North Carolina, participants were enrolled from a broad geographic area, from as far away as Danville, Virginia, 54 miles north, or Fayetteville, North Carolina, 78 miles south. For these participants, it was not feasible to conduct CBT groups with any regularity. Some of the other sites allowed patients to participate in group CBT sessions via telephone.

By necessity, the delivery of the intervention required flexibility regarding the frequency and intensity of treatment, as well as specific session goals and assignments. However, this flexibility had to stay within the limits of fidelity to the treatment protocol. CBT therapists received intensive training and certification by the Beck Institute for Cognitive Behavior Therapy (founded by Aaron T. Beck, M.D., the developer of CBT) and a minimum of 2 h per week of supervision from experienced therapists, many of whom were ENRICHD co-investigators. The CBT sessions were recorded, and adherence to the treatment protocol was documented on standardized treatment data logs. Reviews of audio recordings and treatment logs served as the basis of individual and group supervision sessions. In addition, the Beck Institute staff reviewed the recordings of approximately 20% of the therapy sessions. Regular conference calls between the Beck Institute and the CBT supervisors also helped to promote treatment adherence and therapist competence.

ENRICHD was one of the first large, multicenter RCTs in which behavioral scientists with backgrounds in health psychology and behavioral medicine collaborated with cardiologists, biostatisticians, and other researchers who had little if any prior experience with behavioral intervention research. Everyone had to compromise despite strongly held opinions, in order to make this unprecedented collaboration succeed. For example, the cardiologists had to accept the fact that behavioral interventions for problems like depression in post-MI patients can take weeks or months to complete. This was especially difficult for the physician-investigators who worked in critical care settings, as they tended to think in terms of minutes or hours rather than weeks or months when treating acute myocardial infarctions.

In contrast, the concept of "keep it simple" was taken for granted by the cardiologists, biostatisticians, and investigators who had had extensive prior experience with large, multicenter trials, but was difficult to accept for the behavioral scientists who had primarily worked on single-site studies. For example, the preliminary plan for the trial included an extensive battery of psychosocial questionnaires. Many of these measures assessed factors that were of great interest to some of the researchers involved in the study but that were neither primary nor secondary outcomes of the trial. To the chagrin of their proponents, most of these measures had to be jettisoned in order to contain the cost and the respondent burden of the trial.

For many of the behavioral scientists, ENRICHD was also their first experience in working with a multicenter Data Coordinating Center (DCC). Most DCCs operate within biostatistics departments at universities or clinical research organizations. The DCC for the ENRICHD trial was affiliated with the Department of Biostatistics at the University of North Carolina in Chapel Hill. The DCC serves many functions besides data management and statistical analyses in a large trial such as ENRICHD, including coordinating the efforts of a widely dispersed, multidisciplinary research group, and holding both the investigators and the staff to high methodological and ethical standards for the conduct of the trial. Working with the DCC helped many of the behavioral scientists to become more aware of the importance of seeing beyond parochial research traditions and adapting to the wider culture of medical trials.

One of the most important attributes of that culture is an unshakable determination to continue pursuing significant research objectives despite disappointments and setbacks. Although ENRICHD was carefully designed and well conducted, the primary outcomes were disappointing. The intervention had weak effects on depression and LPSS, and the primary analyses failed to demonstrate that cardiac outcomes could be improved by treating depression and LPSS. Few of the behavioral scientists had ever been involved in a large, expensive, multicenter trial that did not turn out as well as they had hoped, but most of the medical scientists and biostatisticians had experienced similar or even worse disappointments in some of the other multicenter trials in which they had participated. As long as an RCT addresses an important question, is well designed, and is carefully conducted, they do not consider it a "failure" if the primary outcome analyses turn out to be nonsignificant. The negative results of an excellent RCT can be very useful, and secondary analyses can yield very informative findings, as they have in numerous publications based on ENRICHD data. The biomedical scientists were undeterred by the primary results of ENRICHD. The behavioral scientists learned from them that the best response was not to give up, but to keep trying and to conduct more research. Depression and LPSS are still risk factors for cardiac morbidity and mortality, better ways are still needed to help patients overcome these problems, and RCTs will continue to be essential in this line of research.

Summary and Conclusions

This chapter discussed a variety of methodological issues concerning the design and conduct of randomized clinical trials in behavioral medicine. It included issues with broad relevance, including the importance of meeting current standards of mainstream medical research while meeting the unique methodological challenges of behavioral intervention research. It stressed the vital importance of clearly defining the purpose of a behavioral trial before making key design decisions. It also included a number of more specific issues in the design of RCTs, including how the patient population, outcomes, intervention, comparison condition, quality control procedures, and, most importantly, the purpose and objectives of the trial are defined. Finally, it discussed the ENRICHD trial to illustrate how many of these issues affected the design, conduct, outcomes, and interpretation of findings of a major multicenter RCT in behavioral medicine.

All of these issues are important, but only to the extent that researchers in behavioral medicine continue to propose and conduct rigorous clinical trials to address clinically significant problems. Even when high-quality RCTs show that it is possible to improve upon usual care (Timbie, Fox, et al., 2012), it is difficult to change clinical practices in any area of health care and prevention. With a paucity of rigorous clinical trials, it is much more difficult! Unfortunately, there have been too few trials in most areas of behavioral medicine research and very few large, multicenter RCTs in any of them. This fuels skepticism among physicians and health-care policymakers about the clinical utility of behavioral medicine. Many of them doubt whether lifestyle risk factors such as smoking or physical activity are amenable to behavioral intervention or that psychosocial interventions can improve medical outcomes (Relman & Angell, 2002; Thombs, Roseman, et al., 2013).

We believe that the only way to overcome this challenge is for researchers in behavioral medicine to make a serious and sustained commitment to careful, programmatic intervention research. It is not enough to conduct small treatment development studies or small, single-site RCTs. These are important steps, and valuable in their own right, but they are unlikely to have a major impact on prevention efforts, clinical practices, or health-care policies unless they eventually culminate in large, multicenter RCTs. Unfortunately, funding for clinical research is very scarce, and it is especially difficult to obtain funding for large, multicenter trials which can cost millions or even tens of millions of dollars to conduct. Thus, it is imperative for researchers in behavioral medicine to vigorously advocate for funding to support more and larger RCTs and to make use of these funds to conduct rigorous trials of behavioral interventions for prevalent, clinically significant problems.

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Research Approaches of Education, Applied Psychology, and Behavioral Science and Their Application to Behavioral Medicine

6

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Introduction

Behavioral medicine is concerned with the broad and central role of behavior in the prevention and treatment of disease and improvement of quality of life (Fisher, Fitzgibbon, et al., 2011). Because behavioral medicine encompasses interdisciplinary knowledge from across a wide range of theories and best practices in relation to human health and behavioral and social change, it draws extensively on the research methods of education, applied psychology, and behavioral science. These methods are often employed by investigators and program evaluators to make causal inferences about whether organized intervention efforts designed to change health-related behaviors or the contextual factors that shape behavior result in the desired outcomes. But equally importantly, these methods provide valuable tools for formative research that can inform and guide development of evidence-based behavioral medicine programs, as well as program monitoring for ongoing assessment, improvement, and quality assurance.

In almost any discussion of research methods, scholars and practitioners will invariably get into epistemological debates about the relative value of different methods and different approaches. In the biomedical context and much of behavioral medicine research, historically the randomized controlled trial (RCT) has been seen as the "gold standard" by which novel clinical treatments are evaluated for their effectiveness in achieving a desired health outcome. However, given its standard requirement for a placebo, nonintervention, or alternate-treatment control arm, the RCT model of evaluation is limited in providing evidence about the effectiveness and value of the range of behavioral medicine approaches—approaches that now extend beyond the clinic and into the communities in which people live. As a consequence, research and evaluation efforts in behavioral medicine must go beyond the RCT and utilize different and complementary research strategies, designs, and methods to address health disparities and the myriad complexities of behavior and social factors.

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This chapter presents the range of different research strategies, designs, and methods derived from education, applied psychology, and behavioral science that are used in behavioral medicine. The methods discussed in this chapter are often used in conjunction with the methods of RCTs and thus complement the research and evaluation process. Accordingly, we have organized the chapter into several major sections. In the first section, we begin by examining seven key questions that are typically addressed in behavioral medicine and illustrate how the research and program evaluation methods, including qualitative, quantitative, and mixed methods, are utilized in answering each of these questions. In addition to providing a primer on these methods, we include selected examples of how such methods have been applied across a wide and diverse range of problems, practice settings, and populations in behavioral medicine and public health. Although we have organized the sections of the chapter to include descriptions of methods that are principally applied to a specific question or phase of research, it is important to point out that all these methods have overlapping value—whether it is in formative evaluation, process evaluation, or summative evaluation—across the spectrum of the research process, from inception to conclusion. For example, although surveys and focus groups are commonly utilized methods for developing and answering research questions about the problem and the needs to be addressed during the formative phases of research, such methods are often used in the later phases of research and evaluation efforts when results are being interpreted and programs disseminated. In the second section of the chapter, we discuss community engagement in the research process as an integral element of conducting research and evaluation in behavioral medicine, reviewing both the basic concepts and principles of community-based participatory research, including illustrative examples and a discussion of key issues. In the third section, we turn our attention to concepts and issues in the translation of research into practice, a topic of growing interest as a next-generation challenge to those working in both the public health and behavioral medicine communities. Finally, we conclude the chapter with a discussion of some of the emerging challenges of conducting behavioral medicine research and their implications for the future.

Answering Key Research Questions in Behavioral Medicine

As in most applied behavioral and social research, behavioral medicine is oriented toward: (a) describing and conceptualizing behavioral phenomena, (b) understanding and explaining the causal mechanisms underlying behavioral phenomena, and (c) creating interventional programs designed to facilitate change or some alteration in the behavioral phenomena. Thus, the questions behavioral medicine seeks to address include: What is the problem and what is the need? With what intervention can we best address the problem? How was the intervention delivered? Was the intervention effective, and why or why not? Can the intervention outcomes be replicated? And how can the intervention be improved, scaled, and disseminated?

What Is the Problem and What Is the Need?

Health and human service programs are typically designed to serve people with demonstrated need, facilitate positive human development, and provide prevention and treatment resources to promote or restore health. When developing these programs, *needs assessment* is the critical first step in deciding whether there is indeed a need to be met, identifying the data to be gathered to understand the need, and generating data with which to begin the planning process in determining what types of programs, intervention approaches, or resources should and can be feasibly offered that hold promise to address the need or mitigate the defined problem.

Needs assessment typically examines social, behavioral, and epidemiological profiles of the community. It seeks to identify and address potentially modifiable social problems as well as the agencies, institutions, and programs currently serving the community, or addressing a specific need, to define and reconcile the discrepancy between “what is” and “what ought to be.” Approaches to answering these questions will vary, but major sources of relevant information in needs assessment include existing archival data about the problem, the experiences and conclusions of experts who know the situation well, and, perhaps most importantly, the perceptions and opinions provided by those directly affected. Once identified, needs can be prioritized and then used as the basis for setting goals and objectives for intervention programs (Isaac & Michael, 1995).

One straightforward method of assessing the needs of a community is simply to ask people about their needs through social surveys, personal interviews, and focus group interviews. At this phase, it is important to estimate the magnitude of need and avoid falling into the trap of proposing and evaluating potential solutions before fully understanding the scope of the problem and the potential objectives a proposed program might be designed to meet. Moreover, the context of need also should be examined in order to ensure efforts are appropriately directed; it is otherwise possible to have an accurate assessment of a community’s need, but fail to assess the cultural, social, or political context in which a program would be implemented or the community’s capacity to continue support and maintenance of the program.

Assessment and Planning Models

Numerous systematic techniques and planning models have been developed to guide needs assessment and the formative stages of intervention planning. While we cannot describe the many techniques and models available, we focus here on two relevant assessment and planning models that have gained popular use and have demonstrated value in a range of health-related and behavioral medicine research.

Delphi Method The Delphi method (or technique) is an iterative process whose purpose is to gather expert opinion and reach consensus of opinion on a defined topic through multiple iterations. It employs a series of questionnaires that are administered by a facilitator in multiple iterative survey rounds that are, in turn, interspersed with feedback and revisions of answers to the questionnaires in response to the feedback in each round until consensus is reached. Initially developed to improve technological forecasting (Linstone & Turoff, 1975, 2011), the method is especially useful when what is known about a phenomenon of interest is incomplete (Adler & Ziglio, 1996). The Delphi method incorporates components of (a) anonymity of the study’s expert participants and their opinions, (b) multiple rounds of iteration to achieve consensus of opinion, (c) controlled feedback, and (d) the opportunity for quantitative analysis and interpretation of data. Delphi panel studies have been used extensively in health-related research ranging from recent studies designed to clarify concepts of parenting practices around food (Gevers, Kremers, et al., 2014), to the determinants of adolescent coping strategies with cyberbullying (Jacobs, Dehue, et al., 2014), to establishing a framework of behavioral indicators for outcome evaluation of health promotion among individuals with suspected TB patients (Li, Ehiri, et al., 2014).

PRECEDE-PROCEED One of the most prominent and widely utilized models in health planning—PRECEDE-PROCEED—provides a comprehensive planning framework for assessing the health and quality-of-life needs, and for designing, implementing, and evaluating health promotion and other public health programs to meet those needs (Green & Kreuter, 2005). Originally developed to facilitate planning of health education efforts, it has been used extensively and more broadly in health promotion and disease prevention planning, at the national, state and local levels, and globally beyond North America. The model works by guiding program planners and evaluators through an eight-phase series of assessment and analytic steps that result in the formulation of measurable goals and objectives for the program. These are: (a) Phase 1: social assessment and situational analysis; (b) Phase 2: epidemiological assessment; (c) Phase 3: educational and ecological assessment; (d) Phase 4: administrative and policy assessment and intervention alignment; (e) Phase 5: implementation;

(f) Phase 6: process evaluation; (g) Phase 7: impact evaluation; and (h) Phase 8: outcome evaluation. The hallmarks of the model include its flexibility and scalability across health problems, populations, and practice settings; its participatory and iterative nature; and the platform it provides for generating evidence-based best practices. Numerous studies and health program planning efforts have demonstrated its utility. For a bibliography of over 1000 published applications of the model across a wide range of settings, populations, and health problems, see Green (2014).

Quantitative Research Methods

Social surveys provide an opportunity to describe phenomena by examining the responses from a large number of participants and looking for correlations among variables and patterns of cause and effect (McBurney & White, 2010). It is beyond the scope of this chapter to provide more than a brief overview of the survey method. Thus, instead of using illustrations from different levels of inquiry, we will present some general guidelines for the use of survey research in behavioral medicine and some of the considerations the investigator must take into account when planning surveys. There are many excellent texts and other resources on survey methods. Several that may be helpful to those wishing more information are: Aday and Cornelius (2009), *Designing and Conducting Health Surveys*; Dillman, Smyth, and Christian (2008), *Internet, Mail, and Mixed Mode Surveys*; Fowler (2014), *Survey Research Methods*; and Rea and Parker (2014), *Designing and Conducting Survey Research*. In addition, many texts focus on particular aspects of survey research, such as sampling techniques, questionnaire design, question construction, scaling, and data coding and analyses.

Questionnaire Development Survey research relies on the interplay of three key elements in questionnaire development: how a questionnaire is designed, how it is administered, and to whom it is administered. Questionnaire items must be valid, meaning that they must measure what they purport to measure, and they must be reliable, providing consistently reproducible responses (McBurney & White, 2010). Because questionnaires can be labor-intensive and expensive to develop, frequently researchers will use existing questions or instruments rather than designing their own, allowing them to rely on previous assessment work that has been done to establish the validity and reliability of the questionnaire items and to compare their results with those of previous studies that have employed the same instruments. However, when using existing questions in multicultural populations, items should first be tested for ethnic and racial appropriateness and cultural sensitivity, even if the questions have been used successfully with other population groups (Warnecke, Johnson, et al., 1997). Further, when items are translated to new languages or used in other countries or cultures, additional steps must be taken to ensure the quality of the translation and validity of the items. For example, the SF-36 and SF-12—two widely used measures of health status and quality of life—were developed as part of the RAND Medical Outcomes Study, a multiyear, multisite American study that was originally designed to explain variations in patient outcomes in relation to varying health insurance coverage in the United States (Newhouse, 1982; Ware, Kosinski, & Keller, 1996). These measures have been used extensively in the North American context. But use of these instruments in other countries, cultures, and languages has required additional psychometric testing to establish their clinical validity and to evaluate cross-cultural stability of questionnaire items and scoring algorithms (Bullinger, 1995; Coons, Alabdulmohsin, et al., 1998; Fukuhara, Bito, et al., 1998; Gandek, Ware, et al., 1998; Li, Wang, & Shen, 2003; Ngo-Metzger, Sorkin, et al., 2008; Perneger, Leplège, et al., 1995; Persson, Karlsson, et al. 1998).

When designing new questionnaire items, the investigator will need to consider the purpose of the questionnaire and what they expect to answer or accomplish with the research. For example, is the study seeking to simply describe the presence and characteristics of a phenomenon (e.g., “Who smokes during pregnancy?”) (Schneider, Maul, et al., 2008), to understand why and by what mechanism the phenomenon might occur (e.g., "What are pregnant women's knowledge and attitudes towards smoking?") (Owen & Penna, 2001), or to seek or evaluate potential solutions (e.g., "Is smoking cessation counseling being offered to pregnant women by their healthcare providers?") (Zapka, Pbert, et al., 2000). In addition, basic principles of questionnaire construction should be followed, including the use of clear, unambiguous items that are valid and reliable, avoidance of bias, logical sequencing, and permitting the data to be coded and analyzed in appropriate and meaningful ways. Steps in questionnaire development often include administering preliminary surveys, called *pilot-test surveys* (where focus groups may be used) to ensure the clarity of questions, determine the correlation between potential items (Zapka, Fletcher, et al., 1997), and conduct psychometric statistical testing to establish construct item validity and reliability or reproducibility (Meadows, Harvey, et al., 2000).

Method of Data Collection Investigators must also choose the method of administration and data collection. These include face-to-face or telephone interviews or self-administered questionnaires (via paper or Internet-based surveys). Each method of data collection will have distinct advantages and disadvantages. For example, face-to-face interviews allow for the development of rapport with a respondent and can be appropriate for respondents with low literacy rates, such as in a study conducted on behalf of the Government of Tanzania in which over 1800 households were interviewed about provision of health services (Abel-Smith & Rawal, 1992). However, face-to-face interviewing is also labor- and resource-intensive, and results depend on both the skill of the interviewer (some of the Tanzanian surveys had to be rejected due to poor interviewing) and on the willingness of the respondent to be honest rather than saying what they think the interviewer wants to hear (i.e., *social desirability bias*).

Self-administered questionnaires can be cost-effective and help avoid social desirability response biases, but can often result in low response rates and missing data. Moreover, there is no concrete way to know that a respondent understood each question and usually there is little or no opportunity to clarify those questions that may have been misunderstood (McBurney & White, 2010). In using self-administered questionnaires, the researcher also cannot be certain that the intended respondent is the one responding to the questionnaire or if the respondent is acquiring assistance from others. Surveys conducted on the Internet can be highly cost-effective and are often particularly appropriate for sensitive topics since the ability to complete the survey in privacy may result in less social desirability response bias (Cohall, Dini, et al., 2008). Internet-based surveys also include additional benefits, such as controlling for question order that can be administered to respondents based on previous answers. These include branching questions that ask about certain behavior, such as tobacco smoking, and questions thereafter that depend on the answer to the previous question (e.g., if "yes" then answer the next five questions about how much the respondent smokes, preferred brands, etc.; respondents that answered "no" would skip the brand items and be taken directly to the next part of the questionnaire). This kind of control over question sequence can be difficult to accomplish in a self-administered paper-and-pencil survey.

Sampling the Population Investigators must also decide on the kind of sampling design they will use to draw a representative sample from some larger population of interest. This is a critical decision because the generalizability of findings of a study depends heavily on the extent to which a sample may be truly representative of the population. The first set of these designs is *nonprobability samples* and include *purposive samples*. *Purposive samples* are designed to identify potential respondents for some particular purpose. For example, research intending to describe the experiences of Canadian adults with osteoarthritis (Gignac, Davis, et al., 2006) or gay Scottish men with HIV (Flowers, Duncan, & Knussen, 2003) would necessarily seek out those specific populations. Similarly, a study of nursing students' perceptions and health beliefs may focus on the students at a single university (Denny-Smith, Bairan, & Page, 2006), research on patient or provider knowledge and experiences may utilize only individuals at specific hospitals, clinics, or pharmacies (Bakken, Holzemer, et al., 2000; Johnson, Nowatzi, & Coons, 1996; Parker, Baker, et al., 1995; Pole, Einarson, et al., 2000; Secginli & Nahcivan, 2006), and surveys of specific professions may be distributed to potential respondents by using membership directories as sampling frames (Helft, Hlubocky, & Daugherty, 2003; Kenny, Smith, et al., 1993; Story, Neumark-Sztainer, et al., 2002) or at trade shows and professional meetings (Korelitz, Fernandez, et al., 1993). Other examples of nonprobability samples that have been identified include *Quota samples*, which seek to identify a certain number of respondents in the sample; *chunk samples* (sometime referred to as *convenience samples*), which study a group of respondents who happen to be available; and *snowball samples*, which is “chain sampling” that starts with a single or small group of initial respondents (often useful in hard-to-reach populations such as drug users or sex workers) who then identify potential other similar respondents (Aday & Cornelius, 2009). In each case, external validity, i.e., the potential to generalize to a larger known population will vary depending on the sampling design.

The second type of sampling design, which is more powerful, is *probability samples*. In using probability samples, researchers generally obtain respondents in a systematic manner such that the probability that any given individual within a defined universe (sometimes referred to as the *sampling frame*) of potential respondents representing a *population* will have an equal chance of appearing in the sample. *Simple random samples*, *systematic samples*, *stratified random samples*, and *cluster samples* all provide different probability-based methods for selecting appropriate population-based samples from the group of interest (Aday & Cornelius, 2009). National studies on knowledge, attitudes, behavior (Galuska, Will, et al., 1999; Glasgow, Eakin, et al., 2001; Knuth, Malta, et al., 2011; Lantz, House, et al., 1998), disease prevalence (Burney, Luczynska, et al., 1994; Tsugane & Sobue, 2001; Yang, Lu, et al., 2010), and their correlations typically use national probability samples, which allow investigators to generalize to the larger population within a statistically known margin of error (McBurney & White, 2010). In this way, investigators may calculate the probability that any one sample is not completely representative of the population from which it has been drawn; while sampling error cannot be eliminated, the extent of the error will be influenced by the sampling techniques chosen (Kelley, Clark, et al., 2003).

Collecting survey data, however, can be expensive and time-consuming. In some cases, the existing specialized and publicly accessible national data sets, which constitute a source of household and individual survey data for secondary analyses, can permit investigators to answer important questions without the time and expense of collecting new data. In the United States, the National Health Interview Survey (NHIS) (CDC, 2015a) includes US Census data to track health status, health-care access, and progress toward achieving national health objectives among household respondents; the Behavioral Risk Factor Surveillance System (BRFSS) (CDC, 2015b) comprises a monthly cross-sectional telephone survey that state health departments conduct with a standardized questionnaire to collect prevalence data from the adult US population on risk behaviors and preventive health practices that affect their health status; and the Health Information National Trends Survey (HINTS) (NCI, 2015) routinely collects nationally representative data about the American public’s use of cancer-related information and related topics. Some surveys, like the National Health and Nutrition Examination Survey (CDC, 2015c), combine individual interviews with physical examinations of a subsample of respondents to assess the health and nutritional status of adults and children. Such sources of national data have supported studies on a wide range of health topics, including characteristics related to participation in a smoking cessation trial (Graham, Papandonatos, et al., 2008); the influence of lifestyle on inflammation in men and women with type 2 diabetes (Jarvandi, Davidson, et al., 2012); and the relationship between physical activity and general mental health (Kim, Park, et al., 2012).

Finally, sampling designs can be mixed. Some studies, for example, mix sampling techniques by randomly sampling from within a sampling frame such as a professional directory or other listing of potential respondents (Stanwood, Garrett, & Konrad, 2002; White, Speechley, et al., 1995) or from purposively chosen study sites (Kurth, Kamtsiuris, et al., 2008). A study of the health of homeless children and housed, low-income children in Los Angeles utilized such mixed sampling techniques. The study employed a three-stage sampling strategy: (1) a purposive sample of shelters, (2) a systematic sample of families in shelters, and (3) a random sample of one child in each family (Wood, Valdez, et al., 1990). On a broader geographical scale, an investigation of suboptimal utilization of public health facilities in Afghanistan began with a sampling frame of six provinces, within which two districts were selected using mixed sampling technique representing urban and rural populations. Two community health centers (CHCs) were selected within each district and out of the two, one from the center of the district was identified and another from the broader geographical catchment area of the district. At the level of CHC, two villages were then selected: the village in which that CHC itself was situated and another study village from the CHC catchment. In this way, at the level of selection of study sites, priority was given to select a fair percentage of respondents from rural as well as urban areas. Using this method, the investigators gave priority to selecting a fair percentage of respondents from rural as well as urban areas and resulted in a total of 48 villages and 24 health facilities from 12 districts in 6 provinces (Singh, Sharma, et al., 2012). Similarly, an evaluation of the quality of public health services in India had no sampling frame from which to draw respondents. Based on the literature, the investigators chose a sample size of 500 respondents to be drawn from the state of Uttar Pradesh, which was divided for sampling purposes into three geographic regions: eastern, central, and western regions. The sample size of 500 was distributed to these three regions in proportion to the rural population of the respective region, and two districts representing each region were selected randomly and the number of respondents selected from each district was proportional to the rural population of the respective districts. Finally, inclusion criteria required that the respondent should have utilized services at the public health center in the previous 6 months, and initial identification of sampling units was accomplished by seeking referrals from village leaders and the medical staff at the health centers, with subsequent respondents being identified through snowball sampling (Narang, 2011).

Qualitative Research Methods

In comparison to the descriptive and correlational nature of the data obtained in surveys, qualitative research is usually exploratory and seeks to use inductive (starting with observations and developing hypotheses) rather than deductive (starting with extant hypotheses and testing them with observations) approaches to generate novel insights. Curry, Nembhard, and Bradley (2009) have noted that such methods are best utilized when (a) investigating complex phenomena that are difficult to measure quantitatively, (b) generating data necessary for a comprehensive understanding of the problem, (c) gaining insights into potential casual mechanisms, (d) developing sound quantitative measurement processes or instruments, and (e) studying special populations.

Qualitative research differs from quantitative research in that rather than counting occurrences, exploring correlations among variables of interest, and statistically testing hypotheses, qualitative research seeks to describe the complexity and range of occurrences or phenomena and provide a rich basis for generating hypotheses or gaining deeper insights into statistically demonstrated relationship among the variables of interest. Moreover, while quantitative research typically generates numeric data using standardized processes and instruments with predetermined response categories, qualitative research allows for the use of open-ended questions, discussions, and observations. These guided discussions also allow the respondent to identify, describe, or elaborate on concepts and concerns that may not have been previously anticipated by the investigators and not captured with the more closed-format questions of those found in surveys (Curry, Nembhard, & Bradley, 2009).

The two primary methods of qualitative data collection are in-depth interviews and focus group interviews. In-depth interviews allow for the exploration of individual experiences in great detail and can be particularly valuable for sensitive topics since the method maximizes privacy while also allowing the investigator to build rapport to increase candor. Focus groups are equally well suited for explorations of perceptions and traditions of social groups and understanding social processes, as the group interaction dynamic can serve as a catalyst to generate unique insights into understanding (Kreuger & Casey, 2015; Mermelstein, 1999). Research suggests that group discussions can also elicit more critical comments than interviews, with the synergy of the group allowing each participant to reinforce one another's vented feelings (Robinson, 1999). In this way, focus groups may be especially effective at facilitating comfort among socially marginalized or disempowered populations who might otherwise feel reluctant to give negative feedback or who may feel that any problems result from their own shortcomings (Curry, Nembhard, & Bradley, 2009; O'Brien, 1993; Robinson, 1999).

Examples of research in which such methods have been applied include studies designed to illuminate the health beliefs and folk understanding regarding diabetes among British Bangladeshis (Greenhalgh, Helman, & Chowdhury, 1998) and formative research processes focused on intervention development for hard-to-reach population groups by the AIDS Community Demonstration Project (Higgins, Oreilly, et al., 1996). Because of the increasing importance of such methods in health-related research, efforts to formulate and define standards for reporting qualitative research have been undertaken in recent years. For example, the 21-item standards for reporting qualitative research (SRQR) is designed to improve the transparency of qualitative research by providing clear standards for reporting of study methods and findings (O'Brien, Harris, et al., 2014).

As with quantitative methods, investigators using qualitative research methods must carefully define the target group that will be the most beneficial, using systematic scientific methods to develop the sample (Curry, Nembhard, & Bradley, 2009; Robinson, 1999). However, in contrast to quantitative sampling techniques that rely on statistical probability theory, the logic and power of the purposive sampling used in qualitative research lie primarily in the high quality of information obtained per sampling unit. Adequacy of the sample size is relative, a matter of ensuring that the sample is neither too small to support claims of informational redundancy or saturation, nor too large to allow the deep, case-oriented analysis that is the hallmark of so much qualitative work (Sandelowski, 1995). Thus, generally, the aim is to identify participants who are "information rich," have certain characteristics, possess detailed knowledge, or have relevant experience; to study their responses intensively; and to continue data collection until the point of theoretical saturation, i.e., when no new concepts emerge (Curry, Nembhard, & Bradley, 2009). Although it is not possible to define the number of participants in advance, a range of 20–30 individual interviews or 4–6 focus groups with 6–10 participants each is often adequate to achieve saturation (Morgan, 1996; Patton, 2002). However, studies involving more than one target population, more heterogeneous groups, or both, often require more episodes of data collection in order to ensure inclusion of multiple viewpoints. Examples include the AIDS Media Resource Project, which conducted 52 different focus groups with 351 participants (Kitzinger, 1994), and a multisite investigation into ethnic and gender differences in youth smoking which included 178 focus groups conducted in 11 states with 1175 participants (Mermelstein, 1999).

Finally, as with quantitative methods, investigators using qualitative methods should strive to maintain that same scientific rigor that typically characterizes quantitative research. This means aiming to reduce problems such as researcher bias, lack of reproducibility, or limited generalizability.

Mixed Methods

Increasingly, and in part due to a recognition of the complexity of the problems on which behavioral medicine focuses, current evaluation research practice is now emphasizing a blending of the two approaches in which qualitative findings add interpretive richness to the more objective findings of quantitative research. Such *mixed-method* approaches in health-related research have emerged in recent years (Chatterji, 2004;

Chatterji, Green, & Kumanyika, 2001; Clark, 2010; Peterson, Czajkowski, et al., 2013). The inherent strengths of quantitative and qualitative research approaches complement each other, and combining both methods not only reflects the complex nature of the problems facing behavioral medicine and public health, but can also improve the quality and scientific power of the data derived from the investigation of complicated health problems (Creswell, Klassen, et al., 2011). Examples of mixed-methods research include studies of vaccine reminders (Anderson, Sebaldt, et al., 2008), patient safety (Benning, Ghaleb, et al., 2011), HIV and sexually transmitted disease (STD) prevention (Pinto & McKay, 2006; Shain, Piper, et al., 1999), and smoking cessation (de Vries, Weijts, et al., 1992). Combining these two approaches can result in a synergistic effect where the outcome of the two together is greater than the effects of either approach used separately (de Vries, Weijts, et al., 1992).

Reports of qualitative findings enriching understanding of quantitative observations have also become more numerous in the literature in recent years. For example, in the Feeding Young Children Study, a randomized controlled trial of a bottle-weaning intervention among low-income families, the initial research questions at Women, Infants, and Children (WIC) nutritional clinics were formed via nutritionists' observation of 4- and 5-year-old children drinking from baby bottles. A pilot quantitative study confirmed that mothers did typically provide baby bottles to children well past the recommended weaning age (Bonuck & Kahn, 2002), but it was the subsequent focus group discussions that revealed the mothers were typically following feeding advice from the child's maternal or paternal grandmother. Moreover, while the mothers were open to changing behavior and learning new skills, they had concerns about implementing changes that were counter to the grandmothers' opinions and experiences. The qualitative findings put the quantitative child-feeding data into the larger context of family dynamics, and the subsequent intervention not only addressed the mothers' knowledge of feeding behaviors but also provided support and materials to help mothers to broach the topic at home with family members (Hyden, Kahn, & Bonuck, 2013). In this case, the insights gleaned from the qualitative research shed new light on the quantitative results and clarified the information needs of the target audience.

Mixed methods can also provide researchers with additional tools to validate the outcomes of studies. Sometimes referred to as *triangulation of methods*, if the results from each method suggest the same conclusion, then confidence in the results is strengthened (Steckler, McLeroy, et al., 1992). One evaluation design solution that encompasses several phases of evaluation research using mixed methods is the extended term mixed method (ETMM) approach. ETMM designs are long-term research plans following life spans of individual programs or policy initiatives by employing descriptive research methods in the early stages of program adoption and implementation followed by experimental designs at a subsequent stage. ETMM designs deliberately study and document environmental variables as a component of the research plan, allowing for explanations of causality based on both empirical and substantive knowledge gained on the program and its setting. This use of a variety of research methods at multiple points of a program or policy's life span can improve the quality of evidence and strengthen interpretations of causality by helping to shed light on a multitude of context, process, and input indicators. The investigator can also select the key variables and interactions to use as statistical or procedural controls to empirically test process–outcome links (Chatterji, 2004). For example, an evaluation of after-school supplemental education utilizing ETMM involved a year-long study integrating a matched-groups design with classroom observations and surveys. The research began with a 14-week formative phase conducted at the beginning of the semester to explore the program and its environment in depth, with the goal of providing feedback to developers, program personnel, and school staff in order to stabilize treatment delivery and improve fidelity. This "before" phase gathered process data using classroom observations and teacher surveys, and yielded evidence of the extent to which the observed program processes, inputs, and outcomes were consistent with the program's underlying theory and philosophy. In the last 16 weeks of the program, data collection continued with classroom observations and surveys to document changes on program inputs and processes over time in matched classrooms by grade—the summative or "after" phase. In this design, the findings of the formative phase were used to tighten the data-gathering and analytic design of the summative phase, and qualitative classroom observations triangulated the quantitative analysis of teacher surveys and student outcome measures (Chatterji, Kwon, & Sng, 2006).

In summary, the use of quantitative, qualitative, and mixed research methods in behavioral medicine research is critical to gaining an understanding of the problem and needs of the population. The use of such methods in systematic needs assessment enables investigators and program planners to gain an understanding of the scope and extent of the problem, identify potentially feasible approaches to addressing the problem and perceived needs, and set the stage for the formulation and development of intervention programs. Mixed methods are important in gaining a better picture of the impacts and outcomes of intervention programs, often providing insights into the barriers and enablers to intervention success.

Table 6.1 provides a summary of the three research approaches and methods for needs assessment discussed above, including selected characteristics by which the strengths and weaknesses of each method can be assessed.

With What Intervention Can We Best Address the Problem?

Once a problem has been identified, the question of what intervention can best address the problem then becomes the major focus of program developers. Answering this question relies heavily on both formative and process evaluation methods (Dehar, Casswell, & Duignan, 1993). Program and intervention development is typically shaped during a *formative evaluation* phase of research. This phase usually seeks to address questions about program design, process, and outcomes, and identify elements of the intervention approach that will be necessary to change what is known from a needs assessment about the potentially modifiable causal mechanisms of the behavior or circumstances that are the focus of change. During this process, behavioral researchers not only need to understand the incidence and prevalence of a problem but must also gather data that can answer several key questions about how that problem can be optimally addressed.

Formative research typically cannot be conducted from a distance and must include input from the community of interest, as well as from those who have access to and knowledge about the intended audience, in order to create programs that are acceptable, unique, and effective (Posavac, 2011). Formative evaluation research activities can include having members of the intended audience evaluate materials for clarity and effectiveness, conducting surveys or interviews with potential partners or participants to inform the direction and content of program activities, and pretesting recruitment strategies, data collection methods, and pilot intervention delivery with small groups representative of the larger intended audience (Dehar, Casswell, & Duignan, 1993). For example, Peterson, Link, et al. (2014) conducted a three-step approach to developing and evaluating a novel coronary artery disease self-management educational workbook to be used in a novel intervention being tested in a randomized controlled trial (Peterson, Charlson, et al., 2012). First, the investigators conducted interviews using grounded theory methods with a diverse cohort of patients to identify needs and perceptions. Second, they then incorporated the themes that emerged from the qualitative interviews into the design of the workbook content. Finally, they evaluated study participants' use of and experience with the workbook at the end of the 12-month study period, demonstrating that the focus on practical health information, behavior-specific self-efficacy, and how healthy behaviors decrease risk was highly relevant to achieving study outcomes.

In another example, within the Trial of Activity for Adolescent Girls (TAAG), a randomized, multicenter field trial to reduce the decline in physical activity in adolescent girls, each field center

Table 6.1 Summary of research approaches and methods and selected design characteristics

Characteristic	Quantitative methods	Qualitative methods	Mixed methods
Scientific method	Deductive or “top-down”: the researcher uses data to test or verify hypotheses and theories	Inductive or “bottom-up”: the researcher uses data collected in the field to generate new hypotheses and grounded theory	Deductive and inductive
Objectives	Description, explanation, prediction	Description, explanation, discovery	Multiple objectives
Nature of research	Objective; attempt to study behavior under controlled conditions	Subjective, personal, socially constructed; attempt to study behavior in natural environments and understand the context within which behavior occurs	Pragmatic; attempt to study behavior in multiple contexts or conditions
Nature of data and sources	Variables from surveys and experiments	Words, images, categories from documents, observations, interviews, ethnography, field notes	Mixture of variables, words, and images
Lines of inquiry	Closed-ended questions with predetermined approaches	Open-ended questions with a focus toward emerging approaches	Both open- and closed-ended questions focused on emerging and predetermined approaches
Data analysis	Correlation and other inferential statistical relationships	Description and identification of themes and patterns	Quantitative and quantitative presentation of multiple perspectives
Data results	Researcher framed; generalizable findings with a general understanding of respondent’s viewpoint	Respondent framed; particularistic findings with an in-depth understanding of respondent’s viewpoint	Corroborated findings that may be generalizable
Data reporting requirements	Statistical report including correlations, comparisons of means, and statistically significant findings	Narrative report including contextual description, categories, themes, and supporting respondent quotes	Statistical findings with in-depth narrative description and identification of overall themes
Strengths	Uses standards for validity and reliability; relates variables to hypotheses; utilizes unbiased approaches; provides uniform information; can draw correlations between variables and examine changes in variables over time; generalizable and useful for making predictions, particularly when replicated; useful for studying large groups of people	Focuses on concepts, contexts, and settings; allows for exploration and explanation of personal values and experiences using participants’ categories of meaning; can allow for more collaboration with participants; useful for understanding complex phenomena; responsive to local situations and can include in-depth analyses of contexts and environments; flexible and adaptable	Allows for integration of different data at different stages of inquiry; provides context to quantitative findings to supplement findings by allowing individual cases to illustrate larger findings; can add insights and understanding that might be missed with only a single method

(continued)

Table 6.1 (continued)

Characteristic	Quantitative methods	Qualitative methods	Mixed methods
Weaknesses	Susceptible to respondent bias; focus on hypothesis testing may obscure observation of other phenomena (i.e., confirmation bias); researchers' categories may not reflect respondents' contexts; difficult for use with complex or conceptual issues; results may not translate well to specific situations, contexts, or individuals; requires adequate sample size for statistical power	Data collection and analyses can be expensive and/or time-consuming; analyses are subjective and can be more easily influenced by biases and idiosyncrasies; results are not generalizable; difficult to use to make predictions; lack of stringency may not meet acceptability or credibility criteria for some the scientists, community leaders, etc.	Can be difficult for a single researcher to carry out both qualitative and quantitative research, both in terms of workload and skill; can be expensive and/or time-consuming; methodological challenges, e.g., paradigm mixing, interpreting conflicting results

Note. Adapted from Johnson and Christensen (2004)

worked with schools and communities which differed appreciably in geography and ethnic/racial and cultural backgrounds. The multiphase, mixed-methods TAAG formative evaluation research protocol was developed to address these complexities while understanding how to maximize acceptability by schools, parents, and students to enhance potential for program sustainability. The first phase included (a) school surveys to determine physical education (PE) and health education requisites, teaching strategies, physical activity facilities, and after-school programs; (b) surveys of community agencies to identify resources, communication strategies, and the role of staff; (c) a parent survey to determine the parents' and girls' physical activities, access to resources, physical activity barriers, and preferred methods of learning about programs; (d) a girls' activity checklist to determine prevalent and favorite physical activities; (e) in-depth interviews with girls to determine their favorite activities, barriers to being active, social and environmental contexts, and attitudes about PE; and (f) focus groups with boys to understand their perceptions of girls being active. The second phase included focus groups with girls and interviews with PE instructors to refine the development of intervention materials, define meaningful segments for tailoring intervention messages, explore potential channels for delivering intervention messages, and understand the resources and constraints of target school PE departments. By including multiple respondents and data collection methods, the TAAG approach allowed a greater understanding of physical activity in adolescent girls from a variety of perspectives, including teachers, parents, community agencies, boys, and the girls themselves. Thus, the structured modes of data gathering during the formative evaluation phase produced important information that might otherwise not have emerged had representatives of the intended population not been consulted (Gittelsohn, Steckler, et al., 2006).

Similarly, development of a nutrition education program for use in Red Cross chapters throughout the United States went through a multistage process that began with analysis of the program content for technical accuracy and sequencing of materials before having potential instructors and course participants critically examine the program. Formative evaluation research activities then moved into formal pretests of the materials, teaching strategies, and survey instruments, first at 6 sites, then at 10, and finally with a national field test at 51 sites. The program was modified after each stage of the process based on the data obtained before a full-scale implementation was launched on the national level (Dehar, Casswell, & Duignan, 1993; Edwards, 1987). This illustrates two important points: First, there is not always a clear boundary between formative evaluation research methods and the summative methods that are used to assess effectiveness; second, researchers and practitioners can frequently get bogged down in concerns about following rigid rules and making distinctions. This suggests that understanding how underlying processes that are at play may influence the objects of interest in evaluation should be the focus, not allegiance to any one particular method or another.

Other formative evaluation research activities may guide the adaptation or modification of existing programs and resources for new audiences. For example, a behavioral intervention to prevent STDs among minority women was based in part on ethnographic data collected through focus groups; interviews; observations on life and lifestyles, values and beliefs, sexual behavior, knowledge, and risk taking; strategies to motivate behavioral change; and the logistics of implementing a potential intervention. These findings were then integrated into a pre-existing AIDS reduction model to create a new culture- and sex-specific small group intervention (Shain, Piper, et al., 1999).

When utilized most effectively, formative evaluation research is an *ongoing* process that is *integrated* into the development and implementation of a research project, providing assessment information within a feedback loop that identifies the strengths and weaknesses of the project and its intervention approaches as it evolves, informs modifications of measurement instruments, and shapes the evaluative research design and the intervention program (Evans, Raines, & Owen, 1989). Thus, well-designed formative evaluation research will inform monitoring of intervention program delivery as well as the outcomes and process evaluation activities that are used to assess whether efforts and resources are directed as needed and planned and are of sufficient quality and intensity to achieve desired goals for change.

How Was the Intervention Delivered?

Once a program or intervention has been developed and is being implemented, the focus of attention turns to *process evaluation*. This includes evaluating the extent to which the program is being delivered as it was designed (often referred to as *treatment* or *program fidelity*) and the degree to which the program is functioning as designed and achieving the expected goals and objectives. McGraw, McKinlay, et al. (1989) have described five functions common in process evaluation. These include identifying the: (a) extent to which a program reaches the target population; (b) program dose, i.e., frequency of delivery and/or participation in program activities; (c) organizational context or variability within which the program is being implemented; (d) extent to which programs are implemented in line with program goals; and (e) cost of program implementation. Thus process evaluation validates the assumptions made during the program planning stages to ensure that the needs of the intended population as they were identified in the needs assessment and formative evaluation phase are being met and that program activities are being implemented as designed. Seeking discrepancies between the program delivery plan and the reality of implementation allows researchers either to continue implementing the program with fidelity to its original design or modify it appropriately to adapt to the realities or unanticipated barriers encountered during implementation. This is critical because in many studies oriented toward developing and evaluating effective interventions, the planned intervention protocol may need to be adapted in response to the emerging data obtained from process evaluation. Process evaluation can also include a comparison of program plans to actual operation, identification of specific program components that appear to most influence outcomes, and an analysis of the internal dynamics of a program to understand its strengths and weaknesses and the changes in these that occur over time (Dehar, Casswell, & Duignan, 1993). The key to successful process evaluation is making ongoing, careful observations during implementation (especially in the early phase), according critical consideration to the evidentiary weight of these observations, and introducing systematic adjustments in the program or its implementation in response.

It is a mistake, however, to plan evaluation research that focuses solely on the long-term, summative evaluation of program outcomes, and ignore its process, performance, and immediate impact. Thus, two important functions of process evaluation are: (a) assisting in the interpretation of outcomes, and (b) informing future efforts in similar areas. If a program fails to show impact and lacks process evaluations, it will be impossible to know whether the lack of impact is a reflection of failure of theory and program design, failure to implement the program as originally specified, or failure of measurement to detect program impact or effectiveness (Weiss, 1972). If, however, a program is shown to be successful, detailed information about what it consisted of and how it was implemented will be critical for replication and dissemination. Perhaps most common is a combination of the two scenarios: If a program has mixed success achieving its goals, detailed information about program operations will be necessary to identify and adopt in future programs only those features that were successful (Dehar, Casswell, & Duignan, 1993). In short, while summative outcome measures may illuminate which programs perform well and which interventions were associated with a given outcome, it is equally important to know what "key ingredients" (or components) determine a program's success and how those who manage and participate in the program think and behave (Lindsay, 2002).

To illustrate, the "Gimme 5: A Fresh Nutrition Concept for Students" program was a 4-year intervention targeting increased fruit and vegetable consumption by high school students that utilized multiple components: (a) a school-based media campaign, (b) classroom workshops, (c) school meal modification, and (d) parental involvement. For each of these four intervention components, process evaluation strategies were developed to assess program dose, penetration, and utilization, as well as external competing factors. Data collection methods included questionnaires, classroom observations, measurements of student attendance, and assessment of school menus, food offerings, and food use. The process evaluation results not only demonstrated that the intervention was implemented as planned, but also showed how variability in program dose, penetration, and utilization of a multicomponent intervention can influence the outcomes (Nicklas & O'Neil, 2000).

Similarly, a comparison of two variations of a nurse-led psychoeducational intervention to assist oncology outpatients to manage their pain integrated process evaluations via a qualitative study embedded within a RCT of patient outcomes. Using audiotapes of the intervention sessions along with nurse and patient notes to describe the issues, strategies, and interactions experienced during the intervention, the researchers were able to evaluate not only the outcomes of the intervention, but the process of delivering it (Schumacher, Koresawa et al., 2005). In another example, a study of restrictive smoking policies used surveys of employees and supervisors administered before and after the date the policy became effective as primary outcomes measurements. However, qualitative data, including written comments on surveys, focus groups, and structured interviews, were used to elucidate the findings and identify themes and program characteristics which appeared to have the strongest influence on outcomes of the policy (Gottlieb, Lovato, et al., 1992).

Finally, process evaluation research bridges the gap between the intervention design and its impact and outcomes, providing a more comprehensive and well-rounded approach to program evaluation. To illustrate, the SPARK program, a controlled field study of a multicomponent elementary school program to promote physical activity, included a weekly classroom-based self-management program designed to teach behavior change skills such as goal setting and self-instruction to help children generalize physical activity outside of school. An evaluation of curriculum implementation and association between process and outcome was conducted using direct observation of lessons, subjective ratings by teachers and parents, and participation records of students. Investigators found that teachers viewed the self-management curriculum less positively than the physical education curriculum, and teachers were observed implementing the self-management curriculum at an average rate of 65%. Both of these findings may have contributed to the limited outcome effects of the self-management program. The process evaluation thus allowed program coordinators to identify barriers to full program implementation, which could then be used to inform future iterations of the intervention with the goal of improving curriculum implementation by teachers (Marcoux, Sallis, et al., 1999).

Was the Intervention Effective, and Why or Why Not?

The practice of program evaluation research incorporates the systematic collection of data about program characteristics, activities, impact, and outcomes to improve effectiveness, and reduces uncertainty in making decisions regarding what the program does and what it affects (Patton, 1987). If process evaluation has demonstrated how a program has been implemented, an assessment of the impact and outcomes becomes the next step in program evaluation research. *Summative evaluation* is concerned with effects of intervention programming that is both proximal (*impact*) and distal (*outcome*). Moreover, summative evaluation is complicated by the challenges of attributing the causes of behavioral change to intervention (especially in the absence of a control condition or comparison group) and the differing opinions stakeholders will have about what constitutes a successful outcome or how long that outcome must be sustained for the program to be considered a success (Posavac, 2011). In the following sections, we take up concepts of impact and outcome evaluations and provide examples of their application across several settings.

Impact

Much of summative evaluations research focuses strictly on reported changes in attitudes, behavior, or immediate clinical outcomes that are proximal to program implementation.[1] For example, in an STD and HIV intervention program that prioritized female sex workers in China, a women's health clinic was set up near various sites of participants' work (e.g., karaoke bars, massage parlors, and dance halls). Cross-sectional surveys at baseline and postintervention revealed that the rate of condom use with the most recent three clients increased from 55% at baseline to 68% 12 months later, and the prevalence of gonorrhea and chlamydia fell from 26% and 41%, respectively, to 4% and 26%. These results were used to develop national guidelines on sex worker interventions for nationwide replication (Rou, Wu, et al., 2007).

Investigators evaluating an AIDS prevention program for American sex workers found that a mixed-methods approach to evaluation was the most appropriate fit for the impact evaluation of their program. Field staff indigenous to the neighborhood and population was utilized to readily gain access to the community of sex workers; research methods included open-ended interviews with participants and ethnographic field notes, as well as epidemiological questionnaires. This approach allowed respondents to share, in their own words, their feelings about risks for AIDS, which provided primary findings about higher condom-use behaviors with clients versus lower use with husbands or boyfriends. The approach not only addressed research problems endemic to street-based populations but also ultimately provided a more comprehensive assessment of the program's impact than either method could have provided alone (Dorfman, Derish, & Cohen, 1992).

In another example, when Brazilian researchers sought to test the effectiveness of a program designed to improve child growth by training health workers in nutrition counseling, they randomized children to health facilities with trained workers and compared them to those attending facilities with standard care (Santos, Victora, et al., 2001). The research demonstrated that children receiving the intervention had statistically significant weight gain compared to the control group. However, the impact of behavioral programs often depends on factors outside the health system. In this case the researchers had to demonstrate at least six levels of impact, including that it was possible to train many workers in the intervention, that

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[1] When referring to the effects of intervention, the terms *impact* and *outcome* are used somewhat differently in the behavioral and social sciences than in clinical medicine. In public health, proximal effects are often referred to as impacts, whereas more distal effects are called outcomes. In clinical medicine, however, proximal effects are outcomes and the longer-term effects of treatments are thought of as the impact.

mothers were receptive to and understood the messages they received, and that not only the mothers changed their child-feeding behavior but that the children ate the more nutritious food (Victora, Habicht, & Bryce, 2004).

Other impacts of such evaluative research will include measurements of program information reach to the intended audience in an effort to assess relationships between awareness and behavior. For example, the PSI/PMSC Horizon Jeunes was a youth-targeted social marketing program for improving adolescent reproductive health in urban Cameroon through peer education, youth clubs, mass media promotion, and other behavior change communications. Using preintervention and postintervention surveys at an intervention and comparison site, the investigators found that after about 1 year of intervention, knowledge of the program was nearly universal, and the majority of youth had direct contact with the program. Exposure to the intervention had a significant effect on several proximal determinants of preventive behavior, including awareness of sexual risks, knowledge of birth control methods, and discussion of sexuality and contraceptives, as well as an increase in the proportion of young women who reported using oral contraceptives and condoms for birth control (Van Rossem & Meekers, 2000).

Outcomes

Compared to immediate impacts on variables of interest such as attitudes and behavior, the effort to evaluate the longer-term effects of intervention programs on more distal health outcomes, such as health status or quality of life, can be significantly more challenging, as illustrated in the following examples of outcomes evaluation from three different settings.

Community-Based Cardiovascular Risk Reduction Some of the best examples of evaluation of long-term health effects have emerged from the several historic studies of NIH-funded community-based cardiovascular disease (CVD) risk reduction experiments that have been conducted in North America and in Europe. In North America, studies conducted at Minnesota (Luepker, Murray, et al., 1994), Pawtucket (Carleton, Lasater, et al., 1995), and Stanford (Farquhar, Fortmann, et al., 1990) all utilized a common theoretical basis—social learning theory—in designing a multiple-component intervention approach that included mass media and social marketing, community organization, and direct education of health professionals. All the projects were evaluated using quasiexperimental designs, with intervention cities and comparison cities. In the Stanford Five-City Project, comprehensive community health education whose aims were to reduce community CVD risk factors was conducted in several cities in northern California from 1979 through 1992. The intervention addressed multiple cardiovascular risk factors and was delivered to all residents in two treatment communities from 1980 to 1986, using multiple educational methods. To evaluate outcomes, potentially fatal and nonfatal myocardial infarction and stroke events were identified from death certificates and hospital records abstracted from hospital charts, coroner records, physicians, and next of kin. Over the full 14 years of the study, the combined-event rate declined about 3% per year in all five cities. However, during the first 7-year period no significant trends were found in any of the cities; it was only in the final 7-year period that significant downward trends were found in all except one city. The change in trends between periods was in the hypothesized direction but not statistically significantly greater in the treatment cities than comparison cities. The researchers speculated that some other influence (e.g., secular trends) accounted for the observed change in all the study communities (Fortmann & Varady, 2000).

Similarly, the North Karelia Project, a study of CVD prevention in Finland, encouraged community action that enabled local community health coalitions and public health departments to do whatever they could imagine would make sense to bring about community and individual changes in health-related behavior (Puska, Nissinen, et al., 1985; Puska, Vartiainen, et al., 1998). The program was developed by Pekka Puska and his colleagues in the Department of Epidemiology of the National Public Health Institute with field offices at the level of county departments of health and local advisory boards in North Karelia. Community organization in North Karelia included collaboration with existing official agencies and voluntary health organizations so that the new project activities in CVD prevention could be integrated with ongoing, formal public health activities (Puska, Nissinen, et al., 1985). Like many North American CVD risk reduction projects, the North Karelia project set a strong example for the use of multiple channels and intervention approaches, from mass media to cooperation with agricultural and food merchandising groups, for example, to improve the availability of healthy foods such as low-fat milk and other products (Puska, Nissinen, et al., 1985). Mass media interventions included the production of health education materials and messages that were disseminated through local newspapers and community organizations and campaigns. Training activities included not only doctors and nurses but also social workers, representatives of voluntary health organizations, and informal opinion leaders. Training was organized through county-level or other local organizations. Attention to the health system included reorganizing treatment for hypertension and care following myocardial infarction (MI). This included training and development of treatment guidelines. Cooperation with other local organizations included not only the voluntary health agencies but also the critical food industry (e.g., including dairies and sausage factories) and grocery stores (Puska, Nissinen, et al., 1985). Two characteristics appear critical in the North Karelia community organization: (a) the variety of activities and channels included and (b) the attention in all areas to implementation through and in collaboration with local organizations. In comparison to other parts of Finland, the North Karelia campaign led to impressive reductions both in CVD risk factors (Vartiainen, Puska, et al., 1994) and mortality (Puska, Vartiainen et al., 1998), as well as reductions of cancer risk factors (Luostarinen, Hakulinen, & Pukkala, 1995).

Hospital-Based Change in Patient Perceptions and Behaviors Summative evaluation approaches that permit the researcher to observe the effects of an intervention between or among groups randomized to different experimental conditions (McBurney & White, 2010) are common in clinic-based randomized controlled trials. The design involves multiple baseline measures that are often repeated over time. In such designs, each individual in a group is followed and measurements are collected over the period of the study in order to illuminate between-group changes over time. One of the primary advantages of this design is the increased statistical power afforded by removing subject variance; in short, within-person changes in responses in one condition can be directly compared to within-person changes in responses in another condition (Greenwald, 1976; Stangor, 2007). For example, a study to evaluate effectiveness of a brief intervention designed to alter patients' perceptions about their first MI utilized a prospective randomized design in which patients received the intervention or usual care from rehabilitation nurses. Patients were assessed in the hospital before and after the intervention and at 3 months after discharge from hospital. The intervention resulted in significant positive changes in patients' views of their MI, in feeling better prepared to leave the hospital, in reporting significantly lower rates of angina symptoms, and in returning to work faster than the control group (Petrie, Cameron, et al., 2002).

School-Based Adolescent Health School-Based Adolescent Health Care (SBHC) programs were intended to increase adolescents' access to a range of basic health services, to reduce the prevalence of high-risk behaviors, and to serve as demonstration projects to establish whether centers of that type could be established and run effectively in low-income urban communities. Participating organizations included public health departments, teaching and community hospitals, community health centers, and nonprofit community health agencies that operated SBHC programs in 24 junior and senior high schools in 19 communities with populations of 100,000 or more (Lear, Gleicher, et al., 1991). However, limitations curtailed the extent to which outcomes could be measured using random assignment of students to an experimental or control group. Evaluation options were initially limited by the project timeline, in which the evaluation plan was only designed after the health centers began operation. In this way, the SBHC programs exemplified the tension that often exists between public health program delivery priorities and evaluation research agendas. As Knickman and Jellinek (1997) write, while a formal evaluation had always been planned, “the primary question for program planners was whether school-based clinics were viable on a broad scale: would diverse school districts take the risks necessary to get clinics up and running?” (p. 609). The clinics’ provision of sexual and reproductive health-care services had the potential to be controversial and, as such, the program staff focused mostly on designing an initiative that could be implemented in local communities. Only after the project was launched and the communities attempted to start their clinics were the program staff able to direct resources toward formal evaluation activities.

By that point a random assignment design was not possible since schools had already been selected (nonrandomly) without agreeing to the rigors of randomization. Random assignment of students within schools was also ruled out, both for the ethical concerns regarding withholding care and the practical concerns of spillover and potential contamination effects from intervention to the comparison group of students. Instead, the original evaluation design included a matched comparison sample of schools that had not opened health clinics in the same school districts as the SBHC sites. However, senior program leadership became concerned that student surveys about sexual behavior in the comparison schools could lead to parental backlash and undermine the support of the participating school districts to implement the clinics. This in turn could affect the outcomes of the primary evaluation question regarding the feasibility of the initiative. It was decided that surveys of student behavior would exclude comparison schools within the same district and would instead compare changes in high-risk behaviors among students in the schools with clinics to a national sample of urban youths (Knickman & Jellinek, 1997). To measure these outcomes, the research design entailed two longitudinal surveys: one with the health center school students and the other with a national sample of urban youth in the same grades. These parallel surveys conducted over multiple time points gave the researchers a group with which to compare trends in behavior and outcomes. The primary limitation of this method is that such studies are less likely to detect smaller program effects, given natural variation across sites. However, given the challenges of the research, this approach offered credible (if not entirely conclusive) evidence on other program effects (Kisker & Brown, 1997; Knickman & Jellinek, 1997).

Can the Intervention Outcomes Be Replicated?

A replication study is a deliberate repetition of research procedures in a second investigation for the purpose of determining if earlier results can be confirmed and further supported (Polit & Beck, 2008). Replication of findings is one of the most powerful tools available to validate claims in scientific research. By helping to confirm or dispute findings of an original study, replication studies can also promote the generalizability of the original study or allow unsupported findings to be dropped from practice. In other words, investigators can conduct a replication study to see if the findings from an original initiative are applicable, or generalizable, to their population of interest. Although replication can be incorporated into primary study designs, such as those utilizing multiple baseline measures or replicating an intervention among wait-listed controls after a first wave of outcome evaluations are complete, replication studies typically take one of the following three forms.

Identical Replication

The first is an identical replication study in which the original study is repeated exactly with the same sampling procedures, measurement tools, and analyses. For example, in a replication of the Go Sun Smart program, a behavioral intervention focusing on sun safety behaviors of ski resort employees and guests, the original research protocol was repeated at the sites that served as control groups in the original study. Using the same messages, measurements, and analyses, researchers were able to reproduce the results of the original study, in which greater exposure to intervention messages was associated with greater use of sunscreen, sunscreen lip balm, and face covering, but not gloves or overall sun protection (Andersen, Buller, et al., 2009).

Partial Replication

In the second type of replication study, an original study is duplicated as closely as possible, but not identically. Two major hand hygiene promotion interventions previously demonstrated to induce sustained improvement in clinical settings were replicated along with a passive intervention (soap substitutions and introduction of alcohol-based hand rub, with short-lived promotion of the changes) in selected wards of an 800-bed university teaching hospital. Each intervention used a before-and-after study design to assess results only within, not between, programs; the researchers chose this model because although all three interventions were conducted in parallel, there was no intention to compare them because potential confounders identified by previous modeling could not be controlled in statistical tests of significance. By replicating both successful interventions, the researchers were able to confirm that the programs can improve hand hygiene compliance and that the improvements can be maintained postintervention. However, because the interventions were not delivered identically to the original study (e.g., implementation varied based on departmental engagement and leadership), the investigators were able to use differences in outcomes as compared to the original study to identify institutional support, commitment, and guidance as active ingredients in the success of the program (Whitby, McLaws, et al., 2008).

Systematic Extension Replication

The third kind of replication study is a systematic extension replication, which tests the implications of a study in a new setting to establish broad ecologic validity. For example, the initial investigations into the links between procrastination and health in student samples implicated stress-related and behavioral pathways. Researchers who sought to replicate and extend previous findings among community-dwelling adults found that, consistent with previous work, procrastination was associated with higher stress, more acute health problems, and practicing fewer health-promoting behaviors (Sirois, 2007). Conversely, the positive results of an HIV/STI intervention originally targeting urban African-American males in nonschool settings were not successfully replicated in health classes at urban and suburban schools with diverse student bodies. The replication demonstrated increased knowledge, confidence, and behavioral intention among the intervention group but had no impact on sexual initiation, frequency of intercourse, or condom use, leading the investigators to conclude that the behavioral impact of an intervention may not be easily transferable when the program is taught to different groups and/or outside of the original setting (Borawski, Trapl, et al., 2009).

Challenges in Replication

Replication studies can pose challenges. First, one negative replication does not necessarily invalidate an original positive finding. Interpretation of the results of replication studies must take into account the myriad reasons that attempts to repeat the results might not be successful. Interpretations of failure must avoid the error of affirming the null hypothesis. Even if the failure of replication raises questions about generalizability, it cannot falsify the original finding. For example, if the original effect is small, negative results may arise by chance alone. Additionally, the participants or environment in a replication attempt might differ from those in the original study in a way that becomes significant, or a team might lack the skill or resources to reproduce the study correctly (Yong, 2012). Beyond these, numerous features such as those of settings, organizations, implementation fidelity, and populations addressed may moderate the generality of a finding from its original setting to others. Prudence and parsimony suggest always assuming failure of generalization before concluding lack of validity of original findings.

A second source of challenge of replication studies is that, despite the value they may play in understanding behavioral interventions, it can be difficult to fund and publish replications, primarily because they are viewed as adding few novel findings to the existing literature relative to the time and resources spent on the research (Carpenter, 2012; Jasny, Chin, et al., 2011). In spite of virtually all authoritative writing on the subject identifying replication as essential to scientific progress, support for replication is very rare. This is in fact one of the challenges faced in much dissemination research, which is the systematic study of replications, the subject, in part, of our next section.

How Can the Intervention Be Improved, Scaled, and Disseminated?

A variety of methods and tools have emerged that offer practical assistance to help individuals and organizations make improvements in program delivery and outcomes and set the stage for dissemination and scaling (Duke University Health System, 2018; Langley, Nolan, et al., 1996; Moen, Nolan, & Provost, 1999). One of the most practical approaches utilizes *rapid cycle improvement*, in which the emphasis is on implementing small tests of change. These changes are based on ideas which might come from the process and outcomes evaluations, from the literature, from practices seen in other programs, or from new opportunities that emerge as structures evolve (either specific to the program level, or more broadly, such as the development of new technology and media).

Rapid cycle improvement initiatives often utilize the *Plan-Do-Study-Act* (PDSA) cycle. This begins with the "Plan," which includes assembling a knowledgeable, motivated team to develop an *Aim Statement*. The Aim Statement articulates the specific, measurable goals to guide the improvement effort, as well as stated measurement objectives to determine whether the changes were effective. Aim Statements can often be effectively developed by thinking broadly about change concepts, i.e., generic ideas that can be applied to spark a specific change in the situation. Change concepts might include managing time (e.g., reducing startup, setup, or wait time), avoiding mistakes, improving workflow, or minimizing waste.

Thus in PDSA, the plan emerges from trialing, making numerous small changes, and revising, rather than from a protracted planning exercise designed to arrive at some "perfect" plan. The "Do" phase involves carrying out the plan. The change may be tested with only a small number of patients/staff/program participants, and the test period may be as short as 1 day for small PDSA cycles. The *Study* phase involves examining the results to determine if objectives were met. All PDSA activities should be documented in detail to allow for comparison between different plans. Finally, *Act* uses the results to make decisions, incorporate changes into the workflow, and establishes future quality improvement plans. If the improvements were successful on a small scale, they should be tested on a wider scale to ensure an acceptable level of improvement is achieved. At that point, plans should be made to standardize the improvements. If the change was not an improvement, the team should develop a new theory and test it; often, several cycles are needed to produce the desired improvement (HealthIT.gov).

For example, a Michigan public health department utilized PDSA in an effort to improve its older adult influenza vaccine programs. The Aim Statement was, "Increase older adult (65+) influenza immunizations to achieve an 80% influenza immunization rate by the end of the next flu season" with three improvement outcomes measurements: (a) percentage of eligible persons who receive a vaccine; (b) increase in the percent of ordered vaccine that is administered; and (c) increase in the number of sites offering influenza vaccines to older adults. To understand the current vaccination processes, the PDSA team developed a flow chart of the major steps for the health department and community partners involved in annual influenza vaccinations, including ordering vaccine, scheduling clinics, and distributing and retrospectively evaluating the success of efforts.

This revealed that almost all steps were carried out independently, without coordination among the various entities who delivered vaccinations. Further, some community-wide program elements, like public information, were performed by the health department with no input from other providers. Finally, no one was aware of any process to evaluate what strategies were effective across the community while the flu season was in progress, and there was no mechanism within which to provide data or feedback to providers about their patient and community-wide vaccination rates. The team brainstormed potential solutions to these shortcomings, considering potential costs, potential impact, and feasibility of success of each idea. The most promising solutions were tested at 20 randomly selected providers, data were collected and evaluated, the changes to practice were deemed to increase vaccination rates, and the program was standardized and implemented with the full roster of providers the following year (Tews, Heany, et al., 2012).

Engaging the Community in the Research Process

Having reviewed a broad range of research and program evaluation methods to answer the seven questions from needs assessment to dissemination, we turn to a cross-cutting theme—the engagement of communities in program development, research, and evaluation. Researchers and practitioners are increasingly realizing that improvements in population health and the problems of interest in behavioral medicine require changes in a broad range of social determinants of health. Achieving changes in these challenging areas needs to include working with communities through partnerships between researchers, practitioners, and members of the community. Community-based participatory research (CBPR) has emerged in recent decades as a collaborative research approach designed to bridge the gap between science and practice through community engagement and social action to increase health equity by ensuring and establishing structures for participation by communities affected by the issue being studied (Israel, Schulz, et al., 1998, 2001; Minkler, Blackwell, et al., 2003; Wallerstein & Duran, 2010). Some proponents of CBPR have come to use the term more under an umbrella of community organization approaches to intervention. Here we intend a broader use to describe the close relationship between researchers and communities that seek engaged understanding of the challenges those communities face and collaboration in developing responses to them—ranging from better individual clinical care and health education to broad public policy. (See also accompanying chapter by Ramanadhan & Viswanath.)

CBPR involves a reciprocal transfer of expertise, shared decision-making, power, and mutual ownership over the processes and products of the research (Freudenberg & Tsui, 2014; Viswanathan, Ammerman, et al., 2004). It expands the potential to develop, implement, and disseminate effective interventions across diverse communities through strategies to address power imbalances and facilitate mutual benefit among academic and community partners. Thus, at its best, CBPR can not only lay the foundation for efforts that improve population health, but also create broader community capacities for addressing issues that support improvements in other spheres of community development, including the environment, housing, transportation and economic activity, and in policy changes that create a just and humane society (Freudenberg, 1982; Freudenberg, Franzosa, et al., 2015; Freudenberg & Tsui, 2014). It also allows for practicing health professionals to engage in both an analysis and implementation of solutions unique to the specific setting, in collaboration with those who live and practice in that setting (Livingood, Allegrante, et al., 2011). Perhaps most importantly, CBPR encourages and promotes reciprocal transfers of knowledge (Wallerstein & Duran, 2010) by training community members in research (Minkler, Lee, et al., 2010) and including them in intervention development, e.g., the use of former drug users as "translators" in the design of a program to reduce sexual risk among African-American cocaine users (Stewart, Wright, et al., 2012), and delivery, such as through the use of local community volunteers to provide instruction on a physical activity program in Iran (Pazoki, Nabipour, et al., 2007).

The literature identifies several principles of practice to help community–research collaborations in developing, implementing, and evaluating their partnerships. These include the following: (a) identifying the best processes based on the nature of the issue and the intended outcome; (b) academic and community partners learning from each other; (c) capacity building (e.g., the commitment to training community members in research) (Minkler, Lee, et al., 2010); (d) acknowledging the difference between community input and active community involvement, and emphasizing the latter; (e) developing relationships based on mutual trust and respect; (f) acknowledging and honoring different partners' "agendas"; (g) collaborating not only in applying findings but also in determining the ways in which the findings are produced and thus interpreted (Green & Mercer, 2001); (h) using evaluation strategies that are consistent with the overall approach taken in the academic–practice–community partnership; and (i) engaging in long-term commitments to effectively reduce disparities (Baker, Homan, et al., 1999; Green & Mercer, 2001; Wallerstein & Duran, 2006).

Several examples of CBPR from around the world demonstrate how these principles have guided various community health improvement efforts. The first example is of the Mayisha project, which involved a participatory community-based survey among five migrant sub-Saharan African communities in London. The research plan was guided by a community-based collaborative group selected to encompass broad experience in sexual health and HIV research and in HIV prevention with African communities, including representatives from African HIV forums, Client Care Services, Directors of Public Health, and African Health Promotion teams. Community fieldworkers from the local African community were identified through key stakeholders and local advertising and were responsible for recruiting participants to the study. From a practical standpoint, the use of community-based fieldworkers allowed the investigators to ethnically match interviewers to participants. From a larger public health perspective, the use and acceptability of participatory methods allowed the African communities to demonstrate their commitment toward supporting studies of this nature and improving sexual health (Fenton, Chinouya, et al., 2002).

A second example is that of a project undertaken in Beirut, Lebanon. A 3-year CBPR project involving the testing of a psychosocial intervention to improve the reproductive and mental health of married women in a disadvantaged community of Beirut partnered university researchers with a community advisory committee and a local women's committee. Evaluation of this approach found that the women and the broader community felt ownership of the study and that the CBPR approach gave the women voices and allowed for an improved understanding of the community and surrounding reproductive and mental health issues (Kobeissi, Nakkash, et al., 2011).

A third illustrative of CBPR collaboration in the United States began with a participatory, door-to-door health survey of 1000 households in New Castle, a small municipality located in rural Indiana, that revealed a smoking rate of twice the national average. This finding helped galvanize the community into action to develop and implement a variety of health-promoting environmental and policy changes, ranging from restrictions on indoor smoking to initiatives to promote physical fitness and healthier lifestyles. In this way, the CBPR approach laid the groundwork for long-term sustainable changes in support of community-wide improvements in health (Minkler, Vasquez, et al., 2006).

Finally, a CBPR approach that has been used successfully to address substance use prevention through school community health promotion in Iceland provides a good example of a long-term effort (Sigfusdottir, Thorlindsson, et al., 2009; Sigfusdottir, Kristjansson, et al., 2011). School-based surveys in the early and late 90s showed that substance use among 13–15-year-old adolescents was on the rise in Iceland. This led to development of a CBPR approach where academic and practice-based researchers, policy makers, and field practitioners in adolescent health, municipal leisure services, and education came together and collectively organized a program that continues to the present day. This program, referred to as the *Icelandic Model*, emphasizes the school district as a unit of intervention, analysis, and reporting. Population surveys have been carried out annually, with input from all concerned stakeholders, including school personnel and community-based parent groups, and findings on mutually identified risk and protective factors have been analyzed and disseminated for each school district and municipal community taking part in the program. This approach has contributed to a paradigm shift in norms, values, and perceptions about adolescent health and development throughout Iceland. Moreover, during the 15 years that the approach has been ongoing, substance use among ninth and tenth grade students has dropped over 60% in Iceland (Kristjansson, James, et al., 2010; Sigfusdottir, Kristjansson, et al., 2008). In this case, CBPR has provided an empowering opportunity for communities to define and take ownership of a critical problem and find the practical and feasible solutions to address it.

In addition to benefits for the community, this CBPR effort over more than a decade has produced rich new findings illuminating key issues in the field, as well as advancing substance use prevention. These have included new methodologic innovations in conducting ongoing survey research (Kristjansson, Sigfusdottir, Sigfusson & Allegrante, 2014; Kristjansson, Sigfusson, et al., 2013) and investigating and addressing emerging community health challenges, such as the problem of physical inactivity (Eidsdottir, Kristjansson, et al., 2008) and overweight and obesity (Eidsdottir, Kristjansson, et al., 2010, 2013; Thorisdottir, Kristjansson, et al., 2012). The collaborative research has also increased understanding of the relationship of body mass index and depressive symptoms in adolescents (Eidsdottir, Kristjansson, et al., 2014).

For all of its potential to strengthen the collaboration between researchers, practitioners, and lay members of communities to solve health problems, CBPR also poses some challenges. First, logistically, behavioral medicine investigators who adopt the principles of CBPR in their work with communities can face obstacles in several areas: partnership capacity and readiness, time constraints, funding flexibility, translation, and expansion (Macaulay et al., 2011; Minkler, Blackwell, et al., 2003). Second, CBPR can also require researchers to confront and address a range of thorny ethical issues, including how to obtain participation and community consent, tensions created by differentials in power and privilege, racism and ethnic discrimination, and a range of issues around research for social change (Green, 2004; Wallerstein & Duran, 2006). Finally, respect for the community needs to be combined with an understanding that *all human beings* are often inaccurate in their explanations of their own behavior. For example, individuals entering smoking cessation classes often request dramatic portrayals of the harms of smoking (e.g., photographs of blackened lungs) as an aid in their efforts to quit. The role of such "scare tactics," however, is complicated. They may encourage progress in the early stages of contemplating quitting (Hammond, Fong, et al., 2004) or predict quit attempts (Yong, Borland, et al., 2014), but evidence for their impact on actual cessation is still lacking (Borland, Yong, et al., 2009). In one study of different types of support for adults seeking to lose weight, that which received the highest satisfaction ratings was not that in which participants achieved the greatest weight loss (Gabriele, Carpenter, et al., 2011). It seems that collaboration and mutual respect in program planning need to include recognition of these features of the psychology of self-perception, social influence, and attributional processes along with respect for the perceptions of those involved and evidence regarding effective approaches. Despite these potential pitfalls, familiarity with the concepts and principles and the spirit of CBPR, together with good process evaluation, can help investigators and program planners avoid them.

Translating Research into Practice

An emerging area of concern related to the issues of replication and dissemination is the translation of research findings into actionable practice and what has been sometime referred to as the "gap" between research and practice. For example, in the case of community-level efforts to prevent injury, Hanson, Finch, Allegrante, and Sleet (2012) have identified three principal gaps that separate academic researchers, policy makers, health practitioners, and the communities in which change is being proposed. These include: (a) the research-to-practice gap, (b) the efficacy-to-effectiveness gap, and (c) the injury-prevention-to-safety-promotion gap (Hanson, Finch, et al., 2012). In reviewing over 1200 articles published in 12 leading public health and health promotion journals, Oldenburg, Sallis, Ffrench, and Owen (1999) found that 63% of publications were descriptive, 11% were concerned with method development, and 16% were intervention based; only 5% were concerned with institutionalization or policy implementation research, and less than 1% contained diffusion research. This is important for behavioral medicine because it is not at all uncommon for interventions that have been tested under conditions of high internal validity to be altered when they are implemented into practice settings (Cohen, Crabtree, et al., 2008). The literature has sought to address the challenges of translating research into practice (e.g., see Cohen, Crabtree, et al., 2008; Katz, Murimi, et al., 2011) and several approaches to improving the translation of research into practice have been proposed (e.g., see Glasgow & Emmons, 2007). In the following, we review several of these models.

RE-AIM

One of the most widely respected approaches to improving research translation in behavioral medicine research is the *RE-AIM framework*. The RE-AIM framework is one of the primary tools designed to enhance the quality, speed, and public health impact of efforts to translate research into practice. The goal of RE-AIM is to draw attention to essential program elements, including external validity, which can improve the sustainable adoption and implementation of effective, generalizable, evidence-based interventions (Glasgow, Vogt, & Boles, 1999). The five RE-AIM steps for evaluating the potential health impact of interventions are:

1. ***R***each: The absolute number, proportion, and representativeness of individuals who are willing to participate in a given initiative, intervention, or program.
2. ***E***fficacy or ***E***ffectiveness: The impact of an intervention on important outcomes, including potential negative effects, quality of life, and economic outcomes.
3. ***A***doption: The absolute number, proportion, and representativeness of settings and staff or other people who deliver the intervention (i.e., intervention agents) who are willing to initiate a program.
4. ***I***mplementation: At the setting level, implementation refers to the intervention's fidelity to the various elements of its protocol, including consistency of delivery as intended and the time and cost of the intervention. At the individual level, implementation refers to clients' use of the intervention strategies, consistency, costs, and adaptations made during delivery:
5. ***M***aintenance: At the setting level, maintenance refers to the extent to which a program or policy becomes institutionalized or part of the routine organizational practices and policies. Maintenance also applies to intervention effects at the individual level over time, defined as effects of a program on outcomes after 6 or more months after the most recent intervention contact.

RE-AIM's utility and effectiveness derive in large part from its focus on both individual levels (reach and efficacy) and organizational levels (adoption and implementation) of impact (e.g., maintenance can be both an individual- and an organizational-level impact). It is critical to evaluate both levels because each provides valuable independent information about intervention impact. For example, a clinic-based intervention that has large impact on reach and efficacy but is only adopted, implemented, and maintained at a small number of medical practices with specific resources that are not available in typical "real-world" settings would not have sustainable translation into wider practice. If only the individual dimensions of the intervention were used for evaluation, the intervention would appear to have large potential for impact when in reality it has little hope of resulting in a large public health impact because it could not be adopted, implemented, and maintained in real-world settings. Conversely, if an intervention has potential for wide organizational adoption, implementation, and maintenance, but little reach, efficacy, or maintenance at the individual level, the potential impact of the intervention would not likely be achieved because of the deficiencies at the individual levels.

The RE-AIM website (www.re-aim.org) maintains a substantial searchable library of publications utilizing the framework. Examples include the planned evaluation of the BETTER 2 program, which is designed to expand implementation of a chronic disease prevention and screening intervention in primary care settings. Researchers will evaluate the program using RE-AIM to inform a mixed-methods approach, including a descriptive statistics on patients accepting the intervention, qualitative information on implementation and adaptations of the program, longitudinal measures of provider use of the intervention within their practice, and a composite index to assess quantitatively the effectiveness of the intervention (Manca, Aubrey-Bassler, et al., 2014). Likewise, an evaluation of different versions of an Internet-based diabetes self-management support program provides a clear application and interpretation of the RE-AIM model (Glasgow, Kurz, et al., 2010). A three-arm practical randomized trial was used to compare a minimal contact and moderate contact versions of the online program, compared to an enhanced usual care protocol. Primary behavioral outcomes (e.g., healthy eating, physical activity) and secondary biological outcomes (e.g., hemoglobin A1c, BMI) were compared at baseline and a 4-month follow-up. Interpreting the results through the RE-AIM structure, the intervention met several of the criteria for potential public health impact, including that it was feasible and engaging for participants and was able to reach a large number of people. However, there was mixed effectiveness in improving outcomes, and the authors concluded that further research is necessary to evaluate long-term outcomes, to enhance the effectiveness and cost-effectiveness of the intervention, and to better understand the connections between the intervention's processes and its outcomes. In this way, while RE-AIM is most commonly used to report results or compare interventions, it is also useful as a planning tool as well as a method to review intervention studies.

Utilization-Focused Evaluation

Another approach to facilitating translation of research into practice is what has been referred to as *utilization-focused evaluation*. Evaluation researchers must bear in mind that intended users of research, such as community leaders, program managers, policy makers, and public health-related practitioners, are more likely to use findings from evaluations if they understand the research process, are consulted and engaged, and sense ownership of the findings. This approach is the basis for utilization-focused evaluation, a process for making evaluation decisions in collaboration with an identified group of users, with a focus on their intended uses of the evaluation. By actively involving users in this way, the evaluation researcher can prepare the ground work for the use of evaluation findings and train users in the use of findings, which reinforces the intended utility of the evaluation throughout the process (Alkin, 2004). The approach thus places priority on how the evaluation findings will be applied by people in the real world (Patton, 2008).

Utilization-focused evaluation does not advocate any particular evaluation content, model, method, theory, or use. Instead, it is a process for identifying key stakeholders (Bryson, Patton, & Bowman, 2011; Guba & Lincoln, 1989) and helping these primary intended users to select the most appropriate content, model, methods, theory, and uses for their particular situation. This process has been employed to evaluate a wide range of topic areas, including human services agencies (Greene, 1987), a national AIDS prevention program in Switzerland (Dubois-Arber, Jeannin, & Spencer, 1999), and a Canadian compassionate care benefit (Williams, 2010). Along with several guides and toolkits on the topic (Bryson, Patton, & Bowman, 2011; Fetterman, 2000; Patton, 2008, 2012), investigators interested in the logic of the utilization-focused evaluation approach might find it useful to compare the pretest-posttest control group design used to evaluate a problem-solving skills training for adolescents (Tellado, 1984) to the alternative, utilization-focused research plan proposed for the same program (Patton, 1984).

PRISM

A third promising approach that supports translation of research into practice is the Prevention Impacts Simulation Model (PRISM). Originally designed and developed at the US Centers for Disease Control and Prevention and National Institutes of Health to estimate the impacts of public health interventions on the health of populations, PRISM is a systems dynamic simulation tool that includes 22 categories of policy, systems, and environmental change across several broad areas of interventions (Homer, Milstein, et al., 2008, 2010; Honeycutt, Wile, et al., 2014). These categories address medical care, smoking, nutrition and weight loss, physical activity, emotional distress, and air pollution. PRISM can assist users with decision-making about chronic disease intervention by modeling the likely impact of various prevention strategies for cardiovascular diseases, as well as for cancer and respiratory diseases related to risk behaviors such as smoking, diet, and physical inactivity. Moreover, PRISM is capable of modeling both individual interventions and combined interventions and can be used not only to estimate the short- and long-term population effects of intervention and the future costs averted by prevention but also to forecast future outcomes. By integrating the best available evidence on modifiable risk factors and demonstrated interventions, PRISM thus can provide a robust simulation of the impact of proposed or implemented prevention efforts on both indicators and cost of chronic disease.

Emerging Issues and Challenges

The movement toward evidence-based behavioral medicine practice mirrors one that has evolved in clinical medicine over the past several decades. Encouraged by health-care reform initiatives around the world, this movement has been fueled by a rapidly growing foundation of evidence from outcomes research in clinical medicine, behavioral medicine, and public health. Perhaps the most visible demonstration of the evidence-based medicine movement is embodied in the Cochrane Collaboration (2015), which was formed to organize the burgeoning volume of medical research into a searchable and useable evidence base that could benefit decision-making by health professionals, patients, and policy makers. However, with this growth has come a spirited discussion among practicing interventionists, behavioral scientists, clinicians, evaluators, policy makers, and patients about what kinds of evidence actually constitute “the best available scientific data” to inform decision-making in clinical practice. What evidence is most likely to advance behavioral medicine, clinical care, and public health? What are the ideal channels and practices for the dissemination of new knowledge, and for translating research to best practices in real-world settings? And what ethical obligations does the scientific community have to ensure the widest possible dissemination of the benefits of research? While these questions are neither exhaustive nor limited to the research methods and approaches addressed in this chapter, they are nevertheless illustrative of the kinds of challenges behavioral medicine faces going forward. Thus, this final section of the chapter takes up several of what we believe to be some of the most pressing issues these and other questions raise for the field.

What Constitutes Evidence?

Even if in behavioral medicine we limit our investigations solely to pursuing improvements in health, the objectives of behavioral research range widely from proving that some specific therapeutic event or intervention results in some specific outcome, to showing that a set of community-based activities will reward government support of those activities as a means of preventing disease or promoting health. Thus, the idea that any one approach to research would constitute "the gold standard" by which to answer questions across such a wide and variegated range of potential research objectives is preposterous. One need only ask what Copernicus, Darwin, Galileo, and Watson and Crick—all great scientists—have in common? *None of these great scientists had control groups*!

With growing recognition of the impact of health policies not only on health status, mortality, and quality of life but also on national economic prosperity and security, there is growing interest in using research to inform decisions with broad policy implications on sound evidence. However, concern over the soundness of evaluations and the stakes involved has encouraged some conservatism in ascribing value to the broadest range of available data. For example, a number of reimbursement policies in the United States now use evidence reviews of the U.S. Preventive Services Task Force (www.uspreventiveservicestaskforce.org) as the basis for identifying reimbursable services; however, the task force tends to confer considerable weight on evidence generated from RCTs and discounts the evidence from other equally valuable (but not equally valued) research designs. To illustrate the dilemma, consider a report in *The New York Times* (Kolata, 2013) on recent American Heart Association cholesterol guidelines. The story pointed to how "the drafting committee mistakenly relied only on randomized controlled clinical trials, the gold standard of medical evidence, but ignored other strong data [including a wealth of existing genetic and population data] that would have led to different conclusions." This example demonstrates the risk of limiting the evaluation of interventions best evaluated through methods other than RCTs, and highlights the need to identify practical ways of identifying promising approaches to prevention and improved care in whole populations.

Thus, it is not surprising that a primary criticism of the RCT focuses on the need for realistic, pragmatic alternatives to the dominant paradigm of studies requiring "hard" data and statistical proof utilizing highly homogenous patients in academic clinical settings. Such studies may be high in internal validity but they lack the external validity to support effective translation of research findings into policy and real-world practice (Glasgow, 2008, 2013; Steckler & McLeroy, 2008). Differences in culture, social structure, norms, and functions of communities and their populations, moreover, naturally preclude the highly widespread generalizability of results between populations affected by different social determinants (Livingood, Allegrante, et al., 2011). In addition, application of interventions previously demonstrated to be effective using strict research protocols (where internal validity is highly valued) often fail to produce the desired effect in real-world settings (where external validity is highly valued). In some cases, the intervention is initially delivered by trained professional study staff that is highly supportive of patients and motivated toward the success of the study. However, unless the intervention is one that can be easily replicated or continued in the hands of other staff members, interventions often fail to be maintained once study staff leave (Glasgow, Bull, et al., 2002). Moreover, even when programs are successfully continued by site staff beyond the study period, and the intervention is applied in a rigorous manner with high fidelity to the original study design, practitioners may find that the previously successful program is ineffective and fails to produce significant treatment effects (Hallfors, Cho, et al., 2006).

This problem is now sparking development and rapidly growing respect for innovative research and evaluation designs that allow interventions to gain credence on the weight of converging evidence and without the inherent limitations of the RCT. A good example of this movement toward more innovative thinking in evaluative research is the recent Institute of Medicine (IOM, 2012) study of how best to assess the value of community-based approaches to health promotion that go beyond the RCT

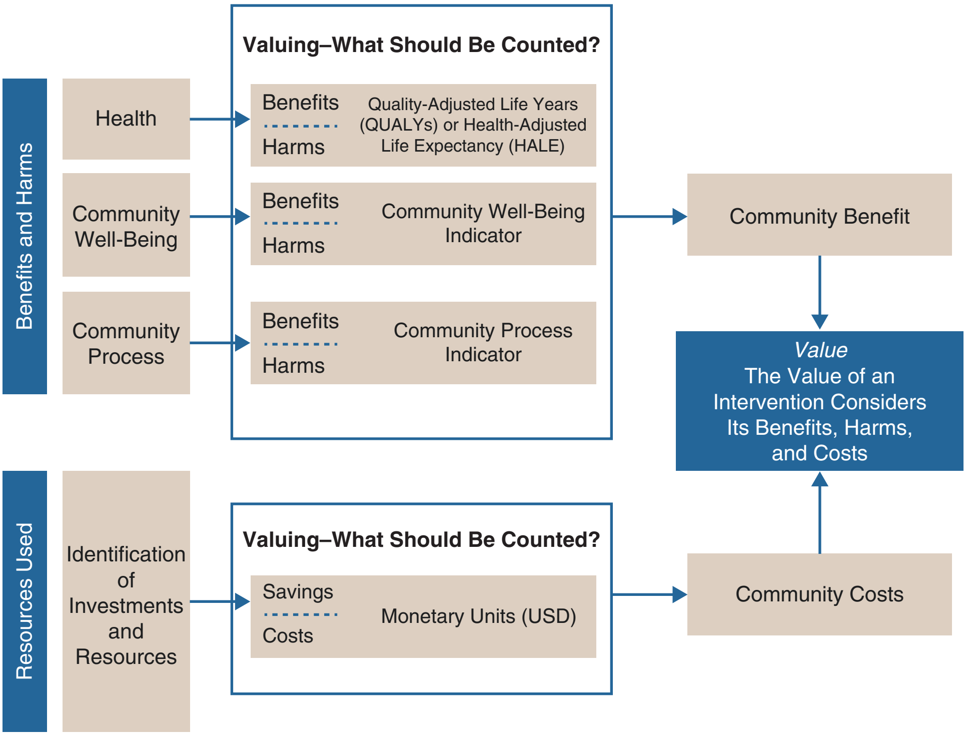

Fig. 6.1 Conceptual framework for assessing the value of community-based prevention interventions (Reprinted with permission from the National Academy of Sciences, Courtesy of the National Academies Press, Washington, DC. A full copy of the report, *An Integrated Framework for Assessing the Value of Community-Based Prevention*, is available at: http://www.nap.edu/catalog.php?record_id=13487)

model of evaluation. The IOM report provides a new conceptual framework (see Fig. 6.1) for assessing the value (which includes the benefits, harms, and costs) of community-based prevention. The report points to the clear need to use constructs beyond individual health in assessing the value of health promotion and public health, including community well-being and community processes, and how public health and health promotion can more effectively assess and incorporate the dimensions of social determinants into programs and interventions. This will require the development of new performance measures, new metrics that will be capable of operationalizing the concepts of community well-being and community process, and ultimately new concepts of community benefit, as well as systematic ways of using the new framework as recommended in the IOM report (Allegrante & Livingood, 2013).

What Are the Objects of Intervention That Explain Variance in the Observed Effect?

A second question of interest has to do with what the objects of intervention (also sometimes referred to as the "active ingredients") that are responsible for and explain the variance in the observed effect. To illustrate, evaluating the effect of a pill that contains a powerful medicine is very different from evaluating a national campaign to reduce obesity and type 2 diabetes. Especially important is that in assessing the effects of the pill, we seek to isolate the effect of the pill from the "confounding" ecologic effects of the context. This is why we conduct RCTs, which allow the investigator to isolate the active ingredient of intervention under highly controlled conditions. For a national campaign to reduce obesity and type 2 diabetes, however, we seek to understand, incorporate, and exploit the effects of context, which interact with intervention components (often synergistically) and will change over time and space, as an integral part of the intervention. Thus, a primary issue for behavioral medicine research concerns the identification of key components of interventions to which outcomes can be attributed and, then, how to disseminate such interventions.

The experience and results of the Diabetes Prevention Program (DPP) illustrate the challenge. The DPP showed that moderate physical activity (150 min per week) and loss of 7% of body weight among those with impaired glucose tolerance significantly reduced conversion to type 2 diabetes in this high-risk group, both in comparison to placebo and to Metformin, a standard medication used to treat diabetes. This "lifestyle" intervention utilized a standard set of materials and a combination of group and individual contacts to promote physical activity and weight loss. However, in the interest of testing the benefits of physical activity and weight loss, *not* any particular way of achieving them, study sites were encouraged to be highly flexible and creative in developing ways that would enable participants to achieve 150 min of moderate activity per week and 7% weight loss. The exciting findings of the DPP, in many respects the greatest impacts identified to date for a fundamentally behavioral approach to a major health problem, raise the question of what precisely should be disseminated. The benefits of 150 min of moderate activity a week and 7% weight loss should lead to diverse efforts to achieve these; however, some voices have called for focus on the particular intervention used in the DPP, "a proven, community-based weight loss program," i.e., "a…program," not multiple approaches to pursuing weight loss and physical activity as the path to saving Medicare $7 billion (Thorpe & Yang, 2011). There is a difference in strategy here: (a) disseminating a "program" that is as well and specifically defined as possible or (b) promoting varied approaches to achieving behavioral impacts, weight loss, and increased physical activity. It is likely that both strategies will have their successes. The difference between them illustrates the challenges interventionists face in recognizing the need for both standardization and flexibility or adaptability in the implementation of programmatic elements of intervention.

What Are the Factors We Need to Study Not Only to Guide Dissemination but Also Adaptation and Implementation? And How Do We Incorporate Them into Research?

Ideally, no investigation should be limited to the researchers completing their project, publishing their manuscript, and moving on to the next project, leaving lessons learned buried in the archives of journals, or worse, not published at all. Finding ways to disseminate effective, affordable, and feasibly scalable interventions that have been demonstrated in research is a major challenge for behavioral medicine as it is for all population health professions. Dissemination should be guided in part toward objectives of sustainability and replicability by communicating to the scientific community not only the results and end point of the project but the explanatory details that drove the findings. This requires proactive consideration of dissemination goals before the program begins as well as meticulous documentation of all steps in the project before it concludes.

In what have come to be called *practical trials*, external validity and replicability are increased through four key features: (a) use of representative patients to represent the range of patients encountered in real-world settings; (b) implementation in multiple settings rather than in those that are expertise- and resource-rich; (c) comparison of conditions that represent current standards of care or alternative treatments (rather than placebo or no treatment) to demonstrate that changes in practice result in significantly better results than current, familiar interventions; and (d) the inclusion of multiple outcomes, such as implementation requirements, costs, and feasibility (Glasgow, 2008). Such trials can provide a much more complete picture of evidence-based practice and strengthen program delivery, but will only do so if the individual study methods and the intervention are reported with sufficient detail and clarity to be fully understood and fully replicated.

In recent years, there has been recognition that translation of evidence into practice will be improved when research design and reporting standards are modified to help quality improvement teams understand both these adaptations and the effort required to implement interventions in practice (Cohen, Crabtree, et al., 2008). Toward this end, and as research knowledge has been accumulated, increased emphasis has been placed on the standardization and comparability of study findings that pertain to practice. A recent example of this is the Transparent Reporting of Evaluations with Nonrandomized Designs (TREND) Statement that provides a proposed 22-item checklist for standardized reporting of behavioral and public health intervention evaluations (Des Jarlais, Lyles, et al., 2004). The goal of this initiative is to increase the utility of nonrandomized study designs by providing a framework within which comparable information across studies can be more easily synthesized and translated into generalizable knowledge (Des Jarlais, Lyles, et al., 2004). It is intended to be a complement to the 25-item CONSORT Statement for randomized trials (Altman, Schulz, et al., 2001; Begg, Cho, et al., 1996) and the CONSORT-SPI (Montgomery, Grant, et al., 2013) that is designed specifically to enhance reporting clarity for social and psychological interventions. While TREND was originally launched to improve public health practice, behavioral medicine also stands to benefit from such transparency in reporting design and methods of quasi-experimental behavioral research. In addition to CONSORT and TREND, similar standards have now been developed for reporting qualitative studies (O'Brien, Harris, et al., 2014) and systematic reviews (IOM, 2011) and meta-analyses (Moher, Liberati, et al., 2009, for the PRISMA Group), along with other ongoing and emerging efforts that have been developed in the last decade to increase the quality and transparency of reporting in health research (Altman, Simera, et al., 2008) and reduce bias in randomized controlled trials (Higgins, Altman, et al., 2011).

Despite such guidelines and "rules," no method of improving rules for gathering and transparency in reporting evidence can eliminate the role of scholarly, professional, or clinical judgment in assessing and applying it. Put simply, there are two broad tasks in this: gathering and assembling evidence and applying it. Perfecting the former does not eliminate the latter. That is, perfecting the evidence does not eliminate the role of human appraisal in judging how and to what it is best applied. Even when we can ensure that policy and practice will be guided by sound evidence, the role of human judgment in applying it remains fundamental.

How Do We Incorporate a System-Wide or Population-Based Approach to Research?

Since the WHO Report on the Social Determinants of Health (Commission on the Social Determinants of Health, 2008) demonstrated the powerful impact of economic, environmental, and social- structural factors on health status, more research effort has focused on these broader determinants. However, much published research has continued to focus on individual determinants of change, largely ignoring the other contexts that shape behaviors (Glass & McAtee, 2006; Golden & Earp, 2012). Broader trials are needed that include impact and outcomes important to decision makers and communities, that address multiple contexts outside the individual level, including the environment in which programs are conducted, and that focus on moderating and mediating factors, economic issues, and social contexts (Glasgow, 2008; IOM, 2012).

Several have called for behavioral medicine and public health to embrace behavioral interventions that are system-wide, population-based, or focused on changes in public policy, which by their very nature require consideration of a broader range of acceptable "evidence" and "outcomes" as well as increased inclusion of the varied contributors to public health (Allegrante & Livingood, 2013; Epping-Jordan, 2004; IOM, 2012; Lieberman, Golden, & Earp, 2013; Livingood, Allegrante, et al., 2011). Limiting the field to individually based, "best practice" interventions for which there is "scientific evidence" from randomized trials not only fails to recognize the key social, policy, media, and other ingredients that actually produce significant results but can also point practitioners in the misguided direction of higher-cost, clinically based interventions (Livingood, Allegrante, et al., 2011). For example, Livingood, Allegrante, et al. (2011) note that, historically, major public health achievements tend to involve a complex and dynamic interaction between society and community rather than following "a linear movement from scientific testing to broad application" of individually focused interventions that have been characteristic of the classic biomedical model. The biomedical model, most notably developed by the US National Institutes of Health, comprises a model of scientific discovery on a continuum that goes from basic and clinical research, to applied research and development, to treatment at the bedside (Levy, 1982). In contrast, key public health achievements of the twentieth and twenty-first centuries, such as the normative changes in tobacco use in many countries, have required attention to a range of individual, social, and institutional factors that influence population health and have been the focus of health promotion (Livingood, Allegrante, & Green, 2016).

Reflecting this "range of individual, social, and institutional factors," recent developments in statistical analysis techniques collectively referred to as *multilevel methods* now allow researchers to design studies that can disentangle individual-level influences from community-level factors such as class, school, work site, residential location, town, city, or county, but still examine all levels at the same time and thus come closer to "clean" effects that may be attributed to different levels (Raudenbush & Bryk, 2002; Snijders & Bosker, 2012). The essential idea with multilevel studies is that findings pertaining to individuals that are close in proximity for any number of reasons (e.g., live in the same neighborhood, attend the same school, and employed at the same workplace) are likely to be caused, at least in part, by similar lifestyles and/or living conditions. Multilevel inquiries thus uphold that research findings are not simply attributable to individuals but also to the social environment and common living circumstances, which in turn may increase the strength of the investigator's interpretation.

The Weight of Evidence and Affirming the Null Hypothesis

Research scientists are by nature skeptical and critical. As a consequence, they are frequently dismissive of propositions with the response that "*there's no evidence for that*". Technically, the refrain, "*there's no evidence for that,*" allows the conclusion of just that, "there's no evidence." However, it frequently leads to an assertion that a particular line of inquiry or endeavor has been shown not to work—this amounts to "affirming the null hypothesis," something most graduate students were taught was not possible. This can grossly constrain development of behavioral medicine and public health interventions of all kinds. The fear of "there's no evidence for that," should not constrain our creativity in developing new and untested approaches (Fisher, 2008).

There are additional problems in weighing the presence and absence of evidence. The law of parsimony, Occam's razor, dictates that science assume the simplest relationship among events until evidence forces more complexity (Fisher, 2008). In light of this, consider, for example, findings of the Guide to Community Preventive Services that sufficient evidence exists for diabetes self-management education in "community gathering places" such as "community centers, libraries, private facilities (e.g., cardiovascular risk reduction centers), and faith institutions" (p. 201) but not if offered through worksites. (Only one study was found reporting self-management education in worksites and it "had design limitations," p. 207). The variability in available evidence from different sites does not constitute evidence that there are significant or substantial differences among them. Parsimony would lead to a conclusion that there is evidence for diabetes self-management education settings in a variety of settings without any strong evidence to differentiate among them in terms of likelihood of success.

Recalling the inebriated individual looking for keys under the streetlight, not because that is where they were lost, but because "the light is better here," we need to be critical of the assumptions we make in assembling evidence (Fisher, 2008). Why disaggregate diabetes self-management education according to community centers, libraries, private facilities, cardiovascular risk reduction centers, faith institutions, and worksites? To what extent do the distinctions among them have a plausible causal role justifying their differentiation? Why not large versus small settings? Daytime versus evening? Clinic- versus community-based? In contrast, perhaps more useful answers would flow from disaggregating by such factors as organizational support for the program, proximity or accessibility to intended audiences, and presence of community resources supporting the program (e.g., safe, enjoyable sites for physical activity). The point here is not just about community sites for diabetes education, but that how we assign evidence to groups or categories and, more broadly, how we manage and categorize evidence will influence the conclusions we draw from it. Parsimony dictates we do not differentiate without evidence. Greater criticality about these processes needs to come before "there's no evidence for that."

Another way to view the dilemmas is to imagine you were in charge of a state department or ministry of health and you were looking for evidence to guide public investment in population-wide prevention of diabetes. In weighing the available evidence to inform your decision, would you prefer to base your decision on 20 RCTs, all of which demonstrated exquisite internal validity showing that a particular approach was effective relative to randomized controls among volunteer samples treated through university research centers? Or would you prefer to base your decision on the findings from practice-based evidence of ten programs testing varied adaptations of an approach and associated community health promotion activities, carried out with urban, rural, and multiethnic community groups, and showing benefits in pre-post analyses and against national norms; associated lessons learned identifying local buy-in from a government or health leader, inclusion of primary care endorsement, and duration of community activities as critical success factors? The point is that evidence can come in many forms and limiting our confidence to evidence generated solely from highly controlled conditions narrows the range of evidence from which we can draw in making decisions about what programs work and under what conditions. Ultimately, the example also points to Green's (2008) notion of the "fallacy of the pipeline" that he argues is implicit in the traditional, unidirectional continuum of translation and dissemination of research into the hands of practitioners who are then expected to implement approaches that have been tested under condition of high internal validity. To counter this fallacy, Green has captured the challenge in what is a now-popular refrain: "If we want more evidence-based practice, we need more practice-based evidence" (Green, 2006, 2008).

Using PRECEDE-PROCEED, RE-AIM, PRISM, and similar models, if we identify needs related to a problem, identify reasonable evidence-based (where pertinent evidence is available) approaches to addressing those needs, implement the program and show it was implemented according to objectives, assess short-term impacts (e.g., reported changes in diet and physical activity), and show objectively measured reductions in the problem relative to appropriate benchmarks, does this not constitute knowledge with utility? This question is of distinct importance for the field of behavioral medicine in light of the urgency with which health disparities must be addressed. For example, in the United States most new HIV infections among youth occur among gay and bisexual males, with a 22% increase in estimated new infections in this group from 2008 to 2010 (Centers for Disease Control and Prevention, 2014). The timeline for an NIH grant to complete a large-scale randomized trial of a behavioral intervention can include 1–2 years devoted to securing funding and 3–5 years (or longer) devoted to conducting the research, completing data analysis and disseminating results, with the potential for the public health impact of the epidemic to increase significantly during that 7–10-year period. Further, this timeframe is particularly inappropriate given the increasing role of new technology as tools for health promotion, for instance the HOPE (Harnessing Online Peer Education) social media intervention which increased HIV testing rates among young men via Facebook outreach and peer education (Young, Cumberland, et al., 2015). Accelerating the discovery, dissemination, and implementation of knowledge is thus a critical imperative.

What Are the Moral and Ethical Obligations of Dissemination?

Finally, no treatment of the topic of the application of research methods from education, applied psychology, and behavioral science to behavioral medicine would be complete without some consideration of the moral and ethical obligations of the researcher. What are our moral and ethical obligations as reflective scientists—whose work is often supported by public funds—to ensure that our scientific work and findings are disseminated? As noted previously, intended users are more likely to accept the utility of research and evaluation results, and more likely to support the dissemination of results, if they understand and feel ownership of the process of the research. This raises two significant issues.

First, beyond publication in peer-reviewed scientific journals, researchers increasingly need to dedicate adequate resources to community-based debriefings, discussion of research findings, and consideration of the implications for practical use. Researchers thus must be prepared to play the role of public intellectual to use their research in affecting change. All partners should be involved in the dissemination of information about the partnership and project findings in forms that all partners can understand and use; this includes reaching multiple audiences (e.g., community members, policy makers, local health professionals, and the lay public) through a variety of communication channels and formats (e.g., radio, newspapers, social media, presentations, handbooks, position papers, testimony, and scientific journal articles), with all partners involved as co-authors and co-presenters to the extent that substantive contribution to the research may require. Thus, it is important to strike a balance between time devoted to the preparation of manuscripts for publication in peer-reviewed scientific journals and developing processes that enable researchers to report results to the broader community and public stakeholders for discussion of the utilities and implications of the research (Seifer, 2006).

Second, many researchers are now considering the ethical implications of publishing in peer-reviewed scientific journals where the published article will be housed behind a "paywall"—accessible only to readers whose academic institutions maintain costly annual subscriptions, or to those who are willing and able to pay a fee for access to a published piece of scientific research. Some critics charge that research funded by public tax funds should be freely available to the public whose moneys have supported the research, while others make the case that open access is a moral issue and that the principle of beneficence obligates scholars to act for the benefit of others. The open-access policies of the US National Institutes of Health (National Institutes of Health, 2014), the Canadian Institutes of Health Research (Canadian Institutes of Health Research, 2014), and the Research Councils, Innovate UK, and Research England of UK Research and Innovation (UK Research and Innovation, 2018) represent notable mandates adopted in the past decade which endorse this philosophy. Nevertheless, the issue of the extent to which the privatization of scientific content undermines the advancement of sciences remains a challenge, with important questions remaining about the system of scientific peer review and publication in which considerable knowledge remains out of reach for much of the general public.

Finally, the argument for open access has also extended to the issue of whether scientific peer review should also be open to broader audiences, including the public, rather than limiting judgments about scientific worth solely to submitting authors, journal editors, and anonymous reviewers. In 2006, the prestigious scientific journal, *Nature*, initiated a trial of *open peer review*. Open peer review is the process of rendering scholarly judgments about the scientific value of research through an entirely transparent process by which the identities of those reviewing the research are disclosed to submitting authors and the public as part of the process. This differs from the traditional peer review process in which the identities of reviewers are anonymous. Despite significant interest in the trial by participating scientists, only a small proportion of those authoring papers chose to participate in the open review. The trial suggests that opening up peer review to broader participation among scientists and the public to comment on the quality and rigor of scientific research may not be as widely popular as believed (*Nature*, 2006).

Conclusion

This chapter has sought to describe and place in context the research approaches of education, applied psychology, and behavioral science and their potential applications to behavioral medicine. We have also attempted to sensitize the reader to the key issues in research and evaluation that will continue to require attention in behavioral medicine. Several final observations are worth making.

First, as we hope the chapter has shown, a wide range of research methods and evaluation designs are available to support the assessment of needs, formulation of intervention approaches, and evaluation of the process, impact, and outcomes of behavioral medicine interventions at the individual, community, and policy levels. Moreover, with the growing recognition of the importance of the broad range of social determinants of health, there is a nexus of complex factors that must be addressed to improve population health. To meet the challenge, more emphasis is now being placed on evaluative designs that value the use of a wide range of methods to assess health outcomes and the clinical, community, and social circumstances that support improvements in health and quality of life. Thus, the focus of this chapter has been on diverse methods in educational, public health, and behavioral science evaluation that may serve a broad range of objectives in order to study and understand complex phenomena and develop effective interventional measures.

Second, there are real and important differences in how interventions are evaluated that have profound implications for what and how much we can learn from the research and programs in which society invests public resources. Simply because research may fail to document a prespecified or a priori outcomes of primary interest, does not necessarily mean a study is not without merit or that something valuable has not been learned. Even “negative” trials of interventions, or studies in which unanticipated outcomes of value have been observed, can yield vitally important insights and new knowledge that can guide others in future work.

Finally, behavioral medicine faces an evolving landscape of issues that will require its scientists and practitioners to work more effectively to engage the community and other stakeholders in designing and conducting investigational studies and program evaluations. Partnerships with other disciplines and with the patients and communities of interest whose health and quality of life we seek to improve promise to strengthen the science of behavioral medicine and the impact it can have through the research and evaluation process.

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7

Theory in Behavioral Medicine

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Introduction

Theory gives direction to the development of research questions and facilitates the interpretation and integration of research findings. Theory may contribute strongly to the development of the science of behavioral medicine, provided that the theory meets the requirements of a scientific theory. Empirically well-founded theory may give direction to the development of valid diagnostic and assessment procedures and the development of effective interventions, as well. Theory may contribute strongly to the application of behavioral medicine knowledge in clinical care and public health.

In this chapter we will first make introductory comments on the role of theory in behavioral medicine research and the need for theoretical rigor. We will also introduce an important distinction between *general* and *focused* theories. We will illustrate the role of theory in behavioral medicine by providing an overview of several general theories in behavioral medicine, specifically psychophysiological stress theories and social cognitive theories on health behavior change. We will also describe focused theories, specifically theories on occupational stress and a theory on functional decline in osteoarthritis. In the last section, we will give some final reflections on the role of theory in behavioral medicine research.

The Role of Theory in Behavioral Medicine Research

The scientific method is a cyclic process involving theories, hypotheses, observations, and conclusions (de Groot, 1971; Dekker, 2008). Scientists use theories to develop a specific hypothesis, which is subsequently tested in an empirical study: the observations in the empirical study result in a conclusion on the truth of the hypothesis and the need for adaptation of the theory. In the deductive approach, "theory" is the point of entry into the scientific cycle; development of the hypothesis and designing an empirical study are the next steps. In the inductive approach,

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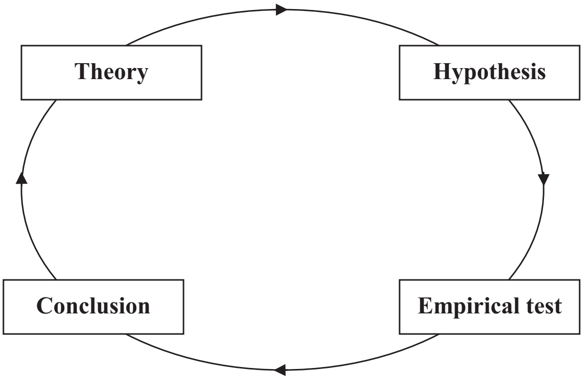

Fig. 7.1 The scientific method: a cyclic process

one starts from empirical data; these observations lead to a theory, which then needs to be tested empirically. The cyclic process, however, is common to both, as is illustrated in Fig. 7.1.

A scientific theory has two main functions, the heuristic function and the integrative function.

1. Heuristic function: Theory gives direction to the development of research questions. Theory provides guidance in developing research questions.
2. Integrative function: Theory facilitates the interpretation and integration of research findings. Theory provides guidance in interpreting empirical facts.

These two functions of theory will be illustrated below. The first function of theory – heuristic function – is to guide the development of research questions. Physical activity has a beneficial effect on cancer-related fatigue. A comprehensive theory on fatigue could lead to the hypotheses that the beneficial effect of physical activity is due to improvement of aerobic capacity (Chinapaw, Buffart, et al., 2012) or due to improvement of mood (Gielissen, Wiborg, et al., 2012). These hypotheses can be tested in a study evaluating whether improved aerobic capacity or improved mood mediates the relationship between physical activity and fatigue. If aerobic capacity, but not mood, is found to mediate the beneficial effect of physical activity, the theory would be revised: physical activity leads to improved aerobic capacity and thereby to a reduction of fatigue (and mood seems to be irrelevant). The further development of the revised theory would focus on exercise physiology (and exclude mood as a pathway). The revised theory would guide the development of the next study, for example, a study on the dose-response relationship between exercise intensity, aerobic fitness, and fatigue reduction. A theory adapted to the most recent empirical findings is conducive to identifying the next step in research. Theory is the point of accumulation of knowledge in a specific field: theory "absorbs" recent empirical findings; the empirically enriched theory guides future scientific research.

The second function of theory – integrative function – is to facilitate the coherent interpretation of empirical findings. Without the integrative framework of theory, empirical research runs a risk of ending up with a set of loose facts which are difficult to interpret. For example, both cognitive behavior therapy and exercise have a beneficial effect on pain in fibromyalgia patients, without substantial differences between these treatment approaches. The lack of a differential effectiveness as such is difficult to interpret. However, it has been theorized that in some patients, cognitive factors (e.g., catastrophizing) perpetuate pain, while in other patients, behavioral factors (e.g., deconditioning) perpetuate pain (van Koulil, van Lankveld, et al., 2010). This theory potentially explains the lack of differential effectiveness: if cognitive factors perpetuate pain, cognitive behavior therapy is likely to be effective (and not exercise); on the other hand, if behavioral factors perpetuate pain, exercise (and not cognitive behavior therapy) is expected to be effective. In a study with a mix of patients (some patients with cognitive factors and other patients with behavioral factors perpetuating pain), both cognitive behavior therapy and exercise will be effective. This explains the lack of a differential effectiveness of these therapies. Thus, theory facilitates the interpretation and integration of empirical findings.[1]

Theoretical Rigor

In current thinking on the science of behavioral medicine, strong emphasis is placed on methodological rigor (e.g., the methodological criteria for conducting and reporting of clinical trials). Much less attention is being paid to the need for "theoretical rigor." This is an unfortunate state of affairs: in order to advance behavioral medicine as a science, theory needs to be developed in a rigorous way. We will shortly discuss the requirements for a scientific theory, and we will give some examples of insufficient theoretical rigor.

A scientific theory consists of a set of concepts and statements concerning a particular domain of reality (de Groot, 1971). Requirements for a scientific theory include (de Groot, 1971; Cramer, 2013):

1. Clear definitions of concepts. Concepts need to be clearly defined.
2. Logical consistency. Statements on the relationship between concepts need to be clearly articulated and logically consistent, meaning that the statements do not contain a contradiction.
3. The theory needs to be falsifiable. Empirical falsification of the hypothesized relationships should be a realistic possibility: the outcome of an experiment must include the option that the theory or hypotheses derived from the theory are wrong.
4. Parsimony, i.e., preference for the least complex explanation for an observation. A parsimonious and sober theoretical explanation is preferred over a complex theoretical framework with more concepts and relationships than are really needed to explain a phenomenon.
5. Restrictiveness. The theory should be restricted to a clearly defined domain of reality.
6. Empirical validity. Empirical observations confirming hypotheses derived from the theory contribute to the empirical status of the theory. The more empirical evidence supporting the theory, the better the empirical status of the theory.

The need for falsification as a realistic possibility has been emphasized by Popper and others (Popper, 1963): it should be a realistic option that in an empirical study, the theory is found to be wrong. That is, one should be able to describe the specific observations that would lead to the falsification or rejection of the hypothesis being tested. The criterion of falsifiable hypotheses is not always met, even in modern science. Confronted with conflicting results, scientists have frequently hypothesized two opposite processes, which are supposed to be operating in different individuals or at different moments in time. In these circumstances, the conditions under which each of these processes is supposed to operate or not to operate need to be clearly specified. Under condition A, process X is operating, leading to an increase in outcome variable O. Under condition B, the opposite process Y is operating, leading to a decrease in outcome variable O. If these conditions (A and B) are not specified, any outcome of an experiment (increase or decrease of O) can be "explained": if the outcome of the experiment is an increase in O, "apparently" process X was operating; if the outcome is a decrease in O, "apparently" process Y was operating. Whatever the outcome of the experiment, there is always an explanation. Unless the conditions under which these processes are supposed to operate are clearly specified, the theory runs the risk of not meeting a crucial requirement for a scientific theory: falsification of the theory should be a realistic possibility.

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[1] This example provides another illustration of the heuristic role of theory as well: the logical next step would be a 2 × 2 study comparing the outcome of cognitive behavior therapy and exercise in patients whose pain is perpetuated by cognitive factors and patients whose pain is perpetuated by behavioral factors.

In chronic pain, pain-related fear and avoidance are contributing to pain and disability. This has led to the formulation of the theoretical "fear-avoidance" model on chronic pain (Vlaeyen & Linton, 2000, 2012). An opposite theoretical model based on endurance-related responses and physical overuse or overload has been hypothesized as well (Hasenbring & Verbunt, 2010). These two theoretical models have been integrated into the avoidance-endurance model of chronic pain (Hasenbring & Verbunt, 2010). In this theoretical model, both avoidance and endurance are hypothesized to cause pain and disability. In this positing of two opposite processes, it is essential to clearly articulate characteristics of patients in whom avoidance is hypothesized to be operating, and characteristics of patients in whom endurance is hypothesized to be operating.

Furthermore, it has been hypothesized that the outcome of each of these processes (avoidance and endurance) may vary with time (Hasenbring & Verbunt, 2010). This introduces even more degrees of freedom: two opposite processes which each are hypothesized to lead to opposite outcomes at different moments in time. This further complicates the task of specifying the observations that would lead to the rejection or modification of the theory, calling for an articulate definition of the exact role of time in each of these processes, in addition to the definition of characteristics of patients in whom avoidance versus endurance is hypothesized to be operating. In the absence of a clearly articulated theory on patient characteristics and the exact role of time, there is a risk that this theory is not falsifiable: two opposite processes which each have an opposite outcome depending on time leave many options for a fit between theoretical explanation and empirical fact.[2]

The criteria of logical consistency of statements and parsimony are not always met in behavioral medicine theory either. Various theories may be available to explain a certain phenomenon. For example, several theories on the role of psychological factors in the development and persistence of chronic pain have been formulated. These include theories on cognitive coping styles (e.g., catastrophizing), pain-related anxiety and fear, helplessness, self-efficacy, pain coping strategies, readiness to change, acceptance, and illness beliefs (Keefe, Rumble, et al., 2004; de Rooij, Steultjens, et al., 2011). Although each theory may provide a parsimonious explanation, the field as a whole offers a bewildering complex explanation of the role of psychological factors in chronic pain: closely related and overlapping concepts, without a clear demarcation between these concepts, and various conceptualizations of the relationships between these concepts and chronic pain, without a comprehensive theory integrating these various conceptualizations.

Apart from an exceptional (but laudable) attempt at theoretical (Sullivan, Thorn, et al., 2001) or empirical (de Rooij, Steultjens, et al., 2011; Nielson & Jensen, 2004) clarification, the field seems to accept this state of affairs. Obviously, this is an undesirable state of affairs. First, the overall theoretical explanation of the role of psychological factors in chronic pain does not meet two criteria for a scientific theory: logical consistency of concepts and statements and parsimony, i.e., preference for the least complex explanation for an observation. Second, empirical studies on concepts derived from these various theories may lead to confusing and contradictory conclusions, sometimes providing evidence for factor X, sometimes for factor Y, and sometimes for factor Z. Reviews summarizing the available literature are helpful, be it a narrative review (Keefe, Rumble, et al., 2004) or a systematic review (de Rooij, Roorda, et al., 2013). However, in the absence of a comprehensive theory facilitating the interpretation and integration of the various empirical findings, such reviews advance the field only to a limited extent. For this reason, Keefe, Rumble, et al. (2004) have called for clear and understandable definitions of concepts used in the explanation of chronic pain, as well as for a comprehensive theory integrating various conceptualizations and findings on psychological factors in chronic pain. Despite obvious relevance, such an endeavor does not seem to have a high priority: only a few studies have attempted to

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[2] These comments do not imply that the authors of this theory are not aware of the need for theoretical rigor.

clarify relationships between psychological concepts in chronic pain (de Rooij, Steultjens, et al., 2011; Sullivan, Thorn, et al., 2001; Nielson & Jensen, 2004). There is an urgent need to develop comprehensive theories which meet the requirements for scientific theory: clear definitions of concepts, logical consistency, the theory needs to be falsifiable, parsimony, restrictiveness, and empirical validity.

General Theories and Focused Theories

General theories in behavioral medicine concern the basic and universal mechanisms explaining how psychosocial, behavioral, and biomedical factors interact in health and illness in general. Major general theories in the field of behavioral medicine include the theories on stress and social cognitive theories on health behavior. These general theories cut across phenomena, populations, and settings.

Empirical research on a general theory primarily aims to test basic, universal mechanisms. Do cognitions predict future health behavior? The general hypothesis that cognitions predict health behavior can be tested in various health behaviors, e.g., smoking cessation, physical activity, or sleep hygiene. The specific health behavior which is used to test the theory is not the main focus of interest – the primary aim of the study is to test whether the general hypothesis that cognitions predict future health behaviors is valid. General theories provide understanding in many different situations. This is the major strength of a general theory: a general theory is a universal "tool," which applies to many phenomena, populations, and settings.

A problem with general theories is that they are insufficiently specific to help understand specific phenomena. General theories provide general explanations (e.g., cognitions predict health behavior) but provide less guidance in understanding a specific phenomenon (e.g., sleep hygiene). More focused theories may have much more potential in explaining specific phenomena: in-depth understanding of specific phenomena may require focused theories on each of these phenomena.

Focused theories concern specific phenomena. A focused theory explains how psychosocial, behavioral, and biomedical factors interact with regard to a specific health issue. Examples of focused theories include the explanation of fatigue in cancer patients, the explanation of the impact of depression on cardiac disease, and the explanation of smoking relapse prevention.

Research on a focused theory, by definition, aims to test the explanation of a specific phenomenon. Does low-exercise self-efficacy contribute to fatigue in patients with cancer? The specific health problem (i.e., fatigue in patients with cancer) is the main focus of interest – the primary aim of the study is to test the hypothesis that low-exercise self-efficacy contributes to fatigue in patients with cancer.

Focused theory is frequently derived from one or more general theories: general theory (e.g., on cognitions and behavior) is tailored to the specific health issue (exercise self-efficacy and fatigue in patients with cancer). Specific issues (such as the impact of chemotherapy on fatigue) are added to the focused theoretical model on fatigue in patients with cancer. This results in a comprehensive focused theory of the specific phenomenon. Focused theories have great potential to improve our understanding of specific health issues. This is the major strength of focused theory: it aims to improve our understanding of specific health issues, thereby contributing to finding solutions for these specific health problems.

Focused theory should be distinguished from pragmatic research. Pragmatic research does not use (focused) theory to guide research. Instead, pragmatic research amasses observations and data. Pragmatic researchers rely on research methods to gather data on a specific health issue. Pragmatic researchers do not develop hypotheses, which are subsequently tested, nor do they use theory to integrate research findings. Pragmatic research does not rely on (focused) theory and does not aim to contribute to the development of (focused) theory.

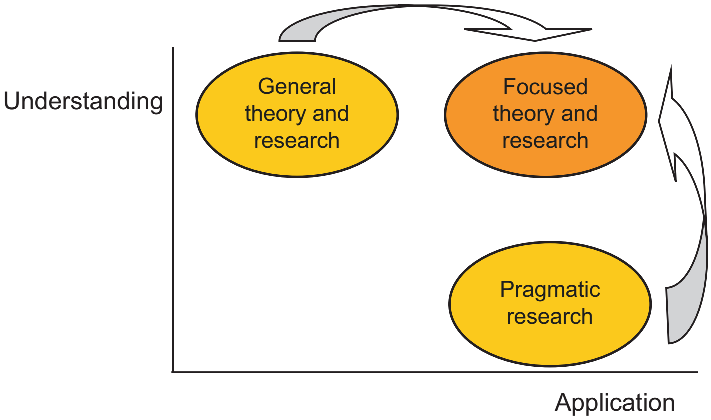

Fig. 7.2 Research based on focused theory: understanding *and* application

It can be argued that shifting from research on general theories to research on focused theories, as well as shifting from pragmatic research to research on focused theories will strongly contribute to our understanding of specific health issues. This shift is illustrated in Fig. 7.2. Research based on focused theory aims *both* to understand *and* solve a specific health issue, as contrasted to research on a general theory (which aims to understand universal mechanisms without attention to specific applications) and to pragmatic research (which aims to gather data on a specific health issue but without attention to theoretical understanding). The approach based on focused theory is expected to strongly contribute to our capability to understand and find solutions for specific health problems.

Summary

In summary, theory has two main functions in science:

- Heuristic function: theory gives direction to the development of research questions.
- Integrative function: theory facilitates the interpretation and integration of research findings.

Theoretical rigor is required, in order to ensure that theory really contributes to the development of science:

- Concepts need to be clearly defined.
- Statements on the relationship between concepts need to be logically consistent and clearly articulated.
- Empirical falsification of the theory should be a realistic possibility.
- A parsimonious theory is preferred over an elaborate theoretical framework.
- The theory should be restricted to a clearly defined domain of reality.
- Empirical observations confirming the theory contribute to its empirical status.

In behavioral medicine, a distinction can be made between:

- General theories which concern general mechanisms explaining how psychosocial, behavioral, and biomedical factors interact in health and illness. A general theory facilitates understanding of many different health issues.
- Focused theories, which concern specific health and illness issues. Focused theories have great potential to further our understanding of specific health issues.

Below, we will first give an overview of two general theories in behavioral medicine, i.e., specifically psychophysiological stress theories and social cognitive theories on health behavior change. These two "grand" theories provide eloquent illustrations of the role of general theory in behavioral medicine. We will then describe two focused theories, i.e., theories on occupational stress and a theory on functional decline in osteoarthritis. These two theories illustrate the potential of focused theories to deepen our understanding of specific health issues.

General Theories on Psychophysiological Stress

During the last 15 years, evidence has been accumulating showing that psychological stress is a risk factor for organic disease, e.g., cardiovascular disease. For example, high levels of overall life stress – a combination of stressors at work and at home, financial stress, and major life events – are associated with a greater than twofold risk for developing a myocardial infarction, which is greater than the risk for obesity and hypertension (Rosengren, Hawken, et al., 2004; Dimsdale, 2008). Work stressors have been found to increase cardiovascular disease risk up to 3.6 times (Bosma, Peter, et al., 1998; Matthews & Gump, 2002) in a dose-response fashion (Chandola, Britton, et al., 2008), with follow-up times between 4 and 12 years, although evidence is not consistent for all types of work stressors and less clear for women (see Backe, Seidler, et al., 2012). Marital conflict appeared to be linked to a nearly threefold risk of recurrent coronary events (Matthews & Gump, 2002; Orth-Gomer, Wamala, et al., 2000). Several other stressors also seem to increase CV risk, such as bereavement or care giving for a spouse with Alzheimer (Dimsdale, 2008; Lee, Colditz, et al., 2003; Vitaliano, Scanlan, et al., 2002). Taken along with similar observations in diseases in areas other than CVD, it seems safe to conclude that stress carries a considerable disease risk. Given the long history of mind and body dualism, a reasonable and important question arises from this literature: how can it be explained that stress, a presumably psychological phenomenon, can have these severe bodily effects? This part of the chapter deals with several of the main developments in general theories that have been employed in the last century to account for the effects of stress on physiology, disease, and mortality.

Early Stress Theories

Historically, there are several general stress theories that have inspired and guided a tremendous amount of research spanning over more than 80 years. Most textbooks start with Walter Cannon in the 1930s, who coined the term *fight or flight* to describe the animal's physiological response to acute threats. This response was characterized by high sympathetic nervous system activation that caused the adrenal medulla to produce adrenaline. Cannon viewed the fight/flight response as part of an organism's striving to maintain a steady physiological state, called homeostasis and in fact defined as early as 1865 by Claude Bernard. Cannon called the external factors that disrupt homeostasis "stress," using this term for what we now like to call "stressors."

The next historical figure, Hans Selye, showed in the 1950s that the bodily response to stress appeared to be a very *general response* to any type of threat to the organism: heat, cold, hunger, thirst, wounds, infections, and last but not least emotional disturbances. Selye developed this finding of a general response into the first formal stress theory, called the general adaptation syndrome (GAS). Typical aspects of the GAS are swelling of the adrenal cortex, increases in glucocorticosteroid release (which is cortisol in primates, including humans), atrophy of the thymus, and development of gastric and duodenal ulcers. Importantly, the GAS consists of three temporal stages, an alarm stage, a resistance stage, and an exhaustion stage, and the latter would finally cause disease and death. Later it became clear that most health damage from stress is due to continued activation (stage 2) rather than exhaustion (stage 3), at least in highly developed human societies.

The notion of the fight/flight response of Cannon is still popular. However, from Selye's findings it became clear that it should be taken metaphorically rather than literally. We do not really "fight" or "flee from" threats such as hunger, cold, or infections. Instead the body's stress response is a general defensive activation response, which is launched whenever there is a threat to the physical or psychological integrity of the organism. Perhaps the greatest insight of Selye was not so much the GAS, but this *generality* of the stress response to a variety of stressors. This generality also implied that the stress response is a phylogenetically very old natural defensive function that humans share with all other vertebrates and many invertebrates. This "old" defense might immediately progress into fight or flight, for example, on the level of intra- or interspecies threat, but it need not. In fact, *actual* fight or flight plays only a minor role in human stress and health.

Biological Stress Responses and Their Psychological Determinants

Biological Stress Responses

These early stress theories have led to a great amount of research, primarily laboratory stress experiments, that have yielded many insights into the physiological and psychological aspects of the stress response. With respect to the physiological aspects, it has become gradually clear that stressors have immediate effects on virtually every aspect of the body: the autonomic nervous system, the cardiovascular system, the immune system, the gastrointestinal system, the endocrinological system, the skeletomuscular system, and so on (Sapolsky, 2004). The biological responses that were the major interest of Cannon (i.e., adrenaline) and Selye (i.e., glucocorticosteroids) were part of two major physiological subsystems involved in the stress response that have become known as the sympathetic–adrenal–medullary (SAM) system and the hypothalamic–pituitary–adrenal cortical (HPAC) system. Together with the autonomic nervous system (ANS), these are still studied as being among the most important "larger" systems involved in the health risk of the stress response, because they govern the activity of the other bodily systems described above. Dysregulation in SAM, HPAC, or ANS has deleterious consequences for the other bodily systems and can lead to disease. A particularly important development in the 1980s and 1990s was research showing that stress can influence immunity and immune-related disease processes, such as wound healing and infections, and that the ANS is anatomically and functionally linked to the immune system. This research was partly triggered by the discovery that severe stressors, such as the loss of a loved one, could lead to immune-related diseases and even premature death. The new field that emerged, psychoneuroimmunology (PNI; Ader, 2007), had a tremendous influence on thinking about stress and health, also in the medical world. Before PNI, the reductionist biomedical model of disease that had been the ruling paradigm in medicine for the larger part of the twentieth century had already been challenged to incorporate psychological and social factors (Engel, 1977). However, it was PNI that made psychological stress truly acceptable in the medical world as a factor influencing bodily health. Rather than one single theory, PNI is a field with many sub-theories and hypotheses. Still, an overall and leading hypothesis has been that stress causes suppression of immune functions, making the body more vulnerable to disease agents, including infectious agents and neoplasia (tumors). Indeed, stress responses appeared to be able to decrease several immune functions, although this is particularly true for chronic and severe stressors. In contrast, mild, brief stressors often have brief immune-enhancing effects, depending on immune parameters (see Ader, 2007).

Psychological Determinants

On the psychological side, several factors were identified to determine the nature and the magnitude of the stress response. These factors involve the objective characteristics of stressors, as well as the perception and interpretation (appraisal) of these stressors. For example, different types of (laboratory) stressors appeared to cause different types of cardiovascular activation. During stressors that are challenging and thus require *active coping*, for example, math-like stressors, cardiac (beta-adrenergic) effects dominate. On the other hand, during frustrating stressors involving *passive coping*, for example, "mirror tracing" or threatening tasks, vascular (alpha-adrenergic) effects dominate (Obrist, 1981; Allen, Obrist, et al., 1987). A more recent theory (Blascovich, 2008) echoes these early findings. According to this theory, the response to stressors that are perceived as "challenging," and thus require active coping, would be characterized by high cardiac output. In contrast, the response to stressors that are perceived as "threatening," and thus requiring passive, vigilant coping, would be characterized by high total peripheral resistance (i.e., "vascular"). The latter is more hazardous when sustained for longer periods, because it mediates the risk of high blood pressure for cardiovascular disease. The contrast of challenge versus threat, either to describe characteristics of stressors or their perception, is a returning concept in stress theories and also a major element in a leading stress theory (Lazarus & Folkman, 1984) that deals in particular with the psychological side of stress.

Another important factor – and obviously related to active versus passive coping – is the *uncontrollability or unpredictability* of stressors. A series of studies in the 1960s and 1970s, by among others Weiss (1970) and Seligman, Maier and Solomon (1971), and coworkers (see Steptoe & Appels, 1989), showed that threatening stimulation such as mild electric shocks in animals led to unhealthy physiological outcomes such as high glucocorticosteroid levels and gastric ulceration. However, this was only the case when the threat was uncontrollable or unpredictable, even when levels of threat were kept equal over conditions. Later it appeared that the *perception* of uncontrollability/unpredictability was enough to yield these deleterious effects (Steptoe & Appels, 1989). Several theoretical models combined uncontrollability with the factor *effort or arousal* involved in coping ("fight or flight") with a stressor. Effort and uncontrollability have also become important factors in leading psychological stress theories, including work stress theories (Karasek, 1979). The effort/arousal dimension and the uncontrollability/ unpredictability dimension were believed to be, to a large extent, independent. For some time (i.e., during the late 1970s and 1980s) the two dimensions were hypothesized to be differentially related to the responses of the SAM and HPAC systems, that is, effort was believed to increase SAM activity, and uncontrollability was believed to increase HPAC activity (Henry & Stephens, 1977; Frankenhauser, 1980). Consequently, some theorists speculated that effort and uncontrollability might also be related to the *diseases* caused by dysregulation in these two systems: cardiovascular diseases (SAM/effort) or infectious disease and cancer (HPAC/uncontrollability) (Fisher, 1986). However, these differential hypotheses concerning physiology as well as diseases never received much empirical support. The biological reality is that the SAM and HPAC systems might be anatomically and functionally too closely connected to allow for these differential relationships. At high levels of activity, such as during stress but also during stress-free physical exercise, both will respond, with the HPAC system (i.e., glucocorticoids) acting slower.

There are numerous other important, more specific psychological factors influencing stress responses, such as previous stressors including early-life stress, gender, social evaluation, social support, individual differences such as self-esteem, neuroticism, and hostility, that can either modulate the stress response directly of by aggravating the stressful events which led to them in the first place. Of particular interest is a new theory of Taylor and coworkers (Taylor, Klein, et al., 2000) that hypothesizes another action tendency in addition to fight/flight, with the equally catchy name "tend and befriend." With oxytocin as biological basis, it holds that affiliation, or coming together in groups, during threatening situations should be taken into account as an important psychological aspect of stress responses.

Theories Linking Stress to Disease Pathways

Action Tendencies and Physiological Preparation

A major challenge for stress theorists has been to explain how psychosocial stress – a psychological phenomenon – can influence the body's systems in such a severe way that it can cause disease. Firstly, why does the body respond to stressors anyway? For this we have to turn to emotion theories. The psychological aspect of the stress response is comprised of negative emotions such as anger, anxiety, and fear. Associations of emotional responses, including the negative emotions, with bodily changes had been studied systematically for a long time, notably in the nineteenth century by Charles Darwin and William James. Most researchers have regarded these bodily changes as a functional part of emotions. The best answer to this first question is provided by more modern emotion theories and is relatively straightforward. These theories make clear that emotions involve action tendencies (e.g., Frijda, 1988), which in turn are associated with physiological activation to *prepare* for these actions. Negative emotions such as anger and anxiety are associated with physiological preparation for fight or flight, that is, vigorous autonomic activity, increasing heart rate, blood pressure, cortisol levels, and suppressing many – temporarily less relevant – biological processes including gastrointestinal, growth, and immune processes (Sapolsky, 2004). In his recent coherent overview of the biology of psychological stress, Lovallo (2005) further clarified and simplified this notion by pointing out that the physiological preparation for fight or flight is basically the same as what happens during preparation for bodily *exercise*. After preparing for exercise, we usually engage in this activity, but we seldom engage in actual fight or flight in modern human society. Still, during the stress response, our body keeps preparing for these actions. This explains the often intense physiological part of the stress response.

Final Pathway to Disease

This brings us to the next question: How does the stress response finally lead to disease or enhance the risk of disease? The link of emotions with disease only started to be systematically studied in the second half of the last century. Until the 1960s, and for some researchers far beyond that decade, the study of emotions and disease was dominated by psychodynamically oriented theories. A core notion was that *specific* kinds of emotional conflicts, when chronically suppressed, would lead to *specific* physiological patterns and diseases (see Nemiah, 1982). For example, intrapsychic conflicts concerning dependence would lead to peptic ulcers. These theories were difficult to reconcile with and did not contribute to growing biological and psychological knowledge. More recent examples are theories about the *physiological costs* of pent-up negative feelings such as anger or anxiety and, conversely, the assumed healthy effects of letting out these feelings in some way or another. However, after decades of research, little evidence has been gathered in favor of these theories (discussed in Vingerhoets, Nyklicek, & Denollet, 2008; Brosschot & Thayer, 1998). In fact, venting one's anger only increases anger and aggressive behavior tendencies as has been shown in numerous experiments (e.g., Bushman, Baumeister, & Phillips, 2001). Also, both habitually expressing anger and suppressing anger appeared to carry serious cardiovascular risks. Their shared "toxic" elements are likely to include the sustained action tendency (i.e., ongoing preparation for fight or flight) and its associated high physiological response (Brosschot & Thayer, 1998).

The intensity of people's physiological responses to stress appeared to be more fruitful as an explanation for the unhealthy effects of the stress responses. This idea was patented in the *reactivity hypothesis*, which has been the conventional hypothesis for over 50 years, and continues to guide many researchers in their research. It states that frequent intense responses to stressors cause biological dysregulation and damage (see Gerin, Pickering, et al., 2000). However, this hypothesis or model of the stress-disease link has received several criticisms. One criticism holds that human physiological responses to real-life stressors are seldom large or intense and are generally as low as physiological responses to regular mild physical stressors, such as walking the stairs (e.g., Halsey, Watkins, & Duggan, 2012), cycling (e.g., Glynn, Christenfeld, & Gerin, 2002), or other types of daily exercise. Another related but perhaps more important criticism is that prolonged physiological activity is far more crucial than incidences of high reactivity (Brosschot & Thayer, 1998; Schwartz, Gerin, et al., 2003; Linden, Earle, et al., 1997). At the same time, it is likely that those who respond intensely during stressors, the high reactors, have longer, more, and exacerbated prolonged activity.

There are exceptions, for example, people who already have a disease are vulnerable to even brief stress responses of low intensity.

Prolonged Physiological Activity

The notion of prolonged activity is also not new; it was already explicit in Selye's GAS theory and emphasized later by Ursin (1978). Surprisingly it did not receive substantial research attention until the 1990s when, rather independently, several research groups suggested new theoretical models of chronic stress. McEwen's allostatic load model explains how prolonged stress causes growing wear and tear on the body that will finally, over time, cause disease (McEwen & Stellar, 1993). Somewhat later, Linden and colleagues (Linden, Earle, et al., 1997) proposed that slow recovery rather than high reactivity explains the health risk of stressors. They also pointed out that particularly *emotional* stressors cause slow recovery and not *non-emotional* stressors such as physical stressors or "threat-free" cognitive stressors, even if the stressor duration is equal. At the same time, Brosschot and Thayer (1998) explicated the role of sustained action tendencies in causing prolonged activation, and they later, together with Gerin, proposed the *perseverative cognition hypothesis* (Brosschot, Gerin, & Thayer, 2006). This hypothesis holds that prolonged activity is caused by the continued mental representation of stressors, independent of the actual presence of these stressors.

Perseverative Cognition

Perseverative cognition is manifested in cognitive phenomena such as rumination and worry. They keep on triggering the fight/flight action tendency and therewith the physiological preparation for that action. The hypothesis emphasizes that prolonged physiological activity does not only occur *after* stressors but also *before* stressors (i.e., anticipatory stress), sometimes even far before them, due to perseverative cognition. This implies that stressors that are feared in the future but never occur can still have strong physiological effects. The more people worry about the future, the more often physiological activation will occur: their bodies are suffering from events that never happen! Conventional stress studies did not – and still often do not – account for perseverative cognition such as worry and rumination, or any other psychological cause of prolonged physiological activation. They also typically fail to measure stressors that have not (yet) happened. By being guided, either explicitly or implicitly, by the reactivity model, they have missed and continue missing a potentially large source of stress responses. As an example, consider a work stressor, such as a bad relationship with one's boss. Actual encounters with that boss may be limited to minutes per day or several hours per week. However, the ruminating about the boss may be constant and causes by far most of the prolonged activity during that period (Gerin, Zawadzki, et al., 2012). The same is true for other chronic stressors, such as racial discrimination, loneliness, low social economic status, care giving, etc. According to the perseverative cognition hypothesis, stressors will not become health risks without sustained worrying or rumination, because there would be no prolonged physiological activation (Brosschot, Gerin, & Thayer, 2006). There is growing evidence in favor of the perseverative cognition hypothesis, specifically with respect to the physiological effects of worry and rumination (Verkuil, Brosschot, et al., 2010).

Finally, the perseverative cognition hypothesis illuminates a special feature of human stress. Worry and rumination are typical human cognitive phenomena. It is safe to assume that other animals' brains are incapable of making cognitive representations of past and future threatening scenarios of such concreteness and vividness that they have physiological consequences. Consequently, chronic stress may truly be called a distinctive human form of stress or a recent "invention" of mankind.

Current Developments

This chapter is far too short to do justice to all other exciting new developments in stress theory and research and can only briefly touch on them. One recent development is the hypothesis that stressors may have consequences even when people are not aware of their own emotional stress response. During the last 15 years, a host of studies has demonstrated that people are not aware of the major part of their cognitive regulation (Bargh & Morsella, 2008). It is likely that emotional cognition is not an exception. People may also not be aware of a – potentially large – part of their stress-related cognition, while this *unconscious stress* might substantially contribute to prolonged activation. Several findings point in this direction, for example, physiological effects of unconscious stress stimuli and prolonged physiological effects of stress during *sleep*, our most important restorative period in life, during which conscious stress-related thought activity is not possible (Brosschot, Verkuil, & Thayer, 2010).

There are several other new developments and challenges of which only five examples will be mentioned and only briefly so. Firstly, there are advances in *genetics*, especially how stress alters gene expression (epigenetics). Secondly, rapidly growing insights from *neuroscience* elucidate brain systems involved in stress, especially the interplay of prefrontal and subcortical areas ("emotional brain"). Thirdly, computer-/Internet-assisted ambulatory (real-life) psychophysiological monitoring is enabling exciting and fast progress, which enables ever more sophisticated testing of prolonged stress processes. Fourthly, there is the increasing and fruitful attention for meditation-based interventions. Finally, evidence is slowly piling up that anxiety disorders and depression are important risk factors for somatic disease. These conditions can easily be understood as prolonged stress responses, with worry and rumination as the core etiological factors in their onset and maintenance (Verkuil, Brosschot, et al., 2010).

General Social Cognitive Theories of Health Behavior Change

This section deals with selected general theories that attempt to explain health behavior change. From a metatheoretical viewpoint, stage models are contrasted to continuum models. This will be illustrated by one example of a continuum model (reasoned-action approach) and one example of a stage model (transtheoretical model), followed by an example of a hybrid model (health action process approach).

Two Approaches to Global Theories: Continuum Models and Stage Models

Models of health behavior change postulate a pattern of factors that may improve motivation and that would eventually lead to sustained behavior change. A distinction is made between stage models and continuum models (Lippke & Ziegelman, 2008). In continuum models, individuals are placed along a range that reflects the likelihood of action. Influential predictor variables are identified and combined in one prediction equation. The goal of an intervention is to move the individual along this route toward action. Such models assume that a person's behavior is the outcome of an intention (e.g., "I intend to run four times a week for at least 30 minutes each time"). Intention forming is seen as being determined by beliefs and attitudes. Therefore, the focus is on identifying a parsimonious set of predictors that includes constructs such as perceived barriers, social norms, disease severity, personal vulnerability, attitudes, or perceived self-efficacy. These are then combined into a prediction equation for explaining behavioral intention and behavior change. The most prominent examples of the continuum model are several theories that have been described as pursuing the reasoned-action approach (see below).

Stage models take the perspective of the clients who reside in different mind-sets while progressing through behavioral phases, whereas continuum models look at theoretical constructs. In the model of action phases, the so-called Rubicon model (Heckhausen & Gollwitzer, 1987), a distinction is made between an initial motivation phase and a subsequent volition phase, an idea that dates back to earlier work by Lewin. Individuals in one phase differ from individuals in the other phase in terms of their goals, readiness to change, and action attempts. The transtheoretical model of behavior change (TTM)

(Prochaska & DiClemente, 1983) makes a distinction among five stages of change, assuming that people are qualitatively different between stages. Based on this assumption, intervention strategies are developed that are tailored to the current mind-set of an individual. Thus, stage theories are mainly put forward with the idea to identify a match between transitory psychological characteristics and suitable treatment components to facilitate behavior change.

Continuum Models: The Reasoned-Action Approach (RAA) Theories

The reasoned-action approach (RAA; Fishbein & Ajzen, 2010) stands for a family of related models, namely, the theory of reasoned action (TRA), the theory of planned behavior (TPB), and the integrated behavior model (IBM). The theory of planned behavior (TPB; Ajzen, 1991) represents a revised version of the theory of reasoned action (TRA; Fishbein & Ajzen, 1975) (for a historical overview, see Head & Noar, 2014). The RAA theories follow a continuum model design that includes distal and proximal antecedents of a given behavior. The core of the model consists of few variables (see Fig. 7.3). Intention reflects a person's readiness or motivation to perform a health behavior. The intention is based on attitude toward the behavior, subjective norm, and perceived behavioral control. Intention mediates between these three factors and the behavior. Attitude toward a behavior is an indicator of the positive or negative value that is associated with the performance of the behavior.

The RAA has become a leading conceptual framework in behavioral medicine over the last four decades, having inspired generations of health behavior researchers. It is illustrated by a simple and intuitive path diagram, with the behavioral intention as the most proximal antecedent of behavior, which mediates between social-cognitive constructs and health behavior. The RAA theories (TRA, TPB, IBM) are very well developed in terms of their formal characteristics of well-defined constructs, hypothesized paths linking them, and falsifiable statements. Another strength of the RAA lies in its parsimony and generality. Together, parsimony and generality designate a broad approach that enables the utilization of the RAA for a large number of research questions. This may be the reason why little has changed since the 1970s, except for minor additions in a more cursory fashion. The main substantial addition was the inclusion of perceived behavioral control in the TPB variant, which later became perceived self-efficacy in the IBM variant. One could see this as an attempt to combine the TRA with the very influential social cognitive theory (SCT; Bandura, 1986). Today, most health behavior theories consider self-efficacy as one crucial component.

The model has been evaluated as being successful in predicting intentions, but less successful in predicting behaviors, which is obvious because the focus is on preintentional variables. In a meta-analysis, Armitage and Conner (2001)

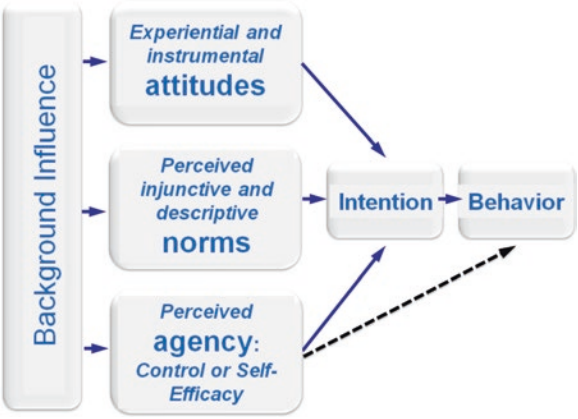

Fig. 7.3 Simplified diagram of the reasoned-action approach theories (RAA; Fishbein & Ajzen, 2010) according to Head and Noar (2014)

reported an average of 39% of explained intention variance, as opposed to an average of 27% explained behavior variance. These percentages are high because many studies in this area are only cross-sectional correlation studies based upon mere self-reports. Due to such basic research designs, the coefficients are often inflated, whereas in longitudinal studies, using objective behavioral outcomes, as well as in experimental studies, the predictive value of the theory is very limited (Sniehotta, 2009). Thus, the RAA theories are mainly intention theories. To transform them into a more powerful behavior change theory, they need to be extended by postintentional predictors that are more proximal to the behavior in question. In the last decade, many researchers have introduced further extensions to the RAA, typically labeled "extended theory of planned behavior." Such useful extensions are postintentional which means that researchers have identified a weak point in the theory, namely, the translation of intentions into action. There seems to be a collective desire to learn more about processes that occur after individuals have formed an intention. In particular, planning (implementation intentions) has become the most prevalent extension of the TPB (for a review see Hagger & Luszczynska, 2014). Such studies that have added planning as a mediator between intentions and behavior, have made a substantial improvement of the utility of the RAA.

Two basic processes in health behavior change can be distinguished, namely, goal setting (motivation, intention formation) and goal pursuit (volition, action). The RAA puts its weight on the initial motivation phase, and this is done very well and in the most general manner, making it a general intention theory for all kinds of behavioral applications. What is also needed in behavioral medicine is an elaboration of the second phase where intentions are translated into action and where one has to deal with initiation, temptation, and relapse. When designing interventions for a particular health-compromising behavior, for example, smoking cessation in already motivated individuals, the RAA is not ideal as it does not account for processes that are involved in such changes. The RAA has, so far, been less convincing as an intervention theory because this would require more treatment-focused experimental work instead of the predominant correlational type of inquiry (Head & Noar, 2014; Sniehotta, Presseau, & Araújo-Soares, 2014).

There are two debatable aspects of continuum models. First, a single prediction rule for describing behavior change implies that cognitive and behavioral changes occur in a linear fashion and that a "one-size-fits-all" intervention approach may be suitable for all individuals engaging in unhealthy behaviors. Consequently, it does not emphasize qualitative changes during the course of time, such as changing mind-sets, phase transitions, or recycling back and forth. According to continuum models, it is not important whether an intervention approach is targeted first toward changing perceived vulnerability, perceived consequences, or perceived self-efficacy. Hence, interventions are not required to be progressed in any certain sequence, but they could be applied in any order, or simultaneously.

Second, traditional continuum models typically did not account for the postintentional phase in which goals are translated into action. This segment between intentions and behaviors is also called "intention-behavior gap" (Sheeran, 2002). It is quite common that people do not behave in accordance with their intentions. For example, unforeseen barriers emerge, and people give in to temptations. In a postintentional phase, various factors can compromise or facilitate the translation of intentions into action. Theorizing about health behavior change should not only emphasize the motivation phase but also consider the subsequent action phase that may be more decisive for behavior change. Advanced continuum models, therefore, need to include factors that help to bridge the intention-behavior gap (e.g., an extended theory of planned behavior). In doing so, it is implicitly assumed that there are at least two phases of behavior change, a motivational one that ends with an intention and a volitional one that peaks in successful performance. Thus, any extension of traditional continuum models into this direction implicitly adopts the idea of distinct processes, stages, or phases in health behavior change. Indeed, this segmentation idea is not foreign to the TPB. Fishbein and Ajzen (2010) argue that one can target unmotivated individuals by changing beliefs and motivated individuals by removing barriers that hinder the translation of intentions into actions. Using the intention as the watershed that divides the audience into two groups, it turns any continuum theory into a stage theory.

Stage Models: The Transtheoretical Model of Behavior Change (TTM)

To overcome the limitations of continuum models, stage theorists have made an attempt to consider process characteristics by proposing a number of qualitative stages. Whereas the focus of continuum models lies in the prediction of intention and behaviors, the major focus of stage models lies in the design of stage-matched interventions. One such approach is based on clinical research on addictions and has become the dominant stage model of health behavior change: the transtheoretical model of behavior change (TTM), also called stages of change (SOC) model (Prochaska & DiClemente, 1983). Its main feature is the implication that different types of cognitions and behaviors may be important at different stages of the health behavior change process. The most common version of the TTM includes five discrete stages of health behavior change that are defined in terms of one's past behavior and future plans (precontemplation, contemplation, preparation, action, maintenance) (see Fig. 7.4). For example, at the precontemplation stage, a problem drinker does not think about quitting in the future. At the contemplation stage, he or she reflects about quitting sometime within the next 6 months but does not make any specific plans for behavior change. At the preparation stage, the problem drinker resolves to quit within the next month and prepares for this step. The action stage includes individuals who have taken successful action for any period of time. If abstinence has lasted for more than 6 months, the person is categorized as being in the maintenance stage. Sometimes a termination stage is added, for example, in the case of smokers who have been abstinent for at least 5 years. The stages are expected to be mutually exclusive and qualitatively different.

People could make multiple attempts to progress from preaction to action stages. However, relapses could occur anytime, resulting in a spiral-like progression through the behavior-change process. In contrast to continuum models, stage models such as the transtheoretical model assume that factors producing movement toward action differ with respect to a person's stage. The identification of stages bears implications for interventions because matching a treatment to the current stage of a target group would lead to better outcomes.

In addition to the described basic stages of change, the TTM also includes ten processes of change, decisional balance (the perceived pros and cons of changing), perceived self-efficacy, and temptation. Processes of change are conceptualized as causes for the transitions between the stages, whereby it is assumed that different processes influence different stage transitions.

A meta-analysis on tailoring interventions pointed to some empirical evidence in favor of stage-matched treatments (Noar, Benac, & Harris, 2007). However, evidence in favor of the TTM and other stage models is mixed. The very nature of stages, their operationalization, the failure to move people from one stage to the next, or the failure to achieve stage-matched effects are points that have been raised (Sutton, 2005).

A major problem that TTM shares with other stage models is the validity of the key constructs. Stage allocation is based on a simple algorithm asking people whether they act or not and if not, whether they intend to do so or not, etc. For example, questions to stage smokers are (1) are you thinking about quitting within the next 6 months? ("No" = precontemplation, "Yes" = contemplation), (2) are you planning on quitting within the next month? ("No" = contemplation, "Yes" = preparation), (3) are you currently quitting? ("No" = preparation,

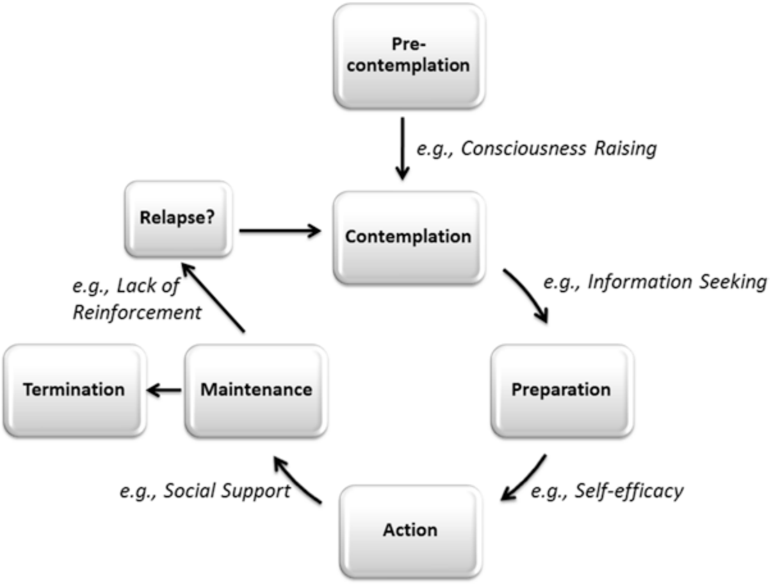

Fig. 7.4 Simplified diagram of the transtheoretical model (TTM; Prochaska & DiClemente, 1983). Stages are within *rectangles*, and transition processes are at the *arrows*

"Yes" = action), and(4) have you quit for at least a month? ("No" = action, "Yes" = maintenance). Sensitivity and specificity need to be addressed to determine the number of false positives, for example. Passage of time might not be the ideal criterion to identify cutoff points in the process of change (Lippke, Ziegelmann, et al., 2009). Self-reports for stages or intentions are subject to intraindividual fluctuation and, therefore, may result in different decisions depending on the time of day, mood, or social influence. For example, one can easily imagine a current smoker fluctuating during the day between a "Yes" (contemplation) and "No" (precontemplation) in response to the question "Are You thinking about quitting in the next 6 months?" Thus, if a particular stage algorithm is not sufficiently valid in a particular health promotion setting, stage-matched interventions may not be successful.

Parsimony in Hybrid Models: The Health Action Process Approach (HAPA)

Developed in 1988 (Schwarzer, 1992), the HAPA was originally an attempt to integrate the model of action phases (Heckhausen & Gollwitzer, 1987) with social cognitive theory (Bandura, 1986). It includes a number of constructs and principles (see Fig. 7.5).

Constructs

Intention In the process of motivation, intention has been regarded as a kind of "watershed" between an initial goal-setting phase (motivation) and a subsequent goal-pursuit phase (volition). When describing health behavior change, it is most helpful to follow this distinction. For example, to gauge the progress of an individual who is supposed to quit smoking and to design therapeutic interventions, the first question to ask should be whether this person is either preintentional or postintentional. To which degree is the person motivated (goal setting), or to which degree is the person making explicit efforts to quit (goal pursuing)? The terms motivation and goal setting pertain to the preintentional phase, whereas the terms volition and goal pursuit pertain to the postintentional phase.

Although the construct of intention is indispensable in explaining health behavior change, its predictive value is limited (Sheeran, 2002). When trying to translate intentions into behavior, individuals are faced with various obstacles, such

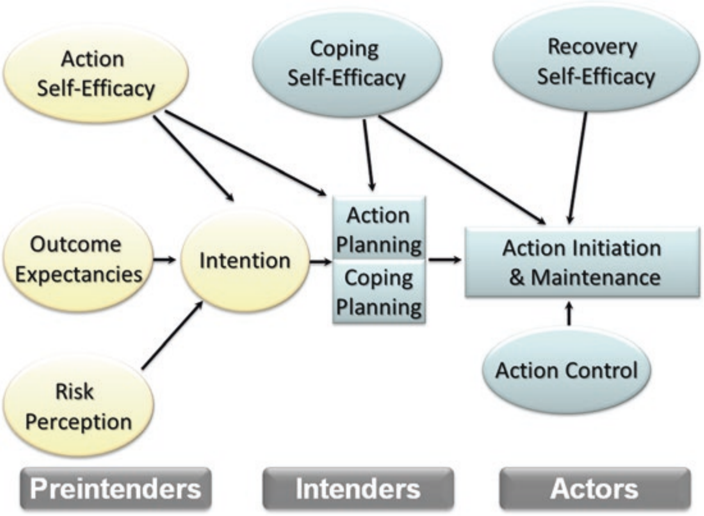

Fig. 7.5 Simplified diagram of the health action process approach (HAPA; Schwarzer, 2008)

as distractions, forgetting, or conflicting bad habits. Godin and Kok (1996), who reviewed 19 studies, found a mean correlation of .46 between intention and health behavior, such as exercise, screening attendance, and addictions. Abraham and Sheeran (2000) reported behavioral intention measures to account for 20–25% of the variance in health behavior measures. If not equipped with means to meet these obstacles, motivation alone does not suffice to change behavior. To overcome this limitation, further constructs are required that operate in concert with the intention.

Risk Perception At first glance, perceiving a health threat seems to be the most obvious prerequisite for the motivation to overcome a risk behavior (e.g., smoking). Consequently, a central task for health communication is not only to provide information about the existence and magnitude of a certain risk but also to increase the subjective relevance of a health issue to focus the individuals' attention on information pertaining directly to their own risk. However, general perceptions of risk (e.g., "smoking is dangerous") and personal perceptions of risk (e.g., "I am at risk because I am a smoker") often differ to a great extent. Individuals could be well informed about general aspects of certain risks and precautions (e.g., most smokers acknowledge that smoking can cause diseases), but, nevertheless, they might not feel personally at risk (Renner & Schupp, 2011).

The adoption of health behaviors should not be viewed simplistically as a response to a health threat. Risk information alone does not help people to change risky behaviors because it does not provide meaningful information about how to manage behavioral changes. Initial risk perception seems to be advantageous in raising awareness and in helping people become motivated to change, but later on other factors are more influential in the self-regulation process.

Outcome Expectancies In addition to being aware of a health threat, people also need to understand the links between their actions and subsequent outcomes. These outcome expectancies can be the most influential beliefs in the motivation to change. The term "outcome expectancies" is most common in social cognitive theory (Bandura, 1986). "Pros and cons" take a similar role in the transtheoretical model (Prochaska & DiClemente, 1983), where they represent the decisional balance in people who contemplate whether to adopt a novel behavior or not. In the theory of reasoned action (Fishbein & Ajzen, 1975), the corresponding term is "behavioral beliefs" that act as precursors of attitudes.

The pros and cons represent positive and negative outcome expectancies. A smoker may find more good reasons to quit ("If I quit smoking, then my friend will like me much more") than reasons to continue smoking ("If I quit, I will become more tense and irritated"). This imbalance in favor of positive outcome expectancies will not lead directly to action, but it can help to generate the intention to quit. Indeed, a key observation of research from the transtheoretical model is the importance of "pros" *more than* "cons" in moving peoples from precontemplation to contemplation and preparation. Outcome expectancies can also be understood as means-ends relationships, indicating that people know proper strategies to produce the desired effects (Hankonen, Absetz, et al., 2013).

The perceived contingencies between actions and outcomes need not be explicitly worded; they can also be rather diffuse mental representations, loaded with emotions. Social cognition models are often misunderstood as being rational models that deal with "cold cognitions." In contrast, health behavior change, to a large degree, is an emotional process that turns into a cognitive one after people have been asked about their thoughts and feelings, thus making them aware of what is going on emotionally. An example of an emotional outcome expectancy is anticipated regret ("If I do not use a condom tonight, then I will regret it tomorrow").

Perceived Self-Efficacy Perceived self-efficacy portrays individuals' beliefs in their capabilities to exercise control over challenging demands and over their own functioning (Bandura, 1997). It involves the regulation of thought processes, affective states, motivation, behavior, or changing environmental conditions. These beliefs are critical in approaching novel or difficult situations, or in adopting a strenuous self-regimen. People make an internal attribution in terms of personal competence when forecasting their behavior (e.g., "I am certain that I can quit smoking even if my friend continues to smoke"). Such optimistic self-beliefs influence the goals people set for themselves, what courses of action they choose to pursue, how much effort they invest in given endeavors, and how long they persevere in the face of barriers and setbacks. Self-efficacy influences the challenges that people take on as well as how high they set their goals (e.g., "I intend to reduce my smoking," or "I intend to quit smoking altogether"). Some people harbor self-doubts and cannot motivate themselves. They see little point in even setting a goal if they believe they do not have what it takes to succeed. Thus, the intention to change a habit that affects health depends to some degree on a firm belief in one's capability to exercise control over that habit. Perceived self-efficacy has been found to be important at all stages in the health behavior change process which led to the development of phase-specific self-efficacy (Ochsner, Scholz, & Hornung, 2013).

Planning Good intentions are more likely to be translated into action when people develop success scenarios and preparatory strategies of approaching a difficult task. Mental simulation helps to identify cues to action. The terms planning and implementation intentions have been used to address this phenomenon. To date, research has accumulated abundant evidence for the effectiveness of planning in behavioral medicine (Wiedemann, Lippke, & Schwarzer, 2012). Meta-analyses have summarized the effects of planning on health behaviors (Gollwitzer & Sheeran, 2006).

One way of planning is the anticipation of barriers and the generation of alternative behaviors to overcome them. This has been called coping planning (Sniehotta, Schwarzer, et al., 2005). People imagine scenarios that hinder them in performing their intended behavior, and they develop one or more plans to cope with such a challenging situation. For example, "If I plan to run on Sunday, but the weather does not permit it, I will go swimming instead," or "If there is something exciting on TV tonight that I do not want to miss, I will reschedule my workout to the afternoon." Coping planning might be a more effective self-regulatory strategy than mere action planning. After people contemplate the when, where, and how of action, they imagine possible barriers and generate coping strategies. Thus, coping planning comes on top of action planning (Wiedemann, Lippke, & Schwarzer, 2012; Scholz, Schuz, et al., 2008). Planning is an alterable variable. It can be easily communicated to individuals with self-regulatory deficits. Quite a few randomized controlled trials have documented the evidence in favor of such planning interventions (for a review see Kwasnicka, Presseau, et al., 2013).

Principles

Principle 1: Motivation and Volition The health behavior change process is divided into two phases. There is a switch of mind-sets when people move from deliberation to action. First comes the motivation phase in which people develop their intentions. Afterward, they enter the volition phase.

Principle 2: Two Volitional Phases In the volition phase, there are two groups of people: those who did not yet translate their intentions into action and those who did. Thus, there are inactive as well as active persons in this phase. In other words, in the volitional phase one finds intenders as well as actors who are characterized by different psychological states. In addition to health behavior change as a continuous process, one can also create three categories of people with different mind-sets, depending on their current location within the course of behavior change: preintenders, intenders, and actors. This is more parsimonious than the TTM (precontemplators and contemplators = preintenders; preparers = intenders; actors and maintainers = actors).

Principle 3: Postintentional Planning Intenders who are in the volitional preactional stage are motivated to change, but they do not act because they might lack the right skills to translate their intention into action. Planning is a key strategy at this point. It serves as an operative mediator between intentions and behavior (for a review see Hagger & Luszczynska, 2014).

Principle 4: Two Kinds of Mental Simulation Planning can be divided into action planning and coping planning. Action planning pertains to the when, where, and how of intended action. Coping planning includes the anticipation of barriers and the design of alternative actions that help to attain one's goal in spite of impediments.

Principle 5: Phase-Specific Self-Efficacy Perceived self-efficacy is required throughout the entire process. However, the nature of self-efficacy differs from phase to phase. This is because there are different challenges as people progress from one phase to the next one. Goal setting, planning, initiative, action, and maintenance all pose challenges that are not of the same nature. Therefore, one can distinguish between preactional self-efficacy, coping self-efficacy, and recovery self-efficacy. Sometimes the terms *task self-efficacy* instead of preaction self-efficacy, and *maintenance self-efficacy* instead of coping and recovery self-efficacy are preferred.

Theory-Based Interventions

When it comes to the design of interventions, one can consider turning the implicit stage model into an explicit one. This is done by identifying individuals who are categorized as preintenders, intenders, and actors. The basic idea is that individuals pass through different phases on their way to behavior change. Thus, interventions may be most efficient when tailored to these particular mind-sets. For example, *preintenders* are supposed to benefit from confrontation with outcome expectancies and some level of risk communication. They need to learn that the new behavior (e.g., becoming physically active) has positive outcomes (e.g., well-being, weight loss, fun) as opposed to the negative outcomes that accompany the current (sedentary) behavior such as developing an illness or being overweight. They also need to develop an optimistic belief that they are capable of performing the critical behavior.

In contrast, *intenders* should not benefit much from health messages in the form of outcome expectancies because, after setting a goal, they have already moved beyond this mind-set. Rather, they should benefit from planning to translate their intentions into action.

Finally, *actors* should be prepared for particular high-risk situations in which lapses are imminent. Interventions help them if they desire to change their routines (e.g., adopting or altering a behavior).

Interventions should not be designed in a pure rational manner because health behavior change is also an emotional process that is being analyzed as a cognitive one only after people have been asked about their feelings. All the theoretical constructs are loaded with emotions in the first place. Thus, treatments need to focus on changes in emotions (for an overview of behavior change techniques, see Michie & Johnston, 2012).

Overviews of leading health behavior theories are provided in some book chapters (health belief model, reviewed by Abraham and Sheeran (2005); protection motivation theory, reviewed by Norman, Boer, and Seydel (2005); social cognitive theory, reviewed by Luszczynska and Schwarzer (2005); transtheoretical model, reviewed by Sutton (2005); and theory of planned behavior, reviewed by Conner and Sparks (2005)). The HAPA is presented in more detail in Schwarzer (2008).

Focused Theories on Occupational Factors in Health and Disease

Occupational Stress Model

Occupational stress has received growing attention as increasing evidence on its role in occupational health has become available. In particular, studies using theoretical models of occupational stress proved to be useful as they identify specific components of the work environment or of the interaction between the work setting and the working person, which adversely affect health. The impact of stressful working conditions on health has been investigated with particular intensity over the past 30 years. A number of theoretical models were developed and tested that identify stressful job characteristics with potentially adverse health effects (Cooper, 1998).

"Stress" is too vague a word to be informative in epidemiologic studies. For example, study participants are sometimes asked whether or not they experience occupational stress. The content may differ according to the individual. One person might perceive occupational stress as a result of time pressure, while another might suffer from a conflict in a personal relationship with a supervisor or colleague. Even if the exposures detected by the answer to such a question predict a health outcome, it would be impossible to intervene because the precise nature of the stressor would be unknown. There have been improvements in the measurement of occupational stress, moving away from the generic idea of stress toward the combination of a few definite concepts based on theories. The introduction of occupational stress models has made breakthroughs in conceptualizing real-life complex phenomena in the workplace. Constructed by a few relevant specific (toxic) components, occupational stress models are applicable to a broad range of occupations. They can be operationalized for experimental as well as epidemiological studies and be useful for the theory-based intervention.

The job demand–control model is one of the most prevailing occupational stress models in the field of behavioral medicine. The job demand–control model includes two components: psychological demands, which tap quantitative and conflicting demands of work, and job control, which measures decision authority and skill utilization over a task. Employees who face high demands and have little control over their work (i.e., job strain) are hypothesized to be at great risk of becoming ill (Karasek & Theorell, 1990). Later, the third component, social support at work, was incorporated (Johnson & Hall, 1988). According to the extended model – the job demand–control–support model – the highest risk of illness is expected in employees with high demands, low control, and low social support.

The predictive validity of the job demand–control (–support) model has been supported by a large number of empirical studies proving the predictions of various health outcomes, particularly cardiovascular diseases (CVD) (Belkic, Landsbergis, et al., 2004; Kivimaki, Nyberg, et al., 2012; Kivimaki, Virtanen, et al., 2006) and depression or psychological distress (Bonde, 2008; Netterstrom, Conrad, et al., 2008; Stansfeld & Candy, 2006). Evidence is accumulating on prospective associations with other health outcomes including musculoskeletal disorders (Rugulies & Krause, 2005) and sickness absence (Suominen, Vahtera, et al., 2007).

Hypothesized Mechanisms Through Which Occupational Stress Leads to CVD

Although several systematic reviews confirmed significant prospective association between occupational stress, including job strain (high demands and low control), and CVD (Belkic, Landsbergis, et al., 2004; Kivimaki, Nyberg, et al., 2012; Kivimaki, Virtanen, et al., 2006), the mechanisms underlying the association between occupational stress and CVD remain still unclear. Exploring the mechanisms is a scientific field providing many research questions (Fig. 7.6).

Much of the figure reflects the general theories on psychophysiological stress reviewed earlier in this chapter. Research however shows the value of articulating this general model among workers and in the specific contexts of work, leading to a focused theory of occupational stress. There are a number of epidemiological studies which address the association between occupational stress and conventional CVD risk factors, including hypertension, type II diabetes, and metabolic syndrome. Job strain (combination of high job demands and low job control) and iso-strain (combination of job strain and low social support at work) have been shown to predict incidence of hypertension (Markovitz, Matthews, et al., 2004; Schnall, Schwartz, et al., 1998), diabetes (Heraclides, Chandola, et al., 2012; Kumari, Head, & Marmot, 2004), and metabolic syndrome (Chandola, Brunner, & Marmot, 2006). Furthermore, sophisticated measurement devices such as ambulatory blood pressure monitoring has made more precise estimation possible rather than static blood pressure measured at clinical settings, and evidence shows consistent associations between job strain and high blood pressure in prospective analyses (Clays, Leynen, et al., 2007; Landsbergis, Schnall, et al., 2003). Recent large-scale pooled analyses also revealed prospective associations between job strain and unhealthy behaviors such as obesity, leisure-time physical activity, alcohol intake, and tobacco smoking (Fransson, Heikkila, et al., 2012;

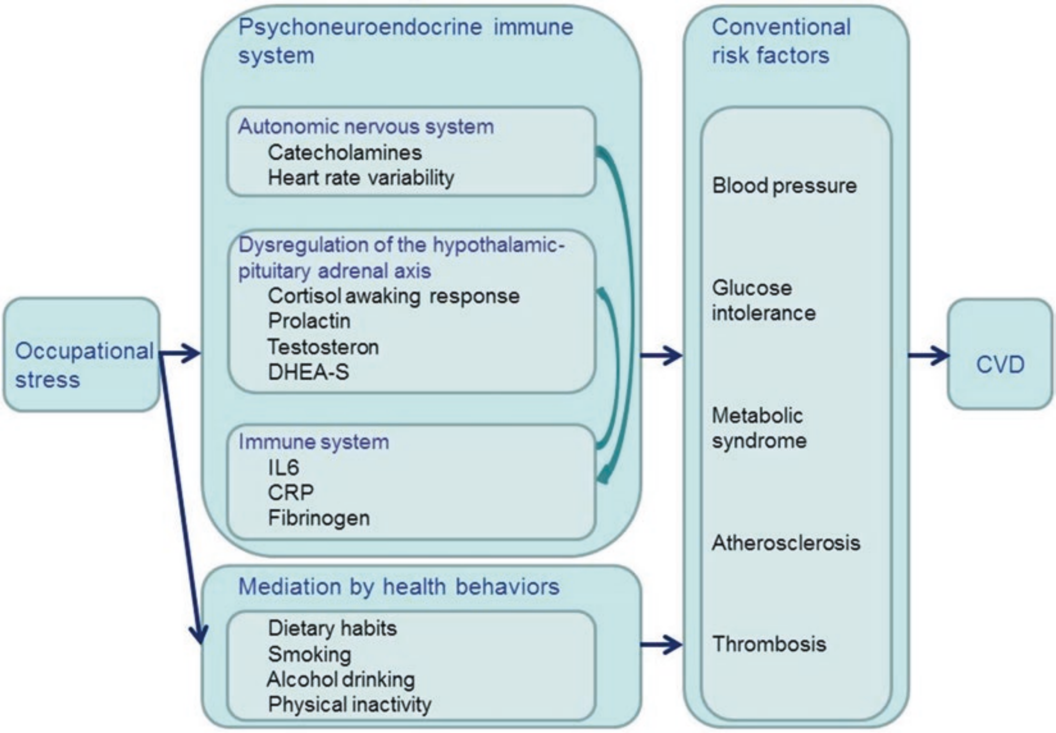

Fig. 7.6 Hypothesized mechanism underlying the association between occupational stress and CVD

Heikkila, Fransson, et al., 2013; Heikkila, Nyberg, et al., 2012; Nyberg, Heikkila, et al., 2012). Although confirmed, the associations seem weak so that hypothesis of an association between occupational stress and unhealthy behaviors are only modestly supported (Siegrist & Rodel, 2006).

Research interests are focusing more on pathophysiological mechanisms. Occupational stress is considered as chronic stressor, and its pathophysiological mechanisms are thought to be in accordance with rapidly accumulating knowledge regarding cardiovascular effects of the stress response (Brotman, Golden, & Wittstein, 2007). Occupational stress may affect CVD through direct activation of neuroendocrine and inflammatory responses to stressors. One of the main axes of neuroendocrine stress responses is the autonomic – sympathetic and parasympathetic – nervous system. Furthermore, occupational stress may affect dysregulation of the hypothalamic–pituitary–adrenal axis. Changes in sympathetic–parasympathetic balance and the tone of the hypothalamic–pituitary–adrenal axis may negatively affect the cardiovascular system. There may be acute effects, such as precipitating myocardial infarction, left ventricular dysfunction, or dysrhythmia, as well as chronic effects, such as accelerating the atherosclerotic process (Brotman, Golden, & Wittstein, 2007). In addition, evidence is accumulating that inflammatory cytokines production is associated with psychological stress.

Several studies investigated cardiovascular activity in response to perceived occupational stress. Strong evidence has been observed in blood pressure elevation in response to job strain (Steptoe & Willemsen, 2004; Theorell, Perski, et al., 1988). Association of occupational stress with repeated activation of the sympathetic nervous system, characterized by high heart rate, lowered heart rate variability, and reduction in high frequency power, has also been explored in occupational settings (Collins, Karasek, & Costas, 2005; Rau, Georgiades, et al., 2001).

Studies on the associations of occupational stress with hormonal measures have produced less consistent findings. Catecholamines such as adrenaline and noradrenalin are relevant biomarkers of sympathetic nervous system arousal. Since adrenaline and noradrenalin have a short half-life in the circulation, urinary catecholamines are often measured in occupational stress research. Some studies showed elevated urinary catecholamine levels among workers with job strain (Evans & Carrere, 1991; Harenstam & Theorell, 1988; Pollard, Ungpakorn, et al., 1996) but some did not (Brown & James, 2000; van der Beek, Meijman, et al., 1995). Interesting findings are associations of job strain with sustained activation of catecholamine (i.e., after work) suggesting slow unwinding of sympathetic nervous activity (Fujiwara, Tsukishima, et al., 2004; Lundberg & Frankenhaeuser, 1999).

The release of corticosteroids represented by cortisol is part of the systematic arousal of the hypothalamic–pituitary–adrenal axis initiated by release of corticotropin-releasing hormone by the hypothalamus. Normally, cortisol release shows clear circadian rhythms and appears to peak at early morning hours, with a low point around midnight. Studies of cortisol regulation in workers with job strain suggest that the regulation is disturbed, but the patterns of cortisol release appeared different by studies. Some studies indicated that morning saliva cortisol levels increased in job strain (Steptoe, Cropley, et al., 2000) or remained lower in low job strain (high job control and low job demands) groups (Alderling, Theorell, et al., 2006), while several others showed reduced rather than heighten cortisol responses among strained group (Fujiwara, Tsukishima, et al., 2004; Rystedt, Cropley, et al., 2008; Steptoe, Wardle, et al., 1998). The latter finding is explained by an inhibited elevation of morning cortisol induced by prolonged stress. In an experimental study which employed a simulated work–office environment allowing for manipulation of job demands and job control in a strict orthogonal fashion, Hausser, Mojzisch, and Schulz-Hardt (2011) found that participants in the high strain condition showed a significantly higher cortisol response compared to participants in the non-strain conditions and that higher demands led to a higher cortisol response in the conditions when participants had low job control but no such increase was found when job control was given.

So far the observed associations of job strain and hormonal responsiveness are not consistent. But literature suggests that clearer overall pictures are expected to be found by introducing into the analyses personal characteristics and histories of the workers, such as anger expression (Steptoe, Cropley, et al., 2000) or exposure to adversity in adolescence (Westerlund, Gustafsson, et al., 2012). Similarly, clearer overall pictures are expected to be found by taking into consideration how long the workers are exposed to job strain (Fujiwara, Tsukishima, et al., 2004; Rystedt, Cropley, et al., 2008) or restricting the study participants to employees whose regulatory system (circadian rhythm) is intact (Alderling, Theorell, et al., 2006). Responsiveness of hormone release can be more clearly distinguished by employing independent manipulations of job demands and control in a laboratory (Hausser, Mojzisch, & Schulz-Hardt, 2011).

A recent systematic review suggests that occupational stress is associated with disrupted immune responses: Nakata (2012) identified 56 studies on the research question. Of those studies, 12 tested whether job strain was associated with immune parameters and five tested the effect of the effort-reward imbalance (ERI) model, another established occupational stress model (Siegrist, 1996). Seven out of 12 job strain studies and all ERI studies showed significant associations between occupational stress and immune parameters. However, many other studies that focused on certain type of jobs that were considered to be inherently stressful and other quantitative workload features such as overwork and self-reported mental demand produced inconsistent or insignificant associations between the stress measurements and immunoglobulin markers and/or cellular immune indicators. Nakata attributed the inconsistent findings to measurement issues of occupational stress, such as the difference in intensity, length, acute, or chronic, along with other methodological shortcomings, including lack of prospective studies with sufficient sample size, residual confounding, and measurement methods of immune indicators with much to be improved. Nakata also pointed out the importance of careful selection of stress measures because some job stress measures may not be suitable for certain occupations and jobs. Well-established occupational stress measures which cover various and broad aspects of working conditions and with high validity and reliability would overcome these shortcomings on stress measurement.

New technologies such as neuroimaging have been incorporated to untangle the complex interactions of risk factors. Functional associations between brain, neuroendocrine, immune, and cardiovascular reactivity were examined in experimental settings (Isowa, Ohira, & Murashima, 2006; Ohira, Fukuyama, et al., 2009) in which researchers manipulated controllability (controllable vs. uncontrollable), while subjects performed a stochastic learning task. Their regional cerebral blood flow, cardiovascular, neuroendocrine, and immune indices were measured simultaneously. The studies showed that immune responses were most directly associated with cardiovascular activities under the uncontrollable condition and that the dorsolateral prefrontal and orbitofrontal cortices are involved in both evaluation of the controllability of a stressor and regulation of immune function. More specifically, redistribution of NK cells as well as mediating autonomic and endocrine responses to a stressor was attenuated or downregulated when the stressor was uncontrollable. These findings that uncontrollability of an analog stressor in an experimental situation inhibits adaptive regulation of immune, cardiovascular, and neuroendocrine responses to stress have obvious relevance to the focused area of occupational stress, given its major emphasis on job controllability.

In summary, epidemiological studies utilizing the demand–control model have revealed prospective associations of job strain and its components (demand/control/support) on conventional CVD risk factors, such as hypertension, diabetes, metabolic syndrome, and health behaviors. Naturalistic and laboratory studies in which high demand-low control situations are manipulated have been uncovering the pathophysiological mechanisms through which job strain lead to CVD. This demand–control model constitutes, then, a focused theory, articulating in the specific features of occupational stress, the broad relationships of general theories on psychophysiological stress.

Lessons from Interventional Research

Stress-reduction approaches in the workplace would be improved by focused theories that might provide useful tools for dealing with real-life complex phenomena in the workplace. Intervention effect could then be evaluated based on the theory.

There are three levels of psychosocial intervention at workplace: individual level, interpersonal level, and organizational level. Of these, organizational intervention is of particular importance because more permanent and efficient effects are anticipated (Burke, 1993; Karasek, 1992). However, the three levels are not mutually exclusive. A strong participatory element is especially important when the organizational intervention study focuses on work organization, communication, or interpersonal relations (Kompier, Geurts, et al., 1998) so that it is necessary to improve not only work environment but also workers' empowerment (Kompier & Kristensen, 2001). Successful participatory organizational interventions would be expected to work in two main ways: (1) by modifying objective stressful conditions in the psychosocial environment and (2) through the active learning that workers experience in direct participation and successfully affecting positive change. The former is based on occupational stress theory that primarily focused on environmental improvement or job redesign rather than behavioral change in symptoms of ill-health. The latter is due to enhanced perceptions of control and influence, development of skills based on organizational learning theory, and self-esteem and social support enhanced by participation, dialogue, and workplace democracy (Mikkelsen, Saksvik, & Landsbergis, 2000).

A team-based, problem-solving intervention was conducted based on active employee involvement, shared work-related goals, and action planning to improve the work environment for stress reduction (Tsutsumi, Nagami, et al., 2009). The theoretical concept that provided the basis for the study was the job demand–control–support model. As introduced in the former section, the job demand–control–support model identifies three psychosocial factors at work whose effects on physical and mental health are the most frequently documented. It was hypothesized that implementing an intervention targeting the theory grounded psychosocial work environment should bring about beneficial effects on workers (a decrease in mental health problem or improvement of job performance) through a decrease in three adverse psychosocial factors – high psychosocial demands, low decision latitude, and low social support.

Exposure to psychosocial job conditions was measured before the intervention as prior hazard identification and at the end of the intervention in order to evaluate implementation of the intervention. For this, the Job Content Questionnaire (JCQ) was employed. The JCQ is based on Karasek's demand–control–support model (Karasek & Theorell, 1990). The results of pre-intervention stress surveillance based on JCQ was visualized to compare Japanese national data and then used as a reference for hazard identification and an index of improvement (Kawakami & Japan Industrial Safety and Health Association, 2001). In addition, a checklist was introduced for organizing workplace-level discussion to identify immediate, low-cost improvements in the workplace. The checklist was developed through a review of related references and the collection of examples of workplace improvements to produce a concrete action plan (Yoshikawa, Kawakami, et al., 2007). Using these tools, workers listed and prioritized issues to be improved in their workplace based on the results of their stress surveillance, then started to improve their work conditions based on the action plans.

Scores on the General Health Questionnaire during the follow-up period improved in the production lines where the intervention was implemented, whereas the score deteriorated in the production lines of the control groups, with a significant intervention effect. In addition, scores for self-reported job performance increased in the intervention group, but decreased in the control groups, yielding a significant intervention effect (quantitative outcome evaluations). According to the job demand–control–support model, these results would be attributable to the improvement of three psychosocial work environment, i.e., decreasing job demands and increasing of job control and/or workplace social support.

Process evaluation examines whether the intervention was properly conducted and then whether the theory underlying the hypothesis was supported. Theoretically, stress-related outcomes can be improved by increasing workers control or social support at work and decreasing job demands. Some studies examined the hypothesis by investigating the mediating effects of job control–demands–support statistically (quantitatively) (Bond & Bunce, 2001; Jackson, 1983). As qualitative methods are useful to examine the richness and significance of people's (context-dependent) experience (Griffiths, 1999), we evaluated the implementation of the intervention by employing qualitative method (post-intervention interviews with those involved in the intervention).

Post-intervention interviews revealed that psychosocial job conditions (job control and social support at work) improved in most intervention lines and that meaningful actions resulted from these improvements. For example, at a line, where job control was improved, the workers dealt with a variety of small parts, and the tasks had not been standardized. The work involved the workers thinking for themselves, and the small units they worked on were formulated according to the specific task. In another line, the workers proposed many improvement plans by mutual agreement. For example, dust was a problem in the line, so they decided to clean up their workplace regularly with all members of the group carrying out the plan (coworker support increased). At the other line, the preparatory table was moved nearer to the task table so that frequently used materials and tools would be placed within easy reach, thus substantially shortening preparation time. Manuals for working procedures were revised by marking specific places, so that workers could refer to them more easily (job control increased). A line leader produced several improvement plans such as labeling materials, inventory control, and gauge instrument improvement, which were then executed. Supervisor support was substantially improved in this line.

Post-intervention interviews also revealed some of the reasons why psychosocial job conditions did not improve in the intervention lines. These reasons included low workers' self-esteem, resistance of veteran workers who were near retirement, and poor human relationships in line, which the line leaders attributed to the poor commitment of the workers, leading intervention not to be effective. The information was considered useful for redesigning the intervention (Griffiths, 1999).

The above example shows the implementation of a participatory intervention for workplace improvement by addressing three adverse psychosocial work factors (high psychological demands, low decision latitude, and low social support) grounded in a focused theory of the job demand–control–support model and their effects on workers' mental health and job performance. Further, the theory guided process evaluation by both quantitative and qualitative methods that provided rich information on how the intervention was implemented and whether the hypothesized mediating effects of psychosocial work factors were valid. Both successful and failed intervention will provide a step forward in occupational stress research as well as further strengthen the theory's validity. Scrutinizing the process will facilitate the interpretation and integration of research findings.

Focused Theory: Functional Decline in Osteoarthritis[3]

Avoidance of Activity in Osteoarthritis of the Knee

Osteoarthritis (OA) of the knee is associated with pain and instability of the knee and leads to activity limitations, such as limitations in walking and climbing stairs. Activity limitations may translate

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[3] This section describes only part of the theory. A full description of the theory is given in Dekker (2014).

into restrictions in social participation, for example, problems with housekeeping and traveling.

The course of functioning in knee OA is highly individual and variable: functioning has been found to improve in some patients, to remain stable in others, and to gradually worsen in still others (Dekker, van Dijk, & Veenhof, 2009; Holla, van der Leeden, et al., 2014). One of the risk factors for functional decline is psychological distress. Psychological distress, i.e., an anxious and depressed mood, predicts future functional decline (Dekker, van Dijk, & Veenhof, 2009; van der Leeden, Veenhof, et al., 2014).

This empirical observation led to the question: how does psychological distress contribute to future functional decline? There is no direct link between psychological distress (i.e., an anxious and depressed mood) and future decline (e.g., limitations in walking and climbing stairs). Thus, the question arises how psychological distress contributes to functional decline. In other words, a theory is needed on how psychological distress contributes to future functional decline. This can be stated more generally. A risk factor provides information on prognosis. Unless the risk factor has a direct impact on prognosis, the risk factor does not explain prognosis, however. Risk factors are part of complex causal mechanisms which determine prognosis. A risk factor in itself is just an observation, not an explanation. Explanation requires theory on the complex causal mechanisms which determine prognosis, as is illustrated below.

It has been theorized that avoidance of activity explains the impact of psychological distress on future functional decline in knee OA. According to this explanation, pain may cause subjects to avoid activity: in knee OA, pain is frequently related to activities such as walking. Avoidance of these activities reduces pain. In the short term, this is beneficial: avoidance of activity causes less pain. In the long term, however, avoidance of activity causes muscle weakness and thereby activity limitations. Physical activity and exercise are required to maintain muscle strength. Avoidance of activity causes muscle weakness, which is an important cause of activity limitations (see Fig. 7.7).

Psychological distress is thought to enhance the tendency to avoid activity, resulting in muscle weakness and activity limitations (see Fig. 7.7). Psychologically distressed patients, i.e., patients with an anxious and depressed mood, lack motivation to exercise or to perform physical activity and avoid such activities. Thus, psychological distress is hypothesized to strengthen the tendency to avoid activity, leading to muscle weakness and activity limitations.

This theory was introduced as an explanation for the observation that psychological distress predicts worsening of activity limitations. Avoidance

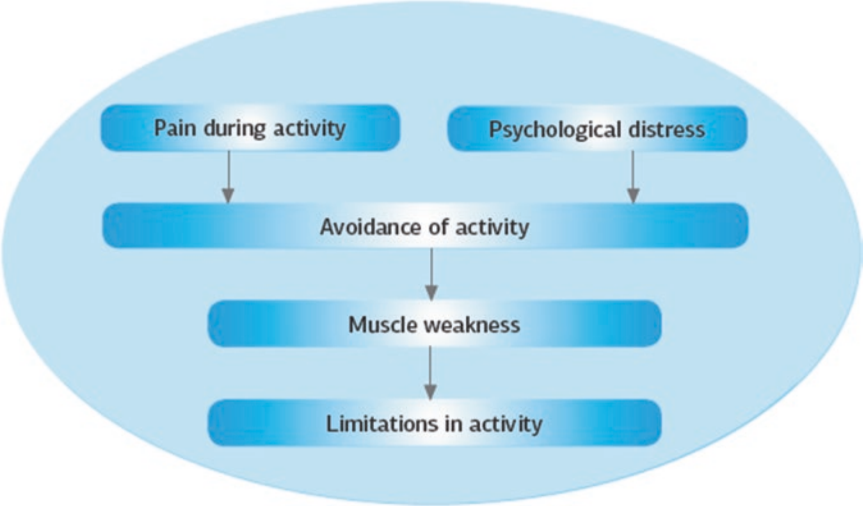

Fig. 7.7 Behavioral explanation of activity limitations: Avoidance of activity

of activity was introduced as an explanation of this phenomenon in 1992 (Dekker, Boot, et al., 1992). Although terminology and some details of the theory have evolved, the basic theoretical model has remained the same over the years.

This theory was tested in a series of studies, generally confirming the validity of this focused theory and illustrating the interplay between theory and empirical findings (Dekker, Tola, et al., 1993; Steultjens, Dekker, & Bijlsma, 2002; Holla, van der Leeden, et al., 2012; Pisters, Veenhof, et al., 2014; Holla, Pisters, &, Dekker, 2014). (i) The first hypothesis derived from the theory stated that muscle weakness mediates the relationship between psychological distress and activity limitations. This hypothesis was tested and confirmed (Dekker, Tola, et al., 1993), which encouraged further research. (ii) The next study focused on avoidance of activity, as this is a central concept in the theory. The hypothesis derived from the theory stated that avoidance of activity induces muscle weakness which results in activity limitations. In other words, muscle weakness mediates the relationship between avoidance of activity and activity limitations. The hypothesis was tested and confirmed (Steultjens, Dekker, & Bijlsma, 2002). (iii) Subsequently, hypotheses were formulated on the impact of pain and psychological distress, as the role of pain and psychological distress had not yet been tested. It was hypothesized that pain induces avoidance, resulting muscle weakness. In other words, avoidance of activity is a mediator between pain and muscle weakness. This hypothesis was tested and confirmed (Holla, van der Leeden, et al., 2012). In addition, it was hypothesized that psychological distress enhances the impact of pain on avoidance (moderation). This hypothesis was rejected (Holla, van der Leeden, et al., 2012). Instead, evidence was found that psychological distress induces avoidance directly, not as mediated by pain, resulting in muscle weakness (see Fig. 7.7). The hypothesis that muscle weakness mediates the relationship between avoidance of activity and activity limitations was tested once again and confirmed (Holla, van der Leeden, et al., 2012). This was a replication of the earlier confirmation (Steultjens, Dekker, & Bijlsma, 2002). Finally, a longitudinal study confirmed the findings from previous cross-sectional studies: in a 5-year follow-up study, the mediating role of muscle weakness between avoidance of activity and activity limitations was confirmed (Pisters, Veenhof, et al., 2014). Thus, starting with cross-sectional studies, the empirical status of the theory gradually became stronger as also a longitudinal study supported the theory.

This progression of findings illustrates *the heuristic function of theory* (see section “The Role of Theory in Behavioral Medicine Research”). The theory has driven a series of studies, gradually deepening our understanding of functional decline in knee OA. The theory indicated which studies needed to be done, in order to understand functional decline in knee OA.

Neuromuscular Exercise in Osteoarthritis of the Knee

Neuromuscular factors other than muscle weakness are known to be associated with functional decline in knee OA. This includes proprioception (the sense of joint motion and position), laxity (the passive range of motion in the frontal plane), and varus–valgus motion (movement of the knee in the frontal plane during walking). These factors are hypothesized to interact with muscle weakness causing instability of the knee and thereby leading to activity limitations. This theory is illustrated in Fig. 7.8. Evidence to support this theory has been summarized elsewhere (Van der Esch & Dekker, 2014).

Based on this neuromuscular theory, a neuromuscular exercise program was developed. It was argued that muscle strengthening exercises may not be sufficient to improve the performance of activities. Exercise therapy may need to target instability and may need to improve neuromuscular control, in addition to muscle weakness. Thus, an exercise program was developed, comprising neuromuscular exercises, in addition to the strength training. Neuromuscular exercise consisted of balance and agility training, aiming at improved perception of knee position and motion and at improved control of the knee.

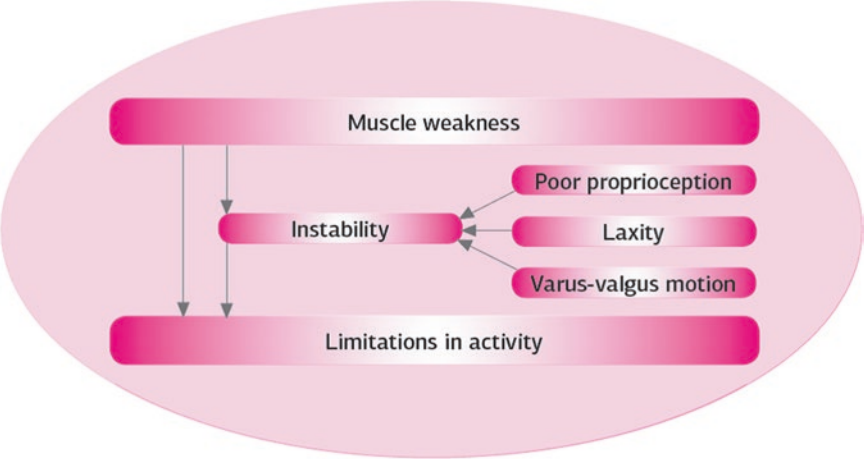

Fig. 7.8 Neuromuscular factors and activity limitations

This approach was tested in a randomized clinical trial comparing an exercise program consisting of neuromuscular exercise (aiming at improved stability of the knee), strength training and functional exercise (aiming at improved performance of activities) with a program consisting of strength training and functional exercise (aiming at improved performance of activities) only. It was expected that the first program would be more effective in improving the performance of activities of knee OA patients than the second program. Unexpectedly, there was no evidence of differential effectiveness of these programs: both programs were highly effective in improving muscle strength, stability, and the performance of activities; but there was no significant difference in effectiveness of these programs (Knoop, Dekker, et al., 2013).

The neuromuscular theory provided guidance in interpreting this unexpected result (see Fig. 7.8). A likely explanation for the negative result of the trial is that muscle weakness has a much stronger impact than the other neuromuscular factors. If muscle weakness is the most important determinant of activity limitations, improvement in other neuromuscular factors is not likely to improve outcome. Another explanation of the negative results of the trial is that strength training not only improved muscle strength but also other neuromuscular factors: if strength training improves both muscle strength and other neuromuscular factors, additional training of the other neuromuscular factors is unlikely to improve outcome (Knoop, Dekker, et al., 2013). Both explanations point to the importance of strength training in knee OA: strength training seems to be the most important modality of exercise therapy in knee OA.

This example illustrates *the integrative function of theory* (see section “The Role of Theory in Behavioral Medicine Research”). The focused theory on neuromuscular control in knee OA was instrumental in developing the tentative explanation of the dominant role of exercise aiming at muscle strengthening. The theory facilitated interpretation of the unexpected, negative result of the trial. Of course, the tentative conclusion that strength training is the most important modality of exercise therapy in knee OA needs further empirical testing.

The Power of Thought

We have summarized two major general theories in behavioral medicine, specifically psychophysiological stress theories and social cognitive theories on health behavior change, as well as two focused theories, specifically theories on occupational factors in health and disease, and on functional decline in osteoarthritis. These theories have several features in common:

- First, the development of these theories shows a cyclical process. The original version of the theory is stated. Empirical observations then indicate the need for adaptation of the original theory. The revised theory is subsequently subjected to further empirical testing. This cyclical process is a key feature of the development of scientific theory.
- Second, the authors of these theories are strongly committed to maintain theoretical rigor. The theories are characterized by clearly defined concepts and logically consistent relationships between these concepts.
- Third, these theories are falsifiable: the theories have been repeatedly shown to be wrong, indeed. Negative empirical findings led to adaptation and further development of the theories.
- Fourth, in revising theories, authors have aimed to maintain parsimony. The health action process approach (HAPA) is a good example of this as described in section "General Social Cognitive Theories of Health Behavior Change" of this chapter. The degrees of theoretical freedom are limited, i.e., parsimony is a distinct characteristic of this theory.
- Finally, each of these theories is restricted to a clearly defined domain of reality. The general theories are restricted to the impact of psychological stress on disease and to health behavior change, respectively. The focused theories are restricted to the impact of occupational stress on health and disease and to functional decline in osteoarthritis, respectively.

Most important, perhaps, each of these fields shows the power of thought. Theory gives direction to the development of research questions – the heuristic function of theory and theory facilitates the interpretation and integration of research findings – the integrative function of theory. Theoretical analysis is vital for the development of behavioral medicine as a scientific discipline.

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8

Advancing Implementation: Toward an Inclusive View of Research in Behavioral Medicine

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Introduction

In the early years of this millennium, having made a major investment in the development of evidence-based innovations, policymakers and others in health and social services were expecting to see dramatic improvements in outcomes for children, families, and individuals in the population. Disappointing results led to examinations that pointed to a growing science to service gap (Institute of Medicine, 2000, 2001; U.S. Department of Health and Human Services, 1999). Evidence-based innovations were slow to be used in typical service settings when they were used at all (Nembhard, Alexander, et al., 2009). Estimates suggested about 14% of the evidence-based innovations were used in practice after about 17 years (Balas & Boren, 2000; Green, 2008). These and other reviews provide clear indications that evidence is not enough to produce socially significant outcomes (Rangachari, Rissing, & Rethemeyer, 2013). The success of an evidence-based innovation is not measured by its effectiveness alone, but needs to take into account the ability to bring the full, intended experience of the innovation into the lives of children, families, and communities.

The science-to-practice gap is being addressed across multiple fields, disciplines, and settings, including education, public health, criminal justice, child welfare, and other social service sectors. A variety of terms, from "diffusion" and "adoption" (Rogers, 1962, 1995) and "dissemination" and "implementation" (Brownson, Colditz, & Proctor, 2012) to "knowledge translation" (Graham, Logan, et al., 2006), "knowledge to action" (Wilson, Brady, & Lesesne, 2011), "knowledge transfer and exchange" (Kiefer, Frank, et al., 2005), and "translational research" (Kelly, Somlai, et al., 2000; Waldman & Terzic, 2010), are commonly used – often interchangeably – to describe inquiry along this continuum of getting from science to practice. Dissemination and implementation (D&I) are sometimes combined as if they refer to a shared approach for getting research evidence into practice (Rabin, Brownson, et al., 2008).

The question "what does it take?" to get evidence into practice is critical so that what can help improve health reaches those it is intended to help. For the sake of clarity, "implementation" includes diffusion (passive spread of innovation knowledge) and dissemination (distribution and transfer of

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information and innovation material), but is not defined by them. Implementation is an active and outcome-oriented endeavor (Fixsen, Naoom, et al., 2005) that is focused on how to support full and effective use of an evidence-based innovation as intended in typical service settings (Fixsen, Blase, et al., 2013a, b; Greenhalgh, Robert, et al., 2004). Implementation remains the missing link in the science to service chain, although the quality chasm may be narrowing.

The Need for Attention to the Process of Implementation

While experimental medicine had been under way for a long time (Bernard, 1865), it was the call for evidence-based medicine (EBM) by Sackett, Rosenberg, Gray, Haynes, and Richardson (1996) that raised expectations of the benefits to be derived from investments in innovation. Shortly thereafter, the Society of Behavioral Medicine established an Evidence-Based Behavioral Medicine (EBBM) Committee that was supported by the National Institutes of Health (NIH) Office of Behavioral and Social Science Research (OBSSR) to explore how core principles of EBM were applied to research on behavioral (non-drug, non-device) interventions (Davidson, Goldstein, et al., 2003). By 2006, the US health-care crisis had arrived and, along with it, the need for a better integrated system of care and coordinated approach to evidence-based behavioral medicine. OBSSR sponsored the Council on Evidence-Based Behavioral Practice, who, from an interdisciplinary approach across medicine, nursing, psychology, social work, public health, and information sciences, developed an evidence-based practice model in evidence-based behavioral medicine (EBBM). In contrast to the sole emphasis of evidence-based medicine (EBM) on research evidence, the EBBM model of research to practice added two parameters: resources (i.e., practitioner expertise) and client/population characteristics (Satterfield, Spring, et al., 2009). This model acknowledged that the translation of research to practice required some degree of client engagement in shared decision making and resources such as trained interventionists and accessible community facilities. The model also acknowledged that EBP occurs in particular organizational and environmental contexts that will influence implementation.

Given the power of EBM advocates expecting that people benefit from investments in innovation, the research budget for the National Institutes of Health (NIH) in the United States doubled between 1995 and 2010 (www.nih.gov). The challenges inherent in this idea came to light when Clancy (2006), then the head of the federal Agency for Healthcare Research and Quality, noted that the $100 billion annual investment in research had very little impact on the $1.6 trillion spent on health-care services. She speculated the lack of impact may be due to federal funding choices through which NIH spends over 99% of its budget to produce evidence-based innovations and less than 1% on how to use those innovations effectively in practice. Perl (2011), a longtime leader in the National Institute on Drug Abuse, cited similar experiences and suggested we are "addicted to discovery." Woolf and Johnson (2005) reviewed innovations and health outcomes and observed that any new innovation would have to be three times more powerful than anything yet produced to realize the same public benefit that would be derived from using already known innovations as intended. With all this in mind, Kessler and Glasgow (2011) suggested a moratorium on funding to produce innovations. They recommended investing heavily in implementation science so that the health-care system could learn to use the innovations already established and available for use.

All of these issues are strong arguments for investing in implementation science, practice, and policy. Hundreds of articles on the topic have been published about implementation strategies, including "one-off" ideas, measures, and approaches with methods and findings varying from one investigator to the next (Tinkle, Kimball, et al., 2013); yet there is little discernable progress that integrates what we are learning and knowing in implementation science in health. Why is that? Answers to this and other questions about what we currently know in implementation science – and how we know it – are the topic of this chapter.

Implementation Science: A Brief History

Looking Across Disciplines

Implementation science, as a self-conscious field of study, has been developing since the 1950s (Fischer, Miller, & Sidney, 2006; Pressman & Wildavsky, 1973; Saetren, 2005; Van Meter & Van Horn, 1975). The interest in implementation was born in analyses of policy outcomes. In the United States, the 1950s and 1960s saw major federal laws providing funds to achieve ambitious goals. The Eisenhower System of Interstate and Defense Highways (passed in 1956), the National Aeronautics and Space Act (passed in 1958), Kennedy's pledge in 1961 to put astronauts on the moon and return them safely to earth by 1969, and Johnson's Great Society programs (passed in 1965) encountered many difficulties even with massive input of federal funding and intervention.

Policy analysts began looking at policy implementation. It is not enough to have enabling legislation that funds departments to administer funds and contracts. The funds have to be administered in ways that assure implementation activities are in place to produce the desired outcomes. McNichol (2006) has a fascinating account of how the Federal Highway Administration had to encounter and overcome obstacles in society (routing based on racism), administration (contracts based on corruption instead of building roadways), and supply (lack of consistency and quality among contractors) to meet the goal of building 50% of the envisioned interstate highway system by 1966 (10 years after passage of the legislation). The National Aeronautics and Space Administration (NASA) was formed as a new agency to administer contracts and fund innovations to accomplish the seemingly impossible task of safely going to the moon and back. Landing on the moon in 1969 dramatically accomplished the vision in the 1958 legislation but not before engineering problems were overcome (e.g., strong metals, heat shields), and many innovations (e.g., silicon-based integrated circuits, lightweight computers) were developed. The highways and moon landings were mission driven, and problems were viewed as opportunities to create solutions to accomplish the goal.

The Great Society programs did not fare so well. The war on poverty, urban renewal, Medicaid, head start and follow-through education, VISTA volunteers, and others were heavily funded and backed by federal authority. By 1982 President Reagan eliminated nearly all of the funding for Great Society programs. Rossi and Wright (1984) provided a retrospective view of the "Golden Age" where science was intended to guide changes in social programs to achieve a Great Society. Unlike the highway and space programs, the effects for Great Society programs were close to zero. The conclusion was that the implementation was the culprit (Pressman & Wildavsky, 1973; Rossi & Wright, 1984; Van Meter & Van Horn, 1975). The intentions of the legislation and federal and state department administrators rarely were actualized in practice and, therefore, could not produce the intended benefits.

The next "Golden Age" for science began with the initiation of the evidence-based movement in the 1990s (Backer, 1992; Roberts, 1996; Sackett, Rosenberg, et al., 1996). The evidence-based movement has rekindled interest in implementation as the missing link in the science to service chain. Networks of researchers and practitioners have galvanized around implementation at state, national, and global levels (e.g., Colorado Implementation Collaborative (CIC), http://www.coloradoimplementation.com/; the European Implementation Collaboration (EIC) http://www.implementation.eu/; and the Global Implementation Initiative (GII), http://globalimplementation.org). Since 2010, the US federal government has invested in a number of evidence-based social policy programs. But without support for quality implementation, they too run the risk of not delivering promised outcomes. Reviews of the literature have documented growth and gaps in knowledge about diffusion and dissemination (Brownson, Colditz, & Proctor, 2012; Greenhalgh, Robert, et al., 2004) and implementation (Fixsen, Naoom, et al., 2005). More recent reviews of numerous frameworks have been conducted to guide diffusion and dissemination (Tabak, Khoong, et al., 2012) and implementation (Meyers, Durlak, & Wandersman, 2012) research and practice. Results from these remarkable advances in implementation science will inform the discussion in this chapter.

Implementation Science in Behavioral Medicine

In EBBM, translational behavioral medicine (TBM) is an approach that concerns the transfer of knowledge from the psychosocial and biomedical sciences in order to develop behavioral interventions to improve health, evaluate the effectiveness of those interventions, and study and improve their implementation in practice and policy. The overarching objective of TBM is to advance, integrate, and actualize knowledge from the research, practice, and policy arenas to improve the health of individuals and communities. Since 2011, implementation-related studies have been reported in *Translational Behavioral Medicine: Practice, Policy, Research*, a scholarly professional journal devoted to the topic that was established by the Society of Behavioral Medicine.

The research-to-practice gap is being addressed from multiple facets. Training institutes for dissemination and implementation research (Meissner, Glasgow, et al., 2013) and knowledge translation (Straus, Brouwers, et al., 2011) have been designed to influence the research itself and make it more relevant and actionable for generating the kind of evidence that can enhance what we know about the research to practice process (e.g., www.ebbp.org). The International Society of Behavioral Medicine (ISBM) has facilitated satellite forums on dissemination and implementation and formed a global network on D&I research (Chan, Oldenburg, & Viswanath, 2015). Some national programs have required applicants to adopt one or more evidence-based strategies that have been specified in a prescribed menu of effective practices (Hawkins, Wilson, & Rodriguez, 2011). Methodologically, professionals are recommending use of alternative research designs and approaches to recast the nature or conduct of research itself to identify and understand the factors that facilitate implementation of behavioral medicine programs, e.g., mixed-methods approaches (Green, Duan, et al., 2015), pragmatic trials (Glasgow, 2013), qualitative comparative analysis (Kane, Lewis, et al., 2014), systems science methods (Burke, Lich, et al., 2015), and effectiveness-implementation hybrid designs (Curran, Bauer, et al., 2012). Others are calling for the need to establish critical evaluation and reporting elements that are relevant to and can assist the situations and decisions of practitioners and policymakers seeking to put research into practice (Neta, Glasgow, et al., 2015). A 2015 Special Issue of the *International Journal of Behavioral Medicine* on *Advancing the Science of Dissemination and Implementation in Behavioral Medicine* outlines evidence and progress from the application of many and varied theories and research methodologies to bridge research to practice (Chan, Oldenburg, & Viswanath, 2015).

Other studies along the evidence-to-practice continuum are examining how to best disseminate and implement evidence-based interventions and integrate them within clinical and community settings. In many cases, studies utilize and test a particular "implementation strategy" to deliver and increase uptake of an evidence-based program; researchers then evaluate changes in client or population outcomes. For example, investigators examined use of a peer-led approach to translate use of a proven, clinic-based diabetes prevention program in a community mental health organization (Schneider, Sullivan, & Pagoto, 2011). In another study, investigators tested the use of commercial smartphone-based devices and applications to improve chronic disease health monitoring behaviors (Vashist, Schneider, & Luong, 2014). Despite some positive results (much like an efficacy trial), such studies often fail to operationalize "what it takes" to support full and effective use of the innovation (also known as the process of implementation). Instead, investigators continue to report the need to understand and then actually address what turns out to be a complex set of factors for how to get evidence-based interventions into practice (Dolcini, Catania, et al., 2014; Spoth, Rohrbach, et al., 2013).

In contrast to "implementation" as its own intervention strategy to deliver an evidence-based innovation (and then measuring client or population outcomes), other researchers are focused on understanding, addressing, and improving factors related to the "how" of implementation. Most real-world practice occurs in complex organizations and contexts, suggesting that successful implementation may necessitate the use of an array of strategies to be effective at multiple levels of an organization or system (e.g., clinician-level competence, organizational culture). Herein, studies use discrete (e.g., training), multifaceted (e.g., training plus reminders), and comprehensive approaches that incorporate multiple implementation strategies or systematic processes to integrate evidence-based innovations into routine care or services (Powell, McMillen, et al., 2012). The comprehensive bundles of implementation strategies align with taking more of a systems thinking approach to implementation, one that understands and embraces the real features of community, organizational, and other contexts (Best & Saul, 2011; Chaudoir, Dugan, & Barr, 2013). These more comprehensive approaches may complicate the task of operationalizing implementation methods in complex, yet typical environments. Doing so, however, may offer greater coverage of potential barriers to change and also build a range of strong and relevant bridges from science to practice that are based in the realities of lower-resourced settings.

Taking an Inclusive Look at What We Are Learning in Implementation

The Case for Universal Thinking in Implementation

What *do* we know about the conditions that affect implementation? Implementation science has a long history based on the experiences of those who are attempting to put evidence-based innovations, legislation, mandates, and good ideas into practice so that they produce intended benefits to individuals and society. The health sector has not paid attention to the broader developments in implementation science, preferring to "stick with their own" and consider only evidence-based innovations and implementation in health. For example, the 121 references in a summary of the need for better theory to encourage better implementation in public health behavior programs (Glanz & Bishop, 2010) included only six citations related to developments outside of health.

The premise of this chapter is that implementation principles are universal. This is a parsimonious assumption, an assumption proven useful to guide advances in science (Thorburn, 1915). In mathematics the methods for computing a mean are the same in health, education, social services, engineering, business, and so on. Why a mean needs to be computed and the meaning of the mean that is derived may vary widely, but the principles are the same. The methods for calculating a mean may vary (e.g., adding and dividing manually, or with a calculator, or using a high-powered computer), but the operations to compute the mean are the same across the various methods. After years of experience, we now can be reasonably sure there is no "health mean" that is different from, say, a "child welfare mean" or a "manufacturing mean."

Instead of looking inward at "health only" information about implementation, health sciences can benefit from implementation science as it has evolved with contributions from a wide variety of fields. A review and synthesis of the implementation evaluation literature (Fixsen, Naoom, et al., 2005) summarized information from agriculture, business, child welfare, engineering, health (including global and public), juvenile justice, manufacturing, medicine, mental health, nursing, and social services. Valuable information also was obtained from complexity and chaos theories, computer science, political science, and organizational sciences. Like statistics, implementation is universal, because it is derived from each of and all these fields. The generalizable principles have much to offer each field, including health and behavioral medicine. By turning to counterparts in other domains, health and behavioral medicine can learn how they are approaching problems, identifying areas of common interest and challenges, and sharing insights and ideas for the mutual benefit and advancement of evidence to practice from each domain.

The remainder of this chapter will discuss why and how the health sector can benefit from a more inclusive view of implementation science. First, human service (including health) settings are complex, the variables interact among various levels of practice and organizations, and the time frames for detecting outcomes are long (Hawe, 2015). This means useful implementation data are difficult to produce in any domain, and a better understanding will evolve from accumulating research data from all domains, including complexity science (Leykum, Pugh, et al., 2007) and improvement science (Ovretveit, 2011). Second, variations in settings and complexity of innovations produce greater exposure to a range of potentially important implementation variables. Variability in other domains can inform effective implementation practices in the health domain. Third, measures of implementation variables have been slow to develop. The lack of common assessments inhibits the development of accumulated knowledge within and across domains. Measures developed in one domain can be helpful in other domains and can advance the science more rapidly.

Frameworks to Guide Implementation

The complexity within human service systems and the well-documented interactions among variables at practitioner, organization, and system levels (Novins, Green, et al., 2013; Lobb & Colditz, 2013) have led to the development of implementation frameworks. The frameworks are designed to organize thinking and guide research and practice when the use of innovations is attempted. They are also intended to offer "incrementally actionable" guidance for leveraging change where other broad frameworks have been less clear (Rangachari, Rissing, & Rethemeyer, 2013). Recently, two reviews of frameworks have been published to guide our understanding of how to get evidence into practice. Tabak, Khoong, et al. (2012) documented 61 frameworks related to diffusion, dissemination, and/or implementation. Of the 61 frameworks, 12 were categorized as specific implementation frameworks. Meyers et al. (2012) outlined the key features of 25 implementation frameworks. Of the 37 specific implementation frameworks documented in these two reviews, only 5 appeared on both lists. The developmental nature and trajectory of implementation science can be seen in the little overlap among the frameworks in these two reviews published in the same year. Also, as outlined in Table 8.1, the date of publication is an indication of the recent expansion of interest in implementation science and practice. Only 4 of the 45 source documents cite frameworks developed before the current millennium, and 22 were published after 2005. More publications about implementation frameworks (20+) have been published in the 6-year period from 2006 to 2012 than in the 15-year period from 1989 to 2005.

Table 8.1 Source documents for 32 implementation frameworks summarized by year of publication

Publication year	Number of source documents
1989–2000	4
2001–2005	16
2006–2012	22
No date (web citations)	3

Amidst the growing number of implementation models, some are well known and applied in health. In particular, frameworks such as RE-AIM (Glasgow, Vogt, Boyles, 1999), PRISM (Homer, Milstein, et al., 2010), CFIR (Damschroder, Aron, et al., 2009), and PARIHS (Rycroft-Malone, 2004) are often cited as important conceptual frameworks for understanding translational processes and interrelated factors that facilitate implementation.

- RE-AIM (reach, effectiveness, adoption, implementation, and maintenance) is a framework that focuses primarily on characteristics of the intervention with some attention to the organization context. It was classified by Tabak, Khoong, et al. (2012) as a framework equally focused on dissemination and implementation and is a frequently used approach (Park, 2015). Reach is the percent and representativeness of individuals willing to participate in receiving the intervention; effectiveness is the impact of the intervention on targeted outcomes and quality of life; adoption is the percent and representativeness of settings and intervention staff that agree to deliver the intervention; implementation is the consistency and skill with which various intervention elements are delivered by the staff (i.e., fidelity); and maintenance is the degree to which intervention benefits are sustained for individuals as well as how long the intervention is sustained for organizations delivering it.

- The Prevention Impacts Simulation Model (PRISM) is designed to estimate trajectories for health and cost outcomes for the entire US population from 1990 to 2040. PRISM includes heart disease, stroke, diabetes, hypertension, high cholesterol, and obesity and accounts for cancers and respiratory diseases related to smoking, obesity, poor nutrition, and physical inactivity. The model includes 14 interventions that are influenced by factors such as access, price, promotion, and regulation. The model reports summary measures of mortality and years of life lost as well as the consequent medical and productivity costs of the chronic diseases and conditions modeled. PRISM represents an interesting approach to modeling interventions in whole systems to maximize public benefit. (It should be noted that another common model of implementation within organizational settings (Feldstein & Glasgow, 2008) also goes by the acronym "PRISM," the practical, robust implementation and sustainability model. This latter-named framework is included in the two major reviews of implementation frameworks as referenced in subsequent parts of this chapter.)
- The Consolidated Framework for Implementation Research (CFIR) is composed of five major domains: intervention characteristics, outer setting, inner setting, characteristics of the individuals involved, and the process of implementation. The intervention is defined in terms of the strength and quality of the evidence. The outer setting refers to patient needs and resources. The inner setting is defined by organization culture and the extent of leadership engagement. Individual characteristics include knowledge and beliefs, self-efficacy, and identification with the organization. The process of implementation includes planning, execution, evaluation, and reflection.
- Promoting Action on Research Implementation in Health Services (PARIHS) is a framework that emphasizes evidence, context, and facilitation factors related to an innovation and its implementation in practice. High-quality evidence that fits patient experiences and expectations is desirable. Context emphasizes organization culture, leadership, and the use of data for improvement in a learning organization. Facilitation is noted as a critical function to ease the tasks related to using an innovation in the midst of existing practices and organization structures.

With these four health-oriented implementation frameworks in mind, what can be learned from looking across implementation syntheses from other fields (e.g., Fixsen, Naoom, et al., 2005) and other, more recent frameworks? What do we know about conditions that affect implementation of any innovation? How can we create, improve, and replicate conditions for effective implementation in real-world settings and systems based on what we know and what we are learning about factors that contribute to effective implementation? (Metz & Albers, 2014; Nichols, Martindale-Adams, et al., 2014; Pagoto, 2011). Answers from such inquiry can guide implementation research and practice across behavioral medicine and other disciplines.

Looking Across Implementation Frameworks

The modest overlap among the implementation frameworks (5 of 37) in two major reviews published in the same year provides a glimpse into the complexity of this work. It also highlights the conundrum facing implementation researchers and potential users of evidence-based innovations: 32 views of implementation. In this regard, they offer information about a range of perspectives from a variety of human service and business fields and can suggest components considered important to the process of using research evidence in human services.

The 32 distinct implementation frameworks identified from Tabak, Khoong, et al. (2012) and Meyers, Durlak, and Wandersman (2012) are listed alphabetically in Table 8.2. As noted in Table 8.2, the frameworks are drawn from work in a number of fields, such as mental health, health care, business, substance abuse, education, violence, drug use, and injury prevention. Source documents are noted in Table 8.2 with a designation indicating whether documents were available in a form suitable for further qualitative analysis. Source documents were not available or suitable for data entry and further analysis for seven (7) frameworks.

The number of frameworks presents a challenge for implementation researchers and potential users of innovations supported by research evidence. Frameworks developed in individual sectors add confusion to a field that has lacked coherence and definition. In their reviews of the literature, Brownson et al. (2012), Greenhalgh, Robert, et al. (2004), and Fixsen, Naoom, et al. (2005) point out the difficulties encountered in the review process. Researchers in different fields with different traditions and interests use different languages to describe a common concept or use common language to describe different concepts. The lack of agreed-upon language for concepts and commonly used measures of implementation variables hinder reviews and prevent quantitative meta-analyses. A similar problem now can be seen in frameworks tailored to particular fields. Winter (2006) states, "The implementation sub-discipline has been characterized by many different approaches representing different research strategies, evaluation standards, methodologies, concepts, and focal areas for research. … The highly fragmented character of implementation research is not very conducive to theory accumulation" (p. 163).

Fixsen and Fixsen (2016) conducted a qualitative content analysis across the 32 specific implementation frameworks to provide guidance for the next generation of research, practice, and theory development. Data from source documents were entered into *Atlas.ti*, the software used to code aspects of each framework. An initial set of codes, themes, and categories was developed based on a prior review and synthesis of the implementation evaluation literature (Fixsen, Naoom, et al., 2005) and based on the open coding and categories developed in the Model Programs Study (Naoom, Blase, et al., 2010). The prefigured categories, themes, and codes were used initially to code the primary source documents in order to narrow the scope of data analysis (Creswell, 2007). While the typological analysis provides a place to begin, there was room for novel themes to emerge from the data. Thus, the codes and illustrative quotations reflect the initial set of codes as well as novel content that did not fit the prefigured coding categories.

The initial results are summarized in Table 8.3. The coding process that examined the source documents noted in Table 8.2 resulted in over 600 pages of coded "quotations." Nearly all of the codes that emerged from the examination were readily grouped into the key components of the Active Implementation Frameworks (Fixsen, Blase, et al., 2015; Metz, Bartley, et al., 2014) – effective innovations, enabling contexts, implementation drivers, implementation stages, implementation teams, and improvement cycles. For example, the codes for capacity assessment, community involvement, organization/system alignment, capacity for change, context, implementation policy, and system intervention are aspects of enabling context in the Active Implementation Frameworks. Quotations associated with those codes were grouped under this column in Table 8.3.

Two additional coding groups emerged that were heavily emphasized by many framework authors – codes for "fit" and "recipients." In particular, in many of the frameworks (Aarons, Hurlburt, & Horwitz, 2011), the psychological makeup of recipients or intended beneficiaries of innovations and the culture and climate of organizations attempting to use innovations are postulated to be important determinants of readiness of "recipients" and "fit." These codes were included in the Active Implementation Frameworks where they are

Table 8.2 The 32 frameworks in the sample and source documents as cited in the reviews of Meyers, Durlak, and Wandersman (2012), of Tabak, Khoong, et al. (2012), and of both reviews

Review	Access	Framework and source documents	Primary focus
Tabak	✓	*4E's process theory* Pronovost, Berenholtz, and Needham (2008)	Health
Both	✓	*Active implementation frameworks* Fixsen, Naoom, et al. (2005) and http://nirn.fpg.unc.edu/learn-implementation	Transdisciplinary
Both	✓	*Availability, Responsiveness & Continuity (ARC): An organizational & community intervention model* Glisson and Schoenwald (2005) and Glisson, Schoenwald, et al. (2010)	Delinquency and mental health
Meyers	✓	*Blueprints – Evidence-based violence and drug prevention programs* Hawkins, Catalano, and Arthur (2002); Mihalic et al. (2004)	Corrections and substance abuse
Meyers	✓	*Community-based prevention services* Sandler, Ostrom, et al. (2005)	Community development
Meyers	✓	*Community-based programs for violence prevention and substance abuse prevention* Stith, Pruitt, et al. (2006)	Community development and substance abuse
Tabak	✓	*Conceptual model of evidence-based practice implementation in public service sectors* Aarons, Hurlburt, and Horwitz (2011)	Human services and child welfare
Both	✓	*Consolidated Framework for Implementation Research (CFIR)* Damschroder, Aron, et al. (2009)	Health
Meyers	✓	*Diffusion, dissemination, and sustainability of innovations in health care* Greenhalgh, Robert, et al. (2004)	Transdisciplinary
Meyers	✓	*Framework to implement strategies in organizations (management)* Okumus (2003)	Business
Meyers	✓	*Getting To Outcomes (GTO): Community-based substance abuse prevention planning* Chinman, Hunter, et al. (2008) and Chinman, Imm, and Wandersman (2004)	Substance abuse
Meyers	✓	*Health promotion and disease prevention* (Guldbrandsson, 2008)	Health
Both	✓	*Implementation effectiveness model* Klein and Sorra (1996) and Klein, Conn, and Sorra (2001)	Business
Meyers	✓	*Interactive systems framework – Injury and violence prevention* Wandersman and Florin (2003) and Wandersman, Duffy, et al. (2008) and Wandersman and Florin (2003)	Corrections, delinquency, and injury prevention
Tabak	✓	*Normalization process theory* May and Finch (2009) and Murray, Treweek, et al. (2010) and www.normalizationprocess.org.	Transdisciplinary
Tabak	✓	*Organizational theory of innovation implementation* Weiner, Lewis, and Linnan (2009)	Human services
Meyers	✓	PARIHS evidence-based healthcare Rycroft-Malone (2004)	Health

(continued)

Table 8.2 (continued)

Review	Access	Framework and source documents	Primary focus
Tabak	✓	*PARIHS – Promoting Action on Research Implementation in Health Services* Kitson, Harvey, and McCormack (1998) and Kitson, Rycroft-Malone, et al. (2008) and Rycroft-Malone (2004)	Health
Meyers	✓	*Prevention and health promotion programs* Durlak and DuPre (2008)	Health
Meyers	✓	*PRISM evidence-based health care* Feldstein and Glasgow (2008)	Health
Meyers	✓	*PROSPER population-based youth development and reduction of youth problem behaviors* (e.g., substance use, violence, and other conduct problems). Richard Spoth and Greenberg (2005) and Spoth, Greenberg, Bierman, and Redmond (2004)	Delinquency and education
Meyers	✓	*QUERI evidence-based health care United States Veterans Administration* Stetler, McQueen, Demakis, and Mittman (2008)	Health
Both	✓	*Replicating effective programs plus framework* Kilbourne, Neumann, Pincus, Bauer, and Stall (2007)	Health
Meyers	✓	*School-based preventive and mental health promotion interventions* Greenberg, Domitrovich, et al. (2005)	Education and mental health
Tabak	✓	*Sticky knowledge* Elwyn, Taubert, and Kowalczuk (2007) and Szulanski (1996)	Business
Meyers		*CASEL* http://www.cdc.gov/globalaids/support-evidence-based-programming/implementation-science.html	Education
Tabak		*Conceptual model of implementation research* Proctor et al. (2009)	Health
Meyers		*Diffusion of innovations in organizations* Rogers (2003)	Agriculture and communications
Meyers		*School-based innovations* Hall and Hord (2011)	Education
Meyers		*Community-based prevention planning* www.pfsacademy.org	Community development
Meyers		*Technological innovations* Van de Ven, Angle, and Poole (2000)	Business
Meyers		*Comprehensive, individualized, family-driven mental health services* Walker and Koroloff (2007)	Child welfare and mental health

postulated to play a key role in staff selection (one of the implementation drivers) and organization exploration processes (one of the implementation stages). However, in the Active Implementation Frameworks, fit and recipients were not given the same central and independent role in determining implementation and innovation outcomes.

Integrating Implementation Frameworks

For current purposes, it is apparent that the health-related frameworks are not unique in some way – the concepts and operations described by Damschroder, Aron, et al. (2009), Kitson, Harvey,

Table 8.3 A summary of the number of quotations coded in 31 source documents related to 25 implementation frameworks. The quotations are organized into categories related to the Active Implementation Frameworks

	Active implementation (Impl.) frameworks						
Reviewed frameworks	Effective innovation	Enabling context	Impl. drivers	Impl. stages	Impl. team	Improvement cycles	Totals
4E's process theory	3	0	5	2	2	3	15
Availability, Responsiveness, Continuity (ARC)	1	7	3	5	6	2	24
Blueprints evidence-based violence and drug prevention programs	2	2	5	6	5	0	20
Community-based prevention services	8	4	6	7	6	14	45
Community-based programs for violence prevention and substance abuse prevention	6	9	18	13	3	7	56
Conceptual model of evidence-based practice implementation in public service sectors	3	17	15	21	4	2	62
Consolidated Framework for Implementation Research (CFIR)	4	13	10	7	5	9	48
Diffusion, dissemination, and sustainability of innovations in health care	7	14	12	9	5	4	51
Framework to implement strategies in organizations (management)	0	13	11	8	3	6	41
GTO community-based substance abuse prevention planning	5	5	9	6	4	5	34
Health promotion and disease prevention	0	0	0	1	1	0	2
Implementation effectiveness model	7	16	16	13	2	5	59
ISF injury and violence prevention	2	10	9	3	8	3	35
Normalization process theory	7	2	2	2	1	1	15
Organizational theory of innovation implementation	3	14	8	12	0	2	39
PARIHS evidence-based healthcare	3	8	5	1	6	1	24

(continued)

Table 8.3 (continued)

	Active implementation (Impl.) frameworks						
Reviewed frameworks	Effective innovation	Enabling context	Impl. drivers	Impl. stages	Impl. team	Improvement cycles	Totals
Prevention and health promotion programs	3	8	14	4	2	3	34
PRISM evidence-based health care	4	6	7	6	3	2	28
Promoting Action on Research Implementation in Health Services- PARIHS	0	2	0	0	2	0	4
PROSPER Population-based youth development and reduction of youth problem behaviors	1	8	5	7	5	4	30
QUERI evidence-based health care	0	6	4	1	1	0	12
Replicating effective programs plus framework	1	0	2	4	1	2	10
School-based preventive and mental health promotion interventions	1	2	6	5	4	2	20
Sticky knowledge	3	4	6	9	6	4	32
CASEL	Source documents related to these seven frameworks were not examined. Some source documents were not in a format (books or internet content, e.g., Rogers, 2003; Hall & Hord, 2011) that could be entered readily into *Atlas.ti* qualitative analysis software. Other source documents were summaries of the literature or descriptions of studies and not intended to be frameworks (e.g. Proctor, Landsverk, et al., 2009; Walker & Koroloff, 2007)						
School-based innovations							
Community-based prevention planning							
Conceptual model of implementation research							
Diffusion of innovations in organizations							
Technological innovations							
Comprehensive, individualized, family-driven mental health services							
Totals	74	170	178	152	85	81	740

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et al. (1998), Kitson, Rycroft-Malone, et al. (2008), and Feldstein and Glasgow (2008) are very similar to the other frameworks and fit equally well into the key components of the Active Implementation Frameworks. As noted in the totals at the bottom of Table 8.3, the frameworks overall included more coded information related to implementation drivers, enabling contexts, and implementation stages. Implementation teams, improvement cycles, and effective innovations also were well represented, although there were fewer coded quotations related to these three components.

The summary presented in Table 8.3 is important for advancing implementation science, practice, and theory. The Active Implementation Frameworks are based on a thorough review of the implementation evaluation literature (Fixsen, Naoom, et al., 2005), analysis of best practices as described by expert purveyor and user groups (Blase, Fixsen, et al., 2005; Blase, Naoom, et al., 2015), and evaluations in organization and system change efforts (Fixsen, Blase, et al., 2013a, b; Metz, Naoom, et al., 2015; Sullivan, Blevins, & Kauth, 2008). The research base and best available practice evidence base provide a comprehensive foundation for the Active Implementation Frameworks. As a comprehensive and evidence-based framework, the Active Implementation Frameworks offer a comfortable fit with the 25 frameworks subject to review and a way to begin to integrate core elements of implementation across disciplines and fields of study in health and other human services.

Effective Innovation

Nearly all of the 32 frameworks point to the use of effective innovations as the goal of implementation science. Effective innovations may be supported by evidence obtained from a range of methods beyond randomized group designs (US Government Accounting Office, 2009). They also emphasize the need to define the core functions and operationalize those functions, so innovations are clear and can be learned, used, assessed, and repeated in practice. The clarity of the core functions is important, so the degree of "adaptation" can be assessed during the adoption process, and so the fidelity of use of the innovation can be assessed in practice. Additionally, clarity of key functions can serve to provide an important level of coherence across similar approaches applied in different settings that are necessarily contextualized based on local culture, resources, and other organizational features (Leerlooijer, Ruiter, et al., 2011).

Implementation Drivers

Implementation drivers attend to the confidence and competence of those delivering the innovation and the organizational context in which they are being delivered. Nearly all of the frameworks direct attention to developing the competency of practitioners, so they know about and are able to use an innovation in practice. Staff training and some form of coaching are seen as essential to developing relevant competencies. The Active Implementation Frameworks include fidelity assessment as a key component of developing competency and an essential outcome of selecting, training, and coaching practitioners to use an innovation. The frameworks in the review were not so clear, and several expressed a tension between assuring fidelity and assuring fit with existing therapies and organizational routines.

Organizational factors were common features of the frameworks with an aim to support practitioners and support necessary training and coaching. Organization factors included data collection and the use of data to help inform decisions by managers and leaders. In behavioral medicine, researchers are noting the role of "data liquidity" – ensuring the availability and free flow of data at the local, "on-the-ground" level – as critical to facilitate implementation (Abernethy, Wheeler, et al., 2011). Leadership was seen as essential to any change process related to the use of innovations in practice. There is good agreement that organizations need to change to accommodate and support the use of effective innovations in practice and that leadership has an essential role in initiating and managing change within the organization and within the broader system in which it operates. Such emphasis on the demonstrative role of leadership in implementation can also be found in behavioral medicine. In particular, a case study of implementation of behavioral interventions for HIV prevention in resource-limited settings identified active program leadership, commitment, and support at the provincial level as essential for program uptake and to ensure program continuity (Jones, Weiss, & Chitalu, 2015).

Implementation Stages

The frameworks varied in the emphasis given to stages or phases of activities, although nearly all of them advised that implementation processes take time. Nearly all of the attention in the frameworks was focused on what the Active Implementation Frameworks refer to as the exploration, installation, and initial implementation stages of implementation. That is, what are the considerations for arriving at a decision to adopt an innovation, what resources are needed to get started and how can they be obtained, and how can practitioners be hired or approached then prepared to begin to use an innovation with appropriate recipients for the innovation. Related research in behavioral medicine has explored the type and timing of individual, organization, sociopolitical context, and innovation factors that influence the adoption, continuation, and continuation of interventions in different settings (Huijg, van der Zouwe, et al., 2015).

As mentioned earlier, the frameworks emphasized the psychological readiness of individuals and the cultural and climate readiness of organizations as critical to the exploration and installation processes. The Active Implementation Frameworks give some attention to these factors but not to the same degree. For the Active Implementation Frameworks, readiness can be created during the exploration and installation processes, and organization culture and climate are seen as outcomes of implementing innovations with fidelity and good outcomes. Thus, beyond some minimal amount, they are viewed as products and not prerequisites.

Implementation Teams

The question of who does the work of implementation was given scant attention in the frameworks. Engaging in exploration activities, providing training and coaching, assuring leadership for change, and so on are actions requiring expertise in order that they be conducted effectively and efficiently. The AIF explicitly include expert implementation teams in organizations and systems as essential to implementation processes. An unplanned, "do it yourself" approach likely will be inconsistent and difficult to improve from one innovation to the next and one organization to the next. Without implementation teams as a key aspect of an implementation framework, other elements become prerequisites since there is no component of the framework to produce what is not already present (e.g., readiness, culture, climate, informed beneficiaries). In behavioral medicine, some researchers are noting the important role of intervention development teams to address a series of structural decision points (e.g., addressing environmental barriers, creating strategies for sustainability) (Rotheram-Borus, Swendeman, et al., 2011). An important distinction here is the composition and function of the team: it is not a team focused on project execution framed by funding parameters, but a team of people with competencies and specific roles to ensure implementation strategies.

Enabling Contexts

The frameworks place considerable emphasis on organizational and system contexts that are needed to support the adoption, use, and sustaining innovations in practice. Such emphases on context are acknowledged as translational behavioral medicine explores how to address and overcome barriers to global implementation. Depending on the framework, the lists vary but often include factors related to referrals, funding, monitoring, rules and regulations, and leadership for changing the features of current organizations and systems that are not conducive to the use of effective innovations and effective implementation methods. Low- and middle-income countries (LMIC) not only suffer from a double burden of disease, but often less available and limited resources, supports, and infrastructure (e.g., size and training of health workforce, public sector system supports) (Oldenburg & Absetz, 2011) that frameworks emphasize as critical for effective implementation. Amidst tremendous resource challenges, practical insights from those working in LMICs demonstrate important ways forward (Baumann, 2011; Baumann, Frederick, et al., 2015). While there is broad acknowledgement of the critical role of context, the frameworks are often silent on who might be accountable for creating contextual readiness or improving contextual fit over time. In the Active Implementation Frameworks, the implementation teams are accountable for these functions and work with leaders at various levels to create alignment and fit where needed.

Improvement Cycles

Little attention is given to improving innovations, implementation methods, organization functioning, and contextual fit after an innovation is put into practice. The AIF make the assumption that the process of getting started will produce many opportunities to get better. It also is assumed that the longer an innovation is in use in an organization, the more it will impact organization and system functioning. Thus, change is expected and improvement cycles are embedded in organizations in the same way training and coaching become standard functions in organizations using EBPs and other innovations. Some investigations in behavioral medicine note relationships between high levels of fidelity and high levels of readiness (contextual factors), suggesting a possible paradox that an intervention may work best for those who need it least. Rather than only selecting for levels of readiness, the field is acknowledging the need for implementation activities to improve factors associated with high fidelity and to measure and monitor fidelity and moderating factors over time (Augustsson, von Thiele Schwarz, et al., 2015).

Applying What We Are Learning: Case Examples

Fall prevention among the elderly presents compelling implementation challenges. The life-threatening consequences for individuals and costly outcomes for society are well documented (Gillespie, 2004; Scott, Wagar, et al., 2010). The research evidence has been so compelling that it has led to updated clinical practice guidelines limiting patient restraints and new policies emphasizing the use of alternative interventions to fall prevention (http://www.law.cornell.edu/uscode/42/1395i-3.html). Despite the evidence and efforts to change practice, the overuse of physical restraint remains common at approximately 5% in the United States (Agens, 2010) and 31% in Canada (Feng et al., 2009). The rate of chemical restraint is estimated at 34% in long-term care facilities in the United States (Agens, 2010), far higher than the recommended rates of 0–5% required for optimal resident care (Guttman, Altman, & Karlan, 1999). Evidence-based alternatives to the use of restraints include lowering beds, using hip protectors to reduce fall-related hip fractures, adding Vitamin D supplementation to enhance muscle strength and bone density, increased supervision, and regular toileting to address incontinence (Cameron et al., 2010; Scott, et al., 2010; Shimada, Tiedemann, et al., 2009). Integrating these into daily practice presents implementation challenges that can be overcome with the purposeful use of implementation supports (Fixsen, Scott, et al., 2011).

In another case example, Metz, Bartley, et al. (2014) used the implementation frameworks to guide the development of a county child welfare program to keep children with their families and out of the foster care system. An implementation team was formed, a usable intervention was developed, and staff were hired, trained, and coached to execute the new ways of work with children and families. Data were collected on the performance of the implementation team and the fidelity with which the intervention was delivered to families in daily practice. Higher scores on implementation team performance (from 1.10 to 1.83 on a 0–2 scale) were related to higher fidelity scores for caseworkers (from 18% to 83%). The purposeful use of evidence-based implementation strategies makes a socially significant difference in outcomes for the intended beneficiaries of behavioral health programs.

In another study, investigators report a successfully translated behavioral intervention (SMART/EST Women's Program) which aimed at reducing distress, improving health, and decreasing risk behaviors for disadvantaged women living with HIV/AIDS in the United States (Weiss, Tobin, et al., 2015). The study translated evidence to clinical practice by using community health center staff (versus research staff) to conduct the intervention. Authors reported equivalence of outcomes between the research-led and community health center staff-led groups. Paradoxically, such outcome data can distract from trying to understand and be able to support the processes for using the innovation elsewhere. Qualitative data on the process of implementation is as essential as quantitative data on endpoints, given the complexity of real-world settings and the challenges encountered. Authors outlined implementation strategies that focused on developing staff competency and confidence, building organizational infrastructure and leadership support, and paying attention to core elements and fidelity at the same time as adapting to local context. Such information about strategies to support both practitioners and organizations in implementation are necessary for the kind of "transferring ownership" that is required to be effective.

Summary, Conclusions, and Future Directions

Advancing implementation science in behavioral medicine is critical for addressing the evidence-implementation gap and corresponding, urgent need for intentional support of evidence-based and public health interventions. With the advent of frameworks, the field of implementation science is moving from making lists to making sense (Nilsen, 2015) and is moving toward mid-range theories of implementation (ICEBeRG, 2006). The compilation and comparison of frameworks provides an inclusive view of implementation research and dependable guidance for those who intend to support the use of evidence-based programs in typical behavioral health settings. In terms of understanding, addressing, and improving factors related to the "how" of implementation, recurring themes include (a) a defined set of an innovation's core components that can guide parameters for necessary adaptations based on context, (b) building the competence and confidence of those delivering the innovation, and (c) developing and strengthening organizational infrastructure to create culture, climate, practices, and policies that support implementation activities. Other themes addressed the nuanced difference between applied research to identify factors influencing implementation and approaches that actively address and improve – rather than try to control – those factors with an eye toward ongoing quality improvement of implementation.

Moving forward, advancing implementation in behavioral medicine will require a combination of evidence from different fields, different perspectives, and different research designs. After all, the evidence-to-practice question herein is not "does this innovation work under ideal conditions?" Evidence from formal trials along with case studies, network analyses, systems thinking, assessments of local context, and other approaches will provide information and improve the evidence flow from multiple perspectives relevant to implementation (Yamey & Feachem, 2011). In addition, most real-world settings for implementation involve complex, multifaceted, existing, and sometimes overlapping programs rolled out by a variety of organizations; and many approaches to effective implementation are multicomponent (Hawe, 2015). Many types of evidence are needed to make research findings more relevant and actionable for implementation, which calls for innovative study designs (e.g., rapid learning designs, simulation modeling) (Rabin & Glasgow, 2015). Learning from and in parallel with other fields such as quality improvement research and empowerment evaluation can also advance implementation in behavioral medicine (Olds & Øvretveit, 2013; Wandersman, Alia, et al., 2015).

The need for many types of evidence in implementation also calls for innovative measurement science (e.g., development of context-relevant measures, longitudinal measures). In particular, agreement about core constructs that affect implementation success and identifiable measures of them will strengthen the coherence and understanding of implementation research. These may include organization, provider, structural, and innovation- and patient-level constructs and demonstrated a reliable association with implementation outcomes (e.g., fidelity) (Chaudoir, Dugan, & Barr, 2013). Examples of implementation measurement include the Seattle Implementation Research Conference Measures Project (www.seattleimplementation.org/) and the Grid-Enabled Measures developed by the National Cancer Institute (http://cancercontrol.cancer.gov/brp/gem.html), both of which are initiatives to compile, enhance, and help harmonize dissemination and implementation measures.

Behavioral medicine and a number of other fields are also giving prominent attention to the issue of community or stakeholder engagement throughout the process of implementation. A number of case studies describe the process of relationship building – between community and academic partners, between professional and community support organizations, and between scientific and community priorities (Pagoto, 2011). Evidence-to-practice efforts at national and global scales will require the leadership and ownership of community and organizational partners. Such participatory approaches – in exploring fit of an innovation, assessing fidelity, sensemaking about socially significant outcomes – have been associated with enhanced buy-in, support of, and momentum in implementation efforts (Huijg, van der Zouwe, et al., 2015; Pinto, Waldemore, & Rosen, 2015).

As implementation science progresses, federal and state agencies are changing to take advantage of the knowledge base. Service dollars are being spent and accounted for, but, without realizing the improvement in service outcomes expected from evidence-based programs, attention now is turning to the fidelity with which evidence-based programs are being used in practice. Data showing poor fidelity associated with poor outcomes (Sanetti & Kratochwill, 2014; Schoenwald, Garland, et al., 2011) has led to increasing interest in implementation methods to consistently produce high-fidelity performance among populations of practitioners. Integrating frameworks will expedite this process and guide funding, quality assurance, and provider organization operations for generations to come.

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Part III

Key Influences on Behavior and the Relationships Among Behavior, Health and Illness

9

Behavioral Medicine's Roots in Behaviorism: Concepts and Applications

Howard Rachlin, Leonard Green,
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The conceptual and empirical approaches of behaviorism in western psychology of the twentieth century provided an important foundation for the development of behavioral medicine. Many key areas of behavioral medicine have their roots in behavior therapy which in turn arose from behaviorism and learning theory (Wolpe, 1969) to address issues of mental health and psychotherapy. Neil Miller, a pioneer in the application of behaviorism to complex behavior and psychotherapy (Dollard & Miller, 1950), was a major figure in the development of behavioral medicine. Biofeedback (Cox, Sutphen, et al., 1998), stress management interventions featuring relaxation and active coping with stressors (Bishop, Kaur, et al., 2005; Levenkron, Cohen, et al., 1983; Penedo, Dahn, et al., 2004; Surwit, van Tilburg, et al., 2002), and group and individual interventions for weight management and smoking cessation (Lichtenstein, Harris, et al., 1973; Stuart, 1967) are all grounded in behavior therapy. These interventions were integral to the early development of the 1960s' self-control and self-management approaches (Bandura, 1969; Goldfried & Merbaum, 1973; Kanfer, 1970) that laid the groundwork for much of behavioral medicine that followed.

The present chapter provides an introduction to contemporary behavioral theory and research. It reviews basic concepts of reinforcement, choice, and stimulus control and, then, their extension in behavioral economics. Extended discussion of smoking cessation and weight management illustrates the application of these concepts to complex patterns of behavior and health. Contemporary behaviorism provides a comprehensive basis for understanding such complex and dynamic behavioral patterns and, at its base, is congruent with broad social and ecological approaches that have emerged in global behavioral medicine and public health.

Consequences of Behavior

Reinforcement

The most fundamental principle of learning theory is that behavior is a function of its consequences. A reinforcer is any outcome that follows a behavior that increases the frequency and likelihood of the behavior in the future. There are two

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broad categories of reinforcers – positive and negative reinforcers. When a behavior results in an outcome that increases the frequency of the behavior in the future, the outcome is said to be a *positive reinforcer*. For example, people who experience a "runner's high" are more likely to go for a run again than those who do not experience that consequence. The behavior of running is followed by some outcome (a "runner's high"), and as a result, that behavior is more likely to occur. In contrast, when a behavior results in the avoidance of or escape from something, and this increases the frequency of the behavior in the future, that outcome is said to be a *negative reinforcer*. Many people put on sunscreen before going outside in order to avoid being sunburned. If they fail to do so and get a burn, they might apply aloe in order to relieve the pain. In the former case, putting on sunscreen is followed by the avoidance of a painful outcome and in the latter case, applying aloe reduces a painful situation. Both fit the definition of negative reinforcement: avoidance or reduction of an outcome (e.g., sunburn) that makes the behaviors more likely to be repeated in the future.

That a reinforcer is defined by its effects on behavior is central to behaviorism. Colloquially, a positive reinforcer often is used interchangeably with the word "reward" or is said to be something "good" or "pleasant." In practice, however, it is important to evaluate the consequence in terms of its effect on the future likelihood of behavior, rather than on one's intuitive notion of what is "good" or "pleasant." Something pleasant does not always reinforce a behavior (e.g., social attention), and something not typically viewed as pleasant can sometimes reinforce a behavior (e.g., yelling and time-out; see Durand, Crimmins, et al., 1989).

All else being equal, a larger or higher-quality reinforcer typically will generate a higher rate of responding (e.g., Trosclair-Lasserre, Lerman, et al., 2008). The delay to when a reinforcer is received also is critical and can sometimes surpass the effects of the amount or quality of a reinforcer. The effectiveness of and preference for a reinforcer, however, is not a stable, inherent characteristic of a reinforcer. An outcome's effectiveness, for example, may be augmented by depriving the individual of the resource and may be diminished by satiation (Raynor & Epstein, 2003). In this sense, then, whether and to what extent an outcome is reinforcing depends on the context within which it occurs. Throughout the chapter, we will return to this central tenant of behaviorism, that the characteristics of behaviors and their relationships with the stimuli and consequences that surround them are dependent on their contexts.

Schedules of Reinforcement

The behavioral requirements for obtaining a reinforcer markedly affect both the rate and the pattern of responding. Schedules of reinforcement determine when a reinforcer is delivered based on the behavior being emitted (for a review, see Murphy & Lupfer, 2014). The simplest schedule of reinforcement is a continuous schedule: Every time the targeted behavior is emitted, it is followed by a reinforcer. Most behaviors, of course, are not reinforced every time they are emitted; rather, behaviors are reinforced intermittently. There are two broad categories of intermittent schedules of reinforcement – ratio schedules and interval schedules. Under ratio schedules, the delivery of a reinforcer depends on the number of responses emitted. Many customer loyalty programs, for example, require that the customer make a fixed number of purchases (e.g., ten) before the next (eleventh) purchase is free. The timing of the purchase is irrelevant; the only contingency determining the delivery of the reinforcer (i.e., the free item) is the number of previous purchases made. Under interval schedules, in contrast, the delivery of a reinforcer depends on the passage of time before a response produces a reinforcer. Checking one's mailbox operates on an interval-like schedule. Mail is dropped off approximately every 24 h. It does not matter how many times the response of checking the mailbox is emitted; the mail will not be received any sooner. On interval schedules, a certain amount of time must elapse before the response will be reinforced.

In general, ratio schedules of reinforcement produce higher rates of responding than do interval schedules. Unlike interval schedules, reinforcement is dependent on the number of responses emitted under ratio schedules. Therefore, the greater the rate of responding, the greater the number of reinforcers earned on ratio schedules. In addition, the faster the responding, the sooner the reinforcer is delivered. In contrast, on interval schedules, higher rates of responding will not markedly increase the number of reinforcers earned.

Schedules of reinforcement can be made more complex than simple ratio or interval schedules by varying the predictability of the reinforcer. On fixed schedules of reinforcement, the response requirement (i.e., fixed-ratio schedule) or time requirement (i.e., fixed-interval schedule) is consistent. In the customer loyalty example, a person must always make ten purchases before the next response is reinforced. Often, however, response requirements are not consistent, and behavior is reinforced after a variable number of responses have been emitted or a variable amount of time has elapsed. Some businesses have instituted variable-ratio schedules on purchases. In these cases, customers are reinforced with a "surprise" free item after they make a number of purchases. The exact number of purchases required to obtain the free item changes each time: Occasionally a person might make 15 purchases before getting a free item whereas on another occasion the item is presented after only a few purchases. Similarly, on variable-interval schedules, the precise amount of time that must pass before a response is reinforced varies with each reinforcer delivery. Checking one's email follows a variable-interval-like schedule in that opening your inbox to check for a message occasionally is "reinforced" by a message, and the time between messages received in one's inbox varies. Checking more frequently does not affect the rate at which emails arrive in one's inbox. Rather, an amount of time must elapse and that amount of time varies – sometimes an email arrives shortly after receiving the last one, whereas other times hours might pass before a new email is received.

Under fixed-ratio and fixed-interval schedules, a *post-reinforcement pause* often is observed in which responding ceases for a period of time after the reinforcer is received. If a rat were required to press a lever 50 times for each food pellet, it would not continuously press the lever. Rather the rat would tend to press the lever 50 times quickly, consume the food pellet when it is delivered, and then wait for a period of time before beginning to press the lever another 50 times. The length of the post-reinforcement pause varies with the ratio requirement: The greater the response requirement, the longer the average post-reinforcement pause. A similar pause in responding following receipt of a reinforcer is observed with fixed-interval schedules, and its length varies with the interval requirement. In contrast, variable-ratio and variable-interval schedules – in which the next response might yield a reinforcer – typically produce reasonably steady rates of responding, with few post-reinforcement pauses.

Alternative Reinforcers

In addition to the amount and quality of a reinforcer and its schedule of delivery, the availability of alternative reinforcers markedly affects the effectiveness of a reinforcer. In rats, for example, plain water (especially when the rat is liquid-deprived) functions as a very effective reinforcer for lever pressing. When rats also are given the opportunity to lever press for sucrose water, however, the effectiveness of the plain water as a reinforcer declines substantially (e.g., Freed & Green, 1998). It is not something within a stimulus that makes it a reinforcer; rather it is the context, which includes the availability of alternative stimuli, that determines whether and the degree to which something is reinforcing. This principle has substantial practical importance. In order to determine whether something is a reinforcer, one must evaluate its effect on behavior within a specific context.

Punishment

Like reinforcers, a punisher affects the future frequency and likelihood of the behaviors that it follows. Whereas reinforcers increase the likelihood of a behavior, punishers decrease the likelihood of the behavior.

Punishment is ubiquitous in everyday encounters. Failing to pay one's taxes can result in a fine or even jail time; talking during class can result in a reprimand or angry glance from the instructor. Skinner (e.g., 1953, 1971) argued for the limited use of punishment and even questioned its long-term effectiveness in behavior change. Punishment reduces the frequency of an undesired behavior, but often it is accompanied by unwanted side effects such as negative emotions and aggression (for a review, see Lerman, Kelley, et al., 2002). Of likely even greater concern is that punishment alone does not directly encourage or teach desired behaviors. If a parent wants a child to play quietly in the playroom, punishing the child for running around does not directly increase the likelihood of playing quietly. Punishment will decrease the likelihood of running around, but it also might increase the likelihood of alternative behaviors, some of which may include other undesired behaviors like fighting with playmates.

Another important consideration is the effect of punishment on behaviors that surround it. Punishing students for being noisy in school may decrease the frequency of noise, but also may punish coming to school in the first place. That is, avoidance of punishers becomes a reason to skip school, whereas reinforcers for appropriate classroom behavior become a reason to attend school. Despite these concerns, mild punishment is effective in reducing many serious problem behaviors and usually will have an even greater effect when combined with reinforcement of desired behaviors (Mayhew & Harris, 1979). It is critical, however, that the overall density of punishment within a situation does not overwhelm the density of positive reinforcers. Otherwise, the response may well be avoidance rather than engagement.

Negative Reinforcement Is Not Punishment

A common point of confusion is the distinction between negative reinforcement and punishment. Recall the definition of a reinforcer as something that, when made contingent on a behavior, *increases* the likelihood of that behavior. A negative reinforcer is "negative" in that its *removal* increases the likelihood of a behavior. A parent might often give in to a child's demands (e.g., asking for candy at the grocery store) or misbehavior so that the child stops engaging in that behavior (e.g., whining). In this case, the child's whining is being positively reinforced. That is, the child's whining results in the parent's giving in (e.g., giving the child candy). In contrast, the parent's behavior of "giving in" is being negatively reinforced: By giving in, the parent escapes from the aversiveness of the child's whining. Both the behaviors of whining and giving in are being reinforced, and thus both behaviors have an increased likelihood of occurring again. A punisher, on the other hand, *reduces* the likelihood of the behaviors that lead to it. A parent might ask that the child shares toys with another child. If the child whines and complains, this might function as a punisher for the parent's asking the child to share. That is, the parent might be less likely to ask the child to share in the future because asking often leads to whining and complaining by the child.

Stimulus Control

Consequences affect the future likelihood of a behavior but, as we emphasize throughout this chapter, behaviors and consequences occur within a context. *Stimulus control* refers to the extent to which a particular environmental context (which may be termed the antecedent) exerts control over the likelihood of behaviors within that context. Antecedent stimuli gain control of a behavior when they predict that some outcome will be more or less likely following that behavior. If a pigeon's key pecking is reinforced in the presence of a green key light, but pecking is not reinforced in the presence of a red key light, the pigeon then will come to peck when the key is green and not peck when the key is red. Traffic signals similarly influence one's driving behavior so that one is more likely to stop at a red light and go at a green light. A sign on the door reading, "Please do not disturb," is a clear indication that knocking will be ineffective or may even lead to an unpleasant response.

Over time, strong stimulus control of a behavior occurs when an individual has learned in which contexts engaging in a particular behavior produces reinforcement (e.g., talking with friends before the class begins) and in which contexts it does not (e.g., talking with friends during class when the instructor is lecturing). As a result of the differential reinforcement, discrimination will be evident and behavior will be more likely to be emitted in contexts that signal reinforcement and less likely to be emitted in contexts that signal either punishment or no reinforcement.

Stimulus control helps explain much of the complexity and sophistication of human behavior. One can see much of child development and high-level adult functioning as the result of a process involving greater and greater stimulus control and finely discriminated behavior. Consider, for example, the highly skilled teacher or coach who somehow seems to know just the "right thing" to say to help an individual feel motivated and confident. Such "emotional intelligence" entails highly nuanced responding to myriad cues in the environment. Interestingly, the highly skilled individual might be unable to explain such fine judgment or instead refer to vague descriptions (e.g., "I just had a sense," "You know it when you see it," etc.). Similarly, the star athlete may be at a loss to answer questions such as, "What made you realize you had the opening to score that goal?"

Unhealthy behaviors often can be considered as reflecting poor or inappropriate stimulus control. For example, cultures with low rates of alcoholism tend to have highly ritualized norms for drinking alcohol in which alcohol typically is consumed only with meals, with family, and during holidays. These rules establish stimulus control over alcohol use within a culture. In contrast, the "obesogenic" food environment in the United States (Brownell & Horgen, 2004) includes a number of unhealthy features, including norms for eating in almost every situation: on meeting, on departing, to celebrate, to mourn, at the start of a work meeting, upon entering an office with a jar of candy at the receptionist's desk, etc. Stuart's (1967) landmark work on behavioral weight control, which is still the basis for much of contemporary approaches (e.g., Johnston, Foreyt and colleagues, *infra*), includes restrictions on the time, place, and even the plates and utensils for eating, in order to reduce the number of stimuli associated with unnecessary caloric consumption.

Although discrimination is critical (i.e., responding differently in the presence of different stimuli), so, too, generalization is essential. Typically, when a behavior-consequence contingency is learned in one context, generalization to other similar, albeit untrained, contexts will occur. In a classic experiment, Guttman and Kalish (1956) observed generalization when they trained pigeons to peck at a key for food when the color of the key was a specific wavelength (e.g., yellow, 580 nm; Guttman & Kalish, 1956). During test trials in which food was not delivered, they presented different wavelengths and measured how much the pigeons responded to each test color. Pigeons responded most to the wavelength that had been presented during training but also responded to similar, untrained wavelengths. Response rates decreased as the wavelengths became increasingly different from that in training, producing a generalization gradient around the original, trained wavelength. Generalization of behavior to untrained contexts clearly is an adaptive mechanism because organisms rarely encounter the exact same context in which they learned a behavior-consequence contingency.

Extinction

We have emphasized that behaviors followed by a reinforcer are more likely to occur in the future and that behaviors followed by punishers are less likely to occur in the future. In addition to punishment, extinction reduces the frequency of a behavior. In extinction, a previously reinforced response no longer is followed by the reinforcer that was maintaining it. The discontinuation of reinforcement leads to the eventual decrease in the frequency of that behavior.

An often worrisome but predictable side effect of extinction is that behavior shows an initial increase in its occurrence, a phenomenon termed an *extinction burst*. A child whose nagging during a shopping trip has often been reinforced in the past with candy will likely nag during future shopping trips. If the parent then institutes extinction by withholding this reinforcement, an immediate outcome is likely to be an increase in the amount of nagging.

In addition to the initial increase in the originally reinforced behavior, extinction leads to an overall increase in *operant variability*. Eckerman and Lanson (1969) studied the variability in topography of a pigeon's keypeck response and observed that variability increased when extinction was instituted (Eckerman & Lanson, 1969). If a complex set of behaviors is extinguished, then variations in the set also will occur in extinction. Consider a study by Neuringer, Kornell, and Olufs (2001) in which rats received food reinforcement after engaging in a particular sequence of behaviors (left lever press, then a key press, and then a right lever press; referred to as LKR; Neuringer, Kornell, & Olufs, 2001). After this behavior set was well established, extinction was instituted in which the rats no longer received food for the LKR response sequence. In addition to the initial increase in the originally reinforced behavior (i.e., extinction burst), Neuringer et al. found that the rats were much more likely to engage in novel behavior sequences (e.g., RRK).

In other cases of extinction, *resurgence* occurs, in which responses that previously had been reinforced but then were extinguished, reappear during the process of extinction of a more recently learned behavior (e.g., Winterbauer & Bouton, 2010). Suppose the parent from the grocery store, for example, successfully extinguished the child's nagging and reinforced polite asking. When the child politely asked for candy, the parent gave her candy. If the parent now decided to completely stop giving candy to the child while at the store (i.e., polite asking is placed on extinction), the previously reinforced but since extinguished response of nagging is likely to reappear during this extinction period.

Even after extinction has been implemented successfully, there will be cases of *spontaneous recovery*: After a period of time following extinction of a behavior, exposure to the context that once had been associated with reinforcement may trigger a reemergence of the behavior. Using the example from above, suppose that after the child's nagging behavior has been extinguished, the parent does not take the child shopping for a few weeks. If then one day the parent takes the child shopping, the child may again start nagging. Fortunately, spontaneously recovered responding typically is less intense than responding observed prior to extinction and is extinguished more quickly. Often, reoccurrence of a previously extinguished behavior (i.e., spontaneous recovery) is mistaken for relapse or as evidence that extinction is ineffective. Spontaneous recovery is a typical outcome of any extinction procedure and should be planned for when implementing a treatment program. Especially important is that inadvertent reinforcement during spontaneous recovery may cause renewed vigor and reinforce a pattern of occasionally testing whether a reinforcer may or may not be available for the behavior.

This takes us back to the important topic of schedules of reinforcement. Depending on the schedule, some behaviors will be more "resistant" to extinction than other behaviors. One might think that a behavior reinforced on a continuous schedule of reinforcement would be more thoroughly "stamped in" or learned and therefore would be more resistant to extinction. However, less consistent and predictable schedules of reinforcement produce behaviors that are more resistant to extinction, a phenomenon termed the *partial reinforcement extinction effect*. A behavior previously reinforced on an intermittent schedule will continue to occur longer after it is placed on extinction than a behavior that was previously reinforced on a continuous basis. Furthermore, variable schedules of reinforcement typically produce behavior that is more resistant to extinction than fixed schedules of reinforcement.

One way of thinking about extinction following different schedules of reinforcement is the ease with which extinction and reinforcement can be discriminated. If the schedule of reinforcement is so unpredictable that it is hard to tell whether reinforcement no longer is available or whether a long break between reinforcers is part of the schedule, then behavior is more likely to continue in extinction.

Coda: Why Basic Behavioral Principles Matter for Health Promotion

Understanding the complexity of reinforcement and extinction is critical for behavioral medicine and health management. If a desirable behavior is not reinforced, then it will eventually decrease. Maintenance of healthy behaviors is not achieved by somehow making behaviors persist in the absence of reinforcement, but rather by finding naturally occurring consequences to reinforce the behavior. If there are insufficient reinforcers for healthy behaviors in an individual's environment, then an individual is unlikely to engage in those behaviors; any attempt in trying to "fix" the individual may prove fruitless and often leads to "victim blaming." Rather, such circumstances call for addressing the lack of reinforcers in the individual's environment, as through community or organizational approaches to health promotion (Fisher, Auslander, et al., 1992).

One way of connecting the reinforcers introduced to initiate behavior change with naturally occurring reinforcers is through extending treatment so that the naturally occurring reinforcers overlap with those used during initial interventions. Consistent with this, the duration of intervention appears to be a major feature of successful health-behavior interventions. In a meta-analysis of self-management programs for diabetes, the only predictor of improved blood-sugar control was the length of time over which contact was maintained (Norris, Lau, et al., 2002). In a study of psychosocial interventions for depression, patients who stayed over 3 months reduced their depressive symptoms and improved their quality of life the most (Forsman, Nordmyr, & Wahlbeck, 2011). Similar results have been reported in studies on weight loss (Wadden, West, et al., 2009; Wing & Hill, 2001; Wing, Tate, et al., 2006) and smoking treatments (Fiore, Jaén, et al., 2008). Furthermore, increasing the variety of reinforcers and contexts in which treatment is delivered will increase the similarity of the intervention with natural contexts. Kottke, Battista, and DeFriese (1988, p. 2888) put it well when characterizing results from one of the first meta-analyses of interventions for smoking cessation: "Success was not associated with novel or unusual interventions. It was the product of personalized smoking cessation advice and assistance, repeated in different forms by several sources over the longest feasible period."

Reinforcers in one's daily life often are delivered on schedules that are like variable-ratio and variable-interval schedules. Moreover, behaviors are maintained by a large number of different reinforcers, each according to a different schedule. This nexus of different consequences that maintain behaviors provides a model for making healthy behaviors more resistant to extinction. Consider approaches for encouraging the eating of fruits and vegetables in an individual who consumes very few of either. Among those for whom eating fruits and vegetables has become routine, a number of reinforcers are likely at play, including daily energy and alertness; maintained healthy body weight; the occasional praise of a doctor, nurse, or spouse; and reminders of health benefits in government reports or other media. The objective for the individual who does not eat fruits and vegetables, then, is twofold: (1) encouraging the initial development of eating fruits and vegetables and (2) transitioning the new habits to control by the incentives that will maintain them in the natural environment.

For the first objective, frequent and clear monitoring, reminders, and reinforcers are helpful. For example, one could set a weekly objective and monitor progress daily. If the achievement of the objective is not a sufficient reward, one could schedule an enjoyable activity as a reinforcer, such as sharing the success in a group meeting or a night out at the movies. After the behaviors have become frequent, the second objective, transitioning to the naturally occurring reinforcers, becomes the priority. To achieve this objective, one could monitor daily mood and energy to make these consequences more salient, share positive experiences with family and friends, or weigh oneself daily, a habit noted as important among those who have maintained appreciable weight losses (Wing & Hill, 2001).

Choice and Behavioral Economics

All behavior involves a choice between engaging in a particular behavior and engaging in some other behavior. We sometimes study individual behaviors without reference to choice or to the context in which the behaviors occur, but the fact remains that all behavior entails choice. If a context has strong stimulus control over a behavior, it may make the behavior highly likely to occur, but there still is a choice. Even with those behaviors that we may experience as somewhat involuntary, like leaving a building upon hearing a fire alarm, the person chooses to leave (as opposed to staying and finishing a phone call or an email) and by doing so, the response of leaving the building is negatively reinforced (the unpleasant alarm is no longer heard). Understanding choice is central to understanding learning and behavior.

Behavioral economics emphasizes the choice context within which behavior occurs. Behavioral economics conjoins the axioms and models of microeconomics and the behavioral principles of psychology and behavior analysis. Despite their distinct origins, the fields of economics and behavior analysis both seek to understand behavior by identifying the consequences of that behavior. In behavior analysis, the consequences are reinforcers. In economics, the consequences of behavior are the commodities that are provided to the individual. Because these are very similar concepts, we will use the terms “reinforcer” and “commodity” interchangeably in the discussion that follows.

The synthesis of economics and behavior analysis has led to a wealth of research on choice behavior with substantial implications for health, including how to arrange incentives to encourage healthy behaviors (Bickel & Vuchinich, 2000). The following section is a brief review of fundamental behavioral economic concepts in the study of choice.

Price and Elasticity of Demand

As already noted, the reinforcing value of a commodity is not a fixed attribute of the commodity. Rather, its value will vary depending on several aspects of the situation, including what other commodities are available. One way of assessing the value of a commodity is in terms of the demand for that commodity. Demand refers to the amount of a commodity purchased at a given price. In behavioral terms, price can be thought of as the amount of responding required to obtain the reinforcer. For example, with rats, the price of sucrose pellets might be ten lever presses per pellet. Demand can be determined by measuring the amount consumed as the number of presses required to obtain a sucrose pellet (its price) is varied. A demand curve plots the relation between price and consumption of a commodity. Figure 9.1 plots the demand for two commodities, electrical stimulation of the brain (ESB) and food, as a function of their increasing price.

Consistent with the law of demand, if the price of a commodity increases, the consumer should buy less of it; if the price decreases, the consumer should buy more. However, consumers are differentially sensitive to changes in price. Demand for a commodity is said to be elastic when consumption (the number of obtained reinforcers) decreases more than proportionally to price increases and is said to be inelastic when consumption decreases less than proportionally to

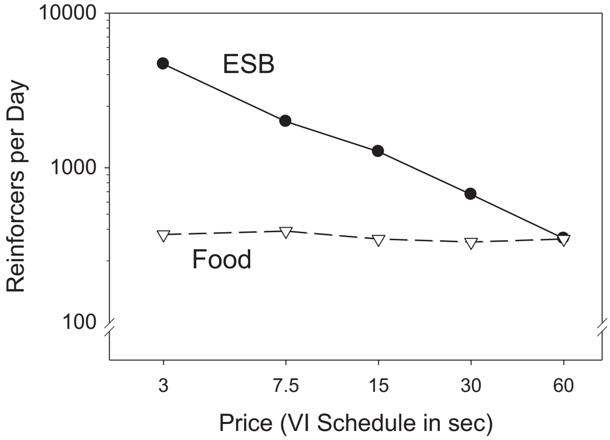

Fig. 9.1 Demand for food and electrical brain stimulation (EBS) in rats as a function of price. The demand for ESB is elastic: as the price increased, rats' demand for ESB decreased substantially. In contrast, the demand for food is inelastic: as the price increased, rats' demand for food remained relatively constant (Data are plotted on log-log coordinates and are from Experiment 2 of "Electrical brain stimulation and food reinforcement dissociated by demand elasticity," by S. R. Hursh and B. H. Natelson, 1981, *Physiology & Behavior*, *26*, p. 280)

price increases (e.g., Hursh & Bauman, 1987). The degree of elasticity can be observed by the slope of the demand curve. As can be seen in Fig. 9.1, as the price of ESB increased, rats' consumption decreased markedly, indicating that demand for ESB was elastic. In contrast, as the price of food increased, rats' consumption remained relatively constant, indicating inelastic demand. Elasticity is one way in which we can understand health behaviors. For example, addiction may be characterized as a relatively inelastic demand for a commodity such as nicotine or alcohol.

Alternatives and Patterns of Choice

Elasticity of demand is not an inherent characteristic of a commodity and its price. Rather, choice of a commodity is influenced by the context and, in particular, what other commodities are available in the situation. Manipulating the price of one commodity affects not only the demand for that commodity (own-price demand) but also the demand for other commodities (cross-price demand).

When offered the choice between two different commodities, an individual may have a strong preference for one over the other. An individual may prefer chocolate to vanilla ice cream but likely will not always choose chocolate ice cream when given that choice. Distributing choices among several alternatives clearly is adaptive in exposing individuals to alternatives in their surroundings, some of which may become advantageous if conditions or challenges change and require new responses and skills.

The allocation of behavior across alternatives is well described by the matching law (Herrnstein, 1961, 1970). Specifically, behavior allocation depends on the reinforcement earned from one alternative and on the reinforcement obtained from other alternatives available. One formulation of the matching law is as follows:

$$\frac{B_1}{B_2} = \frac{R_1}{R_2} \tag{9.1}$$

where B_1 and B_2 are the response rates for two different behaviors, and R_1 and R_2 are the reinforcement earned from each of those behaviors. As is evident from Eq. 9.1, the matching law predicts that a particular behavior (B_1) will occur in proportion to the reinforcers obtained from that behavior (R_1) and in inverse proportion to the reinforcers obtained from alternative behaviors (R_2). That is, the distribution of responses tends to match the distribution of reinforcers obtained from those responses. A pigeon may have the choice between pecking the left key, which produces food reinforcement on average after 1 min (variable-interval 1-min schedule), and pecking the right key, which produces reinforcement on average after 2 min (variable-interval 2-min schedule). The left key has a rate of reinforcement that is twice that of the right key. On average, the pigeon will obtain twice as much food for responding on the left key as for responding on the right key. As a consequence, the pigeon will match that rate, responding twice as much on the left key as on the right.

Notice that the matching law predicts that behavior allocation will be a function not only of the reinforcement earned from a given behavior but also a function of the reinforcement earned from alternative behaviors. If two available behaviors (e.g., eating spaghetti and eating pizza) provide the same amount of reinforcement for an individual, each will be chosen approximately equally, assuming no others are available. If the rate, amount, immediacy, quality, or other feature of the spaghetti is enhanced to make it twice as valuable as the pizza, then choice of spaghetti will increase and choice of pizza will decrease, even though the reinforcement produced from the pizza has not changed.

Clearly, then, our choices do not occur in a behavioral vacuum. It is essential not only to focus on the reinforcement earned from the targeted behavior but also to consider the reinforcement earned from alternative behaviors. It is evident from the matching law that there are two ways to modify a targeted behavior: Change the reinforcement contingency for the target behavior itself (R_1), *or* change the reinforcement contingency for alternative behaviors (R_2). Often the reinforcement earned from a behavior is difficult to modify, but the frequency of the behavior still can be modified by adjusting the reinforcement contingencies for alternative behaviors. In a study by Epstein, Smith, Vara, and Rodefer (1991), for example, overweight children played a game in which they earned two kinds of points, either those that could be exchanged to engage in a highly liked sedentary activity (e.g., watching videos) or those that could be exchanged to engage in a moderately liked vigorous activity (e.g., riding an exercise bike) (Epstein, Smith, et al., 1991). When the reinforcement schedule for earning each point type was identical, the children overwhelmingly spent their time earning sedentary activity points. When the game changed to require more effort to earn sedentary activity points, however, the children switched to spending more of their time earning vigorous activity points. That is, making it more difficult to earn points for one alternative (sedentary activity) increased time and energy directed to the other alternative (vigorous activity). Thus, Epstein and his colleagues were able to promote vigorous activity in overweight children not by adjusting the reinforcement contingency for this activity directly but by manipulating the reinforcement schedule for the sedentary activity.

Economists make a distinction between substitutable and complementary commodities or reinforcers. If a person usually buys broccoli because it is less expensive than asparagus, that person may nevertheless *decrease* consumption of broccoli (even when its price has not changed) and purchase more asparagus if asparagus is in season and its price has declined. Asparagus is economically substitutable for broccoli. Substitutable reinforcers are those that are functionally similar and fulfill similar needs. In many cases of economic substitutability, there is an apparent physical resemblance between the two commodities, but physical resemblance is not necessary. For example, most purchasers will choose among brands of gasoline based on price or convenience, assuming near equivalence among the products. In other cases, however, there may be little apparent physical resemblance between the two commodities. Watching television and playing outside with friends are to a degree substitutable. Commodities are substitutable because of shared, functional characteristics (Green & Freed, 1998). They share common functions but not necessarily common physical characteristics. Substitutes have positive cross-price elasticity: As the price of a commodity increases, consumption of that commodity will decrease while consumption of its substitute will increase. As the ticket prices of movies in theaters increase, people become more likely to watch movies at home.

Complementary commodities, in contrast, are those that are used jointly and thus are consumed in a fairly constant proportion to each other. Complements have negative cross-price elasticity: As the price of a commodity increases, consumption of both it and its complement will decrease. For example, gasoline and automobiles may be considered complements. Increasing the price of gasoline not only will reduce the purchase of gasoline but also will reduce the purchase of automobiles that are inefficient in their use of gasoline. The degree of cross-price elasticity varies because few commodities are perfect substitutes or complements for each other. In the example above, although gasoline is to an extent a complement of inefficient automobiles, it has alternative functions other than driving that might motivate people to purchase it (e.g., motor boats, lawnmowers, etc.). Sometimes two commodities are unrelated: The price of one has little or no effect on the consumption of the other. In cases like this, these commodities are said to be independent.

The effect of price increases on consumption of substitutable and complementary commodities has significant implications for public health policy. For many people, alcohol consumption and cigarette smoking are complementary reinforcers and often are consumed concurrently. Although excessive consumption of either contributes to health problems, in the last few decades public policy has focused more on curbing cigarette consumption by increasing taxes and instituting bans on smoking in many places. Krauss, Cavazos-Rehg, Plunk, Bierut, and Grucza (2014) reported that in the United States, the sale of beer and hard alcohol showed a decrease in those states that significantly increased taxes on cigarettes or instituted much stricter smoke-free air policies (Krauss, Cavazos-Rehg, et al., 2014). States with the largest increases in the price of cigarettes showed a decrease of 26% in the sale of alcohol compared to only a 5% decrease in states with the smallest cigarette price increases. Interestingly, consumption of wine was not affected by changes in cigarette prices or smoke-free air policies, suggesting that wine is independent of smoking. By understanding the interactive nature of price, complements, substitutes, and demand, public health efforts can be better targeted and more effective.

It also may be noted that the behavioral-economic approach has demonstrated that initial degree of preference is not necessarily a predictor of the degree or ease with which a behavior might be modified. Consider, for example, that when rats were given the choice between different reinforcers, Freed and Green (1998) found that the rats had an extreme preference for a high-fat reinforcer (a corn oil solution; Freed & Green, 1998). Nonetheless, consumption could be markedly reduced when its price was increased, but only if there were a palatable substitute available (i.e., a reinforcer of similar value, a mineral oil or a sucrose solution). A healthier but less-palatable alternative (plain water) had little effect on the rats' consumption of the high-fat corn oil solution. These results counter the long-standing belief that very strong preferences necessarily are difficult to change and further emphasize the importance of considering available alternative reinforcers when attempting to modify behavior. They also show that preference is not a fixed characteristic of the individual or of the commodities chosen but is much determined by the context in which they are presented.

Taken together, these findings suggest that the matching law understood within a behavioral-economic framework has broad applicability to human behavior: Humans allocate their time and effort to different behaviors, and they do so according to the relative value of the reinforcers those behaviors produce. Consider, for example, the circumstances of low-income, ethnic minority adolescents and young adults in many settings around the world. The value of reinforcers contingent on education and pursuit of jobs may be compromised by uncertainty, ethnic prejudice, and other disadvantages. In contrast, some criminal behavior may have clear and immediate payoffs. The matching law suggests that the allocation of time and effort to these two types of behaviors will vary according to the relative outcomes of each. Along with the earlier discussion of punishment and reinforcement, the matching law can provide an important strategic perspective: Reducing criminal behavior might be achieved more effectively by increasing the value associated with alternatives (e.g., education or jobs) than by aggressive policies focusing on criminal behavior itself.

Discounting

Discounting is a rich area of research that examines how the delay to a reinforcer (delay discounting) or the likelihood of obtaining a reinforcer (probability discounting) influences choice for that reinforcer. (For a review, see Madden & Bickel, 2010). When alternatives differ along only one dimension, choosing between them can be relatively easy: People generally will prefer rewards that are larger rather than smaller, immediate rather than delayed, and certain rather than uncertain. Choosing between alternatives can be substantially more difficult, however, when they differ along two or more dimensions. Consider the choice between $100 now and $200 in 1 year. Although the larger amount is preferred over the smaller amount, receiving a reward sooner is preferred to getting one later. Because these dimensions (amount and delay) are pitted against each other, choice becomes substantially more complex and difficult.

When offered the choice between the immediate $100 and the delayed $200, many people would choose the immediate $100 despite $200 being objectively twice as much. In cases like this, it is said that the immediately available $100 has greater subjective value than the delayed $200. Subjective value is directly proportional to the magnitude of the reward and inversely proportional to the delay to or odds against receipt of the reward. The way in which subjective value varies by amount, delay, and probability of reward is quite orderly and well-described by a hyperboloid function (for reviews, see Green & Myerson, 2004; Green, Myerson, & Vanderveldt, 2014). Figure 9.2 shows the subjective values of a $200 hypothetical monetary reward plotted as a function of the delay until its receipt (left panel) and the odds against its receipt (right panel). The curves represent the fits of the hyperboloid model to the obtained subjective values.

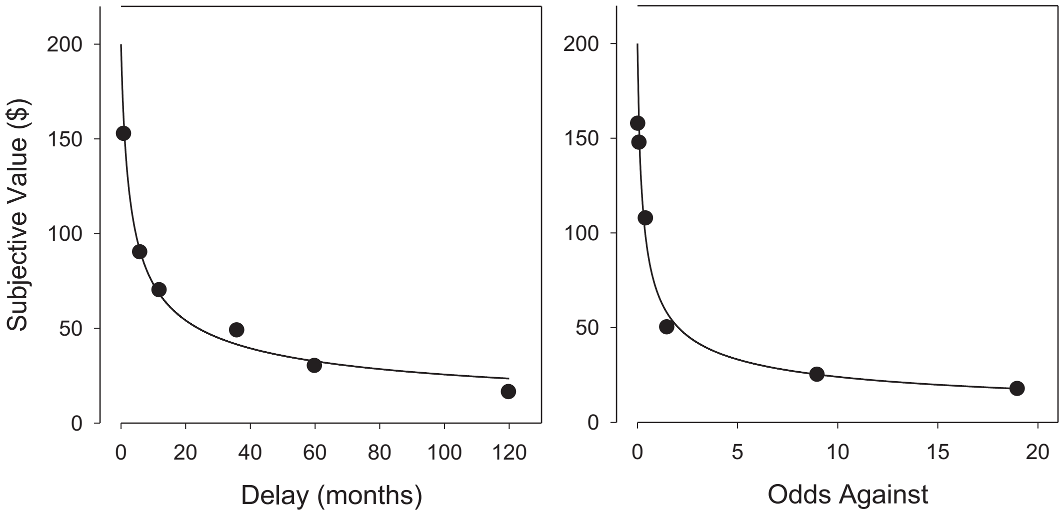

Fig. 9.2 Subjective value of a hypothetical $200 monetary reward as a function of time until receipt (*left panel*) and odds against receipt (*right panel*). The *curves* represent the best-fitting hyperboloid functions (Data are from Experiment 2 of "Amount of Reward has Opposite Effects on the Discounting of Delayed and Probabilistic Outcomes," by L. Green, J. Myerson, and P. Ostaszewski, 1999, *Journal of Experimental Psychology: Learning, Memory, and Cognition*, *25*, p. 423)

The rate of discounting, or the degree to which subjective value declines with increases in delay or decreases in probability, is not necessarily a stable aspect of the reward or of the individual. An individual's rate of discounting varies, for example, depending on the magnitude of the outcome (Green, Myerson, & Ostaszewski, 1999; Kirby, 1997), its quality (Freeman, Nonnemacher, et al., 2012), and whether the reward is consumable (e.g., food, music, etc., Charlton & Fantino, 2008). A common finding, called the magnitude effect, is that rewards of different magnitudes lose subjective value at different rates. With delayed rewards, a larger amount is discounted proportionally less steeply than a smaller amount, whereas with probabilistic rewards, a larger amount is discounted proportionally more steeply than a smaller amount. As can be seen in the left panel of Fig. 9.3, at a delay of 12 months, the $5000 reward is subjectively worth approximately 56% of its undiscounted value. In contrast, at the same delay, the $200 reward is subjectively worth only 35% of its undiscounted value; the $200 is discounted more steeply (i.e., it loses subjective value more quickly) than the $5000 reward. Interestingly, amount has an opposite effect on the rate of discounting probabilistic rewards: At an odds against of 1.5 (a probability of 40%), a $5000 reward is subjectively worth 15% of its undiscounted value, whereas a $200 reward is subjectively worth 25% of its undiscounted value (see Fig. 9.3, right panel).

The relations among subjective value, amount, delay, and probability of reward have substantial implications for health behavior. Consider a worksite program in which all employees who succeed in quitting smoking are entered into a lottery, the winner of which will receive a large reward such as an attractive vacation. Depending on the number of employees, the probability of winning may be extremely low, making this a low-probability but large reward, and so the subjective value of this reward may be steeply discounted. Such a program may be less effective than giving highly probable or certain smaller rewards, (e.g., being able to leave work one hour early at the end of the week) for all who report no cigarette smoking during the week.

Differences in rate of discounting also are apparent across individuals, and often these dif-

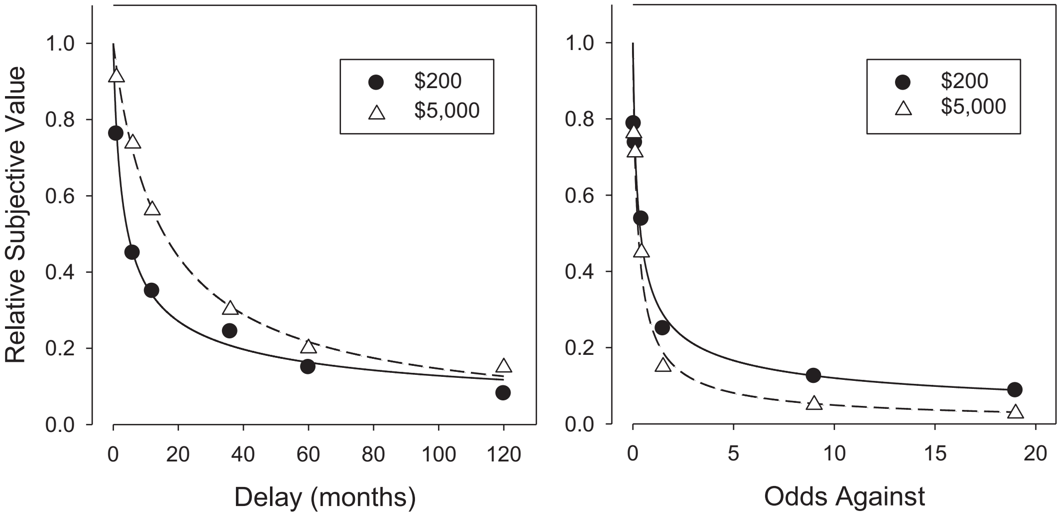

Fig. 9.3 Relative subjective value of $200 and $5000 rewards as a function of time until receipt (*left panel*) and odds against receipt (*right panel*). Larger delayed rewards are discounted less steeply than smaller delayed rewards, but larger probabilistic rewards are discounted more steeply than smaller probabilistic rewards. The *curves* represent the best-fitting hyperboloid functions (Data are from Experiment 2 of "Amount of Reward has Opposite Effects on the Discounting of Delayed and Probabilistic Outcomes," by L. Green, J. Myerson, and P. Ostaszewski, 1999, *Journal of Experimental Psychology: Learning, Memory, and Cognition*, *25*, p. 423)

ferences are related to what are termed impulse-control disorders. One might expect that those who are dependent on a substance would not discount that substance at all. For these individuals, we might expect that it would not matter how delayed or improbable receipt of the substance might be, but that merely the possibility of receiving their substance of choice would compel their behavior. Interestingly, however, nicotine-, alcohol-, cocaine-, and opioid-dependent individuals discount delayed monetary rewards more steeply than controls and discount their drug of abuse even more steeply than monetary rewards (see Fig. 9.4; for a review, see MacKillop, Amlung, et al., 2011). Similar findings have been found with other groups with impulse-control problems, including habitual gamblers (Petry & Madden, 2010) and obese women with binge-eating disorder (Manwaring, Green, et al., 2011).

Discounting applies not only to the direct reinforcers involved in various impulse-control problems but also to the delayed and probabilistic negative consequences of those behaviors (e.g., lung cancer, liver disease, financial insecurity, poorer family interactions, etc.). Because those negative outcomes are delayed and probabilistic, as are the positive consequences of giving up the behaviors (e.g., improved health, financial security, etc.), the problem behavior may remain and treatment interventions may be less effective. For example, cigarette smokers make decisions between smoking now with the increased chance of poorer health later on and experiencing nicotine withdrawal now with an increased chance of better health in the long run. Baker, Johnson, and Bickel (2003) reported that both smokers and nonsmokers discounted delayed health gains (e.g., improving one's health) more steeply than delayed health losses (e.g., making one's health worse). These findings suggest that public health efforts may be improved by framing decisions in terms of avoiding future health losses (e.g., losing the ability to live independently) rather than accruing better health.

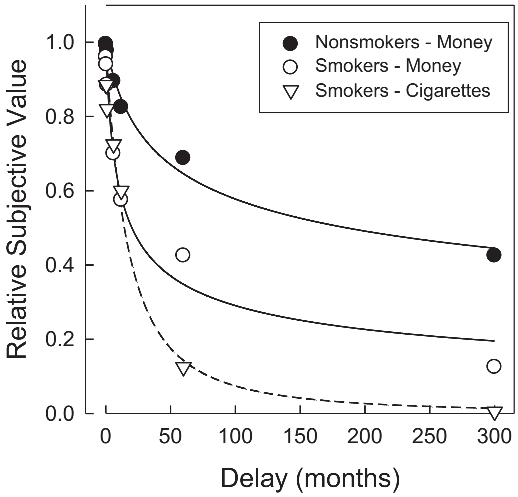

Fig. 9.4 Relative subjective value of cigarette and monetary rewards as a function of time until receipt. The *curved lines* represent the best-fitting hyperboloid function. Cigarette smokers discounted money more steeply than nonsmokers and discounted the value of cigarettes more than money (Data are from Figs. 1 and 2 of "Impulsivity and Cigarette Smoking: Delay Discounting in Current, Never, and Ex-Smokers," by W. K. Bickel, A. L. Odum, and G. J. Madden, 1999, *Psychopharmacology*, *146*, p. 451)

The relation between rate of discounting and impulse-control disorders has been the basis for the argument that discounting may be an underlying trait reflecting an individual's "impulsivity." In this view, impulsivity is choosing the smaller, sooner reward (e.g., an immediate $100) over the larger, later reward (e.g., $200 in 1 year), whereas, in contrast, self-control is choosing the larger, later reward over the smaller, sooner reward. In fact, there is evidence suggesting that degree of discounting is a predictor of later self-control problems (Audrain-McGovern, Rodriguez, et al., 2009; Carroll, Anker, et al., 2010; Yoon, Higgins, et al., 2007). For example, Yoon et al. studied pregnant women who were abstaining from smoking and found that steep delay discounting of monetary rewards was a significant predictor of postpartum relapse at 24 weeks. Similarly, Audrain-McGovern et al. measured delay discounting of monetary rewards in adolescents over several years and found not only that patterns of discounting were relatively stable but also that the initial measurement of the adolescents' discounting predicted onset of smoking in later years.

These results suggest that steep discounting (i.e., relatively strong preferences for more immediate rewards) may be a stable individual difference that can identify those at risk for future impulse-control problems (Odum, 2011). Operating early in life or even prenatally (e.g., El Hajj, Schneider, et al., 2014), social, economic, and developmental factors that may lead to such steep discounting are important topics for future research. For example, it has been reported that people of lower socioeconomic status (SES) tend to discount delayed rewards more steeply than people of higher SES (e.g., Green, Myerson, et al., 1996; Sweitzer, Halder, et al., 2013), suggesting that childhood SES may be an important factor that contributes to impulsive decision making later in life. In particular the relative unpredictability of delayed outcomes that accompanies low SES (see Sherlaw et al. and Siddiqi et al., *infra*) may have a role in shaping such propensities around discounting.

One might expect, then, that steep discounting is a characteristic of individuals and thus explains impulsive behavior problems; the situation, however, is far more complex. Research has shown that delay and probability discounting involve different underlying processes and therefore reflect different "types" of impulsivities rather than a unitary trait (Green & Myerson, 2010). Yi and Landes, for example, found that brief periods of smoking abstinence in cigarette smokers led to an increase in delay discounting but that such abstinence had no effect on probability discounting (Yi & Landes, 2012). As researchers and practitioners further develop models of impulse-control disorders, their efforts may be better served by considering the role of "multiple impulsivities" rather than treating impulsivity as a unitary construct (Green & Myerson, 2013).

Finally, it is important to consider the addictive substance in light of individual propensities around discounting. In this context it is worth noting that research on cigarette smoking and nicotine addiction has long emphasized the remarkable rapidity of the uptake of nicotine with smoking (Henningfield & Keenan, 1993; Pomerleau & Pomerleau, 1987; U.S.D.H.H.S., 1988). It takes only seven seconds from inhaling a cigarette for nicotine to reach the brain. In contrast, nicotine delivered by patches or gum yield much slower uptake. Smokers report considerably more pleasure from smoking than from other modes of nicotine delivery, accounting for relapse to cigarettes from other modes of nicotine delivery which may, over the course of a day, match the total amount of nicotine delivered. This sensitivity to the rapidity of uptake of nicotine appears to parallel the steep discounting of delayed drugs of choice among smokers and individuals dependent on other drugs. Thus, at least in the case of smoking, addiction may require both an individual's propensity for steep discounting and the necessary pharmacokinetics of the drug and its mode of delivery.

Discounting and "Self-Control"

We can see the challenge of many self-control problems such as weight management as a competition between short-term payoffs such as eating enjoyable food and long-term consequences such as healthy body weight. In the 1970s, George Ainslie along with several of us (HR, LG) showed that discounting of short- and long-term reinforcers can provide a model for self-control. Remarkably, they demonstrated this with a series of experiments with pigeons examining choices among long-term goals and the intrusion of more immediate temptations.

For the pigeons, the long-term goal was not that of losing weight or quitting smoking but rather getting 4 s of access to grain (Ainslie, 1974). To get the 4 s access to grain, pigeons had to wait 15 s. To complicate things a little, the pigeons were occasionally presented a red "temptation" key after 12 s. If they pecked this key, they then would get immediate access to the grain, but for only for 2 s. They were in a classic self-control situation: Yield to the temptation key and get an immediate but lesser reward (2 versus 4 s' access to grain), or resist the temptation, wait an additional 3 s, and get access to the larger reward.

Ainslie added one more complication: At the beginning of the 15 s of waiting, a green "self-control" key was presented. If the pigeon pecked it, then the red temptation key was not presented on that trial and the 4 s access to grain was simply presented after 15 s with no temptations along the way. The result? Ainslie showed that some pigeons came to "exert self-control" by pecking the green key, thereby avoiding the temptation, and thus went on to receive the greater, delayed reinforcer.

Pecking the green key to keep the 2-second temptation from ever occurring is similar to setting one's alarm clock. When we go to sleep, we set the clock for when we intend to get up, knowing that otherwise our preference may well be different the next morning when the alarm goes off. We may even set the clock across the room so that the intention at bedtime will be more strongly enforced in the morning.

A subsequent experiment by Rachlin and Green (1972) applied discounting to understanding pigeons' self-control. Figure 9.5 depicts the discounting over time of a larger, more delayed reward (represented by the solid curve) and a smaller, but sooner reward (represented by the dashed curve). Well in advance of either reward (at time T_1 in Fig. 9.5), the relative subjective value of the larger, more delayed reward (LL) is greater than that for the smaller, sooner reward (SS); thus, preference is for the larger, more delayed reward. However, as time to the smaller, sooner reward approaches, its relative value becomes greater than that of the larger, more delayed reward (at time T_2 in Fig. 9.5), and preference reverses to that of the smaller, sooner reward. Such preference reversals follow from the hyperbolic discounting of rewards and have been shown in pigeons, rats, and humans (e.g., Ainslie & Herrnstein, 1981; Green & Estle, 2003; Green, Fisher, et al., 1981; Green, Fristoe, & Myerson, 1994). Because one's good intentions at T_1 fall prey to immediate temptations at T_2, how might one increase the likelihood of ensuring receipt of LL in the face of such preference reversals? Relying on such "ghost-in-the-machine" concepts as willpower or ego strength provides little guidance.

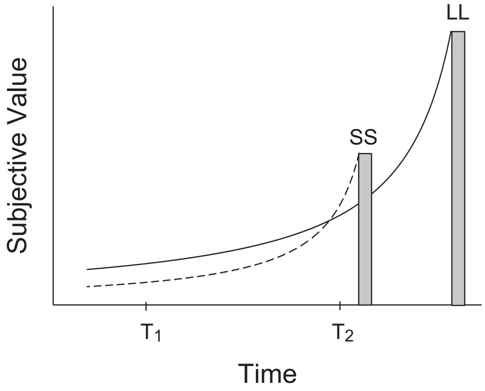

Fig. 9.5 Discounting of a larger, later (*LL*) reward and a smaller, sooner (*SS*) reward. The heights of the *bars* represent the nominal amount of reward, and the *curves* show how subjective values change as a function of delay to each reward. At T_1 the larger, later reward has a higher subjective value, but this preference changes at T_2, at which time the smaller, sooner reward has a higher subjective value

In the Rachlin and Green (1972) experiment, at T_2 pigeons were offered a choice between SS and LL, and invariably chose SS. However, at T_1, the pigeons were offered a choice between making a commitment or not. By pecking a commitment key, only the LL option would then be offered later at T_2; pecking the noncommitment key led to the choice between SS and LL at T_2. In this case, the pigeons that otherwise would choose SS at T_2 had a way to preclude this option and ensure receipt of LL. Indeed, Rachlin and Green found that when the pigeons were allowed to make a commitment response well in advance of when preference would otherwise reverse, all the pigeons came to "exert self-control" by pecking the commitment key at T_1 and thus obtain LL.

The pigeons' behavior is consistent with the view that we do better if we exercise our "willpower" far in advance of temptations rather than waiting for them to become close at hand. The pigeons pecked the key that prevented the temptation from even becoming available more often when the key appeared well in advance of the temptation than when it appeared closer to the time the temptation was to occur. So efforts at self-control will be more successful if we act early, well before temptations are liable to lure us out of our strategy than if we wait for the temptations to be just about to occur. If we wait until the tempting dessert is on a plate in front of us, it will be difficult to resist. But if we shop for food so that no tempting desserts come into our homes, they will be far easier to resist.

The pigeons in the research just described had only one way to exercise self-control. They could simply keep the temptation from happening. Humans have a far wider range of strategies available to them. They can keep the temptation from becoming available, for example, by bringing their own lunch to work and not even going to the cafeteria where seductive desserts lie in wait. But they also can do things like decreasing the attractiveness of the temptations, for example by thinking about all the diseases that cigarettes cause so that, when tempted, the cigarette is not just a reminder of the pleasures of smoking but also a reminder of its perils. Humans also can make their long-term goals more effective in motivating their current behavior. Buying some clothes that you would like to fit into may help elevate the discounted value of the long-term weight loss and thereby help maintain a diet. Working out a schedule of milestones along the path to the long-term goal also may raise the perceived likelihood of the delayed goal as well as provide some reinforcement for meeting the milestones along the way. Being social, humans also can use their friends and family to help them achieve their long-term goals. For example, telling your friends about your plan to achieve some goal adds an incentive of not wanting to be embarrassed among them should you fail to achieve it.

Across all of these plans and strategies, long-term goals, and immediate temptations, two points appear critical in understanding self-control. First is that self-control or yielding to temptation is determined by the *relative* value of the discounted greater, delayed reward and the discounted lesser, sooner reward *at the time* a choice is made. Second, the "secret" to self-control is not some kind of mental energy applied to resisting temptation but rather that of making choices when our preference is for the delayed reward (e.g., at time T_1 in Fig. 9.5), so as to avoid a situation in which the value of the temptation is greater than that of one's long-term goal (e.g., at time T_2 in Fig. 9.5).

Coda: Classical Conditioning

The reader may be wondering why, after a lengthy review of behavioral psychology, the name Pavlov and research in classical conditioning have yet to be mentioned. Unquestionably, classical conditioning is a fundamental area within which behavior and behavior change must be understood. Moreover, interactions between operant and classical conditioning are ubiquitous, and thus one must be aware of contemporary research and theory in each area. The focus of the present chapter is on the interrelation between behavior, its consequences, and patterns of behavioral choices. These, in large part, are not the focus of research on classical conditioning. Nonetheless, in the next section on cigarette smoking, some understanding of classical conditioning processes is needed. Therefore we provide a brief review here.

In classical conditioning, a neutral stimulus is presented such that it predicts an unconditioned stimulus (US). The US is a stimulus that produces an unconditioned response (UR), that is, a response that is not dependent on prior learning. Suppose a bell (neutral stimulus) is periodically presented preceding food (US), which causes an animal to salivate (UR). Because the bell regularly predicts the food, the bell comes to elicit a conditioned response (CR), in which presentation of the bell by itself causes the animal to salivate. That is, over time, given the predictive association between the originally neutral stimulus (bell) and the US (food), the bell, now a conditioned stimulus (CS), comes to elicit conditioned responses (salivation) that precede the unconditioned stimulus. Similarly, as people sit down to enjoy a nice meal, their salivary glands begin secreting saliva in anticipation of the food that is to come. (For presentations of fundamental aspects of contemporary research and theory in classical conditioning, see Gottlieb & Begej, 2014 and Schachtman & Reilly, 2011).

Two features of classical conditioning that have a direct and significant relation to behavioral medicine are highlighted here. The first feature is the extinction of classically conditioned responses. If one often has the urge to smoke a cigarette when drinking with friends at a restaurant, one might think that the way to extinguish this behavior is to avoid the conditioned stimuli (i.e., avoid drinking with friends at a restaurant). However, extinction occurs when the conditioned stimulus is presented without the unconditioned stimulus. Staying with the example then, one must have the drink with friends, but not smoke. Extinction is central to the treatment of fears and phobias, in which one must learn to experience the circumstances associated with anxiety (e.g., entering an elevator) without feeling great distress. Avoiding the feared situation does not extinguish the classically conditioned fear. Rather, experiencing the feared situation (e.g., entering the elevator) without the feared events (i.e., the US; perhaps the elevator breaking down) leads to extinction. An appreciation of extinction also is important in other areas of health behavior, such as learning to watch television or spend time with friends without those being the occasion for unhealthy eating.

The health practitioner should be aware of extinction-related phenomena that may lead to relapse, and thus design interventions with full knowledge of these phenomena. These include spontaneous recovery (the recovery of a CR that occurs when a CS is presented after a period of time has elapsed following extinction), renewal (the recovery of a CR that occurs when the CS is presented in a context different from that in which extinction took place), and reinstatement (the recovery of a CR that occurs after extinction following reexposure to the US), any one of which increases the likelihood of relapse. (For an excellent discussion of mechanisms involved in extinction and for an understanding of phenomena related to relapse, see Vurbic & Bouton, 2014).

A second feature of classical conditioning that is of critical importance to behavioral medicine is the wide range of responses, response systems, and situations to which classical conditioning applies. Many bodily processes are conditionable, including insulin regulation in response to cues associated with ingestion of glucose or with the injection of insulin and regulation of the immune system (e.g., Ader, Felton, & Cohen, 1991; Kyriazis, Soundarapandian, & Tyrberg, 2012; Matysiak & Green, 1984; Szczytkowski & Lysle, 2008). Classical conditioning is also important for understanding substance use and abuse, drug tolerance, drug overdose, and withdrawal. Unconditioned responses to drugs may become conditioned to the circumstances surrounding drug-taking. These may then contribute to troublesome urges and cravings when individuals try to stop drug use but are exposed to circumstances that have been associated with it. Effective treatments should address these conditioned responses to help individuals sustain abstinence (e.g., Cunningham, 1998; Siegel, 1990).

A particularly troublesome impact of the wide range of things that can be conditioned involves the conditioning of *tolerance and opponent processes*. As strong or unusual substances are consumed, the body mobilizes “opponent processes” that resist their effects (Siegel, 1976). Opponent processes in turn reduce the value of a fixed amount of the commodity, requiring more and more to achieve the same effect. Even the casual drinker or smoker experiences some reduced effect with continued use. For the individual heavily dependent on alcohol, nicotine, opioids, or narcotics, this “tolerance” effect is magnified. Those dependent on opioids, for example, may regularly consume amounts of opiates that would kill nonusers.

The opponent processes underlying tolerance may themselves become conditioned responses to whatever environmental stimuli (conditioned stimuli) are present when the addictive substance is habitually taken. An individual addicted to heroin, for example, tends to build up resistance to the primary narcotic effect of the heroin in situations in which the drug is habitually taken. If heroin is taken only in one situation (in one way, in one room, at one time of day, with one other person or set of people present), that situation becomes a conditioned stimulus for tolerance (opponent processes that act against the pleasurable effect of the addictive substance). Then, if the same dose is taken in a new situation, the conditioned stimuli that trigger opponent processes will be absent, and the effect of that very same dose will be much stronger than before – strong enough in some cases to be fatal (Siegel, 1988a, b).

Complex Patterns of Behavior

The previous sections of this chapter have reviewed fundamental concepts of behaviorism and how they may be applied to complex patterns of behavior of health significance, such as addictions. In this, behavioral economics has contributed valuable understanding of how different behaviors may be linked by the common functions they serve, such as in substitution, or by the opportunities and consequences that accompany them, such as in the effects of altered prices of one behavior on the likelihood of others. We turn now to examples of how these principles can be extended to a major health behavior, cigarette smoking, and to a major health condition, obesity.

Conditioning of Smoking

Smoking is an addiction, and the powerful reinforcing properties of nicotine are central to that addiction (Grunberg, Shafer Berger, & Starosciak, 2012). As noted previously, nicotine from cigarette smoking reaches the central nervous system in about seven seconds (Pomerleau & Pomerleau, 1987). In contrast, most disincentives for smoking are subtle or delayed, thus reducing the likelihood of their discouraging smoking. In addition to the immediately direct reinforcing effect of nicotine, smoking involves a complex array of associated stimuli. On the surface, smoking a cigarette seems very simple: The cigarette is lit and placed in one’s mouth, inhalation of the smoke follows, the smoke is exhaled, and so on. However, smoking and inhaling are frequently repeated – over a million times for the individual who has smoked a pack a day for 20 years (Fisher, Jr. & Rost, 1986). As a result, a large range of discriminative and conditioned stimuli come to signal the occasion for reinforcement by nicotine and to elicit conditioned responses that can, themselves, reinforce actions in the “simple” sequence of smoking a cigarette.

Discriminative stimuli alter the likelihood of a response by signaling the relation between the behavior and its reinforcement. In addition, through classical conditioning the circumstances surrounding smoking (the CSs) come to elicit conditioned responses. The complexity of these conditioning effects is increased by the fact that smoking is not a single response but rather a sequence of behaviors. Behaviors in the middle of the smoking chain play many roles. Taking a cigarette out of its package may (1) elicit conditioned responses resembling the pharmacological effects of nicotine that reinforce previous behaviors that led to it, (2) be reinforced itself by the conditioned responses it elicits, and (3) serve as a discriminative stimulus for subsequent behaviors, signaling the likelihood of their reinforcement by nicotine. Each inhalation provides an opportunity to increase “…the thorough interweaving of the smoking habit in the fabric of daily life” (Pomerleau & Pomerleau, 1987). As another example, a stress-producing phone call may serve as a discriminative stimulus, signaling a situation in which the anxiolytic pharmacologic effects of nicotine would be especially reinforcing. The stressful call may result in the behavior of reaching for a cigarette. In turn, reaching for a cigarette may serve as a conditioned stimulus that elicits conditioned responses that resemble those anxiety-reducing, reinforcing effects of nicotine. These conditioned responses may then reinforce reaching for the cigarette. Each action in the chain may both evoke conditioned responses reinforcing earlier actions and serve as a discriminative stimulus for subsequent actions.

The conditioning of smoking is further complicated by the varied reinforcing effects of nicotine. Nicotine can reduce anxiety, improve one’s mood, and function as a stimulant. The same individual may smoke to “get going” in the morning, to feel better after a stressful interaction at work, and to improve his or her mood after a long day. Each of these – getting going in the morning, stress at work, relaxing at the end of the day – can come to serve both as discriminative stimuli for smoking and, following cessation, as conditioned stimuli for withdrawal symptoms or cravings. Furthermore, the circumstances that give rise to such states, such as the time of day, work demands, family conflict, etc., come to signal the occasion for smoking or to elicit conditioned withdrawal symptoms.

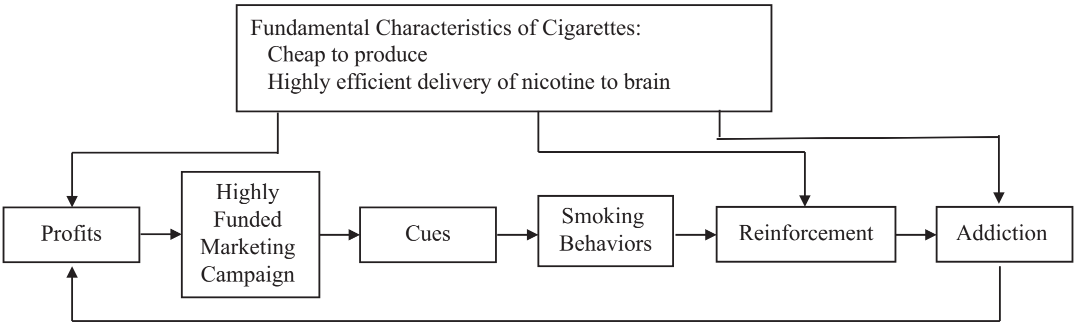

Fig. 9.6 Relations among fundamental characteristics of cigarettes, profits from cigarette sales, marketing of cigarettes, and key processes in smoking behavior and nicotine addiction

From the perspective of conditioning, cravings or urges are conditioned responses to circumstances that have been associated with nicotine delivery (the unconditioned stimulus). Consistent with this perspective, nicotine replacement appears to reduce withdrawal symptoms but does not reduce the desire to smoke (Henningfield & Nemeth-Coslett, 1988). This finding suggests that desires and cravings are dependent on the cues and circumstances associated with previous smoking and not only on nicotine. Simply providing an alternative source of nicotine, then, might not fully diminish those conditioned urges. Similarly, smokers report greater withdrawal symptoms if they quit in their home environment rather than in novel environments such as a residential smoking-cessation treatment program. Presumably, this is because the home environment contains far more conditioned and discriminative stimuli associated with prior smoking (Hatsukami, Hughes, & Pickens, 1985). Quitting away from one's home environment may be a beginning for quitting smoking, but it is unlikely to be the full answer. Given the extinction-related phenomena noted earlier, renewal and reinstatement would be expected upon return to the home environment, thereby increasing the likelihood of relapse.

Multiple Determinants and the Persistence of Smoking

In addition to the reinforcement and conditioning influences discussed, other environmental influences on smoking are well-documented (e.g., Borland, *infra*, Fisher, Brownson, et al., 2004). These include advertising and other marketing approaches, exploitation of social and economic adversity, social and peer influences on smoking among adolescents as well as adults, and the profitability of selling cigarettes over other consumer products. Furthermore, these influences on smoking interact among themselves. For example, the profitability of cigarettes leads not only to the ubiquity of cigarette marketing but in turn to the conditioned responses to cigarette advertisements and promotions and the biological and psychological responses that they trigger (see Fig. 9.6). Reciprocally, success in addicting a large number of individuals and keeping them addicted drives the profitability of cigarette marketing. The multiplicity of determinants of smoking and the many interactions among them can account for much of the persistence of smoking – a persistence otherwise inexplicable in light of smoking's risks. The fundamental concepts of conditioning, reinforcement, and stimulus control help explain how broad environmental influences such as advertising influence smoking at the individual level.

Substitutability of Social Support and Nicotine in Cigarette Smoking

A major theme of this chapter is how behaviorism and behavioral economics help us understand the influence of environmental and contextual influences on behavior. An interesting example is the relation between the behavioral economics concept of substitutability previously discussed and the complex relation between social support and health, characterized most broadly by findings that the absence of social support, namely, social isolation, is as lethal as smoking cigarettes (Holt-Lunstad, Smith, & Layton, 2010; House, Landis, & Umberson, 1988). Social support can provide incentives for life-enhancing behaviors (e.g., exercising) as well as offset the effects of stressors that might otherwise lead to emotional upset. For example, "having much to live for" because of satisfying social relationships may provide incentives for exercising, managing diabetes, and quitting smoking. Furthermore, the presence of social contact and support may guard against depression by offsetting depressed mood in a way that may substitute for mood-elevating effects of nicotine.

If social support is a commodity (i.e., a reinforcer) in and of itself, then it may serve as a substitute for other commodities. Consider, for example, that both social support and smoking appear helpful in coping with difficult life circumstances. Family difficulties, stress at work, or other stressors might increase the probability of choosing to spend time with friends *or* choosing to smoke. If social support were substitutable for nicotine, it might explain the relation between social support and success in smoking cessation (Fisher, Jr., 1997). More specifically, if social support and nicotine are substitutes, then when supportive relationships are limited, the probability of choosing cigarettes would be expected to increase. If companionship provided by a spouse substitutes for nicotine, then it would be expected that widowhood would be associated with increased smoking. Indeed, widowhood (as well as divorce, separation, and single marital status) is associated with greater prevalence of smoking, increases in rate of smoking, and likelihood of relapse among former smokers (Fisher, 1996; Fisher, Jr., 1997).

The benefits of social support while it is available are significant, but economic substitutes lose their power when they are no longer available. Thinking of social support this way may explain why interventions that provide support are effective in encouraging smoking cessation while they are available but lose their influence after they are terminated (Etringer, Gregory, & Lando, 1984; Fisher, Jr., 1997; Lichtenstein, Glasgow, & Abrams, 1986). The fundamental roles of reinforcement and extinction are clear; behavior increases with reinforcement and declines in its absence.

Social behavior, however, may sometimes facilitate smoking rather than substitute for it. Recent quitters frequently relapse while they are socializing. Fluctuations in the frequency of smoking from one day to the next often are associated in a complementary way with socializing so that, for example, going out to a nightclub or bar with friends on a weekend might be associated with increased smoking. Thus, in addition to social support and smoking/nicotine being substitutes, they may also be complements, that is, increases in one will lead to a corresponding increase in the other. Which function these behaviors take, complements or substitutes, may be context-dependent. Stress may lead to substitutability whereas socializing may lead to complementarity. These observations point again to a key theme of this chapter. How behavior is influenced by the events that surround it is not an intrinsic characteristic of the behavior or those events, but, rather, determined by the contexts in which they occur.

Extension to Other Health Behaviors

We have spent a substantial portion of this section discussing the implications of behavioral concepts to smoking behavior, in part, because of its prevalence. However, behavioral concepts also have significant implications for other health behaviors. For example, Vuchinich and Tucker articulated a behavioral economic model of alcoholism that frames choice for alcohol as determined by factors in the environment of the individual dependent on alcohol, such as the availability of social support or contact (Vuchinich & Tucker, 1988, 1996, 2003). The substitutability of social support or contact and of alcohol consumption is a central part of this model. Parallel to the previous discussion of efforts to promote nonsmoking, Vuchinich and Tucker direct attention to the provision of appealing and inexpensive substitutable sources of support and socialization in efforts to promote alcohol abstinence or controlled drinking. Behavioral models also have been helpful in understanding other health behaviors (e.g., diabetes) and in the development of incentive programs (Long, Jahnle, et al., 2012). In the next section, we focus on another major health concern, obesity, and again show how behavioral psychology and behavioral economics help inform understanding of this complex health behavior.

Obesity, Patterns of Behavior, and Teleological Behaviorism

This chapter has detailed ways in which behavior is shaped and sculpted by its contexts, the availability of other behaviors, the economics of their costs and consequences, the circumstances that surround individuals, and their behavioral histories (e.g., over a million puffs linking cigarette smoking with numerous cues in daily life). We now turn to another immense global health problem, obesity (see also Chapter by Johnston et al*.*, *infra*). In our discussion of obesity, we illustrate the application of another behavioral approach, *teleological behaviorism* (Rachlin, 1994), that focuses on *patterns* of behavior.

You might say that there is a difference between a man who intentionally swings a hammer and a man who accidentally swings a hammer, even though the two men are behaving in the same way at a given moment in time. You might suggest that the difference lies inside them, in their intentions. It could be argued that something inside of people must mediate behavioral differences, but the difference between intention and accident is behavioral. The difference between a man purposely swinging a hammer and a man accidentally swinging a hammer can be resolved not by looking inside him, but by looking at more of his behavior. A man accidentally swinging a hammer will not be hammering a nail or building a floor.

Teleological behaviorism focusses on patterns of behavior extended over time rather than on isolated actions. The question of why one of us (HR) is writing this paragraph cannot be broken up into the question of why he is writing this sentence, why he is writing the next sentence, and so forth. Rather, you have to look at why he is working on the chapter as a whole. If he had to decide whether to write each sentence individually he'd have writer's block – since there is no reinforcement for writing each sentence individually. Correspondingly, in the area of weight control, there is no reinforcement for each act of unhealthy food refusal and healthy food choice. It is sometimes said that the reinforcement for such acts is delayed; however, refusal of a single candy bar tonight does not make one suddenly a slimmer, healthier, and happier person 3 weeks later. A single act of self-control is not reinforced – now *or ever*. Reinforcement of acts such as refusing a candy bar is to be found not in particular acts themselves but in the value of a pattern of acts strung out over time. This value may be extrinsic to the pattern (e.g., social approval) or more closely linked to the pattern itself (e.g., the pleasure of playing a favorite piece of music).

Two things need to be emphasized. First, in teleological behaviorism, the unit to be explained is not the individual act or behavior, but a pattern of behavior that extends over time. Consider this in contrast to the criticism that behaviorism looks only at isolated stimuli and responses without considering things like the goals or purposes of the individual. A second key point will emerge in this discussion: Patterns of behavior may be shaped and sustained in themselves – as patterns – without reinforcement of their particular component acts. In fact, patterns may be reinforced and sustained even despite a negative value of their component acts. After all, every discrete act of an organism, even a pigeon's peck, is itself a complex pattern of sub-acts. A peck nevertheless may be reinforced without explicit reinforcement of its components. A third key point is that the events and consequences that signal the occurrence of and reinforce patterns of behavior may change over time. The cues, reinforcers, and behaviors that lead to weight loss are not the same as those that sustain a substantial weight loss over a number of years.

Readers may be surprised that the language in the pages that follow sounds more mentalistic than they may have expected. Teleological behaviorism accepts mental terms such as perception, imagination, and even willpower, although it defines those terms strictly as patterns of behavior (see Rachlin, 1994, 2014). Their validity in describing a given act (e.g., refusing a candy bar) does not depend on the existence of internal events at that moment in time (e.g., activity in some place in the brain), but on external, observable events (the past performance and consequences of the behavior) spread out over time. A pattern of refusing, say, a second croissant with morning coffee is under the control of external stimuli – a pattern of what one sees when stepping on the scale or looking in the mirror, medical reports, compliments from friends, and so forth – and not some interior muscle-like substance in the brain called "willpower" that the individual somehow squeezes whenever she or he wants to do something not immediately rewarding.

The following observations about obesity and weight loss come from this teleological, behavioral viewpoint. In addition to suggesting new ways of addressing obesity, they serve as examples of teleological ways for thinking about behavior in health and in general.

Economics and Reinforcement: The Escalating (Relative) Joys of Obesity

Teleological behaviorism and behavioral economics have much in common. Both specify the relation between behavior and consequences, and the key to both is the maximization of favorable consequences (Kagel, Battalio, & Green, 1995). Economic theory assumes that people behave so as to maximize utility under any given set of constraints (prices and budgets in economic language and reinforcement contingencies in behavioral language).

Looking at maximization over time introduces a key issue. Often, behavior that maximizes utility in the short run does not maximize utility in the long run. The immediate pleasures of overeating are clear. Millions of years of food scarcity in the history of humankind have developed a tendency to eat whenever food is available. For many of those living in upper-income societies food is virtually always available, and so we tend to overeat. However, although overeating may maximize utility in the short run (e.g., it produces immediate pleasure), it negatively affects health and social acceptance in the long run.

Eating has many reinforcers, but what are the consequences of patterns of eating? If each act of eating is reinforcing and the individual eats more and more, then too often the consequence of this pattern is weight gain. Each act of eating is reinforced, but the aggregate effects are negative. Patterns have both short- and long-term consequences and each must be considered.

If overeating leads to weight gain, then weight gain, itself, may start to affect other behaviors. We could say, oversimplifying, that as weight is

Behavior ≠ Behavior ≠ Behavior

"Accidentally" and "intentionally" swinging a hammer are distinguished not by characteristics of the behaviors, per se, but by the patterns of which they are a part, their settings and contexts. The details of the patterns of behavior and their settings are critical; swinging a hammer ≠ swinging a hammer.

In contrast to this emphasis on behaviors being defined by the patterns of which they are a part and the settings and contexts in which they occur, we often read about "medical decision making," "treatment adherence," or "self-management" as if they were unitary behaviors or homogeneous sets of behaviors. To say that adherence = adherence = adherence, regardless of whether the adherence is to a daily aspirin, to a 10-day course of antibiotics, or to a plan to use epi-

continued

nephrine to control anaphylaxis, is similar to saying that swinging a hammer = swinging a hammer, regardless of whether the hammer swinging is part of hanging a picture on a wall or tearing down a wall.

Adhering to daily dental hygiene, taking one's blood pressure pill daily, and adhering to a regimen of stretching before exercise may each fall within some broad category of adherence. However, they are very different patterns of behavior and are carried out in very different contexts with very different discriminative and conditioned stimuli and incentives guiding their performance. If we summarize knowledge about adherence or self-management or other behavioral objectives as if they were unitary actions divorced from their contexts, our knowledge and consequently our interventions will fail to address important characteristics and nuances of them. In behaviorism, this emphasis on the specificity of behavior and its contexts is absolutely fundamental. There may be a few things that different types of decisions have in common, or different types of adherence, or different types of self-management. This, however, cannot be assumed. Rather the determinants of a behavior need to be verified within the particular circumstances in which it is to occur. (See introductory chapter by editors, *infra.*)

gained, the probability of reinforcement from eating is generally maintained, but the probability of reinforcement from other activities declines (e.g., it becomes harder to move about, fatigue may increase, and some social opportunities that depend on feeling comfortable about one's body or being viewed as attractive, may be lessened). Moreover, the more weight is gained, the more this gap increases. Returning to the matching law described earlier, we can substitute the terms eating (E) and other activities (OA) into Eq. 9.1:

$$\frac{B_{\mathrm{E}}}{B_{OA}} = \frac{R_{\mathrm{E}}}{R_{OA}} \tag{9.2}$$

As R_{E} becomes increasingly greater than R_{OA}, the frequency of B_{E} relative to B_{OA} also will increase. This leads to greater weight gain, which further decreases R_{OA} and thereby increases R_{E} relative to R_{OA}. This cycle may then continue in a classic positive feedback loop. Sadly, individuals may reach a point where eating becomes their most valued and one of only very few pleasurable activities, putting them on a very distressing course.

Superimposed on this dynamic evolution of relative incentives for eating and doing other things, there may accrue additional positive and negative reinforcers for being overweight. First, there may be physical tasks that cannot be performed. If mowing the lawn becomes a major undertaking, then someone else in the family is likely to be mowing the lawn, negatively reinforcing the pattern of obesity. Inactivity or sloth is strongly disapproved in many societies. But a thin, able-bodied teenager doing little all day but watching television is likely to be perceived as more socially deviant or even hostile than an obese teenager doing the same thing. For obese people of any age, along with social disapproval, many cultures may provide a certain measure of social accommodation. If sufficient weight is lost and it changes the reactions and expectations of others, then a formally obese person might feel the loss of that accommodation.

Another source of negative reinforcement may stem from the social effects of obesity. Nearly every teenager is nervous about the introductions to the opposite sex provided by their culture, whether dances at schools or meetings arranged by families. But there often are sufficient social forces to overcome that obstacle. For an obese teenager, however, such countervailing forces may be relaxed, the dance missed, and the evening spent watching television. Additionally, in cultures in which physical attractiveness is endorsed as a contributor to romantic choices, obesity may reduce attractiveness, thereby reducing the long-term consequences of romantic relationships but, in the short run, negatively reinforcing obesity by providing escape from the stressors of early negotiation of such relationships. Turning to possible positive reinforcement, the obese teenager, boy or girl, is less of a threat to other teenagers of the same sex and therefore may find it easier than would a non-obese teenager to develop same-sex friendships.

Weight Control Should Precede Weight Reduction

As noted earlier, there is a natural tendency among pigeons, rats, and people to increase behavioral variability when things are not going well (e.g., during extinction). This tendency serves us well in most real-life situations – as it has served our ancestors. The general term for such a strategy, built into all of us, is "win-stay, lose-shift" (Levine, 1959, 1994). As long as things go well, keep doing what you were doing; as soon as things start going badly, increase the variability of your behavior by trying something else. Reinforcement determines which behaviors survive and which are extinguished. In order for reinforcement to work, however, behavior has to vary.

This tendency toward variable responding extends to eating. If things start going badly in life (as they inevitably do for all of us at some time), our natural tendency will be to increase the rate of other valued acts that, for many of us, include eating. This propensity toward variability in responding may explain an important characteristic of the literature on weight loss. People seem much more adept at weight loss (restricting their eating for relatively limited periods of time), than they are at weight maintenance (minimizing variability in their eating over extended periods of time).

The problem with losing weight first and then trying to maintain it is that reaching one's goal weight is the most vulnerable point of weight control. One must increase caloric intake modestly so as to stop losing weight, but not so much more as to gain weight. If one waits until a goal weight has been achieved, it is likely that weight regain will happen before a pattern of weight-maintenance eating is established. The result may then be "win-stay, lose-shift" with frustration, further weight gain, etc. Focusing first on the relatively easy weight loss and then regaining during the relatively more difficult weight maintenance leads to the "merry go 'round" of weight loss, weight regain, weight loss, and so on that is indeed a common pattern.

Weight reduction and weight maintenance constitute a sequence, much like a chain schedule of reinforcement. Usually it is a good idea to begin training with such schedules with the final link first. If you want to train your dog to fetch your slippers and then drop them in front of you, you should first train your dog to drop the slippers, and only after that has been learned, to fetch them. Similarly, after individuals have learned to maintain their weight within a given range, it will be easier for them to reduce their weight and then maintain it within the new range than it would be to learn to maintain their weight only after reducing it. In fact, once having developed reliable patterns of weight maintenance, the individual can titrate these strategically, generally maintaining regular consumption around, perhaps, cultural or religious holidays and then reducing consumption to lose a few pounds that may have been gained. This is reflected in studies of those who have maintained weight loss for extended periods of time. They tend to report regular monitoring of their weight and quick response to weight gain (Wing, Tate, et al., 2006).

The essence of this message is not to add or take away behaviors, but to reduce their variability. Dietitians assert that "anything can be built into a diet," including highly preferred treats or sweets. The problem is not eating some of such foods, but eating highly varying amounts such as in binges. Research with both human and nonhuman subjects (Allen Neuringer, 2004) has found that a pattern of reduction in variability of behavior may be explicitly reinforced. So, we can look at low variability itself as a feature of patterns of behavior to be reinforced.

Weight Maintenance Is a Lifetime Project

The plentiful availability of food in many segments of society, together with our inheritance of eating patterns appropriate for the environment of scarcity faced by our ancestors, impose problems for all of us. Let us again consider the differences between maintaining one's weight and maintaining nonsmoking. The individual who has not had a cigarette for over a year or so (for some it can take considerably longer) is usually able to relax about smoking in day-to-day activities. This person may need to be careful around high-risk situations, such as a stressful interaction at work or perhaps celebrating with alcohol and with friends who smoke, but most hours of most days, there is little need to do very much to stay off cigarettes. In contrast, maintaining weight loss requires many choices of the right food throughout the day for the rest of one's life. The decisions may eventually become almost automatic, but they still need to be made, and the unhealthy choices (e.g., eating too much, poor food choices, etc.) are almost always present and occasionally reintroduced such as on holidays, birthdays, and family celebrations.

Habits, Both Bad and Good, Are Situation Bound

Heroin addiction was very common among American soldiers in Vietnam. When the war ended, officials became concerned that the returning soldiers would bring their drug habits home with them, but, surprisingly, this did not happen (Robins, 1993). For most soldiers, the contexts (e.g., stimulus control, reinforcement contingencies) provided by army life in Vietnam and life in the United States were very different.

In the area of weight control, it is common that people who may have trouble controlling their eating under normal conditions nonetheless control it on religious fast days such as during Yom Kippur, Lent, or Ramadan. The special conditions of the holiday isolate it from the rest of life, and reinforcement differs in different contexts signaled by different discriminative stimuli. In weight control, this specificity of reinforcement to discriminative stimuli is both a disadvantage and an advantage. The advantage is that, by following rules for a time, we can change the relations between cues and eating and establish patterns of healthy eating. This can be done in two ways. First, by practicing healthy eating at regular meal times and in a room for eating (and not, for example, in front of the television set), those cues come to be associated with healthy eating. Second, by eliminating eating from other situations (such as while working or perhaps driving in a car), those situations are extinguished as cues for eating, and desires to eat in them are lessened. By following such rules for a few weeks, the healthier eating habits become conditioned and the patterns they comprise become increasingly more automatic. As a wise dietitian, Dr. Ruth Brennan, once put it to EF, “It's not what you eat between Christmas and New Year's; it's what you eat between New Year's and Christmas.”

In addition to the situational cues for eating, we carry around with us a set of cues from one environment to another within our own bodies; sooner or later we get hungry wherever we are. For many of us, “junk food” is almost always available. Eating unhealthy food in response to such hunger cues may then carry over into new situations under the discriminative control of those hunger cues.

Negative and Positive Addictions

The economists Stigler and Becker (1977) distinguish between negative and positive addictions (Stigler & Becker, 1977). Negative addictions are often the ones we identify as addictive or unhealthy, such as smoking cigarettes, drinking alcohol, taking heroin or cocaine, or overeating. Beyond a certain point, the more you smoke, drink, take heroin, overeat, etc., the worse your health gets, the more you feel disapproval from others, the worse your social life gets, the worse your job performance gets, and, as we have discussed in terms of the matching law, the more you may have to rely on the negative addiction as a source of pleasure. There is another crucial theoretical property of negative addictions: As their rate increases, tolerance builds up. The defining property of a negative addiction is that the higher its rate, the less reinforcing or valuable each marginal unit of consumption. The more you drink, the less reinforcing a single drink.

Positive addictions, on the other hand, are activities that many people spend a lot of time doing but usually do not identify as addictions. Positive addictions such as physical exercise, social activity, reading serious literature, listening to classical music, stamp collecting, or doing crossword puzzles are generally considered to be good for an individual. For Stigler and Becker (1977), the crucial property of positive addictions is the opposite to tolerance: The more one engages in the addictive activity, the more satisfying it becomes. The more proficient we become at playing a musical instrument, the more satisfying each "unit of consumption" is each time we play a song. The healthier one becomes, the more a morning walk or yoga becomes enjoyable.

Imagine Ralph existing in a world where the only activities available are positive and negative addictions. To make the illustration still simpler, let us represent the group of negative addictions by a single one, overeating, and the group of positive addictions by a single one, exercising. Ralph's world is so constrained that during his waking hours, when he's not eating, he's exercising, and when he's not exercising, he's eating; if he spends 90% of his time eating, he must spend 10% exercising; if he spends 60% of his time exercising, he must spend 40% eating.

For this hypothetical situation, let us stipulate that at every combination of eating and exercise, from 20:80 to 50:50 to 90:10, the marginal value of eating (the value of the very next unit of it) is higher than the marginal value of exercise. This immediate preference applies all of the time, whatever the overall ratio.

Because eating is a negative addiction, as it increases, the value of each unit of food decreases. To keep the total value of eating at a high level, Ralph has to eat more and more. If he eats more and more, he will be exercising less and less. Compounding this, because exercising is a positive addiction, as he exercises less and less, the value of each unit of exercise decreases. The less

Setting and Following Rules

Several times, we have talked about how people can commit themselves to following a particular rule or plan. The reader may wonder whether this is really behaviorism. It seems to suggest that, independent of all the conditions influencing their behavior, people can just decide to do something and proceed with it, determined only by that decision.

We can think of rules as discriminative stimuli that emerge in our own behavior. Recall the complex chains of behaviors and stimuli we discussed in the case of cigarette smoking in which, say, the behavior of sitting down to relax becomes, itself, a discriminative stimulus for reaching for a cigarette. From a teleological behavioral perspective, the patterns of behavior under the control of discriminative stimuli like rules, commitments, or to-do lists are patterns of behavior that some of us have learned better than others. That is, some of us have learned to conform our behavior to the "do list" we write in the morning, just as almost all of us have learned to conform our driving to a red light. That we wrote the "do list" and the government installed the red light does not alter the fact that, once they exist, both influence behavior by their relationship with overall probabilities of consequences, even though a single violation of either may often have no immediate consequence. That setting and following our own rules is something we learn can be seen in the fact that different people are better at different rules and commitments. The accountant may be very good at abiding by commitments to update records before the end of each business day. The professional athlete who extends her career past the age of 40 may be very good at keeping the commitment to daily conditioning, sleep, and healthy diet. So, returning to the example, some of us may have learned to do things like "not letting myself take a break until I have worked for 1 h." The difference here is not one of internal fortitude, but of what patterns we have learned.

time Ralph spends playing basketball, the worse his fitness and skill, the more effortful and the less fun playing basketball becomes. Thus, the more Ralph eats, the worse both eating and exercise become. Not only does his long-term health and happiness decrease, but the immediate pleasures he gets from both eating and exercise decrease as well – going down in parallel.

Although the hypothetical example for Ralph is extreme, one can easily imagine similar patterns in real life as eating commands more and more time and attention, leaving less time for other reinforcing activities, which then become less and less pleasurable. A similar dynamic may play out in drinking alcohol, as drinking more becomes necessary to gain pleasure, resulting however in less time and attention devoted to other, positive addictions which then become less and less pleasurable.

You may well ask: If this theory is true, why are we not all addicts? If the marginal utility of the negative addiction is always higher than that of the positive addiction, then how can positive addictions gain a foothold in competition with negative addictions? The answer is that if we have grown up in environments in which longer-term rewards are reliably delivered and in which we have been constrained by parents and other social influences from choosing the immediate pleasure, our choices have become patterns under the control of the overall ratio of good to negative consequences they yield. To some extent, we all have developed such patterns. Otherwise we might never get out of bed in the morning. But, as beneficial options become more and more abstract and spread out over time, they become less likely to gain control over our choices.

Economic Substitutability and Positive and Negative Addictions

Are there positive addictions that substitute for negative addictions? Surprisingly, there are. Considerable evidence exists that, as discussed earlier, social support may substitute for cigarette smoking and heroin and cocaine consumption (Green & Fisher, 2000). Another likely candidate for a substitute for overeating is exercise. That is, overeating and exercising may share some common reinforcers that support one substituting for the other. From this perspective, the effectiveness of exercise in weight control may lie not so much in the calories exercising consumes but in its economic substitutability for overeating.

Exercise has the further advantage over social activity as a substitute for eating in that our social system does not impose a degree of complementarity on exercise and eating. It is easy – in fact almost necessary – to eat while socializing in our society, but difficult to eat while swimming, riding a bicycle, or playing basketball. This constitutes some theoretical support for the common wisdom that an exercise program should be an important part of any weight control program. But if the effectiveness of exercise lies more in its substitutability for eating than directly in calorie reduction, there is a reason to include training in other positive addictions (music appreciation, playing a musical instrument, reading literature, collecting stamps or baseball cards, playing chess or computer games, calligraphy) as well as social skills as part of weight control programs.

Most weight loss or weight management programs begin with people monitoring their eating and looking for ways to eliminate harmful patterns, while learning key features of a healthy diet and trying to increase these. The ideas outlined here suggest a very different way of beginning a weight management program. Because of the need to find economic substitutes for highly pleasurable eating patterns, often those that are especially pleasurable in circumstances of stress or distress, the Teleological Weight Management program might begin by assigning participants the task of developing a new or cultivating an existing positive addiction that would substitute for eating. This would be a primary resource for circumstances in which unhealthy patterns are provoked by the stressors of (most people's) daily life. The criteria for selecting such a substitute would be that it will be reliably pleasurable to the individual and not harmful or unhealthy. It would not need to be especially healthy but, so that it might work as a substitute for unhealthy eating, it would need to be convenient in most all circumstances of daily life.

Also, as a first step and recognizing the centrality not of weight loss but of weigh maintenance, participants would monitor their diet and learn how to maintain their weight. With that skill in place, it may be *relatively* easy to reduce consumption for a period of time so as to lose some weight and then return to maintenance. This combination of positively addictive substitutes for harmful eating patterns and weight maintenance punctuated by periods of caloric restriction to reduce weight might offer new approaches for long-term patterns of healthy eating and weight maintenance.

Conclusions: From Behaviorism to Behavioral Medicine to Public Health

There is a fundamental compatibility between the behavioral perspective that is so important to and essential in the origin of behavioral medicine, and an ecological perspective that has achieved prominence in much of behavioral and social science and public health. As depicted in Fig. 9.7, both behavioral and ecological perspectives share an emphasis on contexts, be they termed "stimuli," "reinforcers," "setting events," "experience," "learning history," "ecological layers," or "social, cultural, community, economic, and policy influences."

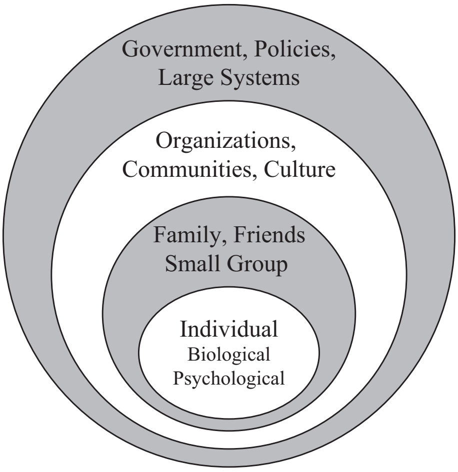

Fig. 9.7 Ecological model of health behavior

In ecological approaches (McLeroy, Bibeau, & Steckler, 1988; Stokols, 1992), the behavior of the individual is viewed as guided by layers of influences, including the family, proximal social influences such as social networks and neighborhoods, organizational influences such as worksite and community systems and healthcare systems, and larger social influences such as government, policy, and large economic structures. Different models may specify different layers of influence and different components of each, but they share two important emphases: (1) that the behavior of the individual reflects the influence of all the layers and (2) that the layers interact in their influence so that, for example, communities may influence families and families may also influence communities.

Both behavioral and ecological perspectives share an emphasis on how experience across a wide array of settings shapes behavior. Ecological perspectives add attention to how organizational and policy levels provide structure to the more immediate settings – the stimuli and reinforcers – that organize individual experience. Both also share the assumption that the same approaches to analyzing individual behavior can be applied to the behavior of larger social units such as groups or organizations and the ways they are influenced by *their* environments.

There is a practicality to the emphases placed by both behavioral and ecologic perspectives on the contexts that surround individuals. Both focus interventions on that which can be directly measured and manipulated. Whether it is the social network or community-based organization and health campaign, or individual coaching to establish patterns of self-control around diet, programs driven by ecological and behavioral perspectives focus on things that are "actionable." For behaviorism, this reflects the philosophical rejection of inferred, intraindividual constructs like intention and willpower. For ecological perspectives, it may be more of an emphasis on the contextual rings around the individual rather than inferred psychological structures within the individual.

Both reject the "victim blaming" attribution of chronic, harmful patterns of behavior to some stable, psychological characteristics of the individual without reference to the contexts that led to the development of those behavior patterns.

In *Science and Human Behavior*, Skinner (1953) addressed the broader influences on individual behavior that the ecological perspective emphasizes (Skinner, 1953). There he extended the fundamental principles of behaviorism to the understanding of large patterns of behavior like religion and the behavior of social groups. For example, in talking about how environmental influences shape the god/father metaphor in religious practice, Skinner argued that the emphasis on god/father as the source of protection reflected reinforcement contingencies operating on religious organizations. He argued that the financial support and loyalty of adherents to a religious group reinforces its development of effective metaphors for gaining influence over those adherents. The metaphor of god/father persists because it works, because this behavior of the organized religion is reinforced by the support of the adherents it draws. Without using the term "ecological," Skinner clearly wrote in its spirit, showing how events at different ecological levels might reinforce each other.

Many who embrace an ecological perspective nevertheless reject behaviorism as mechanistic, suggesting it treats individuals as objects. (For examples of misrepresentation and misunderstanding of behaviorism's and Skinner's views, see, e.g., Dinsmoor, 1992; Todd & Morris, 1983, 1992). This may rest on rhetorical confusion rather than substantive disagreement. In his provocatively titled book, *Beyond Freedom and Dignity*, Skinner (1971) argued that the "myths" of "freedom" and "dignity" as intrinsic human characteristics encourage policies that hold the individual responsible for her or his behavior, an attributive tendency much akin to victim blaming. At the same time, Skinner argued that these myths distract our institutions, government, and culture from more effective approaches to promoting healthy and adaptive behavior. From the perspective of creating interventions to advance human progress and quality of life, Skinner argued that we must recognize that humans are not intrinsically free and autonomous. The key issue then is not assuming that freedom and autonomy are automatic, but providing interventions and developing environments that promote the skills and behaviors that make people feel free and dignified. Perhaps rapprochement lies in shared objectives of people being treated with dignity and feeling free, not an assumption that freedom and dignity are guaranteed by human nature.

"Control" is sometimes the sticking point. Skinner talked about being able to control behavior for the good of the individual and the group and society. The usage, even in work intended to emphasize the role of the individual (such as the book title *Self-Control: Power to the Person*; Mahoney & Thoresen, 1974), seems, from the perspective of twenty-first-century empowerment, to impose something of an authoritarian cast on what we more commonly now refer to as "self-management." In their early extensions of Skinner's work to clinical and community applications, Krasner and Ullmann (1973) recognized that all control is partial and multiply determined, and so they titled their book *Behavior Influence and Personality: The Social Matrix of Human Action*, anticipating much of the integration of behaviorism with broad social influences and patterns of behavior, as emphasized here. From all these perspectives, "control" appears to be just an oversimplification. We are talking about very complex varieties of "influence."

In the twentieth century, behaviorism provided concepts for understanding how the circumstances that surround the individual shape and guide behavior, including behaviors of great significance for one's health. Evolution of behaviorism into behavioral economics and teleological behaviorism of the late twentieth and twenty-first centuries emphasize the relationships among patterns of different behaviors and the contexts that surround them. Key among these are the ways in which different behaviors and contexts – sometimes very different behaviors and contexts as in the case of cigarette smoking and social support – may interact and how understanding these relations can inform prevention and improve care. The concepts and findings of behaviorism and behavioral economics are fully compatible with the contextual emphases of ecological perspectives. Indeed, behavioral models may be thought of as providing the fundamental building blocks from which ecological models emerge. Key to both models, and for a humane practice of behavioral medicine, is recognizing the essential functionality or rationality of an individual's behaviors when understood in the contexts from which the behaviors have arisen.

Finally, behavioral economics and teleological behaviorism emphasize a number of linkages. Finite resources, whether dollars, Euros, RMB, or hours in a day, link behaviors so that allocation of resources to one at some point limits allocation to others. Substitutability and complementarity help us understand how some behaviors promote each other and others may tend to lessen each other. The matching law along with concepts of positive and negative addictions help us understand how investments of our time and energy in one pattern of behavior may influence opportunities in other areas of our lives. The patterns of behavior that are the focus of teleological behaviorism help us understand how coherence among the many actions that comprise playing the piano, conducting a community meeting, or writing a chapter may be shaped by the molar consequences of those patterns. So, too, ecological perspectives help us understand the linkages among policies, organizations, communities, families, and individuals, how working at any one of these levels is likely to influence and then, reciprocally, be influenced by the others. Recent developments such as in epigenetics and environment X gene interaction emphasize further the failure of essentialist or reductionist models in illuminating the complexity of lives. The integration of behavioral and ecological approaches, encouraged by their shared emphases on contexts and connections among contexts, may provide an ecological behaviorism to guide future work in behavioral medicine and public health.

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Genetics, Behavior, and Behavior-Genetic Interactions in Health Risk

10

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Knowledge about the genetic determinants of both health and disease has the potential to improve the diagnosis, treatment, and prevention of many illnesses. While the role of heredity has long been recognized in the study of illnesses, current research is aiming to gain a better understanding of the human genome. This first section of the chapter reviews key features of modern genetics and its development. Table 10.1 provides key definitions and terminology. Included terms are underlined at their first mention throughout this chapter.

Modern genetic research essentially began in 1866, and mainly focused on Mendel's law (after Gregor Mendel, the "father of modern genetics") and the so-called Mendelian diseases, which, according to Mendel's laws, are regulated by a single gene and passed on from one generation to the next. In particular, geneticists attempted to correlate Mendelian diseases (examples of these are Huntington's disease, cystic fibrosis, or sickle cell anemia) with genetic variants or markers with the help of so-called linkage analyses. Linkage studies basically illustrate the co-inheritance of marker alleles and specific traits within families. In 1869, the physician Johannes Friedrich Miescher successfully isolated nucleic acids – the active ingredient of the then unknown deoxyribonucleic acid (DNA). A further milestone was reached in 1875, when Francis Galton conducted the first twin studies. In 1941, the geneticists Edward Tatum and George Beadle published a work revealing that genes[1] code for proteins, explaining for the first time how genes are able to direct metabolic processes in cells. Shortly thereafter, in 1944, Oswald Theodore Avery discovered the material from which genes and chromosomes are made: DNA. In a major development of this history, James Watson and Francis Crick were the first to describe the iconic double helix shape of the DNA in 1953, which was based on the work of Rosalind Franklin and other scientists. In 1962, they received the Nobel Prize in Physiology or Medicine, jointly with Maurice Wilkins, for this discovery.

The next aim of many scientists was then to completely decode the human genome. Beginning

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[1] The most recent gene definition is conceptualized as follows: "The gene is a union of genomic sequences encoding a coherent set of potentially overlapping functional products" (Gerstein, Bruce, et al., 2007).

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Table 10.1 Key definitions and terminology

Term	Short description	An example	Cross reference
Additive genetic component	The effect of one allele on another allele at the same genetic locus	If two alleles are codominant, then the heterozygote is exactly intermediate in phenotype relative to the two homozygous types	Allele; locus (include cross reference to other terms in the table)
Allele	One of several alternative forms of a gene or DNA sequence at a specific chromosomal location (locus); produce variations in a genetically inherited trait	Different alleles produce different hair colors (brown, blond, red, black, etc.)	DNA; locus
Allele frequency	The proportion of a particular allele among the chromosomes carried by individuals in a population	In Caucasian populations, the frequency for the serotonin transporter polymorphism (5-HTTLPR) is about 40% for the L allele and about 60% for the S allele, respectively	Allele; chromosome
Autosome	Any chromosome other than the sex chromosomes (X and Y)	Humans have 22 pairs of autosomes, which are numbered according to their sizes, i.e., the higher the number of genes the lower the number. Chromosomal anomalies typically result in miscarriage early in pregnancy. One exception is, e.g., Down syndrome (tripling of chromosome 21)	Chromosome
Base pair	Two complementary nucleotides joined by hydrogen bonds	Base pairing occurs between A and T and between G and C	Nucleotide
Candidate gene	Due to its location on a chromosome that was found to be associated with a disease, this gene is assumed to cause the disease	The 44 base pair insertion/deletion polymorphism in the promoter region of the serotonin transporter gene associated with altered transporter expression and serotonin uptake	
Carrier	An individual who has one nonfunctioning gene for a recessive disorder can transmit that gene to his or her offspring	The human blood type AB presents an example of allele codominance because the allele IA and IB are both expressed and contribute to the phenotype (blood group AB)	Gene; recessive
Chromatin	The complex of DNA, RNA, and proteins that makes up uncondensed eukaryotic chromosomes		Chromosome; DNA; RNA
Chromatid	One of the two halves of a duplicated chromosome; each chromatid contains a complete double helix, and the two are exact copies of each other		Chromosome; double helix
Chromosome	Structures within the nucleus of eukaryotic cells composed of chromatin and visible at cell division (condensed chromatin)		Chromatin
Codon	A nucleotide triplet that specifies an amino acid or a translation stop signal	Examples for start codon: AUG, ATG Examples for stop codon: UGA, UAG	Nucleotide; triplet
Crossover or crossing over	The breaking and rejoining of homologous chromatids during early prophase I of meiosis, resulting in recombination		Chromatid; recombination

Deletion	The removal of one or more nucleotides from the DNA	ABC → AC Williams syndrome [neurodevelopmental disorder, "elfin" face] results from a deletion of medium size on chromosome 7. Other examples are cystic fibrosis or certain bowel cancers	DNA; nucleotide
Dizygotic or fraternal twins	Derived from two separate ova, thus not identical twins		
Deoxyribonucleic acid (DNA)	Carrier of the genetic information of organisms, usually double stranded DNA consists of a class of nucleic acids identified by the presence of deoxyribose, a sugar, and the four nucleobases		Nucleic acids; nucleobase
Dominance	The interaction of genes that are on the same allele, with one gene being dominant	Allele "A" is dominant over the "a" allele	Epistasis
Dominant	(In human genetics) Describes any trait that is expressed in a heterozygote	For a dominant disorder, one gene functioning abnormally is sufficient to cause the disorder, as in Marfan's syndrome or Huntington's disease. The dominant eye color is brown	Heterozygote
Double helix	The shape that two linear strands of DNA assume when bonded together		DNA
Endophenotype	Endophenotypes are internal phenotypes that can be discovered by a biochemical test or microscopic examination and have emerged as an important concept in the study of complex neuropsychiatric diseases	An endophenotype may be neurophysiological, biochemical, endocrinological, neuroanatomical, cognitive, or neuropsychological in nature such as the stress response measured by cortisol	
Epigenetics	Changes in gene expression that can also be inherited transgenerationally (from mother cell to daughter cell, or sometimes from parent to child), but are not produced by a change in DNA sequence	DNA methylation is the best understood epigenetic mechanism. Acetaldehyde, the conversion product of ethanol, has the potential to interrupt the methylation of histones relevant for gene expression. This might have implications during early prenatal organ development	DNA
Epistasis	The interaction of genes that are not alleles, in particular, the suppression of the effect of one such gene by another	Influence of gene B over gene A Two genes are responsible for the coat color of Labradors. One gene controls the color, and the other gene determines whether the color is expressed (i.e., the pigments are deposited in the coat)	Allele; gene
Gene expression	The process by which the information from a gene is translated into a functional gene product. The sequence is read in groups of three base pairs (codon) that correspond to one amino acid		Codon; nucleotide; nucleic acid; methylation
Gene mapping	Determination of the relative positions of genes on a DNA molecule (chromosome or plasmid) and of the distance, in linkage units or physical units, between them	Maps guide research to hypothesized genes impacting common disorders like diabetes, heart disease, and psychiatric conditions	DNA; chromosome; linkage

(continued)

Table 10.1 (continued)

Term	Short description	An example	Cross reference
Genome	All the genetic material in the chromosomes of a particular organism For the human genome, the set of different DNA molecules comprises 25 different DNA molecules	The first complete human genome was published after 13 years of work in 2003 by the Human Genome Project (today it takes only 1 or 2 days)	Chromosome; HGP
Genome-wide association studies (GWAS)	Platforms to genotype individuals for very large numbers of variants across the whole genome	GWAS (>100,000 SNPs) are recorded in the Catalog of Published Genome-Wide Association Studies of the National Human Genome Research Institute (http://www.genome.gov/gwastudies/)	Genome; genotype
Genotype	The genetic constitution of an individual, either overall or at a specific locus as characterized by its physical appearance or phenotype		Allele; locus; phenotype
Haplotype	A series of alleles found at linked loci on a single chromosome that tend to be inherited together This term can also refer to a cluster of single nucleotide polymorphisms (SNPs) that are generally inherited together	The International HapMap Project aims to identify patterns of SNP groups (= haplotypes or haps) describing patterns of genetic variation in human disease and response to pharmaceuticals	Allele; chromosome; SNP
Heredity	The transmission of characteristics from one generation to the next	E.g., the ability to curl the tongue	
Heritability	The proportion of the causation of a character or trait that is due to genetic causes	Highest heritability estimates have been found for body mass index (0.6–0.9)	
Heterozygote	An individual is heterozygous at a locus if he/she has two different alleles at that locus	Aa	Allele; locus
Homozygous	An individual is homozygous at a locus if he/she has two identical alleles at that locus	AA or aa	Allele; locus
Human Genome Project (HGP)	Scientific research project to identify all of the approximately 20,000–25,000 genes in human DNA and, furthermore, to determine the sequences of the three billion chemical base pairs that make up human DNA		Base pair; DNA; gene
Insertion	Adding of one or more extra nucleotides into the DNA	ABC → ABDC The fragile X syndrome and Huntington's disease are caused by a mutation in which a certain DNA segment is repeated	DNA; nucleotide
Linkage	The tendency of genes or other DNA sequences at specific loci to be inherited together as a consequence of their physical proximity on a single chromosome	A classic example of linkage-analysis-based disease gene identification is the gene responsible for cystic fibrosis	DNA; chromosome; locus
Linkage disequilibrium	Particular alleles at two or more neighboring loci show allelic association if they occur together with frequencies significantly different from those predicted from the individual allele frequencies	While linkage describes the physical linkage of two or more loci, LD describes the statistical association between two or more loci	Allele; locus; linkage
Locus	The specific physical location defining the position of an individual gene or DNA sequence	The chromosomal locus of the serotonin transporter gene (SLC6A4) is 17q11.2, with 17 indicating the chromosome number, q indicating the long arm, and 11.2 representing the position on the arm: region 1, band 1, sub-band 2	DNA; gene

(Genetic) marker	A genetic marker is a gene or short sequence of DNA used to identify a chromosome or to locate other genes on a genetic map	Two genetic markers associated with sensitivity to estrogen alterations after birth predict postpartum depression with high accuracy	DNA; gene mapping
Mendelian principles/laws	Gregor Mendel described three principles/laws, which he summarized from his extensive experiments studying the patterns of heredity for acquired characteristics	Three Mendelian principles: Law of uniformity, law of segregation, law of independent assortment	
Methylation	DNA methylation is one of several epigenetic mechanisms that cells use to control gene expression. During methylation, a methyl group is added to a substrate. This generally leads to silencing of the gene's transcriptional activity; the gene is "switched off"	Methylation of tumor suppressor genes has been linked to heightened tumor activity due to their transcriptional silencing	DNA; epigenetic
(DNA) Microarray	Thousands of genes (in known locations) are placed on a glass slide called a gene chip. A DNA or RNA sample is added, and complementary base pairing produces light that can be measured	Affymetrix, Agilent, Exiqon, Illumina (in alphabetical order)	Pathway analysis
Monozygotic or identical twins	Derived from a single ovum, thus identical twins		
Mutation	A permanent, heritable change in the DNA sequence of a particular gene	A substitution in the beta-hemoglobin gene causes sickle cell anemia	DNA; gene
Nonallelic genes	Genes located at different loci on the same chromosome or on different chromosomes. Altogether, they influence the phenotype	Individuals lacking a protein called the H antigen (absent fucose transferase) appear to have blood group O even if they have the A and/or B genes, the Bombay phenotype	Epistasis
Noncoding DNA	Sequences of DNA that do not code for amino acids lying either between or within (introns) genes	The ENCODE project, which started in 2012, looks into this "junk DNA" constituting about 98% of human DNA	DNA
Nucleic acid	A large molecule composed of nucleotide subunits	Deoxyribonucleic acid (DNA), ribonucleic acid (RNA)	Nucleotide; DNA; RNA
Nucleotide	A unit of nucleic acid composed of phosphate, ribose or deoxyribose, and a purine or pyrimidine base	Nucleoside + phosphate group → nucleotide	Nucleic acid
Pathway analysis	A set or network of genes that is actually expressed at a specific time point		
Phenotype	The observable characteristics (physical or chemical expression) of an organism's genes, including the result of any test that is not a direct test of the genotype	E.g., the color of eyes and hair	Genotype
Pleiotropy	The production by a single gene of two or more apparently unrelated effects	Mutations in the gene coding for phenylalanine hydroxylase result in phenylketonuria characterized by mental retardation, reduced pigmentation of skin and hair, and seizures	Gene
Polygene	A gene whose individual effect on a phenotype is too small to be observed but which can act together with others to produce observable variation	Testosterone regulates the development of what are referred to as secondary sexual characteristics (e.g., a lion's mane); however, testosterone also relates to behavioral traits like aggression	Gene; phenotype

(continued)

Table 10.1 (continued)

Term	Short description	An example	Cross reference
Polygenic	Of, relating to, or determined by polygenes	E.g., height, skin color	Polygene
Polymorphism	Genetic variations in DNA sequence among individuals occurring in more than 1% of a population	E.g., Single nucleotide polymorphism (SNP), copy number variations (CNV), insertion/deletion, variable number of tandem repeats (VNTR)	DNA; SNP; copy number variations
Protein	A large molecule composed of one or more chains of amino acids in a specific order, which is determined by the base sequence of nucleotides in the gene coding for the protein Proteins are required for the structure, function, and regulation of the body cells, tissues, and organs, and each protein has unique functions	E.g., enzymes, hormones	Nucleotides
Quantitative trait loci (QTL)	A locus important in determining the phenotype of a continuous character	QTL analysis links genotypic and phenotypic data	Locus; phenotype
Recessive	A character is recessive if it manifests only in the homozygote	E.g., Cystic fibrosis, sickle cell anemia. Recessive eye colors are blue, grey, and green	Homozygote
Recombination	The exchange of genetic material between chromosomes during meiosis	The construction of immunoglobulin genes is the result of recombination	Chromosome; mutation; crossover
Ribonucleic acid (RNA)	A chemical found in the nucleus and cytoplasm of cells, which plays an important role in protein synthesis, and other chemical activities of the cell. The structure of RNA is similar to that of DNA but only consists of one strand with its main function of translating DNA into protein	There are several classes of RNA: messenger RNA (mRNA), transfer RNA (tRNA), ribosomal RNA (rRNA), and micro RNAS (miRNA), each serving a different purpose	DNA
Sex chromosome	Sex chromosomes (humans have two: X and Y) determine sex. A fetus with two X chromosomes becomes a biological female, while male fetuses have both the X and Y chromosome in their cells	Anomalies in the number of sex chromosomes are typically associated with sterility and infertility, and underdevelopment of sexual characteristics, e.g., the Klinefelter syndrome (XXY) or the Turner syndrome (X)	Autosome
SNP (single nucleotide polymorphism)	Any polymorphic variation at a single nucleotide, which make up about 90% of all human genetic variation. SNPs occur every 100–300 bases along the human genome	In addition to the variants (S and L alleles) of the serotonin-transporter-linked promoter region (5-HTTLPR) of the serotonin transporter gene (SLC6A4), there is also an A > G SNP upstream of the repetitive region that comprises the 5-HTTLPR, which shows a functional significance of this marker	Genome; nucleotide
Transcription factor	Proteins that recognize specific DNA sequences and control the transcription of these sequences to messenger RNA, i.e., controlling which genes are turned on or off. Approximately 3000 transcription factors are expressed in humans	Heat shock factor, transcriptions factors regulating the expression of the heat shock proteins that are involved in the cells' response to elevated temperatures	DNA; RNA
Triplet	A unit of three successive nucleotides (or nucleotide bases) in a molecule of DNA or RNA that codes for a specific amino acid and forms our genetic code, called codon	There are 64 different codon combinations (4 nucleobases) but only 20 amino acids; some code for the same acid, and some code for "start" and "stop" signals	DNA; nucleotide; RNA
Zygote	The fertilized egg cell		

in 1990, the Human Genome Project finished the first complete sequencing of the human genome in 2003. Interestingly, this project determined only 20,000 protein-coding genes, constituting only 2% of the total genomic sequence. The remaining 98% are not protein coding and are part of a complex network of transcription factors including, for example, long noncoding ribonucleic acid (RNA; Mercer, Dinger, & Mattick, 2009) or miRNA (see below). Not long after the Human Genome Project, the International Haplotype Map (HapMap) project of the human genome began, aiming to identify and catalogue genetic similarities and differences in human beings. HapMap was conceived to serve as a resource for researchers, enabling them to find genes that affect health, disease, and individual responses to medications and environmental factors. The complete data set was published in 2009. The ENCODE project, which began in 2012, investigates "junk DNA," i.e., the noncoding regions of the genome outside the genes which might also play a role in our genetic makeup.

The genome-wide association (GWA) study approach is currently very popular as researchers are able to identify genes, or genetic variations, for complex traits and diseases. With the help of GWAS, markers across complete sets of DNA, or genomes, can be scanned rapidly. Using this approach, participants with a specific disease and those without are investigated to find certain genetic variations that occur significantly more often in people with the disease and can thus be considered "associated" with this particular disease. These are recorded in the Catalog of Published Genome-Wide Association Studies of the National Human Genome Research Institute (http://www.genome.gov/gwastudies/).

All of these latest developments of meaningful tools and contemporary methodological approaches have contributed to the exploration of disease susceptibility genes and have thus impacted the field of behavioral medicine. Despite the accumulation of knowledge on genetic factors in health and disease over the past 150 years, however, a detailed understanding of how genes impact human behavior and experience remains elusive. A critical issue for behavioral medicine is that the field still lacks in-depth knowledge regarding the extent of how variations in specific genes (e.g., polymorphisms) are responsible for individual differences in behavioral characteristics that may be associated with health and illness. As an example, six key observations in genetics can be identified, which may help to further advance behavioral medicine research.

First, identifying genetic determinants of psychological traits may improve our understanding of how such traits develop and manifest. Most conceptualizations of, for example, personality traits are not rooted in biology: For neuroticism, one of the best-researched personality traits, it is shown that about 50% of the variance is attributed to genetics (Loehlin, 1992). Nevertheless, there is evidence that some genes are associated with some personality traits. For instance, Zuckerman's (2005) psychopharmacological model suggests associations of dopamine, serotonin, and noradrenalin with sensation seeking. Second, studies of intelligence and stress illustrate that multiple genes with small effect sizes, so-called quantitative trait loci, may affect any one trait. Thus, any one gene may participate in more than one trait (such as the serotonin polymorphism that has been associated with depression, anxiety, and neuroticism; Caspi, Sugden, et al., 2003; Hariri, Mattay, et al., 2002; Lesch, Bengel, et al., 1996). This kind of polygenic determination of behavior or health states by thousands of genes is much more the norm than the simple models of genetic influence first identified by Mendel. Thus, "finding *the* gene for" some disease is unlikely to be a successful search. Third, environmental variables, for instance, (early) life experience, have the potential to regulate gene expression. The mechanism behind this may involve epigenetic or other regulatory processes, which are still poorly understood. The term epigenetics describes heritable changes in the gene expression, which are not due to any alterations in the DNA sequence. The best-known epigenetic marker is DNA methylation and will be described more detailed later (*see* section "Epigenetics"). Fourth, research suggests that the scale of these epigenetic changes may be very large, thus affecting many hundreds of genes that participate in complex molecular signaling pathways (such as for cancer). Fifth, recent observations on the role of genetic markers in medication responsiveness have the potential to improve individualized treatment of illnesses. Sixth, the observation that there is an extensive range of variations in genes will influence research on protection against and susceptibility to illness and, ultimately, improve prevention.

These observations illustrate the potential impact of genetic findings on research questions relevant for behavioral medicine. This chapter will describe past and current research and highlight starting points for future research in the area of behavioral medicine. The first part of this chapter, which will introduce the key concepts in genetics, will be followed by a second, more extensive part on genetic findings in health research.

The aim of this first section is to provide an overview of the key concepts and approaches in genetics. Individual differences in the development of physiological systems determining our behavioral dispositions are partially dependent on the variation in the genetic code stored in the deoxyribonucleic acid (DNA) molecules of all cell nuclei and mitochondria. In parallel, exposure to various environmental factors such as intrauterine environment (e.g., prenatal stress), early-life development, diet, peer and family attachment, or illnesses influences our behavior as well, particularly when we are genetically susceptible to a specific response to such environmental factors. Genetic and environmental factors may either have independent main effects on the variation in behavioral traits or interact with each other (i.e., gene-environment interaction; see below). The DNA between any two human genomes is almost exactly the same (99.9%), but a difference in the sequence can be detected every 1000 or 1500 base pairs. This difference of 0.1% in the sequence of the DNA is the source of all genetic variation in humans and is responsible for hair color and blood group but also for susceptibility to disease. The human DNA consists of 22 autosomal chromosomal pairs and one pair of sex chromosomes, and both together are termed the *human genome*. In the following, we will discuss genetic variation and behavior with regard to monogenetic vs. polygenetic trait variations, approaches of quantitative vs. qualitative/molecular genetics including gene-environment interaction and epigenetics, and more recent concepts such as genomics and proteomics.

Most human genetic traits, i.e., habitual patterns in an individual's behavior, emotions, and cognitions, can be classified as either monogenetic – that is, determined by only a single gene – or polygenetic (and, thus, complex). While useful, this distinction between monogenetic and complex traits can, however, be overly simplistic. Traits that appear to be monogenetic can also be influenced by a variation in multiple genes, while complex traits can be predominantly influenced by variation in a single gene. Both concepts will now be explained in more detail. We also introduce the terms pleiotropy, which describes the effect of one single gene affecting multiple traits, and quantitative trait loci (QTL), which explains how phenotypic data (such as traits) and genotypic data (such as biological/molecular markers) are linked together via statistical methods.

Basics of Behavioral Medicine

Monogenetic and Polygenetic Trait Variations

Variations in *monogenetic traits* are strongly influenced by variation within a single gene and recognized by their classic patterns of inheritance within families. Monogenetic traits formed the basis for "classic" genetics, and prominent examples are Huntington's disease, cystic fibrosis, and hemophilia. However, it has become clear that this very strict single factor inheritance conforming to Mendelian principles is relatively rare, due to the fact that any genetic variation can result in different isoforms (protein variants with altered functional efficiency). The importance of such variation for the protein function often depends on the position of the variation in the base triplet. A single base substitution (SNP, single nucleotide polymorphism) is the most abundant form of

DNA variation in the human genome. It has been estimated that the entire human population harbors approximately 10 million so-called "common" SNPs, with a minor allele frequency (i.e., the percentage of all living humans that have the rarer nucleotide for this SNP, as opposed to the other, more frequent, nucleotide) of greater than 5% in the human population. A base pair substitution in the first or second position is usually more significant than in the third position of the triplet and can lead to considerable consequences: (1) occurrence of a stop codon (termination of translation), (2) mutations which lead to a shift in the reading frame (disruption of the complete polypeptide sequence after the occurrence of the variation), and (3) insertions or deletions of several base pairs or repeat expansions, which do not have any "normal" function to sequence variability but may lead to the absence of a protein (e.g., as is the case with phenylketonuria, PKU) or the formation of dysfunctional or toxic proteins (e.g., Huntington's disease).

Although functional variation based on protein isoforms is clearly important, it accounts for only a small proportion of the total variation caused by genetic differences. A much larger share of the total variation leads to significant differences in the regulation of gene expression (the synthesis of a functional gene product); this type of variation does not result in a different protein but in an increased or reduced expression of the same protein.

Unlike monogenetic traits, *polygenetic* and, of course, most complex traits do not follow patterns of Mendelian principles and are believed to result from variation within multiple, nonallelic genes and their interaction with behavioral and environmental factors. Usually, these nonallelic genes cannot be precisely localized in the genome or identified. Moreover, these genes typically have a small effect but are large in terms of quantity. Polygenetic traits usually characterize continuous traits such as height or hair color. In contrast, polygenetic examples apply to disruptions in, for example, blood pressure or insulin resistance, leading to hypertension and type 2 diabetes.

Pleiotropy and Quantitative Trait Loci (QTL)

Polygenetic traits should not be confused with the concept of pleiotropy, which occurs when a single gene has an effect on the expression of two or more phenotypic traits. For instance, testosterone controls the development of what are referred to as secondary sexual characteristics, but testosterone is also associated with behavioral traits such as aggression. A gene that controls the levels of testosterone would have a pleiotropic effect, i.e., on the expression of many secondary sexual traits, which can be morphological as well as behavioral in nature. The basic principles of monogenetic effects still apply for polygenetic effects in an extended manner. However, there are numerous traits that are under the influence of a variety of genes, with different allelic effect sizes and allele frequencies. Moreover, nonadditive genetic effects, which are due to dominance and epistasis (the latter describing the event that the expression of one gene is affected by the expression of one or more independently inherited genes) as well as a range of environmental influences, also need to be considered here. In terms of environmental influences, intrauterine environment, diet, climate, parenting style and attachment, peers, diseases and accidents, traumatic events, chronic stress, and many more play a pivotal role for all human traits.

Robert R. Plomin, who set up one of the earliest molecular genetic experiments to look at normal variation in human traits, was the first to describe the principle of quantitative trait loci, a model which attempts to explain the genetic basis of variation in complex traits (Plomin, Owen, & McGuffin, 1994). With this model, he tried to explain variation in human intelligence and outlined the concept of genome-environment correlation (see section "Gene-Environment Interaction").

Quantitative traits refer to phenotypes (or characteristics) that show a discrepancy in terms of degree; they can be ascribed to polygenetic effects and are thus the product of two or more genes and their specific environments. The genetic impact on the development of several personality traits (e.g., neuroticism) has been suggested to reflect the interaction of many common alleles. A single phenotypic trait is generally settled on additive effects of many different single traits; on the other hand, several quantitative trait loci (QTL) are associated with a single trait also. One advantageous methodological tool for statistical genetics is QTL mapping, which is necessary to determine the complexity of the genetic architecture underlying a phenotypic trait. This method requires two strains of organisms that differ genetically regarding a trait of interest. Furthermore, genetic markers that distinguish between the parental lines are needed. QTL mapping can be used to examine whether a phenotype is shaped by many independent loci, or by a few loci, and whether those loci interact. This can provide information on how the phenotype may be evolving. In the latest methodological development, classical QTL analyses are combined with gene expression profiling by DNA microarrays.

Approaches of Quantitative and Molecular Genetics

While quantitative genetics is the study of continuously measured traits (e.g., height or weight) and their mechanisms, the field of molecular genetics makes use of methods of both genetics and molecular biology in order to study the structure and function of genes at a molecular level. Both approaches will be explained in detail below.

Quantitative Genetics

Estimation of Heritability in Humans

A central question in behavioral medicine is whether observed variation in a particular trait is due to environmental or to genetic factors, which is often expressed as the "nature vs. nurture" debate. As we now know that genetic variation in a population can result from a variety of factors, such as mutations in the genome (i.e., variations in the order of bases in the nucleotides) or selection, how can we estimate trait heritability?

Heritability, which is often abbreviated as h^2, is the relative contribution of genetic variation to phenotypic variance due to all additive and dominant genetic factors. It is the proportion of the variance in a trait among individuals, which is attributable to differences in genotype among them. Often, this term is also applied in reference to the resemblance between parents and their offspring. Within this framework, high heritability implies a strong resemblance between parents and offspring regarding a specific trait, while low heritability implies a low level of resemblance between them. Heritability can range between 0.00 (no genetic contribution) and 1.00 (all differences in a trait reflect genetic variation) but can also be described in percentage terms. For human behavior, there is no predetermined number to estimate heritability, but most estimates of heritability are found to lie in a moderate range of 0.30 to 0.60.

Family Studies

One approach to examining heritability is the use of family studies. Such studies serve as a methodological tool for understanding the well-being and healthy development of individuals within their families as well as regarding internal family relations across the whole lifespan. For instance, they examine the familial aggregation of quantitative traits such as blood pressure or insulin resistance and usually include dynamic relations within the family (such as hierarchy dynamics or gender roles) as well as the family's interactions with broader social institutions such as school, university, or workplaces. However, family studies are unable to identify whether an aggregation of a trait or disorder is due to genetic or environmental factors. For example, a high correlation of blood pressure readings among a family may be due to shared genetic characteristics, shared food and exercise patterns, or shared stress patterns, to name only a few.

Twin Studies

Twin studies, which, by definition, study family resemblance, have been and remain a powerful tool in genetics. Monozygotic twins (MZ) develop when a fertilized egg divides before it nestles into the mother's uterus. MZ twins are thought to inherit identical genetic material (i.e., 100% shared genetic material), with the exception of imprinting patterns, i.e., differentially methylated maternal and paternal alleles. By contrast, if there is more than one egg released from the ovaries during the woman's menstrual cycle and different sperms fertilize each egg, the result would be nonidentical twins, also known as dizygotic twins (DZ) or fraternal twins. DZ twins are like regular siblings and, on average, share 50% of their genetic material. When twins are raised together, they share parts of their environment, presumably to the same extent for MZ and DZ. In line, as early as 1869, Sir Francis Galton already pointed out a major shortcoming of such studies: The degree of genetic relatedness can be confounded with the degree of shared family environment. For example, monozygotic twins not only share the same set of genes but may be treated more similarly than dizygotic twins or siblings and may share more features of family environment than siblings born several years apart. A shared environment includes potentially important factors such as parental socioeconomic status (SES), neighborhood, school, sports club, family diet, or parental attitudes and child-rearing style. Galton's solution for separating the genetic and shared environmental effects on the trait resemblance of family was as follows: He set up a study (which he called "a unique experiment of nature") in which he compared monozygotic and dizygotic twins with the goal of looking at both the impact of genes and the impact of environment on human traits. By observing monozygotic twins who are reared together, the impact of environment on interindividual differences is reduced to a minimum, and thus the impact of genes can be calculated accordingly using linear equations. The classical twin study is based on the above-mentioned specific assumptions regarding MZ and DZ twins, and, thus, four possible components and interactions as well as correlations can contribute to the total variance in a specific trait: "unique environmental factors" (such as prenatal exposure to hormones, friends, diet, sleep patterns, exercise), "shared environmental factors" (such as SES, diet, family, household, and neighborhood environments), "additive genetic factors" (i.e., the contribution of several genes for one trait, such as the interaction of allele A1, A2, and A3 which promotes neuroticism independently), and "dominant genetic factors" (i.e., the effect of a dominant allele compared to the recessive allele, such as the short allele of the serotonin transporter polymorphism, which produces less serotonin transporter than the long allele). See Table 10.2 for summary of differences among groups commonly used in this line of research. Shared, environmental, additive, and dominant genetic factors can cause twin resemblance, while unique (thus non-shared) environmental factors cannot resemble each other. The contribution of additive genetic, shared, and unique environmental influence to the total variance can be estimated by comparing correlations between MZ and DZ twins, when there is no proof of dominance found. Furthermore, twins who are reared apart or are fostered/adopted together and raised by foster/adoptive parents offer yet another possibility to identify the heritability of human traits. Finally, discordant monozygotic twins, who share the same genome but differ at the phenotypic level, offer the possibility to identify gene expression-relevant events that took place

Table 10.2 How different groups compared in heritability studies differ in the extent of influence by additive genetics and shared environment

	Additive genetics	Shared environment
MZ reared together	↑	↑
DZ reared together	→	↑
Siblings reared together	→	↑
MZ/DZ reared apart	↑/→	–
MZ/DZ reared together by foster parents	↑/→	↑
Siblings reared apart	→	–
Non-related reared together	–	↑
Non-related reared apart	–	–

MZ monozygotic, *DZ* dizygotic
↑ Large effect
→ Medium effect
– No effect

post-zygotically in prenatal and early postnatal development (see section "Epigenetics" below).

Adoption Studies

In 1876, the first researcher to undertake adoption studies was again Sir Francis Galton, and many researchers have conducted such studies ever since. Adoption studies are used to compare adopted individuals with non-adopted individuals in a general or clinical population. Generally, adopted adults or children are compared to adults or children in their birth family who were not adopted. Adoption studies open up the possibility to illustrate the impact of both environment and heredity on a variety of issues. Given that adopted children are not reared by their biological parents, it is possible to compare similarities and differences to the birth family since the impact of heredity and environment on individual personality traits can be calculated. One of the earliest adoption studies was conducted by Heston (1966) in which they investigated 47 adopted children whose biological mothers suffered from schizophrenia and compared these children to 50 adoptees whose mothers had not been diagnosed with schizophrenia in order to look whether schizophrenia has genetic disposition. They found that schizophrenia may have a strong genetic component, as 10% of the children became schizophrenic themselves. A multitude of even larger studies on this question followed and confirmed a strong genetic basis for the development of schizophrenia (e.g., Kendler, Gruenberg, & Kinney, 1994). This approach is not, however, without room for error or confounding. Researchers often fail to differentiate between individuals who were adopted as healthy infants and those who were not healthy at birth. Moreover, frequently, no distinction is drawn between individuals who were adopted as infants and those who were adopted at a much later age. Age plays an important role, as some children who are adopted later on in their lives have already been subject to environmental influences and, in a few cases, might have been victims of abuse, neglect, or abandonment. A study in Romanian children adopted in the United Kingdom confirms this by showing lower cognitive scores, such as verbal, perceptual, or memory competencies, in children adopted at older ages and being institutionalized compared to young and non-institutionalized adoptees (O'Connor, Rutter, et al., 2000). The data shows that the most important factor in gaining cognitive competencies (as measured by using the McCarthy Scales of Children's Abilities, McCarthy, 1972) was moving in an adoptive home. However, individual differences were better explained by the duration of separation, i.e., the group of children who were adopted between the age of 0 and 6 months were scoring significantly higher than those children who were adopted between the age of 6 and 24 months.

While there are obvious advantages inherent in quantitative genetics, such as estimating heritability in the "natural population" and large sample sizes, there are also some shortcomings. For instance, heritability estimations are often based on samples from different countries and are thus subject to the influence of culture and society. Moreover, excluding shared environmental influences (e.g., shared time before/after the separation) and ensuring the reliability of measures are complicated. For instance, it is difficult to validly and reliably operationalize antisocial behavior, as both the social environment and social desirability play a role in terms of this construct, and both of these factors are often confounded with the questionnaire and interview measures.

Molecular Genetics

Molecular genetics bears the potential to explore the molecular basis of human behavior and psychological illnesses. Individual differences in the genetic makeup and their manifestation (e.g., via the expression of a receptor in the human brain) can have an impact on our behavior. As mentioned above, genetic research has grown enormously over the last years. Differences in phenotypes among individuals are, to a considerable extent, due to genetic variation, which is "saved" in molecules of our DNA. The branch of molecular biology that is concerned with the structure, function, evolution, and mapping of the entire human genome is called genomics. In the following, we will briefly review different methodological approaches, which enable the location in the genome of genes that are responsible for various physical characteristics and behavioral traits to be determined.

Methodological Approaches

Linkage Studies

Linkage studies illustrate the co-inheritance of marker alleles and traits within families. Genetic linkage describes the tendency of genes to be inherited together during meiosis if they are located near to each other on a chromosome. Genes whose loci are nearer to each other are less likely to be separated onto different chromatids during chromosomal crossover. For this reason, these genes are described as "genetically *linked*." Linkage analysis is often used to map genetic loci by the use of observations of related individuals.

Association Studies

Association studies constitute another approach to search for genes that have a functional impact on human behavior. While linkage analysis looks at the association between parts of the DNA and physical or behavioral traits (linkage signal = candidate genes), association studies compare subjects with and without this trait in order to identify their distinctive genotypes. The goal of association studies is to search the genome for small variations, which are called single nucleotide polymorphisms (SNPs). With this approach, researchers look at hundreds or thousands of SNPs at the same time and search to identify (vulnerability) genes that may contribute to the development of a certain disease or may be related to a high-risk trait (such as neuroticism, which is related to the onset and relapse of major depression).

Genome-Wide Association Studies

Due to rapid technological progress, *genome-wide association studies (GWAS)* nowadays represent a promising method to study complex, common diseases in which many genetic variations contribute to a person's risk of developing an illness by examining SNPs across the whole genome. Large-scale GWAS have become viable as a result of the development of high-throughput genome-wide genotyping arrays or chips. It is known that the entire human genome consists of 10^9 base pairs and, moreover, that one of 1000 base pairs contains a polymorphism. The genetic basis of several diseases has already been successfully identified as a result of the GWAS approach, including diabetes, Parkinson disease, and Crohn's disease. It is believed that future GWAS will not only identify more SNPs associated with chronic diseases but will also shed light on the variations that affect a person's response to certain drugs and influence interactions between a person's genes and the environment. With the help of more sophisticated approaches such as functional and behavioral genomics, researchers are able to describe gene functions and interactions and observe effects of the genome on human behavior.

Candidate Gene Approach

GWAS screen the entire genome to identify genetic markers of risk. This approach is therefore non-candidate gene driven, similar to the association and linkage study approaches. By contrast, by knowing the frequency of the allele and distribution of the trait in a population, candidate gene studies test whether a particular allele in a so-called candidate gene and a trait co-occur above chance level. For these studies, biological candidates or candidates due to location (genetic linkage) are selected a priori and based on specific hypotheses. This selection is based on assumed or empirically validated causative biological or physiological roles of genes. While the indirect candidate association approach employs presumably functional variants that are associated with the outcome/trait of interest, in the indirect candidate association approach, only the tagSNPs are targeted, and hence, genotyping costs can be tremendously reduced. A very prominent functional example is the 44 base pair insertion/deletion polymorphism (5-HTTLPR) in the promoter region of the serotonin transporter gene (*SLC6A4*). This polymorphism results in an altered transcriptional efficiency and thus in altered transporter expression and serotonin uptake in the presynaptic cell (Lesch, Bengel, et al., 1996).

Case-Control Studies

Case-control studies involve a group of cases with a disease of interest and well-matched controls. These studies investigate subjects who already have a disease or trait and thus enable the determination of characteristics of these patients that differ from those who do not have this specific disease or trait. In genetic case-control studies, the frequency of alleles or genotypes is compared across cases and controls by means of statistical analyses. To enable this comparison, controls need to be unaffected by the disease of interest and need to be well matched for ethnicity, age, sex,[2] and similarity of previous environmental exposures. A difference in frequency of an allele or genotype of the polymorphism between the two groups indicates that the genetic marker may increase the risk of the disease or likelihood of the trait or may be in linkage disequilibrium with a polymorphism.

Concepts of Molecular Genetics

Gene-Environment Interaction (GxE)

Studying individual differences in behavioral medicine has the power to increase our knowledge of phenotypic variance, and thus of psychological traits, in human behavior. These individual differences are due to variations in multiple genes, environmental factors, and gene-gene as well as gene-environment interactions. The nature-nurture debate, one of the oldest arguments in psychology and biology, deals with the question of whether a person's development is predisposed in his or her DNA or whether it is influenced by life experiences and environment. The current state of knowledge indicates that both play important roles in human development. There are examples of pure genetic effects (such as blood group, hair color, or Huntington's disease), pure environmental effects (such as speech/language), or combined effects (such as weight or skin color) on physical and biological characteristics and human behavior.

Differences in genetic factors cause people to respond differently to the same environmental exposure. In the very first molecular genetic study to report such a gene by environment interaction (GxE), Caspi and colleagues (2002) discovered that a common variation within the gene that codes for monoamine oxidase A (MAOA) moderates the effects of childhood maltreatment on aggressive behavior later in life. Almost in parallel to these findings on early adversity, the same work group was able to demonstrate that the effects of life stress on later depression are moderated by the 5-HTTLPR genotype, insofar as carriers of the short allele showed twice the level of depressive symptoms, frequency of a diagnosis of depression, and probability of suicide ideation/attempts than non-carriers. Another GxE interaction for the 5-HTTLPR genotype was reported in an imaging study (Canli, Qiu, et al., 2006), in which carriers of the short allele exhibited greater brain activation in the amygdala (serving as an *endophenotype*, see below) as a function of life-stress experience. In these same individuals, more life stress also correlated significantly with higher levels of rumination, which is known as a risk factor for depression, while non-carriers exhibited the opposite pattern: Here, more life stress was associated with reduced amygdala activation and less rumination.

Importantly, the interaction between genes and environment can be just as validly considered as environmental modification of genetic influence or as genetic modification of environmental influence (Fisher, 2008). For example, Pima Indians in the United States show "the highest prevalence of type 2 diabetes mellitus … of any population in the world." Yet, Pimas living in Mexico have relatively low levels of diabetes. Ample evidence links genetics to diabetes *within* the Pima population (Pratley, 1998). Thus, the relationships among genes, environment, and diabetes among the Pimas can be stated in either of two ways:

- Genetic factors associated with membership in the Pima population have a strong influence on prevalence of diabetes among a population exposed to the obesogenic environment of US diet and food distribution.

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[2] Even though differences between men and women cannot be attributed solely to biological differences, we will use the term *sex* throughout this chapter.

- The obesogenic environment of the United States has a strong influence on prevalence of diabetes among a population genetically predisposed to high rates of diabetes.

Gene-Gene, Gene-Age, and Gene-Sex Interactions and Gene-Environment and Gene-Gene Correlation

Besides an interaction between genetic and environmental factors, genetic, aging, and gender factors might also be interrelated*:* *Gene-gene interaction* can contribute to the initiation and maintenance of protective and risk behaviors, which in turn decrease and increase the risk of poor health outcomes. *Gene-age interaction* and *gene-sex interaction* describe the impact on variance components by genetic and environmental variance due to the effects of age and sex. Several studies have already investigated the likelihood of heterogeneity in genetic effects by age and sex. This field of research is able to specify how different genetic and environmental factors may be influential in both sexes and in different age cohorts. The investigation of gene by sex interactions, for example, is necessary to explain differences in terms of genetic susceptibilities and regarding the sexual dimorphism of complex traits.

The model of *gene-environment correlation* aims to strengthen the argument that environment and genetics are dependent on one another. This notion further indicates that the genetic impact may overcome environmental experience. There are three kinds of *gene-environment correlation:* (1) *passive gene-environment correlation*, (2) e*vocative (or reactive) gene-environment correlation, and* (3) *active gene-environment correlation.*

Endophenotype Principle

Endophenotype (such as brain activation in the amygdala mentioned above) is a term from the field of genetic epidemiology, which refers to phenotypic expression endogenous to the individual as opposed to exogenous. Thus, focusing on endophenotypes is intended to keep investigations closer to clear genetic connection. Bernard John and Kenneth R. Lewis first expressed this concept in 1966, when they claimed that the geographical distribution of grasshoppers cannot only be described by "exophenotype" (e.g., interactions between genotype and environmental characteristics such as climate and food sources) but, more essentially, needs to be explained by the individuals' internal "endophenotype." Endophenotype is a versatile measure for investigating and explaining individual characteristics. Typical examples are abnormalities in cognitive-affective processes, which are related to differences in sustained attention, executive function, event-related potentials, or localized brain measures, but also endocrine measures such as differences in the stress response (as measured by the stress hormone cortisol). Note that endophenotypes like differences in attentional processes might be related to exophenotypes such as differences in ease of learning a new language, given exogenous exposure to it. The contribution of genetic variation shows a considerably larger effect size when it is mapped onto the endophenotype, which is closer to the level at which a gene operates, compared to more distal exophenotypes which are subject to a broader range of influences in the environment. The power of the endophenotype approach is demonstrated by a fast-growing body of literature on functional brain imaging studies of individuals genotyped for the 5-HTTLPR polymorphism. This research tradition began with a study by Hariri et al. (2002), who reported a significant association between the short allele of the 5-HTTLPR polymorphism and an increased amygdala activation (serving here as endophenotype) in response to negatively valenced faces.

Epigenetics

An interesting and increasingly popular explanation for some complex patterns of environmental influence on genotypic expression is "epigenetic programming." Epigenetic programming triggers changes in gene activity (such as turning genes on or off and altering their expression levels) and does not involve DNA sequence alterations. One of these epigenetic mechanisms is DNA methylation, in which methyl groups are added to the cytosine bases on DNA (folate, for example, is a methyl donor molecule). A groundbreaking study showing an association of early maternal behavior and

DNA methylation moderating the stress response in rats in later life has been published by Weaver and Meaney (Weaver, Cervoni, et al., 2004). This study shows evidence of "epigenetic programming," which potentially might be reversible. This modification is thought to be more stable than other histone modifications and might possibly lead to lifelong changes. The functional consequences of methylation are a reduction or silencing of gene expression. A rather more complex mechanism involved in the manipulation and expression of DNA is posttranslational histone modification (e.g., methylation, phosphorylation, acetylation, and ubiquitination), with molecular evidence culminating in the "histone code" hypothesis proposed by Strahl and Allis (2000). This hypothesis assumes that these modifications provide marks where chromatin-associated proteins bind in order to change (i.e., activate or repress) the chromosomal state and thus to regulate access to DNA. The general process contains the alteration of the ability of histones to attract DNA via chemical modification, which is generally assumed to be in a constant state of change. A third mechanism of epigenetics is RNA interference, which involves smaller RNA molecules such as micro-RNA (miRNA) and small interfering RNA that are binding on messenger RNA, and thus either increase or decrease messenger RNA activity.

As a consequence of the mechanisms described above, epigenetic changes complicate any precise predictions of the phenotype based on structural DNA. The view regarding some of what were previously considered to be "hard" facts of genetics needs to be revised: For many decades, scientists believed that everything in our genome was written in stone. It is now quite clear that genes are still important but that they definitely do not function solely on their own. Genes can be turned on and off by various sophisticated mechanisms in the exogenous environment (e.g., maternal nurturing) or in the cell itself and through the lifelong variability of epigenetic modification patterns. The observation of the latter calls into question the long-held notion that "genes cannot be changed." In fact, it is not only the sequence of base pairs that regulates the human organism and its cellular mechanisms; there are also numerous processes influencing gene expression and thus life. Can it still be assumed that an environmental event is unable to leave a mark in our genome? Current research indicates not, as event-induced epigenetic changes can be passed on from one generation to the next (soft inheritance). This has been observed, for example, in the Dutch Famine birth cohort study (http://www.dutchfamine.nl). This cohort comprises individuals who were prenatally exposed to the Hunger Winter of 1944/1945 in the Netherlands. When the third generation of this cohort study is examined, it will be possible to investigate whether epigenetic changes can also be inherited transgenerationally. Findings of this cohort study also show that individuals are perhaps most vulnerable to epigenetic influences during prenatal and early postnatal phases but that epigenetic changes can occur at any age (Rakyan et al., 2010). Finally, it is known that even an individual's family lifestyle matters, e.g., the diet of our parents and even grandparents, or what they have experienced during their lives (see also below; e.g., the Överkalix study, Lalande, 1996). Recent knowledge regarding epigenetic mechanisms illustrates the far-reaching effects of health-related behavior (i.e., quitting smoking, changing our dietary habits) on our genes and possibly also the genes of our children and grandchildren. For a more in-depth discussion of the concept of epigenetics and findings relevant for behavioral medicine, see the following sections.

Gene Expression

Gene expression is the process by which the information that is encoded in the gene is translated into the products, which are present and operating in the cell (either proteins or RNAs). The cell reads the sequence of the gene in groups of three bases (codon), which correspond to one of 20 different amino acids used to build a protein. DNA sequences where cytosine (C) is directly followed by guanosine (G) and both C and G are linked by a phosphodiester (called CpG dinucleotides), are prone to methylation, i.e., the addition of a methyl group ($-CH3$). This addition leads in general to reduced transcriptional activity, whereas low-methylated DNA shows increased activity. Thus, the level of methylation and therefore gene expression determines which genes are currently "readable" and which specific gene products (proteins) are expressed.

Gene expression has been the focus of several recent studies on micro-RNA (miRNA), i.e., small non-peptide-coding RNAs, which regulate gene expression and are partially complementary to messenger RNAs (mRNAs). miRNAs were first targeted in animal studies (Lee, Feinbaum, & Ambros, 1993; Weaver, Cervoni, et al., 2004). Besides regulating genes, these miRNA also play a role for other important functions in the cell, such as cell proliferation, differentiation, and apoptosis. Emerging data suggest that, for example, stressful experiences can alter biogenesis of miRNAs, but can also impact the expression of mRNA targets, and the activities of miRNA-protein complexes (Leung & Sharp, 2010). While miRNAs usually suppress the expression of target transcripts, some researchers have suggested that miRNAs can also turn into activators during the cellular stress response (Leung & Sharp, 2007). Despite conflicting views within the field, miRNA seems to play multiple key roles in mediating diseases as well as the consequences of stress (Hunsberger, Austin, et al., 2009; Leung & Sharp, 2007).

Following this introduction of the most relevant terms (an overview of other important concepts, such as genomics and proteomics, can be found in Table 10.3 *Recent Concepts*), approaches, and key concepts in genetics, this

Table 10.3 Recent concepts

Term	Short description
Genomics	Genomics is a discipline in genetics that aims to determine the DNA sequence of the entire human genome and fine-scale genetic mapping including heterosis, epistasis, and pleiotropy. Contrary to the static approach of genomics, functional genomics concentrates on the dynamic aspects such as gene transcription, translation, and protein-protein interactions
Functional genomics/ behavioral genomics	Functional genomics is a field of molecular biology that attempts to make use of the vast wealth of data produced by genomic projects (such as genome sequencing projects) to describe gene (and protein) functions and interactions
Proteomics	Proteomics can be used as an experimental approach to describe the information contained in genomic sequences in terms of the structure, function, and control of biological processes and pathways. Proteomics aims to study biological processes comprehensively by a systematic analysis of the proteins expressed in a cell or tissue. Mass spectrometry is currently used as an important tool in proteomics
Deep sequencing	Deep sequencing provides not only the sequence but also frequency of RNA molecules that are present at any particular time in a specific cell type, tissue, or organ. The numbers of mRNAs that are encoded by individual genes are known to be an indicator of protein-coding potential and thus a major contributor to phenotype
Fine mapping	Fine mapping seeks to allocate the sequence of genes and their relative distances from one another on a specific chromosome. Fine mapping entails the identification of markers that are tightly linked to a targeted gene
Next-generation sequencing	DNA sequencing is used to determine the precise order of nucleotides within a DNA molecule. Next-generation sequencing is a group of high-throughput sequencing technologies that parallelize the sequencing process in order to produce thousands or millions of sequences at once
Metabolomics	Metabolomics is the study of biochemical processes that involve metabolites of an organism. These small molecules can function as catalysts such as enzymes or have interactive effects such as pheromones. In contrast to proteomics or genomics, metabolomics provides more detailed information of the biology and chemistry in a living organism. Moreover, as there is a strong connection between the metabolome and the genotype of an organism, its physiology, and environment (such as diet), metabolomics offers a unique opportunity to look at genotype-phenotype as well as genotype-envirotype relationships
Pharmacogenetics/ pharmacogenomics	Pharmacogenetics is the study of how an individual's genetic inheritance affects the body's response to drugs in terms of therapeutic but also adverse effects. It is thus the intersection of pharmaceuticals and genetics and offers beneficial effects on detailed knowledge about, e.g., medication, disease screenings, and health care

chapter now continues with an overview of the broad and substantial genetic influences on behavior and health risk. At the same time, interactions with behavioral and environmental factors necessary for phenotypic expression of genetic influences will be reviewed. Given this chapter's aim of providing the reader with an overview of behavior-genetic interactions in terms of health risk from a behavioral sciences perspective, it is not possible to provide an extensive review here. Therefore, suggestions on where to find further, more detailed information will be made.

The Role of Genetics in Health

As outlined above, only a small number of diseases and behavioral traits are caused by a single gene (e.g., Huntington's disease or cystic fibrosis). The majority of diseases (and behavior in general) are influenced by multiple genes (polygenetic), and it is known that one gene may affect more than one trait (pleiotropy) and also that genes interact to form phenotypic variance (epistasis or gene-gene interaction). This complexity is further increased by the effects of environment (environmental risk factors such as early-life stress, attachment style, social norms, or influence of peer and family behaviors), the interaction of genes and environment, and changes of gene expression throughout human life (epigenetics). The following section will provide a summary of past and more recent research in this context.

In the last years, increasing attention has been paid to the interaction between environmental factors and individual characteristics, such as personality traits. To provide just one example of this, research was able to show that novelty seeking (a personality trait that describes behavior of increased exploration of novel and unknown situations, objects, or stimuli) may increase susceptibility to the effects of advertising of tobacco (and possibly other substances) or that it increased the likelihood of exposing oneself to environments where tobacco is more readily available (Jamner, Whalen, et al., 2003).

Genetic susceptibility and its functional consequences (such as the 5-HTTLPR polymorphism and serotonergic function) play a major role in the explanation of health and health-related behaviors. It will be shown that there is substantial evidence from behavioral genetics research using twin and adoption studies, as well as from molecular genetic approaches looking at candidate genes, and that there are strong effects of genetic influences on variations in health and health risk behaviors. Different aspects of health and behavior are influenced by genetics. This section will discuss genes whose variations may increase susceptibility toward the initiation of health risk behavior and disease. Furthermore, genes involved in the progression and exacerbation of risk behavior, or genes involved in the sensitivity and responsivity of individuals to environmental risk factors, will be reviewed and summarized. In addition, genes that may interact with genes (epistasis or gene-gene interaction) known to predispose an individual to risk behavior and disease, and which are thus associated with protection against these outcomes, will also be mentioned.

This section will also describe how genes and environment do not influence health and health-related behavior independently but rather interact synergistically, i.e., genetic susceptibility factors may only constitute a risk under specific adverse environmental circumstances (see, e.g., interactions between polymorphisms, traumatic childhood experiences, and depressive mood in the abovementioned Caspi study (Caspi, Sugden, et al., 2003; for an overview of gene–environment interplay, see Rutter, Moffitt, & Caspi, 2006)). We will highlight that future research needs to consider the impact of many interacting factors (e.g., family and school environment) that act simultaneously and are in turn dependent on other factors (e.g., socioeconomic status). Importantly, there are also covariates and potential moderators of genetic effects that constitute more essential features of human identity such as race/ethnicity, sex/gender, and age. We will place a particular focus on the first two aspects, i.e., the modifying effect of ethnicity and sex on the relationship between genes and environment.

This chapter will not go into detail with respect to animal research, in which molecular geneticist is able to map genes that are involved in the behavior of, for example, mice, rats, flies, or even worms by simply removing (or "knocking out") the respective gene. In this regard, we refer the reader to Flint and Mackay (2009), who reviewed the genetic architecture of quantitative and complex traits in different species and discussed the difficulties in identifying genes that are responsible for complex traits. Laboratory studies in rodents, especially mice, mirror findings from human studies and show small-sized effects of multiple genes.

Sex/Gender and Race/Ethnicity

In the following, two key factors that might have an impact on health or health-related behavior and their genetic underpinnings will be discussed: sex/gender and race/ethnicity. On average, women have a higher proportion of body fat and lower blood pressure than men. Eating disorders are more prevalent in women. On the other hand, alcoholism and smoking are more prevalent in men, although the frequency of alcoholism and smoking in women has been increasing in the last years. These are just a few of the well-recognized differences between men and women in terms of behavior and health. Similarly, significant health disparities between African-Americans and Caucasians are well recognized, with higher rates, for example, of hypertension, stroke, or diabetes in African-Americans, ultimately resulting in a life expectancy gap of more than 4 years. Interestingly, breast cancer may be more common in Caucasian women, but African-American women have a greater risk of dying from breast cancer (Cronin, Richardson, et al., 2012). This is attributable to the fact that African-American women more often have aggressive tumors (genetic factor) and are less likely to receive adequate breast cancer screening (environmental factor). However, grouping individuals according to their race/ethnicity can only explain a small proportion of genetic variation, with only 10–15% explained variance due to differences between members of different groups (Ioannidis, Ntzani, & Trikalinos, 2004). This section will briefly introduce sex/gender and race/ethnicity as moderators of genetic impact on specific phenotypes.

The Behavioral-Genetic Investigation of Sex Differences

This first part will describe the effects of sex on genes and how sex moderates the effects of genes on behavior. First, the terms *sex* and *gender* need to be clarified. While sex is a classification based on biological differences, gender is a classification originating in the social construction of cultural distinction (i.e., behaviors, lifestyles, and environment) between men and women. The biological difference not only evolves from the presence or absence of the Y chromosome or different primary reproductive hormones but also from highly coordinated physiological systems that serve sex-specific functions. A simple example is the role of insulin in fat metabolism, which functions as a negative feedback signal on energy homeostasis and reduces body fat in men, while in women, it serves to keep the fat stored (necessary during pregnancy and lactation).

Some conditions like hemophilia and color blindness are more prevalent in men because the gene that causes the condition is recessively inherited and located on the X chromosome. As a further example, a condition called androgen insensitivity syndrome often garners public interest.[3] This is a condition in which chromosomally male individuals with a genetic variant of the androgen receptor (which results in an inability of the cell to respond to androgens) have testes and high androgen levels, while their genitalia, secondary sexual characteristics, and musculature are differentiated as women. By the time of the Atlanta Olympic Games in 1996, when sex testing became mandatory during Olympic Games, women with this condition

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[3] Androgen sensitivity seems to be overrepresented in female athletes. For a recent discussion on sex verification and performance of athletes, see (Tucker & Collins, 2010).

had to compete as men. In 2012, before the Summer Olympics in London, the International Olympic Committee released new regulations that now follow a hormonal definition of sex (abandoning the requirement of a genetic screening). Women are now tested for their individual testosterone levels and their body's response to testosterone.

Both examples illustrate what are called *sex-limited genetic effects*, which means that a genotype is expressed (= the phenotype) in one sex but not in the other. Genetic influences may also play different roles in men and women, the so-called *sex-modified genetic effects*. There is good evidence that genes contributing to vulnerability differ between men and women. From twin studies, the genetic correlation[4] between the sexes can be estimated, i.e., the degree of similarity of genetic risk factors that influence a particular trait. As an example from psychiatry, different genetic risk factors seem to predispose men and women to developing major depression, with values of +0.55 and +0.63, respectively (Kendler, Gardner, et al., 2001; Kendler, Gatz, et al., 2006). In line with this finding, alcohol dependence was found to show correlations of less than 1.00, indicating only partially overlapping disease-related genes between men and women (Prescott, Aggen, & Kendler, 1999). Taking into account the effects of environment and gene-environment interactions, twin study data on smoking initiation reveal that the magnitude of genetic and environmental factors differs between the sexes and that this is also dependent on cultural background. Regarding the risk of smoking initiation, shared environmental effects are more important in women, while genetic factors seem to be of greater importance in men (Heath, Cates, et al., 1993). In sum, to fully understand genes with a potential to impact health risk behavior, one must consider this sex-specific expression of genes.

The Study of Ethnicity in Behavioral Medicine

In some ethnic minorities, there are higher prevalence rates of chronic diseases such as diabetes and cancer, and some diseases seem to be regionally distributed. For instance, hemochromatosis, a disorder in which the body absorbs too much iron from the diet, is most common in Northern Europeans. This observation led to increased attention being paid to racial/ethnic disparities in health across different countries. Furthermore, a discussion on the definition of the term race was also initiated. In anthropology, *race* refers to a group of people who share specific hereditary and observable physical (skin color, hair type, etc.) or biological (blood group, metabolism) characteristics. However, this description is controversial since a person who is categorized as black in one society might be considered non-black in another. In contrast, *ethnicity* is used for a group of individuals of the same geographic origin, religion (ideologies, common beliefs, religious mores), language, and culture (laws, regulations, problem-solving, structural and institutional forces). All of these common characteristics shape an individual's perception and view of reality. Since the concept of race defined as genetically distinct subspecies of humans is no longer accepted due to modern genetic information (genetic ancestry and geographic ancestry are correlated, while race do not correlate well with genetic ancestry, Bamshad, 2005), this chapter will use the more accurate term of ethnicity or ethnic group.[5]

A prominent example of a genetic effect being moderated by ethnicity (and sex) is the level of the serotonin metabolite 5HIAA in cerebrospinal fluid, which is affected by the short and long serotonin-transporter-linked polymorphic region (5-HTTLPR) genetic variant of the serotonin transporter gene (see above). Besides a higher

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[4] A correlation coefficient of 1.00 means that the same genes influence a trait, while a value of 0.00 indicates absolutely no relationship, i.e., the same trait is influenced by completely different genes in men and women.

[5] To assess race/ethnicity, most studies simply ask "What is your race?" Since there is no biological or genetic test (assuming that race is defined by means of biological and genetic differences), participants' answers are mainly a cultural and subjective construct.

frequency of the long allele in Europe (and Africa) and a lower frequency in America (and Asia), the short allele variant (resulting in lower serotonin transporter mRNA transcription) is associated with high values of 5HIAA in African-Americans (and women) but low values in European Americans (and men) (Williams, Marchuk, et al., 2003). That is, ethnicity appears to moderate the effect of genotype in the case of the serotonin transporter gene. Thus, ethnicity and sex need to be taken into account when determining the functional effects (here serotonergic functions) of such polymorphisms. This is an example of how historic events, migration patterns, selection pressure, and geographic origin result in the occurrence of very different genetic allele frequencies and thus also contribute to the different presence of disease-related alleles.

Historically, research in the area of interethnic differences has always been a matter of controversy and debate. Apart from obvious ethical and political considerations, one of the most important shortcomings in this regard is of a methodological nature. Great caution must be taken when employing measures and scales that were designed and validated in one ethnic group (often Caucasians) and then applied to other groups (e.g., cognitive tests). Thus, a possible ethnic bias needs to be taken into account in these measures. Furthermore, research has also been biased by a lack of attention to within-group variability. For instance, among 25 other subgroups, Mexicans, Puerto Ricans, and Cubans constitute the Hispanic/Latino group, and yet each is genetically and ethnically different from the others. In line with this, the abovementioned analysis of 134 meta-analyses of studies using genetic association designs found that within-group variability accounts for 85% of genetic variation and not, as assumed, differences between groups (Ioannidis, Ntzani, & Trikalinos, 2004). Importantly, the effects of genes might differ due to the presence of other genes (gene-gene interaction) or specific environmental circumstances (gene-environment interaction). Hence, predicting differences in disease risk is complicated across different ethnic groups but also within these groups. This heterogeneity of genetic and environmental sources of variability is well illustrated in the observation of the geographic variation[6] of chronic diseases such as cancer, coronary heart disease, and stroke, despite similar behavioral risk factors (unhealthy diet, physical inactivity, obesity, alcohol use and smoking, unemployment). Why do the same risk factors lead to differences in chronic disease patterns in different regions? Behavioral genetics studies are beginning to identify the sources of variability by differentiating both genetic and environmental factors.

One of the most studied variables in the context of ethnic disparity in health outcomes is socioeconomic status (SES), which will be discussed in more detail in the next section. Differences in SES (e.g., higher income, higher level of insurance, and lower poverty rates in Caucasian households) substantially account for health inequalities between ethnic groups. However, adjusting for SES status does not completely eliminate ethnic disparities. Other contributing factors, genetic or environmental, also need to be considered. Future research will need to face the challenge of incorporating genetic factors, i.e., a biological susceptibility to disease, complex environments, and their interaction in the examination of health inequalities. Whether a functional polymorphism might be considered a harmful (vs. risk/vulnerability) or protective factor in the development of disease is generated and/or shaped by environmental factors (gene-environment interaction). A better understanding of these intricate relationships is also critical for risk-prevention programs. As already discussed in the context of cognitive ability tests, a risk-prevention program that is designed for and proven to be effective in one ethnic group might be less effective or completely fail in another. Thus, it is also essential to consider the environment as a modifying factor when designing and testing future intervention strategies.

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[6] The Division for Heart Disease and Stroke Prevention of the Centers of Disease Control and Prevention offers constantly updated maps that document mortality and hospitalization rates including ethnic disparities.

Environmental Risk Factors: Chronic Stress, Low Socioeconomic Status, and Lack of Social Support

Although genes partially determine interindividual differences in susceptibility to many diseases, an increasing number of studies suggest that environmental factors and especially gene-environment interactions play a pivotal role in the etiology of various psychiatric conditions (Caspi, Sugden, et al., 2003; Kendler, Kuhn, et al., 2005; Neumeister, Konstantinidis, et al., 2002). This section will present some of the most intriguing findings regarding environmentally based factors and their interaction with genetic factors on health and disease, with a specific focus on psychiatric conditions. We will focus on three highly relevant environmental factors: chronic stress as one of the major health risks in modern societies, SES as one of the most studied variables associated with health disparities among groups, and lack of social support as a factor which interacts with and worsens the effects of chronic stress and low SES.

It is well known that early-life stress has a major impact on an individual's well-being. The first years of life are crucial for physiological and psychological development as well as behavior (Nater & Skoluda, 2013). Stressful experiences during this critical period may increase vulnerability to psychiatric conditions later in life (Kaufman, Yang, et al., 2004). One pathophysiological mechanism underlying this relationship might be an effect of chronic stress on gene expression, the process of protein production from a gene's coding sequence. In studies in which chronic stress was operationalized as social loneliness and chronic threat of losing a loved one or close person, analyses indicated that these stressors were able to upregulate the activity of inflammatory genes and downregulate the activity of immune-restricting pathways (Miller, Chen, et al., 2008). Theoretically, the ultimate effects of being chronically exposed to such stressors may be inflammation-related diseases such as obesity, cardiovascular diseases, or mood disorders.

Another landmark study, which demonstrated the interaction of genes and environment in shaping our behavior, was published in 2003 in the journal Science and has already been reviewed above. In short, the 5-HTTLPR polymorphism had no effect on depressive symptoms in the absence of stressful life events but showed a very large effect when individuals experienced four or more stressful life events. Findings of this study provoked a still ongoing debate about the gene-environment interaction between stressful life events, 5-HTTLPR genotype and depression, and led to a multitude of replication studies. As is often seen in research on molecular mechanisms in psychiatric conditions, the likelihood of replication was 50%, with higher-quality studies being more likely to detect a relationship (Risch, Herrell, et al., 2009). Interestingly, most recent research indicates an effect of sex, with a positive replication in women.

Moreover, it was shown that in Caucasian samples, the short allele of the 5-HTTLPR polymorphism not only predicts vulnerability in the face of negative experiences but also resilience in the case of positive experiences. Therefore, current research also includes potentially positive effects of "risk" genes, which are accordingly called "susceptibility" or "plasticity" genes (genes that seem to make individuals more susceptible to environmental influences, potentially both in a positive and negative way). One might wonder whether there might also be genetic effects on individual differences in terms of exposure to risk factors. Twin studies suggest a surprising heritability of exposure to life events, of about 40% (Plomin, Lichtenstein, et al., 1990).

But how is it possible that life events, which are supposed to be entirely environmental, turned out to be not entirely environmental? Indeed, it appears that some people select an environment that increases their likelihood of experiencing stressful life events. This environmental niche-picking is termed gene-environment correlation. Usually, researchers distinguish between independent and uncontrollable events, such as car accidents, and dependent and controllable stressors, such as quitting a job. According to this theory, a higher heritability is hypothesized for controllable events, and only modest heritability is hypothesized for uncontrollable events. Most studies provided support for this notion (40–50% for controllable events vs. 20% for uncontrollable ones) and found, in general, similar scores for men and women.

Importantly, the abovementioned effect of chronic stress on the activity of inflammatory genes was even more pronounced in individuals with low SES backgrounds, who seem to perceive more threat in stressful situations (Chen, Miller, et al., 2009). Besides these moderating effects of SES – i.e., how much money we make, what educational level we achieve, etc. – it has been suggested that SES is also in our genes. In quantitative genetic studies, income was shown to be moderately heritable (possibly accounting for 10–30%), with greater effects for men (Björklund, Jäntti, & Solon, 2005; Taubman, 1976). Higher estimates of about 50% have been found for educational background (Behrman & Taubman, 1989; Tambs, Sundet, et al., 1989). It may be reasonably assumed that the genetic factors underlying monetary income and educational level are similar (Rowe, Vesterdal, & Rodgers, 1998). However, given the notion of complex gene X environment interaction, direct effect of genes on variations in SES is quite questionable. It is more likely that these influences are mediated via genetic effects on intelligence and personality. In this context, personality traits have been shown to explain a significant part, for example, of SES variance (Chapman, Fiscella, et al., 2010). Future studies will have to examine the pathways by which genetic factors pave the way from predisposition to behavioral differences in different areas of social life.

It also seems reasonable to assume a significant impact of genetic factors on our social environment, e.g., how much social support we receive from others or how much social support we perceive ourselves to receive. It is well documented that both received and perceived social support are associated with physical and mental health. This association may be mediated by a potential buffering effect on the negative consequences of chronic stress. The question whether social support underlies genetic factors has been examined using twin studies. Results of these studies showed moderate heritability but, at the same time, also highlighted the importance of shared environment (e.g., Kessler, Kendler, et al., 1992). Twins share many environmental characteristics that comprise social support (relatives, friends), accounting for a considerable amount of environmental contributions to social support. Another important factor in the context of social support is the quality and quantity of social networks, i.e., the number and subjective evaluation of social interactions and relationships. While the quality of social networks was associated with clear genetic effects, the quantity of social relationships was not found to be heritable. Notably, a sex difference emerged for the relative contribution of genetic and shared environmental factors to the quality and quantity of social networks (Agrawal, Jacobson, et al., 2002): Only in women was the support of relatives (constituting a qualitative aspect of social support) influenced by genetic factors, and shared environmental factors played a significant role for the number of confidantes (the quantitative aspect).

Research on possible candidate genes that may be relevant in the context of social support is still in its infancy. However, initial evidence from molecular genetic studies looking at the neuropeptides oxytocin and vasopressin is very promising: Gene association studies focused on variations in the arginine vasopressin receptor 1A (AVPR1A) gene which have been associated with altruism, partner bonding, marital problems, and perceived quality of social relationships but have also been implicated in autism. Additional functional experiments examining neurophysiological correlates of these genetic variants showed a link between AVPR1A polymorphisms and amygdala activation (for a review see Donaldson & Young, 2008). In brief, the shorter repeat alleles are associated with reduced transcriptional activity of the AVPR1A gene, and this seems to be related to heightened amygdala activity. Increased amygdala activity might, in turn, be related to heightened fear responses in social situations and phobic and avoidance behavior, while decreased amygdala activity has been associated with aggression and hypersociability. Another promising candidate gene is the oxytocin receptor (OXTR) gene. Studies looking at the functional consequences of variants in this gene provided first evidence of a modulating effect of OXTR on the stress-buffering effects of social support (for a discussion on molecular genetic studies focusing on OXTR, see Kumsta & Heinrichs, 2013).

These genetic variations exert their phenotypic effects through their effects on gene expression. The underlying genomic mechanisms of the effects of social environment on health can be explored via the assessment of genome-wide transcriptional activity. Transcriptional activity was shown to be altered in subjects suffering from chronic social isolation, with especially heightened activity of inflammatory pathways (Cole, Hawkley, et al., 2007). This study was one of the first to show an association between a social environmental risk factor (social isolation) and increased pro-inflammatory activity and thus elevated disease risk.

Whether epigenetic inheritance also plays a role, i.e., whether social stress-induced modulations of transcriptional activity are stable and transmitted to the following generation, remains an open question. Research in animals provides evidence for a transgenerational effect of chronic social stress: Stress-induced heightened corticosteroids seem to impact behavior throughout the lifespan but also across generations (Hunter, 2012). In humans, behavior and attachment have been shown to be transferable between generations (Benoit & Parker, 1994; Hautamaki, Hautamaki, et al., 2010; Kim, Capaldi, et al., 2009), but specific molecular mechanisms remain unknown.

Overall, this brief overview of three selected environmental factors shows that these are at least partially heritable. At the same time, the findings also highlight the notion that genetic and environmental factors are closely related in shaping how we, and possibly our children, perceive and respond to our environment.

Health Risk Behaviors

This section describes behavioral genetics studies dealing with genetic and environmental effects and their interaction on typical health risk behaviors. Examples of those health risk behaviors will be alcohol and tobacco use, unhealthy eating behaviors, and physical inactivity.

Alcohol Use

In most prevalence studies on alcohol use, behavioral definitions established by the Centers of Disease Control and Prevention were used. This includes “having at least one drink of any alcoholic beverage in the past 30 days” for alcohol use and “having five or more drinks at one time in the past 30 days” for binge drinking. To address recent progress in research, more refined definitions also include trajectories of alcohol use initiation and progression. Harmful use is defined as abuse that is causing physical (liver cirrhosis, cardiovascular diseases), mental (depressive symptoms after heavy drinking episodes), and social (family and marital conflicts) damage. Harmful use should be distinguished from dependence. Alcohol dependence, also known as alcoholism or alcohol addiction, is a chronic condition characterized by a strong craving for alcohol, inability to limit drinking, and continued use despite related harmful consequences. According to the WHO, harmful use of alcohol results in more than two million deaths each year, making excessive alcohol consumption the third highest cause of preventable disease and disability (after tobacco and lifestyle factors, such as poor diet and physical inactivity). The highest consumption levels are found in Western and Eastern Europe, while abstinence levels are especially high in countries with large Muslim populations. Risky drinking (defined as drinking alcohol to the point of intoxication) was shown to be lowest in Western European countries and highest in the Russian Federation. This pattern of drinking was also shown to occur more frequently in Southern Africa and Mexico. As a further example of ethnic differences, Hispanic adolescents (8th grade) have the highest prevalence of risky and heavy drinking (defined as having consumed more than five drinks in a row in the last 2 weeks) in the United States (Johnston, O’Malley, et al., 2013). The lifetime risk for alcohol dependence ranges between values below 2% for individuals living in African countries and about 15% for men and

8% for women living in Western countries. Prevalence rates of alcohol dependence lie at about 4% in the general population. Thus, alcohol dependence is very common, and differences between countries and ethnic groups need to be kept in mind.

Due to the harmful consequences of alcohol abuse and dependence, the study of the causes of alcohol dependence, including genomic mechanisms, is of pivotal importance. Historically, illuminating the causes of alcohol dependence by studying families of alcoholics was complicated by the fact that alcoholics often have no family by the time they are identified as alcoholic; many individuals no longer have identifiable family ties. As described above, alcoholism has detrimental social consequences, and alcoholics often have broken family relationships, like higher divorce rates (Waldron, Heath, et al., 2011), making it difficult to obtain data from family members. Hence, the more attractive approach was to study twins and adoptees and ask them as well as a third party (e.g., their doctors) about their alcohol-related behavior. Data from one of the largest twin registries (Swedish twin registry, which includes information from the Swedish Temperance Board registration for alcohol abuse[7]) showed a concordance rate of 47.9% in monozygotic twins compared to 32.8% in dizygotic twins regarding Temperance Board registrations (Kendler, Prescott, et al., 1997). Following these initial findings, twin and adoption studies provided further evidence for the substantial effect of genes on alcohol use, misuse, and dependence. The heritability of the latter was estimated to lie at about 40–60%. Findings from adoption studies revealed that adopted-away sons of parents with alcohol problems have a four-fold increased risk of developing alcohol dependence compared to adopted-away sons of parents without this problem. Having a first-degree relative with alcohol dependence leads to a seven-fold increased risk of also developing alcohol dependence. Looking at sex differences in heritability, estimates regarding early alcohol-related behavior, including early onset of alcohol dependence, did not differ significantly between women and men. With respect to late-onset alcohol dependence, heritability was found to be higher in women.

In contrast to the study of other psychiatric disorders (such as schizophrenia), molecular genetic studies in the context of alcohol dependence have the advantage of being able to examine good candidate genes. Hypotheses on such candidate genes have been derived from the obvious differences between people in terms of their immediate response and sensitivity to the effects of alcohol. Enzymes involved in the conversion of ethanol to toxic acetaldehyde and benign acetic acid are therefore perfect physiological candidates. One of these enzymes, acetaldehyde dehydrogenase (ALDH), is quite prominent: About 43% of people in East Asian populations have a scarcely working form of the ALDH gene, resulting in high levels of toxic acetaldehyde and the typical flushing reaction (red skin, headache, feeling awful) when drinking alcohol. Therefore, individuals with this gene variant are rather unlikely to develop alcohol dependence. However, candidate genes have not been restricted to alcohol-metabolizing enzymes. Other candidate genes that have been examined are involved in processes mainly located in brain structures related to the reward circuits and corresponding neurotransmitters, such as dopamine, serotonin, and norepinephrine. Genetic mutations in these systems may also result in interindividual differences in different alcohol-related behaviors including use of alcohol, responses to alcohol, craving, and dependence. Subjects with a particular genotype of the dopamine transporter (which stops the action of dopamine through blockade of presynaptic reuptake) were shown to develop strong withdrawal symptoms, such as seizures and delirium tremens. This effect can be explained by the effect of dopaminergic neurotransmission on GABAergic and glutamatergic pathways (for a review of the role of GABA receptors in alcohol and nicotine dependence, see Cui, Seneviratne, et al., 2012). Genetic predisposition can thus result in an imbalance of excitatory and inhibitory neurotransmission.

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[7] This register records all subjects who were arrested due to drunkenness or committing a crime under the influence of alcohol.

Although a vast knowledge base on candidate genes has been gathered, little work has been undertaken in terms of testing the effects of environmental factors and gene-environment interaction. The few studies which tested these relations concentrated on sociocultural context (such as educational attainment, family factors, marital status) and adversity (such as early trauma, e.g., childhood abuse and maltreatment and stressful life events). Summing up these studies, the initiation of drinking seems to be mainly determined by environmental factors, while genetic factors seem to play a more important role in the development of alcohol dependence given initial exposure. It can also be concluded that the magnitude of genetic effects varies considerably between different environments: genes play a four- to fivefold more important role in an environment that is characterized by more peer role models, greater neighborhood instability, and higher rates of alcohol sales. By contrast, environmental factors are more important, and genetic influences are more modest in communities characterized by higher social stability and structure. For instance, the gene pool of US Mormons is probably rather similar to the rest of the Euro-American population, but given their environmental influences, those genes are likely to have a lower impact on phenotype.

One may assume that an urban environment, with its greater mobility potential (to move into and out of different regions), would provide an adolescent with more potential friends and activities and thus allow a higher probability for risk genes to be expressed (gene-environment interaction). Marital status seems to moderate the magnitude of genetic influences on alcohol dependence, with greater risk in single or divorced compared to married carriers of a risky gene variant. It might be hypothesized that marriage may buffer the effects of risky genes for alcohol dependence, for instance, through heightened social support and stability. Besides this effect of environmental factors on the expression of risky genotypes, there might also be an effect of genes on the subjects' response to the environment. For instance, genes known for their involvement in the psychophysiological response to environmental stressors (sensitivity to environmental risk factors, i.e., gene-environment interaction) have also been implicated in alcohol use. It is hypothesized that stressors are more strongly related to alcohol use in subjects with certain gene variants. Consistent findings were shown for the corticotropin-releasing hormone receptor 1 gene (CRHR1), indicating that the high-risk allele was only associated with higher alcohol consumption when subjects were also exposed to early-life stress and negative life events. Far less consistency can be summarized for the length polymorphism in the promoter region of the serotonin transporter gene (5-HTTLPR). Individuals with the less functional short allele who experienced more stressful live events or maltreatment were at greater risk of more frequent and heavier drinking. However, there is also evidence that the long variant is the risky genotype, while some studies found no gene-environment interaction at all. For a summary of gene-environment interaction studies in alcohol dependence and a critical review of the limitations of these studies, we refer the reader to Young-Wolff, Enoch, and Prescott (2011).

In sum, the impact of genetic factors on potentially addictive behaviors such as alcohol consumption is well researched. More current research also highlights that genes may also influence the exposure to risky environment, i.e., drugs. This example of a gene-environment correlation (in contrast to the abovementioned response to the environment as an example of a gene-environment interaction) describes the phenomenon that individual variability in, for example, the exposure to drugs and regular drug use is partly genetically determined. For instance, adolescents with genotypes associated with propensity to risk-taking behavior tend to have friends with greater substance use and select lifestyles that lead to higher exposure to environmental risk. Other moderators of the genetic risk for alcohol disorders, with evidence from different studies, are availability of a substance, deviant behavior within the peer group, poor parenting style, financial problems, and a lack of pro-social behaviors such as volunteering or helping others. Future research should focus on these gene-environment correlations while interpreting findings of gene-environment interactions. Furthermore, research needs to clarify whether an unknown third variable may account for the observed interaction. Additionally, examining gene-gene interactions (epistasis) and environment-environment interaction and genetic susceptibility will also enhance our understanding of risk factors for alcohol misuse and dependence. Moreover, looking at (endo-) phenotypes that are more closely related to distinct aspects of alcohol dependence such as withdrawal, tolerance, and mediating traits like cravings will help to integrate and replicate studies in this context.

There is also plausible evidence for an involvement of epigenetic mechanisms in the context of alcohol dependence. As we have learned above, folate levels are an important regulator of DNA methylation, and changes in these levels might impact normal development. Here, alcohol plays an important role: One effect of ethanol is reduced folate activity, which results in altered DNA methylation and thus altered gene expression. Other ethanol-induced effects are functional changes during the processes of acetylation, methylation, and phosphorylation of histones (Shukla, Velazquez, et al., 2008). Furthermore, the abovementioned conversion product of ethanol, acetaldehyde, has the potential to interrupt the methylation of histones relevant for gene expression. Besides these direct effects of ethanol on gene expression, there are also more indirect and distant effects. During gastrulation (i.e., the early phase during pregnancy when organs are developing), alcohol seems to be related to lower levels of DNA methylation, which are known to retard this process of differentiation and development. Several studies provide evidence for the involvement of miRNAs in alcohol dependence, with ethanol decreasing their expression. This, in turn, might be related to apoptosis in certain cells. Current knowledge about these processes mainly stems from investigations with rodents, and the ethanol-related regulation of gene expression in humans still needs to be addressed in future studies.

To sum up, alcohol use and dependence are influenced by (1) genes related to how alcohol is metabolized and the rewarding effects of alcohol; (2) the environment in which we live (family factors, stressful life events), (3) epigenetic mechanisms that can be directly related to the effects of ethanol on acetylation, methylation, and phosphorylation of histones; and, perhaps most important, (4) interactions among all of these such as in genetic influences on behaviors leading to exposure to more risky environments or environmental influences on expression of genes related to experience of stress and its impact on alcohol use. The next section will summarize quantitative and molecular genetics findings for another substance with high addictive potential: nicotine.

Smoking

It is important to point out that there are many parallels between smoking and alcohol use in terms of gene-environment interaction. At the beginning of the twenty-first century, the prevalence of tobacco use ranges from above 30% in Eastern European countries and Chile to values below 10% in Asian and African countries. Nevertheless, low- and middle-income countries have the highest prevalence rates (about 80%). In 2004, 5.4 million deaths worldwide were attributable to tobacco, again with higher rates in low-income countries. Among tobacco-attributable diseases, cardiorespiratory diseases and cancer are the most prevalent. Thus, reducing the rates of smoking or even preventing people from starting to smoke in the first place is of great interest to public health. Most smokers begin their smoking career during adolescence or early adulthood. Interestingly, one fifth of young adolescents (aged 13–15 years) worldwide have already taken up smoking. The rate of young adolescent smokers is especially high in countries with fewer prevention efforts and less politically based intervention (such as increasing prices, raising legal age for the purchase of tobacco, or banning vending machines and tobacco advertising). In line with this, research shows that the motivation to start smoking is strongly influenced by the environment. In fact, such diverse environmental factors as smoking habits of peers or family, being exposed to family conflict, or tobacco industry marketing and advertising campaigns have been related to an increased likelihood of becoming a smoker.

However, there is also evidence that genetic factors play a role. Genes might predispose an individual to smoking initiation via their impact on psychological traits such as novelty seeking and impulsivity (Audrain-McGovern, Nigg, & Perkins, 2009). These traits have been shown to be significantly hereditary and to not only increase the risk of initial smoking but also to influence how people respond to initial nicotine exposure and their likelihood of further nicotine use (see also below). In line with this, research highlights the importance of individual differences in the psychophysiological effects of nicotine, nicotine tolerance, the effects of nicotine on cognition, the rewarding effects of nicotine, and the effects of nicotine deprivation. Thus, once initiated, genetic factors play a major role in the maintenance of smoking and the development of nicotine dependence. Results from quantitative genetic studies show that there is an inherited susceptibility to the rewarding value of nicotine. About 60% of the variance of nicotine dependence can be attributed to genetic factors (Kendler, Thornton, & Pedersen, 2000). Summarizing the findings from twin studies, the risk of being a current smoker is mainly hereditary, with about 55% of the risk being due to genetic factors, about 24% due to shared environmental variance, and about 21% due to individual-specific variance. These studies further showed a significant impact of genetic factors on different aspects of smoking such as initiation, persistence, and ability to quit (for a detailed review of the literature, Li, Cheng, et al., 2003; Sullivan & Kendler, 1999). Interestingly, heritability estimates (expressed as % variance) were not consistent across age groups, which is not surprising given the emergence of other factors that, over time, explain more or less variance. As well, an age by sex interaction emerged, showing decreasing heritability with age in men and increasing heritability with age in women. Moreover, this literature and more recent genome-wide linkage scan analyses support the notion of ethnic differences in terms of genetic factors contributing to nicotine dependence. African-Americans and European Americans differ in their loci of chromosomes, which have been associated with nicotine dependence. In African-Americans, a region on chromosome 5 has been identified, while chromosome 7 was found to be of particular importance in a European American sample (Gelernter, Panhuysen, et al., 2007).

Studies analyzing different gene variants have looked at specific candidate genes in the context of neurobiological pathways involved in nicotine metabolism as well as in the reinforcing and addictive effects of nicotine. These studies provided evidence for an effect of genetic variations in the dopamine, serotonin, and opioid pathways and the nicotinic acetylcholine receptors (for a summary of selected findings from the tobacco genetic literature, see Swan, Lessov-Schlaggar, et al., 2009). Dopamine transporter and receptor polymorphisms have been repeatedly associated with nicotine dependence: It was shown that smokers who have a genetic variance associated with lower basal dopamine exhibited an enhanced dopamine release in response to nicotine (Brody, Mandelkern, et al., 2006), which indicates a higher rewarding effect of nicotine in these subjects. Another enzyme involved the dopaminergic reward circuit that might have a role in the etiology of nicotine dependence is catechol-*O*-methyltransferase (COMT), which is involved in the degradation of catecholamines. Genetic variation in the COMT gene associated with reduced activity of this catecholamine-degrading enzyme (*Met* allele) reduces the likelihood of developing a nicotine dependency (Beuten, Payne, et al., 2006). In this context, a gene-sex-ethnicity interaction might be relevant: Beuten et al. also showed that some gene variants were protective in African-American women, while others were protective in European American men only. It is further well known that nicotine intake increases brain-derived serotonin and, conversely, that nicotine withdrawal decreases serotonin levels. Consequently, the serotonin transporter gene polymorphism (5-HTTLPR) was also studied in the context of nicotine dependence. Research shows that subjects with the short allele genotype of the 5-HTTLPR were less likely to quit smoking (Hu, Brody, et al., 2005). Additionally, these subjects also had higher values of neuroticism. Thus, the short form of this polymorphism has been associated with a temperament trait that might predispose the individual to feelings of anxiety, irritability, and depressed mood as well as exaggerated emotional responses to external stimuli, all of which may be mitigated by the pharmacologic effects of nicotine. It is therefore assumed that the association between the 5-HTTLPR genotype and smoking behavior is mediated via personality, stress responses, and the consequent heightened reward value of nicotine.

Research has also focused on genetic polymorphisms involved in the metabolism of nicotine. Prominent examples are cytochrome P450 isozymes, which are responsible for the biotransformation of different endogenous and exogenous substances including nicotine. Variations in these isozymes have been implicated in the variance of the amount of smoking and nicotine levels between individuals. Research is focusing on genetic variations in two isozymes: CYP2A6 and CYP2D6. Mutations in these genes result in a reduced production and activity of the isozymes or, under homozygote conditions, in a complete absence of this metabolic pathway (in this case the nicotine-metabolizing pathway) (Malaiyandi, Sellers, & Tyndale, 2005). Subjects with gene variants associated with normal metabolization smoked significantly more, had higher rates of nicotine dependence, as well as a higher risk of lung cancer compared to those with reduced metabolization. Molecular genetic methods (using GWAS) confirmed these previous results and showed strong associations between smoking and nicotine dependence and some other genetic variants: In particular, the involvement of the different alpha subunits of the nicotinic acetylcholine receptor gene, especially the CHRNA5-CHRNA3-CHRNB4 gene cluster, has been studied quite often. A group of genetic variants (i.e., SNPs) of this gene complex increased the risk of heavy compulsive smoking and craving, measured via cigarettes smoked per day (e.g., Stevens, Bierut, et al., 2008). This provides clear evidence that variants in the CHRNA5-CHRNA3-CHRNB4 gene cluster are functional.

Results of these GWAS studies can provide further guidance for more specific candidate gene association studies in the future, suggesting the inclusion of previously unanticipated risk genes for nicotine dependence. Furthermore, one of the latest innovations in this context is the inclusion of other methodological approaches that examine the functional significance of these variants and associated neurobiological phenotypes. These intermediate phenotypes, such as nicotinic acetylcholine receptor availability, are more closely related to specific genes and might provide a solution to the limitation of even large GWAS studies, which at best explain only 1–2% of a specific phenotype. For instance, there are several reports showing associations between specific genes and smoking behavior, although some studies failed to replicate these associations. One reason for this might be the failure to include the aforementioned intermediate phenotypes or to take into account environmental factors.

While family, twin, and adoption studies of the last two decades clearly demonstrated the existence of gene-environment interactions in smoking behavior and nicotine dependence, studies which examine these associations directly are surprisingly rare. In line with the assumption that environmental factors might play a larger role during adolescence, the school environment was shown to moderate genetic influences on smoking behavior. As an example, one study found that the highest heritability estimates were observed in schools in which the most popular students were smokers (Boardman, Saint Onge, et al., 2008). This supports the assumption that individuals may have specific genetic characteristics, but the environment enables or limits the effects of these characteristics. An enabling effect of environmental factors also explains the sometimes large differences in heritability estimates between studies. It is highly unlikely that heritability estimates will remain constant when there is actually no constant environment. As already noted above, environmental factors change over time explaining more or less variance. One should keep in mind that there are never more than 100% variance to explain by both heritability and environmental factors. Another study found that lower heritability estimates were observed in schools with mainly non-Hispanic and Caucasian students, a finding which emphasizes the role of ethnicity. Ethnic groups may differ, for example, in their behavioral norms (such as whether and how much they smoke) or availability of financial resources, which in turn might constrain the effects some genes might have. One further example of the large impact of environment-related factors is religiosity, which was shown to be related to lower prevalence rates of smoking initiation and to attenuate the additive genetic component for smoking initiation (Timberlake, Rhee, et al., 2006). The additive genetic component for smoking initiation in this study ranges from about 80% in subjects with low self-reported religiosity to less than 10% in subjects who described themselves as being religious and as considering religious faith as very important. The inhibitory effect of environmental influence on genetic factors was also reflected in a twin study, which showed a smoking prevalence rate of less than 1% in Chinese women, while about 60% of Chinese men were smokers (Lessov-Schlaggar, Pang, et al., 2006). The authors explain this discrepancy through the reduced access of Chinese women to social contexts in which smoking is common. This study clearly demonstrates the existence of gene-environment interactions in smoking behavior, i.e., cultural factors that may prevent women from smoking. Parental monitoring seems to be another moderator of genetic vulnerability to smoking and smoking initiation. In a twin study, high parental monitoring was shown to decrease genetic effects, while low parental monitoring appeared to fundamentally promote genetic effects on adolescent smoking (Dick, Viken, et al., 2007). Thus, the degree of genetic effects on adolescent smoking behavior varies depending on parental behavior (gene-environment interaction).

As noted earlier in this chapter, parental behavior is not only important during childhood and adolescence. Even before contraception, predisposition to a number of diseases can be preprogrammed by parental smoking behavior. Experimental studies investigating transgenerational effects are impossible in humans, so research has to rely on observational findings. Besides evidence for epigenetic modifications in smokers, paternal smoking was shown to be associated with altered miRNA expression in sperm (Marczylo, Amoako, et al., 2012). This provides evidence for a mechanism of epigenetic modulations that can be passed on to the next generation (transgenerational inheritance). Furthermore, maternal cigarette smoking during pregnancy has been related to higher DNA methylation (i.e., lower gene expression levels) in the BDNF gene of their adolescent offspring, suggesting a downregulation of this key regulator of brain development (Toledo-Rodriguez, Lotfipour, et al., 2010). There is also first evidence that epigenetic modifications might be predictive for future disease. A study on childhood asthma showed effects of maternal and grandmaternal smoking on the offspring's risk of asthma (transgenerational inheritance) (Li, Langholz, et al., 2005) Furthermore, long-term effects of smoking on methylation levels and thus expression of genes known to be involved in, for example, coagulation have been found in cancer patients (Shenker, Polidoro, et al., 2013).[8]

Similar to studies on alcohol dependence, future studies should include more intermediate and sophisticated phenotypes that are more closely related to specific characteristics of smoking behavior, such as measures of cognitive function, craving, impulse control, motivational measures, or biological abnormalities (e.g., alterations in specific brain regions). To address the question of the extent to which environmental factors influence genetic properties, studies are in need of reliable measures of the environment. The latter in particular requires interdisciplinary research,

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[8] EPIC (European Prospective Investigation into Cancer and Nutrition) is a well-designed genome-wide epigenetics study and shows a pattern of DNA methylation that was able to distinguish between smokers who developed cancer and those who did not. This might offer the possibility to screen for cancer risk by means of DNA analysis.

including knowledge from social psychology, economics, politics, and cultural studies.

In sum, smoking is influenced by (1) genes involved in nicotine metabolism as well as in the reinforcing and addictive effects of nicotine; (2) the environment, which enables or limits the effects of genetic characteristics (peers in school who smoke, religiosity, parental monitoring); and (3) epigenetic mechanisms such as maternal and grandmaternal smoking via their impact on methylation levels in the offspring. To complement these points (which mirror knowledge in alcohol dependence), interactions among genes, environment, and epigenetics become more and more evident as, e.g., cultural influences that prevent some groups from smoking and the phenotypic expression of risky genes, or protective gene variants that differ between ethnic groups depending on sex (a gene-sex-ethnicity interaction).

Paradoxically, decreased smoking rates were introduced as one factor in the occurrence of higher obesity rates. The suppressing effect of nicotine on appetite was discussed as a possible mechanism for this. The next section will deal with obesity and unhealthy eating behaviors and their genetic and gene-environmental causes.

Obesity

With its easily accessible and palatable diet and motorized mobility, modern society strongly contributes to increasing rates of obesity. Until the late nineteenth century, obesity was a rather rare phenomenon. One century and related industrialization was enough to completely change this picture. According to data from the WHO and the Organization for Economic Cooperation and Development (OECD), current obesity rates (BMI $\geq$ 30 kg/m^2) vary from less than 5% in Korea and Japan to values above 30% in Mexico and the United States. Across all countries, the childhood obesity rate is about 20%, with the highest rates in the United States (≈35%) and Greece (≈41%). There seem to be differences between different ethnic groups with respect to criteria of obesity and obesity-related health consequences. Some nations had to refine the diagnostic criteria of obesity, since, for example, population studies in Asians show associations between BMI and obesity-related chronic diseases at a much lower BMI level. In this context, Japan defines obesity as having a BMI $\geq$ 25 (The Examination Committee of Criteria for 'Obesity Disease' in Japan, 2002) as there is evidence for a progressive increase of hypertension, hyperglycemia, and dyslipidemia in Japanese individuals at even lower BMI values. Comparable with estimates in smokers, severely obese people are hypothesized to die 8–10 years earlier compared to slim people. Excess body weight has been linked to impaired physiological functions, including deficient immune function and increased cortisol secretion, potentially leading to altered responses to stressors which in turn might lead to disease. Adipose tissue is known to be a major source of inflammatory cytokines and prothrombotic factors. Obesity is therefore a major risk factor for chronic diseases such as coronary heart disease, diabetes, cancer, or depression. The development and perpetuation of obesity is the result of a complex interplay of social, emotional, motivational, and also genetic factors. A significant proportion of the risk of developing obesity is attributable to changes in lifestyle in modern Western societies, which favors unhealthy diets involving the consumption of high energy/caloric food and supports a sedentary lifestyle.

For this reason, and owing to the increased obesity rates that have arisen in such a short period of time (from an evolutionary perspective), genetic causes may be assumed to be rather unlikely, meaning that environmental factors would then explain most cases. In contrast to this assumption, however, numerous studies estimating heritability of susceptibility to obesity-related phenotypes range from 6% to 85%, depending on the population under study (Yang, Kelly, & He, 2007). Estimates for individual differences in BMI or body fat range between 45% and 85% (Silventoinen & Kaprio, 2009). Importantly, these estimates depend on the population examined. For instance, research indicates that children's total body fat is related to a higher heritability estimate compared that of adults. There are also risk factors of obesity related to medical conditions (such as insulin resistance) and psychiatric disorders (e.g., depression is associated with poor diet quality and low physical activity levels) or single gene disorders (e.g., Prader-Willi or Bardet-Biedl syndrome), in which obesity constitutes part of the illness. However, such major genetic effects on obesity are rare, accounting for only a minor proportion of obesity-related morbidity, and their functional consequences (such as abnormal resistance to insulin) remain to be elucidated.

Normally, common forms of obesity are polygenetic. Molecular genetic studies reveal a large number of vulnerability genes that are related to obesity phenotypes such as BMI, appetite, and diet. Hence, various studies examined the effects of genetic variations related to lipid and glycometabolism as well as hunger and satiety (as discussed below). It is generally believed that genetic factors influence obesity via their contribution to (1) the susceptibility to a generally unhealthy diet in a particular social environment and (2) an individual's likelihood of developing obesity in response to a particular level of energy intake and caloric consumption. Most recent advances in our understanding of genetic susceptibility to obesity and unhealthy eating behaviors come from genome-wide association studies. So far, 30 distinct fat-regulating genes have been discovered (Willer, Speliotes, et al., 2009),[9] with different effects between ethnicities. Among other things, a risky genotype was found in the fat mass and obesity-associated (FTO) gene, the first and most robust gene shown to be associated with obesity and obesity-related phenotypes.[10] Various studies and meta-analyses support the role of the *FTO* gene in obesity in Europeans and Asians, an effect that could not be confirmed in African populations. Additionally, specific variants of the melanocortin 4 receptor, brain-derived neurotrophic factor (BDNF), agouti signaling peptide, leptin and leptin receptors, or cholecystokinin A receptor genes are important factors in obesity[11] (summarized in Comuzzie & Allison, 1998; for a meta-analysis see Willer, Speliotes, et al., 2009). Influencing the rewarding value of food and food preferences, mutations in the dopamine transporter and dopamine 2 receptor have been associated with obesity. It is hypothesized that obese individuals show a heightened reward expectation from viewing and smelling food but otherwise show a weak dopamine-related signaling. This attenuated signaling may then result in a deficit in delivering the reward, which is then compensated by eating more to achieve the expected reward level. However, studies confirming this hypothesis remain to be conducted.

Results from family, twin, and adoption studies further suggest that eating behaviors (satiety responsiveness, enjoyment of food, eating rate, slowness of eating) are not only genetically influenced but are also influenced by environmental factors. Heritability estimates indicate that the contribution of genetic factors lies in the range of 50–60% and around 10–20% for shared or unshared environmental factors, respectively. Interestingly, physical activity is able to switch off the effects of the FTO gene. Physical activity was shown to result in a two-point lower BMI among homozygous carriers of the risk allele variant of the FTO gene, which is normally associated with higher BMI (Kilpeläinen, Qi, et al., 2011). This modifying effect of physical (in) activity also occurs in the insulin-induced gene 2.

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[9] It should be kept in mind that even when all of these genes are combined, they only account for 2% of the disease state (Speliotes, Willer, et al., 2010).

[10] The FTO gene is expressed in the brain, especially in the hypothalamus, which is known to be involved in reward. Subjects who have two copies show a 70% chance of being obese. Variants of this gene have been associated with an altered chosen diet, the total intake of fat and calories, and the release of oxytocin.

[11] All of these factors are involved in pathways of energy intake and/or metabolism, with FTO being involved in regulation of cell respiration in adipocytes; MC4 increasing body temperature and suppressing hunger; BDNF being involved in the central processing of satiety/hunger signals; agouti signaling peptide antagonizing melanocortin 4 receptor function, downregulated during acute stress what might result in inadequate behavioral responses as, e.g., binge eating; leptin and the leptin receptor regulating adipose-tissue mass as well as satiety/hunger; and the cholecystokinin A receptor being involved in the regulation of satiety, the release of beta-endorphins and dopamine, and the contraction of smooth muscles in the gallbladder and stomach.

Thus, physical (in)activity may increase the phenotypic effect of a risky genetic makeup or, conversely, is able to dampen negative effects (Andreasen & Andersen, 2009). Established in 2007, the "MuTHER" ("Multiple Tissue Human Expression Resource") project collected different tissue samples from more than 850 twins and was able to detect what the authors term a "mastery" gene for obesity: KLF14. This gene is known for its direct influence on behavior. KLF14 influences the activity of many other distant genes known to be involved in BMI and blood sugar levels (Small, Hedman, et al., 2011). The KLF14 gene is also a good example of a process called imprinting. In general, the offspring receives the same genes from both parents, but with respect to the KLF14 gene, the father's gene is switched off. Thus, activity of the KLF14 gene is inherited from the mother.

On the other hand, obesity is not only a consequence of fat-regulating genes but also of these genes regulating our dietary patterns, i.e., choice of food. Twin studies showed a surprisingly high heritability of 30–40% regarding whether individuals prefer vegetables and salad; meat, fried food, and chocolate; or coffee and alcohol (Breen, Plomin, et al., 2006; de Castro, 1993). As already mentioned above in our discussion on alcohol use, there is also evidence of gene-environment correlations in the context of obesity. The frequency of fast-food restaurant visits was shown to be substantially heritable in adolescents. However, it remains unknown whether this factor (fast-food restaurant visits) is a moderator (the strength of the effect of genes on obesity depends on fast-food restaurant visits) or a mediator (genes only have an effect on obesity in the presence of fast-food restaurant visits). This finding clearly demonstrates the need to keep in mind that there might be a third variable involved in gene-environment interactions. Findings show that our genes, together with factors and habits related to ethnicity (like beliefs or values), form our food choices. As seen for other health risks, ethnicity was shown to have a strong impact on dietary patterns: Influences on child-feeding behavior not only differed between ethnic groups (e.g., greater food restrictions in African-American mothers), but ethnicity was also shown to be differentially linked to fat mass, weight, and energy metabolism in the offspring. To illustrate this, African-Americans gain a higher percentage of energy from fat compared to European Americans (Weyer, Snitker, et al., 1999). However, these differences cannot be explained by ethnicity alone. Importantly, the confounding effect of SES needs to be acknowledged. See Fig. 10.1 for a schematic of the many relationships among genes, other biological influences, environment, behavior, and sociocultural factors in obesity.

Another interesting finding is that obesity not only runs in families, but having a mother who is obese during pregnancy increases the offspring's risk of obesity. The mechanism that is discussed to underlie this finding may be an effect of fetal nutrition on gene expression. This is an example of the thrifty phenotype hypothesis (also called Barker's hypothesis, after Hales and Barker (1992) who were the first to publish this hypothesis), which states that adult diseases originate in fetal experiences. The fetal nutritional situation results in adaptations, also on the molecular level, that might predispose an individual to obesity in later life. In animal studies, it was shown that these adaptations can be transferred from one generation to another. Epigenetic research in humans is still in its infancy, but initial findings are promising: Results suggest that even genetically identical twins show considerably different gene expression patterns shortly after birth, which might explain the difference in risk for later disease in this group. Not only fetal nutrition, but also nutrition during adulthood, might affect gene expression levels. It has been shown that a diet low in folic acid can decrease overall DNA methylation (Shelnutt, Kauwell, et al., 2004).

One of the most valuable cohorts for our understanding of the effect of prenatal and early postnatal experiences on adult disease is the Dutch Famine birth cohort (see above). For instance, the insulin-like growth factor 2 (IGF2) gene of individuals who were prenatally exposed to malnutrition was shown to be less methylated (Heijmans, Tobi, et al., 2008), providing first evidence for transient epigenetic changes due to

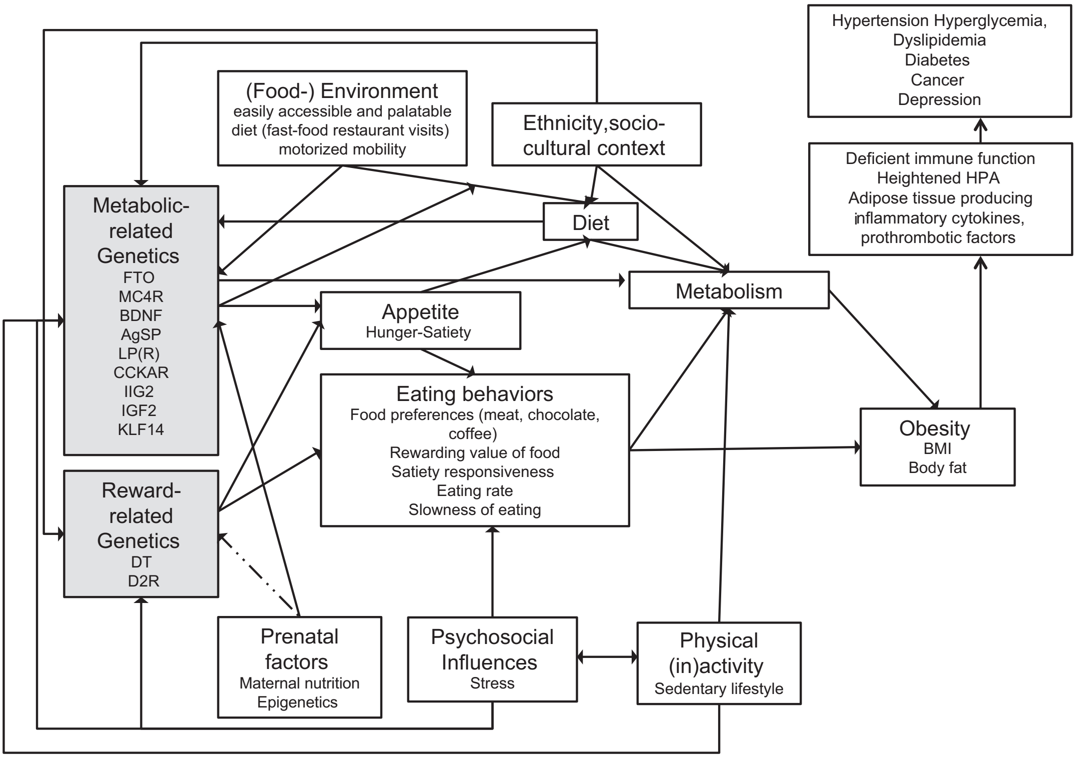

Fig. 10.1 Schematic representation of the kinds of complex relationships among genes, other biological influences, environment, behavior, and sociocultural factors in obesity

early hunger experiences. This altered (higher) transcriptional level of the IGF2 gene might be translated into later disease, since elevated circulating levels of IGF2 have been shown to be associated with obesity (Frystyk, Vestbo, et al., 1995). This cohort will also offer the possibility to study the question of whether it also matters what our grandparents ate at critical times in their lives. With the investigation of the third generation, scientists will be able to determine whether the observed epigenetic changes are also transmitted transgenerationally (Kaati, Bygren, & Edvinsson, 2002). If the food choices of our (grand)parents can alter the offspring's genome, one might wonder whether it is also possible to switch our genes on and off by certain substances in order to live a healthier and longer life. While no conclusions can be drawn at this point, there is intensive research on the effects of nutrients and other substances on the activity of genes involved in metabolism (and possibly obesity) and the stress response (Maurice, Haiser, & Turnbaugh, 2013).[12] Future research will have to show how these changes result in disease and how environmental influences and nutrition can be adapted accordingly.

To sum up this section, obesity is influenced by (1) genes operating in the pathways of energy intake and metabolism, (2) what we choose to eat (and its impact on gene expression), (3) environmental factors (psychosocial stress, cultural factors, but also prenatal factors like maternal nutrition), (4) epigenetic mechanisms such as shown by transgenerationally inherited effects of

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[12] This study, published in the high-ranking journal *Cell*, shows the effects of xenobiotics, environmental toxins, on gene expression levels of human gut microbes.

hunger experiences, and (5) interactions of, e.g., both values/beliefs and genes forming our choices of food. In the next section, one of the most prominent causes but also forms of treatment of obesity will be discussed: physical (in) activity.

Physical (In)activity

In this section, the terms exercise and physical activity will be used according to their distinct meanings, with (1) *physical activity* being considered as any movement that results in energy expenditure (including window cleaning, gardening, going to work by bike, or activities of daily living) and (2) *exercise* being defined as structured and planned movements with the intention to increase physical fitness. Physical fitness comprises cardiovascular fitness, musculoskeletal strength, lean body mass and fat, endurance, and flexibility (Caspersen, Powell, & Christenson, 1985). To improve physical fitness and reduce the risk of noncommunicable diseases[13] and depressive symptoms, adults aged 18–64 years are advised to do at least 150 minutes of moderate-intensity aerobic physical activity (such as brisk walking, running, and bicycle riding) per week, performed in bouts of at least 10 min. For additional health benefits, adults should double this recommended time (WHO, 2010). Nevertheless, less than 50% of people worldwide meet this recommendation (although men are somewhat more active than women). Rates of physical inactivity differ between countries, with the highest rates in the United States and the Eastern Mediterranean region and the lowest rates in the Southeast Asian region. It is clear that people differ in terms of their participation in exercise and physical activity. The question therefore arises of whether genes also contribute to this variance. Results from twin studies provide strong evidence for genetic influences on exercise behavior, with estimates in the range of 50–70% in adults of different geographic origin (Stubbe, Boomsma, et al., 2006). Interestingly, the estimates for shared and unique environmental factors differ largely between age groups, with major influences of shared environment in children (25–70%; Huppertz, Bartels, et al., 2012). Barely any effect could be found in middle and late adolescents and adults, except in girls during their early adolescence. Here, a substantial part of the variance (46%) seems to result from shared environmental influences (van der Aa, De Geus, et al., 2010) such as encouragement and receiving positive feedback from family members and peers. This complete disappearance of shared environmental effects during adolescence might be explained by the fact that actual physical skills and performance determine whether a specific exercise behavior is maintained. Furthermore, the impact of genes on the degree of physical activity becomes more important when the impact of environmental factors decreases, such as a decrease in family feedback on physical activity after having left home. Whether these heritability estimates are of similar magnitude in older adults still needs to be examined. With respect to unique environmental influence, factors such as the characteristics of neighborhoods, i.e., sidewalks, streets, and parks, showed the strongest influence (72%; Duncan, Goldberg, et al., 2008). Regarding sex-related differences in heritability estimates, genetic factors seem to play a larger role in men (>65%) compared to women (<50%). As expected, genome-wide linkage scan studies revealed suggestive linkages in regions that harbor genes related to exercise ability, i.e., muscle performance and muscle blood flow. Especially in adolescents, these exercise ability genes determine whether an individual is good at sport and therefore maintains participation in this sport. Other candidate genes, therefore, should be related to endurance, physical mobility, motor coordination, and strength. One of these genes influencing fitness and physical performance is the angiotensin-converting enzyme (ACE) gene, which degrades vasodilators and stimulates the vasoconstrictor angiotensin II, which in turn increases muscle strength for power performance. Other genes of interest are the insulin-like growth factor 1 gene, which regulates muscle mass and strength gains, beta-adrenergic receptors regulating cardiac function and metabolism,

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[13] Medical conditions or diseases which cannot be transferred among people and are not infectious in their origin

or the alpha-actinin-3 gene playing a role in muscle contraction. With respect to the alpha-actinin-3 gene, a higher XX genotype frequency (deficiency of alpha-actinin 3 and thus impaired muscle performance) has been found in endurance athletes, while the *RR* genotype has been associated with strength and power (of relevance, for example, in sprint-related sports). Interestingly, the mutation (XX) is more common in Asian and European populations, while only 1% of African populations show this mutation. In line with this, Olympic-level sprinters have the lowest incidence of this muscle performance-impairing mutation. The ACE gene is one of the most studied genes in the context of physical performance. An insertion (I) or deletion (D) of a 287 bp fragment results in three variants (II, ID, DD), with the D allele being linked to increased ACE activity and thus higher power performance, which in turn favors strength gain from training. By comparison, the *II* genotype has been shown to be more prevalent in endurance athletes, in whom high muscle bulk is less favorable and higher metabolic efficiency is needed (Scanavini, Bernardi, et al., 2002). Further research, however, called these initial findings into question and showed no consistent effect of ACE gene variants on physical performance (Doring, Onur, et al., 2010; Hagberg, Rankinen, et al., 2011; Puthucheary, Skipworth, et al., 2011). Linkage studies identified a section on chromosome 18q being related to physical inactivity, and there is evidence that the melanocortin 4 receptor gene is proximal to this region. This gene was also shown to be involved in physical activity levels, possibly due to its role in metabolic rate and energy expenditure (see also the previous section on obesity). Other genes involved in the maintenance of exercise might be related to body composition and the acute affective responses to exercise. A gene which we discussed above in the section dealing with obesity (and thus an example of pleiotropy) also showed relations to positive mood changes during exercise: the FTO gene. However, findings did not quite fit together, since those people with the risky genotype for higher BMI values also showed the highest change of positive affect in response to aerobic exercise (Karoly, Stevens, et al., 2012). Again, the involvement of the dopaminergic reward system was also implicated in this context. The TT (A1/A1) genotype has been associated with lower physical activity as well as obesity and hypertension (Simonen, Rankinen, et al., 2003). In the future, knowledge about the effects of specific gene variants might guide the development of exercise interventions and potential adaptations, i.e., personalized exercise training. For a comprehensive human gene map for genes related to physical performance and fitness, we refer the reader to “The human gene map for performance and health-related fitness phenotypes” (most recent (seventh) update, Bray, Hagberg, et al., 2009) and the latest volume of the IOC Encyclopaedia of Sports Medicine series (Bouchard & Hoffman, 2011).

Despite the extensive knowledge regarding various genetic factors involved in physical activity, there is still little understanding of how the environment interacts with these genetic variants. Multiple features of the environment that might modify the effects of risk genes on physical inactivity have been suggested. Social environmental characteristics that support a sedentary lifestyle such as computerized work, television, and video games, natural environmental characteristics such as shopping malls located very far from the city, and architecture of the neighborhood including parks, cycle paths, and walking paths are prominent examples. Studies looking at the effects of gene variants together with influencing effects of environmental factors on the level of physical activity are underway, but it is not yet possible to draw any conclusions.

Epigenetic effects could also be important in the context of exercise behavior and physical activity. While gene expression levels and changes in overall DNA methylation status are of major importance for genetic factors being ultimately translated into disease, only a small number of studies have addressed epigenetic mechanisms in the context of physical activity. One of these studies provided evidence of lower levels of DNA methylation in sedentary individuals (<10 min/day spent being active) compared to those who are more active (about 30 min/day). The genome of physically active subjects seems to be more likely to methylate and thus harder to be switched on (Zhang, Cardarelli, et al., 2011).

This might have implications for the occurrence and development of later disease. In other words, the expression of risky genes is hampered, and thus their influence is reduced in the more physically active subjects. Furthermore, animal studies hint at an effect of prenatal malnutrition on locomotor activity. Future human studies to examine the effects of early nutrition on physical activity and exercise behaviors are clearly warranted. Turning from the effects of genes on physical activity to the effects of physical activity on genes and gene expression, physical activity is able not only to reduce the influence of genes on body composition (thus, individuals with the greatest genetic risk of developing obesity would benefit the most from physical activity) but also to alter gene expression levels. Early studies were able to show an effect of even moderate physical activity on adrenergic and metabolic-detecting receptor mRNA. Other pathways altered by short bouts of exercise are related to inflammation, stress, and apoptosis, which might therefore provide the molecular mechanism for how physical activity is related to different aspects of health.

In conclusion, physical (in)activity is influenced by (1) genes related to endurance, physical mobility, motor coordination, and strength, (2) the environment (e.g., encouragement and receiving positive feedback from family, architecture in the neighborhood such as paths), (3) epigenetic mechanisms with evidence of an effect of physical activity on methylation status and mRNA levels, and (4) there is also first evidence for how the environment interacts with genetic variants to modify the effects of risk genes.

Conclusion and Future Outlook

As outlined above, the majority of behavioral traits and diseases are influenced by many genes (polygenetic), by some genes that affect more than one trait (pleiotropy), and by epistatic effects (genes interact to form phenotypic variance). Quantitative genetic studies further highlight the effects of shared and unique environmental factors and the interaction of genes and the environment. Moreover, examples have been shown of gene-environment correlation (e.g., adolescents with high risky genotypes tend to have friends with greater substance use and select lifestyles that lead to higher exposure to environmental risk). Most recent advances in our knowledge regarding epigenetic mechanisms highlight the plasticity of genes expressed and proteins produced. Even a gene of risk need not be seen as a vulnerability factor but rather as a factor of susceptibility – both according to its “negative” meaning (i.e., under specific circumstances, higher risk of developing disease, or unfavorable behavioral trait) and its “positive” meaning (i.e., being also more sensitive to behavioral change during interventions). Accordingly, studies involving tens of thousands of subjects show that only a tiny part (1–2%) of disease or trait variance is due to direct or simple, unmoderated effects of genes.

Importantly, the field of behavioral genetics focuses on traits that appear to lie on continuous spectrums. This makes it difficult, if not impossible, to find and differentiate cases and non-cases, which in turn is necessary to conduct research on the trait’s genetic basis. Quantitative genetics (twin, family, and adoption studies) and molecular genetics (linkage analysis, GWAS) suggest some genetic links, but no single gene has been conclusively identified to affect alcohol and nicotine dependence, obesity, or physical (in) activity. In addition, the perception of environment is filtered through the individuals’ memory, emotions, and personality. It might therefore be assumed that self-report measures of environmental facets (such as interaction with parents or siblings, peer group, social support, life events, education, SES, work-related stress) also reflect an individual’s genetic makeup.

While there is some knowledge about differing prevalence rates of unhealthy behaviors (alcohol and nicotine consumption, unhealthy diet, sedentary behavior) between ethnic groups, barely anything is known about possible genetic and environmental risk factors in these groups. However, to be able to design health interventions aimed at reducing morbidity and mortality related, for example, to alcohol use, future studies need to acknowledge specific target subgroups as defined by particular risky genes, environmental risk factors, and their interactions. Importantly, the contribution of inheritance associated with specific ethnic groups and variables of the sociocultural context also need to be considered. As our understanding of the mechanisms by which biological and environmental variables interact to shape health-related behavior advance, there will likely be a strong interest to apply this knowledge to therapeutic diagnostics and interventions. Further studies are necessary to replicate current findings and, for example, to explore responsiveness to medication (pharmacogenetics) and to prevent illnesses by clarifying unhealthy lifestyles. For instance, the short allele of the 5-HTTLPR gene has been associated with poorer responses to selective serotonin reuptake inhibitors (Stein, Seedat, & Gelernter, 2006). Depending on the substance, a large amount (20–95%) of variations in responses to drugs, including adverse drug reactions, seems to be attributable to the effect of genes and gene variants (e.g., Fabbri, Di Girolamo, & Serretti, 2013). Advanced new perspectives of psychobiologically oriented genetic approaches are proteomics and metabolomics (see Table 10.3 *Recent Concepts*).

Finally, research on the role of genetic risk factors in human health and behavior also requires an ethical discussion about the opportunities and limits of behavioral genetics. Personal genetic information is highly sensitive, and dealing with this information must be subject to ethical standards. Currently, such standards are rarely created and established. Knowledge of genetic predisposition might influence not only our own identity but also how we are treated by others (i.e., stigma or parents becoming overprotective and thus restrictions in opportunities that would otherwise be available). Furthermore, scientists need to realize that, currently, only a small proportion of the population has sufficient knowledge to interpret and apply genetic information. Informed consent and the subject's decision regarding whether or not to be informed about individual study results therefore need to be based on intensive educational work prior to participation; without such educational work, many cases of consent can hardly be considered to have been "informed." Moreover, avoiding the misuse of information, e.g., reporting genetic test results to family members or insurance companies, must be part of this process. As an example of detailed discussion of these concerns, we refer the reader to the debate on prenatal and preimplantation genetic diagnosis.

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11

Stress and Emotions

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Introduction

Stress and emotions are basic notions with relevance to several scientific disciplines, including behavioral medicine. At the same time, these notions are also part of everyday human experience. This interference between common types of human experience and their scientific analysis has produced some challenges to the advancement of scientific understanding, in particular in case of the stress concept. From the perspective of history of science, "stress" as a fuzzy concept almost disappeared from rigorous scientific inquiry a few decades ago, after the pioneering discoveries of Walter B. Cannon (1929) and Hans Selye (1998). This crisis was mainly due to the notion of stress as a nonspecific response of the body to nonspecific biological, chemical, physical, or social agents that were assumed to elicit a "general adaptation syndrome" via the activation of the hypothalamic-pituitary-adrenocortical (HPA) axis of the organism (Selye, 1950). However, it is not possible to define stress exclusively by an organism's physiological changes. As Herbert Weiner noted, "physiological changes cannot be separated either from the nature of the experience, the context in which it occurs, or the behavioral response of the organism" (Weiner, 1991). Thus, due to its lack of discrimination and specificity, the notion of stress almost lost its scientific significance. Yet, in the early 1970s, this situation changed due to several important innovations. In experimental psychophysiological research, it became evident that stress responses varied according to the quality of the challenge (termed "stressor") and the availability of the person's ability to cope with this challenge. A person's sense of control over a threatening challenge and over his or her ability to cope with the challenge was identified as a crucial element in the stress process, which triggered different autonomic and neuroendocrine responses (Henry & Stephens, 1977; Mason, 1975). In line with this notion, psychological stress theory emphasized the role of subjective appraisal processes as determinants of emotional and physiological responses to the experience of a challenging

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situation and, thus, proposed a transactional stress concept (Lazarus & Folkman, 1984).

A further innovation came from the emerging field of social epidemiology where distinct socio-environmental stressors (e.g., critical life events, social exclusion, chronic workload) were associated with incident physical or mental diseases, using prospective population-based study designs (for recent review, see Berkman, Kawachi, & Glymour, 2014). As a result, a body of knowledge accumulated over the past 30 years across a broad spectrum of scientific disciplines that demonstrated the far-reaching impact of stressful experience and emotional responses on health and well-being. More recently, methodological progress in the field of neuroscience, and particularly brain imaging, opened a new dimension of studying the affective and cognitive processing of stressful experience.

How can this broad field of knowledge reasonably be structured in the frame of a chapter to this handbook? As mentioned above, a scientifically promising stress concept analyzes interactions between challenging extrinsic situations (stressors); the cognitive, emotional, and behavioral processes of the individual persons coping with them; and their short- and long-term consequences for bodily functioning, health, and disease.

In the *first section* (section "Social Stressors and Stress-Related Diseases"), we deal with those (mainly social) stressors that were shown to increase the risk of incident stress-related physical and mental diseases. Two such diseases are chosen as exemplary cases, cardiovascular disease (CVD) and depression. Three main reasons justify this choice. First, CVD and depression are likely to remain the leading causes of premature mortality and disability worldwide over the next few decades (Lopez, Mathers, et al., 2006). Any new knowledge with relevance to the prevention and treatment of these disorders is therefore highly relevant. Second, international research linking stress with the development of these diseases is particularly well developed, thus allowing for comparative analysis, accumulation of evidence, and new insights into psychobiological processes underlying these associations. Third, CVD and depression are not independent entities but are intertwined in complex ways, thus illustrating the complexities and comorbid processes underlying major chronic diseases in modern societies.

The *second section* (section "Person-Related Factors in Stress and Emotion Research") is concerned with individual appraisal and coping processes, with a special focus on emotions, their modification by personality attributes, and the biological processes linking emotional experiences to physiological stress responses. Again, instructive examples of major research findings are discussed with relevance to CVD and depression.

In the *final section* (section "Implications for Behavioral Medicine and Concluding Remarks"), we briefly discuss future directions of research with relevance to behavioral medicine and provide some concluding remarks. Many topics of this chapter will be dealt with in more detail in later parts of this handbook.

Social Stressors and Stress-Related Diseases

Theoretical Background

How are stressors classified in terms of their quality, duration, and intensity? An obvious distinction concerns natural occurrences, including biological, physical, and chemical hazards and disasters (e.g., earthquakes), on the one hand and man-made stressful conditions on the other hand. Although the former ones may have a long-lasting adverse impact, man-made stressors often produce more pervasive effects due to their specific *quality* and long duration. Main man-made stressors occur in a social context and are experienced as part or consequence of interpersonal relationships. This is most obvious in case of physical violence, power relationships, deception, humiliation, and loss. Therefore, social stressors are considered potent determinants of stress-related disorders and have been subject to extensive research (Weiner, 1991). Based on this argument, the focus of this section is put on social stressors.

Further on, stressors are classified according to their *duration*. In this regard, Segerström and Miller (2004) propose five different types of stressors: (1) acute time-limited stressors (e.g., a mental arithmetic task as a laboratory challenge); (2) brief naturalistic stressors (e.g., an academic examination); (3) stressful event sequences (often termed "acute or subacute life event") where a crucial event (e.g., loss of a spouse) elicits major changes and adaptations; (4) chronic stressors, characterized by their stability over time and their impact on core social roles (e.g., social isolation, chronic workload); and (5) distant stressors that occurred in an early stage of the life course but have a long-lasting impact (e.g., sexual abuse in childhood as a cause of posttraumatic stress disorder). Research in this field has mainly explored chronic social stressors, including traumatic events in early life and including those chronic stressors that originated from a critical life event (e.g., unemployment).

It is more difficult to classify stressors according to their *intensity* or severity because the experience of intensity is moderated by individual appraisal and coping processes (see below section "Person-Related Factors in Stress and Emotion Research"). However, at a general level, the intensity of a stressor depends on the level of threat evoked in the exposed person, that is, on the severity of a potential loss following failed control or mastery (loss of life, loss of social status, etc.). Subjectively appraised importance, novelty, and controllability (including avoidance) are relevant parameters of experienced stressor severity.

In order to provide a *theoretical framework* for the explanation of health-adverse effects of major chronic social stressors, their impact on basic needs of a person's self-regulation must be considered. At least three basic needs of successful self-regulation are eventually threatened by social stressors, and these threats may elicit recurrent negative emotions and enhanced autonomic arousal (Siegrist & Marmot, 2004). The first one is the need of belonging to a social network, of being affiliated with significant other persons. As social animals, humans are essentially dependent on communication and interpersonal exchange. Conditions which deprive them from realizing this need are experienced as stressful, as is the case in people who are socially excluded and isolated, or who lost significant others and whose important social ties were destroyed.

A second basic need of successful self-regulation concerns a person's ability to act and perform, to realize his or her potential, and to make a meaningful contribution to life. Here, agency in terms of autonomy and self-efficacy is crucial, and core social roles are available in every society to meet this need. Yet, opportunities to develop one's own capabilities and to acquire and maintain one or several appropriate social roles that provide autonomy and self-efficacy are limited. Being "locked in" a deprived socioeconomic position, being excluded from work or from reproduction, or having a boring job with little control and skill discretion are examples of social stressors that prevent this need of successful self-regulation and, thus, trigger enhanced stress reactions.

Third, people strive for positive self-experience in terms of favorable self-esteem. As self-esteem to a large extent is contingent on appreciation received from significant others, lack of esteem and recognition is often experienced as stressful, in particular if own achievements have been invested in exchange of expected rewards. Therefore, reward frustration in core social roles acts as a powerful social stressor due the emotional afflictions exerted on people's self-esteem.

In the next paragraph, these three types of social stressors are more closely defined in terms of theoretical models, and these models are linked to elevated risks of the two stress-related disorders under consideration, CVD and depression. Before doing so, it is important to mention that social stressors can be identified at more distant or more proximate sites of a societal structure. For instance, an urban region or a deprived neighborhood may be considered a more distant social stressor that is identified at the level of aggregate data. In these instances, a social context matters for health, even if characteristics of individuals living in this context are taken into account. There is some convincing evidence available from studies applying multilevel statistical approaches that indicate elevated risks of individual ill health within such contexts (Diez Roux, Merkin, et al., 2001; Kawachi & Berkman, 2003). Yet, in view of the strength of scientific evidence and having in mind the paradigm of behavioral medicine, we consider more proximate social stressors that are identified at the level of individual persons where their direct effects on emotions and stress reactions can be studied.

Effects of Stressful Experience in Core Social Roles on CVD and Depression

In terms of methodology, best available evidence of associations of all three types of social stressors (related to belonging, self-efficacy, and self-esteem; see above) with health outcomes derives from prospective epidemiological cohort studies. This type of study is considered a gold standard because of its temporal sequence (exposure assessment precedes disease onset), its sample size (based on statistical power calculation and allowing for adjustment in multivariate analysis), and the quantification of subsequent disease risk following exposure (odds ratio [OR] of disease in exposed versus nonexposed individuals). Therefore, mainly results of cohort studies are summarized here.

Social Isolation and Lack of Social Support

Two dimensions of experiences related to the need of belonging are distinguished, a structural and a functional dimension. The structural dimension describes the availability of one or more stable social ties (e.g., living alone or with partner, size or density of a social network), whereas the functional dimension describes the utility of social relationships (availability and quality of social support). Both dimensions matter for health, but in case of social support, an additional qualification is important. If support is needed but not available, this type of social stressor reduces health, similar to the effect of social isolation. If support is needed and available, it may not only have a direct favorable effect on health, but may additionally act as a protective resource, buffering the intensity of stressful experience evoked by other types of adversity (Berkman & Krishna, 2014; Kawachi & Berkman, 2014). A meta-analytic review summarized the current state of knowledge about the effects of structural and functional aspects of social relationships on mortality risk (Holt-Lunstad, Smith, & Layton, 2010). Although the majority of the 148 studies included in this review used all-cause mortality as an outcome measure, several investigations were restricted to CVD mortality. As these latter findings paralleled those of all-cause mortality and as cardiovascular disease is the leading cause of adult mortality, results may be valid at least for fatal CVD. Unfortunately, no information on depression-related mortality is available as studies in which mortality was a result of suicide were excluded. In this meta-analysis, the likelihood of survival was calculated as a function of availability or quality of social relationships. Overall, the study found a 50% increased likelihood of survival among participants who were socially integrated or received social support compared to those who were socially isolated or suffered from lack of support. This effect size was similar in men and women, in different age groups, and in participants from different regions of the world. In more detail, the structural dimension seemed to be somewhat more relevant than the functional dimension as effect sizes were strongest for complex measures of social integration (odds ratio (OR) = 1.91) and for social network (OR = 1.45), whereas receiving social support had a weaker effect (OR = 1.22) (Holt-Lunstad, Smith, & Layton, 2010).

This conclusion of an inverse association between availability and quality of social relationships and mortality corroborates earlier findings, most importantly the pioneering Alameda County study, where men and women who lacked ties to significant others were 1.9–3.1 times more likely to die in a 9-year follow-up period than those who had many more contacts (Berkman & Syme, 1979). While some, but not all, studies report similar findings for incident nonfatal CVD, there is more solid evidence on the detrimental role of social isolation and lack of support among people who survived an acute myocardial infarction (Berkman & Krishna, 2014). For instance, a classical study of 2320 male survivors of acute myocardial infarction observed that patients who were socially isolated were more than twice as likely to die over a 3-year period than those with more social ties (Ruberman, Weinblatt, et al., 1984).

The other exemplified stress-related disorder, depression, has also been associated with poor social relationships and social isolation although fewer prospective reports are available. The fact that social isolation is associated with higher rates of suicide was discovered more than 100 years ago by one of the founding fathers of medical sociology (Durkheim, 1897). Since then, several investigations demonstrated (1) that bereaved persons without a network of friends were at greater risk of developing affective disorders, (2) that deficiencies in social support increased the susceptibility to mental disorder, (3) that emotional support from a confidant exerted a protective effect on risk of depression, and (4) that loss of a significant person (usually a parent) early in life had long-lasting detrimental effects on mental health (Stansfeld, 2006). In conclusion, the risk of suffering from one of the most widespread chronic diseases with often deleterious outcomes, CVD and depression, is significantly elevated in people who are exposed to the social stressors of isolation or exclusion and lack of social support. Importantly, in terms of effect size, the influence of social relationships on the risk of death is comparable with the one exerted by some behavioral risk factors for mortality associated with these diseases (e.g., physical inactivity or excessive alcohol consumption) (Holt-Lunstad, Smith, & Layton, 2010).

Lack of Autonomy in Core Social Roles

It was argued that agency in terms of autonomy and self-efficacy exerted in core social roles is crucial for physical and mental well-being and that these opportunities are unequally distributed across societies, leaving those in *lower socioeconomic positions* at higher risk of disadvantage. In fact, a social gradient of major chronic diseases, including CVD and depression, has been established across the whole of a society in many prospective studies (Marmot, 2004). With each step one moves down on the social ladder, the worse one's physical and mental health is likely to be. This social gradient is particularly steep in midlife where odds ratios of CVD are more than twice as high among members of the lowest as compared to members of the highest socioeconomic group. A similar strength of association was reported for depression (Lorant, Deliege, et al., 2003).

A vast literature explored major explanations of this substantial social gradient of health. In his impressive account, Michael Marmot states that distinct social stressors that are more prevalent among lower socioeconomic groups account for a substantial part of this gradient although interactions with health-adverse behaviors and with adversity in early life need to be considered as well (Marmot, 2004). Three chronic social stressors are of particular relevance: poverty (low income), unemployment, and poor quality of work, preventing agency in terms of autonomy and self-efficacy.

It is difficult to distinguish the effects of *poverty* from those of low socioeconomic position as income serves as a major indicator of socioeconomic status. However, some studies suggest that income contributes to poor health mainly through its impact on material life circumstances, such as unhealthy food, poor housing, or lack of safety measures (Glymour, Avendano, & Kawachi, 2014). Other investigations maintain that distinct psychosocial influences on health interact with material constraints due to low income, such as feelings of relative deprivation, recurrent worry, and pessimism or impaired self-worth (Wilkinson & Pickett, 2009). Chronic financial difficulties were shown to increase the risk of CVD as well as the risk of depression (Shaw, Dorlin, & Davey Smith, 2006).

Long-term unemployment is perceived as a powerful social stressor because it prevents people from maintaining a core social role in adult life, the work role. Work has primary significance as it is normally a prerequisite for regular income and as it provides opportunities for personal performance and achievement. Moreover, it is mainly through work and employment that social status in adulthood is acquired and maintained and that a core social identity outside the family is developed. These resources are lost if people are laid off and if chances of reentry into the labor market are poor. Prospective research evidence demonstrates increased all-cause and cardiovascular mortality risks of unemployed compared to permanently employed men and women (Dupre, George, et al., 2012). Depression was less frequently analyzed in longitudinal studies of unemployed people, but was identified as an important health problem in a large study that controlled for mental health at study onset (Dooley, Prause, & Ham-Rowbottom, 2000). Recent evidence demonstrates elevated suicide risks following long-term unemployment (Milner, Page, & LaMontagne, 2013). Precarious work characterized by job instability, forced temporary work, and experience of organizational downsizing equally increases the likelihood of suffering from adverse cardiovascular events and depressive episodes (Ferrie, Westerlund, et al., 2008; Siegrist & Dragano, 2012; Vahtera, Kivimäki, et al., 2004). *Poor quality of work,* preventing agency in terms of autonomy, control, and self-efficacy, was identified as a third type of social stressors that increase the susceptibility to stress-related disease. A leading theoretical model of stressful work, the *demand-control model*, is of central importance in this respect, and this model has been tested in a large number of prospective epidemiological investigations (Karasek & Theorell, 1990).

This model posits that stressful experience at work results from a distinct job task profile defined by two dimensions, the psychological demands put on the working person and the degree of control available to the person to perform the required tasks. Jobs defined by high demands and low control are stressful because they limit the individual's autonomy and sense of control while generating continued pressure ("high job strain"). Under these conditions, excessive arousal of the autonomic nervous system (ANS) is expected to occur that is not compensated by a relaxation response following the experience of control and mastery. Importantly, a low level of control or decision latitude manifests itself in two ways, first as lack of decision authority over one's tasks, and second as a low level of skill utilization, as evidenced by monotonous, repetitive work. Overall, "high-strain jobs" seem to follow a social gradient. The higher one's level of professional training and skill, the less likely is one's probability of working in a "high-demand-low-control" job.

At present, a substantial number of reports derived from prospective studies on the associations between poor quality of work in terms of the demand-control model and cardiovascular disease are available (Steptoe & Kivimäki, 2012). In summary, despite some negative findings, the majority of results indicate a moderately, but significantly elevated relative cardiovascular morbidity or mortality risk following exposure to "high strain" compared to nonexposed individuals. Findings are more consistent in men than in women and more consistent in middle-aged as compared to early old-age populations. Additional studies found partial support for associations of work stress with major cardiovascular risk factors, such as hypertension, altered blood coagulation, and the metabolic syndrome (Chandola, Britton, et al., 2008).

More than a dozen cohort studies analyzed the demand-control model with regard to depression. Again, a majority of studies found elevated risks although effect sizes were smaller and were often restricted to single components of the model (Bonde, 2008). Interestingly, one investigation assessed work stress over time and found an elevated risk for depression following a deterioration of quality of work (Wang, Schmitz, et al., 2009).

In view of a large body of knowledge, we can conclude that poor quality of work in terms of the demand-control model acts as a chronic social stressor that contributes to the burden of stress-related disorders to a remarkable extent.

Reward Frustration in Core Social Roles

Missing or inappropriate social reward can be a stressful experience, in addition to lack of control, in particular if own achievements have been invested in exchange of expected rewards. To identify reward frustration in core social roles, and specifically in the work role, a complementary theoretical model, "effort-reward imbalance," was proposed (Siegrist, 1996). This model is concerned with stressful features of the work contract rather than the profile of job tasks. It builds on the notion of social reciprocity, a fundamental principle rooted in an "evolutionary old" grammar of interpersonal exchange. Social reciprocity lies at the core of the employment (or work) contract, which defines distinct obligations or tasks to be performed in exchange with adequate rewards. These rewards include money, esteem, and career opportunities, including job security. Contractual reciprocity operates through norms of return expectancy, where efforts spent by employees are reciprocated by equitable rewards from employers. The effort-reward imbalance model claims that lack of reciprocity occurs frequently under specific conditions and that failed reciprocity in terms of high cost and low gain elicits strong negative emotions with special propensity to sustained autonomic and neuroendocrine activation and their adverse long-term consequences for health. According to the theory, contractual nonreciprocity is expected if one or several of the following conditions are given: "dependency," "strategic choice," and "overcommitment."

"Dependency" reflects the structural constraints observed in certain types of employment contracts who have no alternative choice (e.g., due to low qualification or advanced age). "Strategic choice" describes a condition where people accept high-cost/low-gain conditions of their employment for a certain time because they tend to improve their chances of career promotion and related rewards at a later stage. "Overcommitment" points to a psychological reason for a recurrent mismatch between effort and reward at work. People characterized by this motivational pattern of excessive work-related overcommitment may strive toward continuously high achievement because of their underlying need for approval and esteem at work.

This model too has been extensively applied in recent years, and a number of prospective studies were conducted to test its ability of predicting cardiovascular and affective disease. Concerning CVD, early studies reported an almost twofold elevated risk of incident fatal or nonfatal disease in working people reporting a marked imbalance between high efforts spent and low rewards received in turn, whereas this risk was somewhat lower in more recent investigations (Backé, Seidler, et al., 2012; Kivimäki, Virtanen, et al., 2006; Steptoe & Kivimäki, 2012). In addition to manifest CVD, the progression of subclinical atherosclerotic development was studied where people suffering from effort-reward imbalance at work exhibited increased carotid intima media thickness, not only in Western societies, but also in China (Xu, Zhao, et al., 2010). Moreover, some evidence points to associations with established cardiovascular risk factors, in particular hypertension (Gilbert-Ouimet, Trudel, et al., 2014).

The second outcome, depression, was strongly associated with the components of this model assessing reward frustration at work (Siegrist, 2009). A meta-analysis documented an 80% increased risk of newly manifested depression in stressed versus nonstressed employees over a mean observation period of 5 years (Stansfeld & Candy, 2006). Complementary evidence from psychobiological studies reveals increased pro-inflammatory activity and reduced immune functioning associated with this type of chronic social stress (Bellingrath, Rohleder, & Kudielka, 2010; Nakata, Takahashi, & Irie, 2011). In summary, these results and complementary findings with other indicators of poor health confirm the significance of social reward deficiency as an independent determinant of stress-related disorders.

Having discussed adverse health effects of distinct social contexts which are not adequately responsive to people's emotional needs, it is nevertheless important to stress the role of individual differences in coping with social demands and threats and in responding to them at the cognitive, emotional, and physiological level. Therefore, a more detailed study of individual variations in dealing with stress and emotion is needed. This is the task of the next section.

Person-Related Factors in Stress and Emotion Research

Different Levels of Person-Related Factors in Stress Research

When analyzing the effects of various kinds of stressors on health outcomes, it is important to consider the different levels of internal person-related factors that modulate this relationship.

Emotional States

First of all, stressful events can impact on physiological functioning by giving rise to negative emotional states such as depression, anxiety, or anger, just to name a few. These emotional states have a spectrum of different facets with different intensities. Depression includes sadness, sorrow, unhappiness, and at its maximum despair, whereas anxiety ranges from tension to dread on the extreme end of the scale. Anger can range from a subtle annoyance or irritation to feelings of fury and aggression, manifesting itself in various behaviors ranging from shouting and threatening of others to physical assaults (Smith, 2010). Such affective states should be distinguished from more enduring, mostly more dysfunctional negative attitudes toward others, such as hostility. Hostile persons seem to create and thus live in a social environment which is characterized by high levels of interpersonal conflicts and low levels of social support (Smith, Glazer, et al., 2004), contributing to increased psychosocial vulnerability which further potentiates the risk of negative health consequences. Negative emotional states as well as more enduring emotional behavioral patterns such as hostility have repeatedly been shown to play a role in the development and exacerbation of coronary heart disease (CHD) (for a recent review, see Chida & Steptoe, 2009; Frasure-Smith & Lesperance, 2010), whereas positive affective states on the other hand may serve as protective factors against cardiovascular disease risk and vulnerability for infection (Steptoe, Dockray, & Wardle, 2009).

Emotion Regulation Strategies and Enduring Cognitive-Behavioral Patterns

To some extent, people are able to influence which emotions they experience after a stressful event and how they are expressed. Such emotion regulation strategies seem to be crucial for physiological adaptation. The considerable intra- and interindividual variability in the psychological and physiological effects of stressors on health outcomes may be attributed partly to how individuals perceive and think about the stressors. Appraisal theory postulates that the way one interprets the meaning of specific events determines the emotions one experiences in reaction to this event. Psychophysiological studies of cognitive reappraisal and coping have tried to elucidate its neural basis and how changes in emotional responses can be associated with physiological outcome parameters (Harvey, Nathens, et al., 2010; Ochsner & Gross, 2005; Weinberger, Schwartz, & Davidson, 1979). For example, cognitive reappraisal used to modulate affective responses was shown to be associated with activation in the prefrontal cortex as well as goal-appropriated increases or decreases in amygdala activation (Ochsner, Bunge, et al., 2002; Ochsner, Ray, et al., 2004).

In most studies that investigate the impact of stress and coping on health, stressors are treated as discrete events followed by singular goal-directed coping strategies. However, this research strategy fails to address the fact that some events or coping strategies have prolonged effects on physiology. For some people, the impact of a stressor persists over longer periods of time as they rehearse the stressful experience in their minds, a process termed rumination. Rumination has been repeatedly shown to prolong and deepen episodes of depression (Lyubomirsky, Layous, et al., 2015; Nolen-Hoeksema, 2000), and depressive subjects have been shown to differ from healthy controls with respect to the proposed cognitive processes of rumination, namely increased attention to negative information or better memory for negative than positive stimuli as well as global deficits in cognitive control (Gotlib & Joormann, 2010; Whitmer & Gotlib, 2013). Studies on the role of metacognitions even suggest that the extended, ruminative thinking style plays a more crucial role in the development of emotional disorders than actual, negative thought content (Yilmaz, Gencoz, & Wells, 2015). The perseverative cognition hypothesis (PHC) postulates that rumination may prolong physiological activation by the amplification of acute stress responses, a delayed recovery as well as the reactivation of stress responses later in time (Brosschot, Gerin, & Thayer, 2006), which in the long run will lead to or aggravate adverse health outcomes.

Other cognitive-behavioral patterns that may impact on the way we cope with stressful situations are certain trait aspects such as perfectionism (Wirtz, Elsenbruch, et al., 2007) or overcommitment at work (see above) (Siegrist, Starke, et al., 2004). In a number of studies, evidence has been accumulated linking levels of perfectionism with stress-related health outcomes such as depression, anxiety, or eating disorders (Egan, Wade, & Shafran, 2011).

Personality Traits

Neuroticism finally is a broader personality characteristic, which is generally defined as "the tendency to experience distress, and the cognitive and behavioral styles that follow from this tendency" (McCrae & John, 1992). As a global trait, neuroticism includes several more specific characteristics such as anxiety, depressive symptoms, worry, anger, and irritability but also nonaffective aspects such as self-consciousness and low self-esteem. In their taxonomy of personality traits, Watson and Clark (1984) describe a trait very similar to neuroticism which does not include the above-mentioned nonaffective aspects which they labeled negative affectivity. It is important to note that in the literature on health effects of personality, the labels neuroticism and negative affectivity are often used interchangeably. High levels of neuroticism are commonly seen in anxiety and mood disorders (Weinstock & Whisman, 2006), and it has been proposed that biased cognitive processing is the underlying mechanism for this association (Canli, 2008). A large body of research supports the notion that neuroticism is also associated with serious physical health problems, most prominently CHD (Suls & Bunde, 2005). Studies lend support for the assumption that about 50% of the variance for neuroticism is of genetic origin, whereas the remaining variance can be explained by environmental and unknown factors (Canli, 2008). Concerning the molecular genetics of neuroticism, most work has focused on a gene variant in the regulatory region of the serotonin transporter gene (5-HTT). A common deletion of a 44 base pair in the regulatory region of 5-HTT produces a gene variant that is physically shorter than the 44-base-pair insertion variant. The short variant produces less of the transporter than the long variant. Lesch et al. (1996) demonstrated that individuals who carry one or two copies of the *5-HTT* short variant have higher levels of neuroticism than individuals who carry only the long variant.

The "distressed" or Type D personality is a concept closely related to neuroticism, mostly studied in patients with CVD. A line of studies with both cardiovascular patients and healthy individuals demonstrated that Type D personality is a general propensity to psychological distress that affects cardiovascular outcomes (Denollet & Conraads, 2011; Denollet, Schiffer, & Spek, 2010; Widdershoven, Kessing, et al., 2013). Type D individuals are inclined to experience negative emotions and to inhibit self-expression in social interaction. In line with the results on neuroticism, heritability of Type D personality has been estimated to vary between 34% and 50% (Kupper, Boomsma, et al., 2011; Kupper, Denollet, et al., 2007).

Psychiatric Disorders

Finally, one should differentiate between negative affectivity within the normal range of emotional experience and diagnosable emotional disorders with psychopathological significance such as mood and anxiety disorders.

Next to the above-discussed environmental and psychological factors, the importance of genetic factors for the development of emotional disorders has been convincingly demonstrated in family and twin studies. Kendler et al. (2006) recently showed that 38% of the susceptibility to develop major depression is due to additive genetic factors. However, during the last years, several genome-wide association studies (GWAS), which allow the simultaneous analysis of many common SNPs, instead of a single candidate gene, failed to find a genetic variant that achieved genome-wide significance in predicting depression (Major Depressive Disorder Working Group of the Psychiatric GWAS Consortium, 2013). When looking at the impact of genetic factors in interaction with environmental events on the other hand, a seminal study published by Caspi et al. (2003) demonstrated that the association between the number of *5-HTT* short variants and later depression is a function of life stress history, a finding which was later confirmed in a study by Kendler et al. (2005). Finally, new insight has been gained by recent approaches studying epigenetic changes induced by environmental factors, contributing to changes in neural circuits and endocrine systems that are associated with stress-related diseases such as depression (Menke & Binder, 2014). It has been shown that early adversity impacts on gene expression patterns by changing DNA methylation and histone modification, thereby most likely increasing disease risk (Mill & Petronis, 2007; Tsankova, Renthal, et al., 2007). Thus, the occurrence of emotional disorders is closely linked to stressful life events and as a consequence to alterations in the regulation of various stress-sensitive physiological systems, such as the hypothalamus-pituitary-adrenal (HPA) axis or the locus coeruleus-norepinephrine (LC/NE)/autonomic system (see below). It is therefore not surprising that affective disorders are a common risk factor for physical disease, most prominently CVD (Nabi, Shipley, et al., 2010; Seldenrijk, Vogelzangs, et al., 2015).

Biological Mechanisms Linking Emotional Factors to Stress Responses

To better understand how emotional factors such as affective states or more enduring individual trait aspects may lead to an increased susceptibility to disease, a detailed understanding of possible underlying biological mechanisms is essential. The following section will briefly elaborate the physiology and regulation of two major stress-sensitive systems, the hypothalamus-pituitary-adrenal (HPA) axis, which represents the slow arm of the stress response, and the locus coeruleus-norepinephrine (LC/NE)/autonomic system, representing the fast arm.

The Hypothalamus-Pituitary-Adrenal (HPA) Axis

The HPA axis serves as a central control system of an organism, connecting the central nervous system (CNS) with the endocrine system. The HPA axis is vital for the support of normal physiological functioning and enables organisms to maintain homeostasis under acute stress. Incoming stress signals from higher centers of the brain are integrated in the hypothalamic paraventricular nucleus of the hypothalamus (PVN), which then coordinates the immediate behavioral, autonomic, and neuroendocrine responses to a stressor. In the face of challenge, neural stimulation of the PVN leads to the release of corticotropin-releasing hormone (CRH), which then initiates the secretion of adrenocorticotropin (ACTH) from the anterior pituitary. The primary target of ACTH is the adrenal cortex, where it triggers the secretion of glucocorticoids (GCs) and to a lesser extent mineralocorticoids and adrenal androgens (Chrousos & Gold, 1992). GCs are among the most versatile of hormones with a wide range of physiological effects. The best studied are those on carbohydrate metabolism and immune function. In order to adapt to the increased metabolic demands under acute stress, GCs enhance circulating levels of energy substrates like glucose, free amino acids, and free fatty acids (Chrousos & Gold, 1992; McEwen, 2003).

The acute stress response also entails the activation of the immune system to respond to challenges such as wounding and infection that (in evolutionary terms) are likely outcomes of a stressor. The rapid recruitment of leukocytes into sites of surgery, wounding, infection, or vaccination is essential for an effective immune defense network. In case of chronic stressors, GCs generally dampen immune and inflammatory responses. Additionally, GCs have important regulatory effects on the cardiovascular system, on response to hemorrhage, as well as on behavior, appetite control, and affective and cognitive processes, like learning and memory (McEwen, 2003). Dysfunctional regulation of the HPA axis has been associated with various psychosomatic and stress-related pathologies (for reviews see Heim, Ehlert, & Hellhammer, 2000; Raison & Miller, 2003).

The Locus Coeruleus-Norepinephrine/Autonomic System

The locus coeruleus-norepinephrine/autonomic system is located in the brain stem and centrally regulated by the hypothalamus and the locus coeruleus (LC). It functions globally as an alarm system, and when activated, it initiates the discharge of norepinephrine from an extremely dense network of neurons throughout the brain. This results in enhanced arousal, vigilance, and increased anxiety. The sympathetic division of the autonomic nervous system plays an important role in the adaptation to stressful situations, via its peripheral effectors: the sympathetic nerves and the adrenal medulla (Chrousos & Gold, 1992). The parasympathetic division of the autonomic nervous system typically acts to oppose the effects of the sympathetic nervous system (Tsigos & Chrousos, 2002). The adrenal medulla responds with the systemic secretion of catecholamines (predominantly epinephrine). The sympathetic nerve terminals, which line the vasculature, release norepinephrine. In the face of challenge, catecholamine secretion leads to a rapid mobilization of energy stores (through increased supply of free fatty acids and glucose by glycogenolysis and lipolysis) as well as a downregulation of less important organ functions (e.g., those of the gastrointestinal tract and reproductive systems). Furthermore, catecholamines have a substantial impact on cardiovascular functioning during stress, increasing heart rate, cardiac output, and blood pressure. Other effects include enhanced respiratory extraction of oxygen via airway dilatation, enhanced platelet aggregation, and reduced clotting time (Kudielka & Kirschbaum, 2007). Norepinephrine also activates the amygdala, the principal brain locus for fear-related behaviors, and enhances the long-term storage of emotional memories in the hippocampus and striatum. Reciprocal neural connections exist between the HPA axis and the locus coeruleus-norepinephrine/autonomic system. CRH and norepinephrine stimulate each other primarily through α1-noradrenergic receptors. Thus when working in concert, the HPA axis and the LC/NE system can produce short-term and more sustained stress responses (Tsigos & Chrousos, 2002).

Exemplary Evidence Linking Emotional Factors and Stress-Related Health Outcomes

Scientific evidence for the role of psychological stress and related emotions in disease processes has been accumulated by several distinct lines of research, which include acute stress experiments, cross-sectional observational (field) studies, as well as prospective longitudinal studies trying to predict future disease risk. The following section will summarize exemplary evidence from various studies with different methodological approaches on a continuum of emotional experience with increasing severity. First, the effects of a distinct negative emotion such as anger as well as the effects of the more enduring negative attitude hostility on health outcomes will be outlined. In a next step, evidence on stable personality characteristics (neuroticism and Type D) will be highlighted and finally the impact of negative emotions with pathological significance, that is, clinical depression on health will be summarized. As was already noted in the introduction, we decided to focus on CVD and depression as disease outcomes. With respect to depression, it is important to notice that it can be seen as both, a disease outcome in itself and a predictor of physiological disease outcomes such as CVD. When it comes to physiological alterations that may precede the development of CVD and depression, we will outline exemplary results on changes in HPA axis regulation, alterations in the functioning of the locus coeruleus-norepinephrine/autonomic system, and changes in immune parameters.

The Association Between Anger, Hostility, and Health Outcomes

The idea that a hostile attitude toward others and related affective experiences can have a negative impact on physiological functioning has a long history in behavioral medicine research (Barefoot & Williams, 2010). Dysregulation of the HPA axis is one potential mechanism that could explain the negative health outcomes associated with hostility and anger. A finding by Steptoe et al. (2000) supports this notion. In a study with school teachers suffering from high job strain, anger expression has been demonstrated to predict elevated levels of early morning salivary cortisol. Looking at HPA axis regulation after acute stress, however, current data draw a different picture. In a recent study by Brydon et al. (2010), hostility was not related to cortisol reactivity to stress, a finding which is in line with results from a meta-analysis, investigating the association between different emotional and psychosocial factors and physiological responses to laboratory-induced stress in healthy populations by Chida and Hamer (2008). With respect to autonomic nervous system dysregulation, the authors found hostile individuals to be more prone to react with larger and more prolonged increases in heart rate and blood pressure to laboratory mental stress. High levels of hostility and anger have also been shown to be associated with greater blood pressure reactivity (Christensen & Smith, 1993) to social stress and less nocturnal blood pressure dipping (Thomas, Nelesen, & Dimsdale, 2004). Interestingly, anger suppression (anger-in) compared to anger expression (anger-out) has been shown to be a significant determinant of carotid artery stiffness, a major risk factor for cardiac events, independent of blood pressure (Anderson, Metter, et al., 2006).

The immune system is another stress-sensitive system that seems to be affected by the experience of hostility and anger. Suarez et al. (2002) demonstrated that in a sample of 62 healthy men, hostility was positively associated with lipopolysaccharide (LPS)-stimulated expression of tumor necrosis factor-alpha (TNF-α), a pro-inflammatory cytokine. In a study that was aimed to assess how hostile marital behaviors modulate wound healing, as well as local and systemic pro-inflammatory cytokine production, Kiecolt-Glaser and coworkers (2005) observed that higher levels of hostile behaviors were associated with a significantly reduced wound-healing rate as well as to larger increases in plasma IL-6 and TNF-α values in the morning after a conflict compared to a social support interaction. Furthermore, the interaction between depressive symptoms × hostility has been also shown to be associated with increases in IL-6 and C-reactive protein (CRP) in a sample of 316 healthy older adults (Stewart, Janicki-Deverts, et al., 2008). In the presence of depressive symptoms, hostility may augment inflammatory processes relevant to CVD. In a recent study by Brummet and colleagues (2010), a similar effect was shown for an acute stress condition. The interaction term depressive symptoms × hostility predicted the CRP response to an emotional recall task. Those subjects with the combination of high symptoms of depression and hostility had the largest CRP response. Hostility is also associated with platelet reactivity, a key pathophysiological pathway in the onset of CVD (Shimbo, Chaplin, et al., 2009), and has been shown to be associated with endothelial dysfunction as an early indication of atherosclerosis (Raikkönen, Matthews, et al., 2004). To summarize, there is a multitude of findings that indicate a direct link between affective states such as anger and biological alterations that are responsible for an increased susceptibility for disease endpoints like CVD. A recent meta-analysis by Chida and Steptoe (2009) demonstrated the relationship between anger and hostility and increased cardiac events even in initially healthy populations. Anger and hostility were furthermore associated with a poor prognosis in patients who already suffer from coronary heart disease (CHD). The latter effects were even stronger, suggesting that patients who score high on the trait hostility might experience more frequent anger episodes, which could accelerate the recurrence and perpetuation of the disease. Interestingly, a gender difference in respect to vulnerability was observed in the healthy populations. Here, the association between anger and hostility and CHD events was stronger in men than in women. This sex effect is in line with results from the above-mentioned meta-analysis from Chida and Hamer (2008), where anger and hostility were related to stronger cardiovascular responses to psychological stressors in men than in women. Thus, the repeated experience of increased stress reactivity in daily life might be of pathophysiological significance for CHD in men.

However, according to this review based on observational studies (Chida & Steptoe, 2009), anger and hostility lost their predictive power for the occurrence of CHD events in healthy populations as well as in patient populations when a variety of behavioral covariates such as smoking, physical activity, body mass index (BMI), and socioeconomic status were fully controlled for (Chida & Steptoe, 2009). Thus, next to the above-described physiological pathways, it can be hypothesized that effects are also mediated via behavioral pathways, especially since there is considerable evidence that hostility is related to a variety of adverse health behaviors such as poor diet, reduced physical activity, or smoking (Bunde & Suls, 2006). This reasoning is in line with a prospective study in which Siegler et al. (1992) followed up over 4000 college graduates for 25 years. Those with higher hostility scores at age 18 later reported lower exercise rates, higher alcohol consumption, smoking rates, as well as higher body mass indices.

The Association Between Neuroticism, Type D Personality Traits, and Health Outcomes

As already outlined above, there are stable differences in the experience of distress and negative affect, and several mechanisms could explain the relationship between the personality traits capturing this tendency, such as neuroticism or Type D personality, and the development of CVD. It might be assumed that neuroticism, as it reflects the tendency to experience increased stress levels, is associated with increased basal HPA axis activity reflected in increased cortisol levels throughout the day. However, studies which investigated the association between neuroticism and HPA axis activity rendered inconclusive results. Two recent studies used a momentary assessment measurement approach to investigate the association between neuroticism and diurnal cortisol levels. Hauner et al. (2008) observed flatter cortisol profiles in male adolescents with high levels of neuroticism, whereas Nater et al. (2010) demonstrated a positive association of neuroticism with cortisol levels throughout a measurement period of six days. Schommer et al. (1999) on the contrary found no association between circadian salivary-free cortisol patterns as well as cortisol responses to acute psychosocial stress and levels of neuroticism. In a recent gender-specific analysis by Oswald et al. (2006), higher neuroticism scores have however been shown to be related to a blunted cortisol response to acute stress only in women. In their meta-analysis on the influence of chronic psychosocial factors on responses to acute laboratory stress, Chida and Hamer (2008) did not find an association between neuroticism and HPA axis reactivity.

Looking at changes in autonomic functioning however, the meta-analysis by Chida and Hamer (2008) reported a decreased cardiovascular reactivity, and furthermore poor cardiovascular recovery in response to acute psychosocial stress, to be related to neuroticism and negative affectivity. In accordance with the findings on the relationship between anger and immune system regulation, also neuroticism was shown to be associated with alterations in inflammatory markers (Kiecolt-Glaser, McGuire, et al., 2002). In a recent study by Sutin et al. (2010), high levels of neuroticism were associated with higher levels of the pro-inflammatory cytokine interleukin-6 (IL-6) in a population-based sample controlling for relevant covariates.

Similar to neuroticism, Type D has been associated with various health outcomes in healthy subjects. Williams et al. (2009), for example, demonstrated in a study on 84 healthy young adults that Type D personality was associated with increased cardiovascular stress reactivity, including higher heart rate, blood pressure, and cardiac output. Type D however has been primarily studied in patients with CVD. In survivors of acute cardiac events, it was shown to be related to increased cortisol levels (Molloy, Perkins-Porras, et al., 2008; Whitehead, Perkins-Porras, et al., 2007), and in chronic heart failure patients, Type D was associated with an increased activity of pro-inflammatory cytokines (Denollet, Schiffer, et al., 2009). With respect to the long-term prognosis of health outcomes, including revascularization, myocardial infarction, as well as cardiac death, the pooled effect size of nine prospective studies indicated that Type D personality was associated with a more than threefold increased risk of poor long-term prognosis (Denollet, Schiffer, & Spek, 2010). To sum up, physiological changes in major stress-sensitive systems have been shown to be associated with the tendency to experience negative emotions, captured through the personality traits neuroticism and Type D personality, which pose these individuals at a greater risk to develop CVD. However, also behavioral factors seem to play an important role, when trying to explain the adverse effects of neuroticism and Type D on health. Both constructs have been shown to be related to negative health behaviors such as unhealthy lifestyle (poor diet, smoking status) or low adherence to medical treatment (Mroczek, Spiro, & Turiano, 2009; Williams, O'Connor, et al., 2008).

The Association Between Clinical Depression and CVD

As pointed out above, there is a substantial overlap between personality traits related to emotional distress and diagnosable psychopathology. Here, exemplary evidence on the relationship between stress-related physiological dysregulation, major depression, and CVD will be summarized. However, also other subtypes of depression such as seasonal affective disorders (SAD) (Thorn, Evans, et al., 2010), atypical depression (Gold & Chrousos, 2002) or bipolar disorder (Daban, Vieta, et al., 2005) have been linked to various alterations in the regulation of stress-sensitive systems such as the HPA axis or the autonomic nervous system.

One of the most reliably reported neurobiological alterations in psychiatry is a hyperactivity of the HPA axis (Stetler & Miller, 2011), involving elevated secretion of corticotropin-releasing hormone (CRH) in major depression. A significant percentage of depressed patients have been shown to hypersecrete cortisol, as manifested by increased 24-h urinary free cortisol and elevated plasma and cerebrospinal fluid concentrations of cortisol, nonsuppression of cortisol and ACTH following dexamethasone administration, and increased volume of the pituitary gland and of the adrenal glands (Holsboer, 2001; Pariante, 2009). Hypercortisolism has been discussed to be one of the main biological mechanisms explaining the link between major depression and CVD because it increases the risk of hypertension; it weakens endothelial repair mechanisms and contributes to increased levels of cholesterol and triglycerides (Musselman, Evans, & Nemeroff, 1998; Whitworth, Williamson, et al., 2005). Altered activity of the autonomic nervous system (ANS) is another pathway implicated in the development of major depression. Cross-sectional studies have demonstrated that depressed patients with CHD as well as patients with the melancholic subtype of depression are more likely to have decreased heart rate variability (HRV) (Carney, Freedland, et al., 2002; Kemp, Quintana, et al., 2014). Furthermore, reduced baroreflex cardiac control also has been shown to correlate with depressive symptom severity in CHD patients (Watkins & Grossman, 1999).

Increases in biomarkers of inflammation in both the periphery and the brain have also been observed in depressive patients in numerous studies (Raison, Capuron, & Miller, 2006), and a state of chronic low-grade systemic inflammation is significantly increased in clinical depression (Carney, Freedland, et al., 2002). Such low-grade systemic inflammation, characterized by an increase in circulating levels of pro-inflammatory cytokines and acute-phase reactants, such as TNF-α, IL-6, and CRP, and by a decrease in the levels of anti-inflammatory cytokines (such as IL-4 or IL-10), crucially contributes to the development of atherosclerosis (Kilic, Ural, et al., 2006). Finally, depressive symptoms are associated with increased risk of cardiac events and are furthermore associated with worse outcomes in patients with diabetes and rheumatoid arthritis (Rosengren, Hawken, et al., 2004; Rugulies, 2002).

Implications for Behavioral Medicine and Concluding Remarks

The fact that extrinsic stressors and social contexts interact with individual coping strategies and emotional experiences, thereby inducing a variety of potentially harmful physiological responses, has direct implications for behavioral medicine. First of all, additional experimental research demonstrates that the major social stressors discussed so far in an epidemiological framework in section "Social Stressors and Stress-Related Diseases" can be – comparable to the intrinsic factors – directly linked to indicators of psychobiological pathways possibly underlying the observed statistical associations with disease endpoints. These indicators include cardiovascular and hormonal responses, markers of immune function and inflammation, or measures of allostatic load. Reviews are available for social isolation and lack of social support (Uchino, 2006 and Uchino et al, infra), for low socioeconomic status (Seeman, Epel, et al., 2010), and for the two work stress models (Chandola, Britton, et al., 2008; Siegrist, 2009). Thus, there is some credibility in assuming a causal relationship between social stressors and disease susceptibility, which may be relevant in terms of probabilistic risk assessment in individual persons. In fact, several screening tools were proposed for risk assessment among groups of vulnerable people.

Second, despite the difficulties of conducting randomized clinical trials in this field, preliminary findings from intervention studies indicate that reduction of a social stressor can exert favorable effects on the health and well-being of exposed people. This was documented in work settings using the two work stress models discussed (Bourbonnais, Brisson, & Vezina, 2011; Limm, Gundel, et al., 2011; Theorell, Emdad, et al., 2001) and, with mixed results, in studies that increased social support (Holt-Lunstad, Smith, & Layton, 2010). Third, as the majority of interventions in behavioral medicine, whether in primary or secondary prevention, take place in therapeutic settings, the improvement of individual skills and capabilities of coping with social stressors defines a primary goal of intervention. In addition to the more general techniques of relaxation, meditation, stress inoculation, anger management, and self-assertiveness, a specific cognitive-motivational intervention can be derived from the theoretical framework outlined. It concerns the modification of work-related attitudes of achievement and commitment. We mentioned that overcommitted people contribute to recurrent experience of reward frustration by overtaxing their resources without considering their long-term consequences. Cognitive-behavioral change attempts at reappraising work demands and motivations for excessive engagement. In line with a more realistic assessment of "cost-gain" relations at work, the ability to observing some mental distance from one's involvement in obligations is strengthened. People are trained to decline inappropriate demands and to experience self-esteem from sources other than work and achievement (Aust, Peter, & Siegrist, 1997). In a further intervention study based on the model of effort-reward imbalance, a significant reduction of perceived stress reactivity after 1 year was achieved (Limm, Gundel, et al., 2011). These are just a few examples illustrating the possible benefit of behavioral interventions that contribute toward strengthening people's sense of belonging, to reinforce their self-efficacy, and to support their self-esteem even if social contexts are not fully responsive to these needs.

Finally, a few studies investigated the effects of stress management not only on behavioral outcome measures and subjective stress ratings but also on the physiological stress markers discussed above. Gaab et al. (2003), for example, demonstrated that cognitive-behavioral stress management training following the principles of the stress inoculation training developed by Meichenbaum (1985) can influence endocrine responses and cognitive appraisal under acute laboratory stress in healthy male adults. The reduction in the cortisol stress response to the Trier Social Stress Test (TSST) in the treatment group compared to a wait control group was related to a different cognitive appraisal of the situation. Subjects in the treatment group appraised the situation as less stressful and generally coped better with it. The authors argue that the stress management training exerted its effects through the modulation of the cognitive and affective processing of stressful stimuli. In a follow-up study, the same group set out to investigate whether the effects of the stress management training were stable over time and generalizable to both genders. The previously observed attenuation of cortisol stress responses 2 weeks after the stress inoculation training was also observed after a time interval of 4 months. Furthermore, the attenuation of the cortisol response to stress could be observed in both men and women (Hammerfald, Eberle, et al., 2006). Also, a more resource-oriented form of stress management training, according to the Zürich resource model, was shown to modulate cortisol stress responses to the TSST, 3 months after the training in healthy male subjects (Storch, Gaab, et al., 2007). Gaab et al. (2006) also observed effects on stress hormone regulation with regard to real-life stress, that is, an academic exam. University students received a cognitive-behavioral stress management training 8 weeks before an important exam. Subjects in the treatment group compared to a wait control group reported less anxiety and lower levels of somatic symptoms throughout the period prior to the exam. Interestingly, on the day of the exam, subjects in the wait control group displayed attenuated cortisol awakening responses, which did not match with the cognitive appraisal of the upcoming stressor. It is speculated that the observed dissociation between the psychological and biological stress responses, namely high subjective stress combined with the inability to mount an adequate physiological stress response in the control group, might be an indication of a dysregulated HPA axis, probably as a consequence of chronic stress. With respect to patients suffering from CVD, Blumenthal et al. (2005) demonstrated in a large randomized control trial that exercise in combination with a stress management training reduced emotional distress and improved markers of cardiovascular risk more than usual medical care alone.

Finally, mindfulness-based stress reduction (MBSR) has received growing attention in clinical research, and recently biomarkers have been included to validate the self-reported benefits of the program (Matousek, Dobkin, & Pruessner, 2010). However, results regarding potential effects on HPA axis regulation are still mixed (Brand, Holsboer-Trachsler, et al., 2012; Creswell, Pacilio, et al., 2014; Lynch, Gander, et al., 2011; Stefanaki, Bacopoulou, et al., 2014), which may in part be explained by differences in program structure, sample characteristics, and the fact that both basal cortisol levels and the cortisol response to acute stress have been studied. While intervention research continues to be a task of primary importance to behavioral medicine, innovative research directions are equally relevant. One such promising approach concerns the study of positive affective states and their effects on health and well-being. There is growing evidence that positive well-being may be linked to health-buffering effects. Analyses of associations between positive affect and neuroendocrine, cardiovascular, as well as inflammatory activity documented lower cortisol output over both a working day and a leisure day and lower heart rate assessed by using ambulatory monitoring methods over the day (Steptoe, Wardle, & Marmot, 2005). Moreover, the plasma fibrinogen response to acute stress was smaller in individuals who reported higher levels of positive emotions (Steptoe, Dockray, & Wardle, 2009). Enhanced parasympathetic cardiac control may be a process through which positive emotions can protect against CVD (Bhattacharyya, Whitehead, et al., 2008; Raikkönen, Matthews, et al., 1999). To sum up, a number of studies demonstrated that positive affect is significantly associated with psychobiological alterations that could have protective effects against stress-related diseases. Finally, positive affect and positive traits such as optimism and hopefulness were also shown to relate to reduced mortality with stronger effects in healthy populations than in those with existing illnesses in a recent meta-analysis of prospective studies by Chida and Steptoe (2008).

Furthermore, alternative methods of measuring emotions, not retrospectively but in daily life, such as ambulatory assessment, allow the investigation of subjective experiences linked to a particular time and context. Growing evidence seems to suggest that this approach is especially well suited to study associations between emotional states and various biomarkers compared with traditional self-reported traits (Conner & Barrett, 2012; Kudielka, Gierens, et al., 2012). In conclusion, rich evidence on associations between emotions and stress offers new insights into the biopsychosocial dimensions of human health and disease. At the same time, new opportunities are given to reduce the burden of disease and to promote health, at both the individual and population levels.

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12

Social Support and Physical Health: Models, Mechanisms, and Opportunities

Bert N. Uchino, Kimberly Bowen, Robert Kent de Grey,
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Scientists have long-noted an association between social relationships and health. More socially isolated or less socially integrated individuals are less healthy psychologically and physically, and more likely to die.

(House, Landis, & Umberson, 1988, p. 540)

The statement by House and colleague (1988) over 25 years ago has survived the test of time. Social relationships are reliable predictors of all-cause mortality rates, as well as more specific physical health outcomes such as cardiovascular and infectious disease (Berkman, Glass, et al., 2000; Cohen, 2004; Holt-Lunstad, Smith, & Layton, 2010; Uchino, 2004). These epidemiological studies typically rely on the broad distinction between structural and functional aspects of support (Cohen & Wills, 1985). Structural measures tap into the extent to which a person is situated or integrated into a social network (e.g., married, contact with family members). Functional measures are based on the particular supportive functions served by our relationships such as emotional support (e.g., expressions of caring). These functional support measures can be further differentiated based on whether that support is perceived to be available or actually received by the recipient (Barrera, 1986).

In this chapter, we first briefly review evidence linking structural and functional measures of social support to physical health outcomes. We then present an interdisciplinary, multilevel model that incorporates the mechanisms responsible for such links. The evidence for primary pathways in the model is discussed followed by emerging perspectives and issues. Finally, we discuss the intervention, practice, and policy implications of the work linking social support to physical health outcomes.

Social Support and Physical Health

Researchers have examined links between social support and more general (e.g., mortality rates) and specific (e.g., cardiovascular disease) indices of health. Two early studies were particularly important in stimulating work in this area. In 1979, Berkman and Syme examined thousands of participants from Alameda County, California. They found that structural measures of support (i.e., social integration) predicted lower mortality rates even when considering standard control

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variables like initial health status. Several years later, Blazer (1982) studied a community sample of older adults in Durham County, NC. Even when considering standard control variables such as physical health status and smoking, perceptions of functional support predicted lower mortality rates. These results held even when considering structural measures of social integration such as those utilized by Berkman and Syme (1979), thereby showing an independent association between functional and structural support with physical health.

Since these seminal studies, there have been many others that have linked social support to physical health. In a recent meta-analysis, Holt-Lunstad, Smith, and Layton (2010) examined 148 studies comprising over 300,000 participants from around the globe including the United States, Europe, Asia, and Australia. They found that social support overall was associated with a 50% increased likelihood of survival (OR = 1.50). Importantly, the link between social support and mortality was consistent across age, sex, initial health status, cause of death, and follow-up (Holt-Lunstad, Smith, & Layton, 2010). Indeed, effect sizes for these associations were comparable to standard biomedical risk factors including smoking, alcohol consumption, and physical activity. To put it plainly, social support appears to be as important for life expectancy as not smoking.

Although these structural and functional measures of support predict mortality, it is not the case that all measures are consistently predictive of health outcomes. In the recent meta-analysis, there was significant variability on mortality based on how support was operationalized (Holt-Lunstad, Smith, & Layton, 2010). These authors found that simple structural measures of support such as living alone/with others were not significantly related to survival. However, composite structural measures of support (i.e., aggregated across marriage, close friends, volunteer work) showed strong links to greater survival (OR = 1.91). This finding is consistent with the English Longitudinal Study of Ageing which found that a composite measure of social isolation significantly predicted lower mortality rates (OR = 1.26) after adjustments for a comprehensive set of covariates including demographic factors, health status, and depression (Steptoe, Shankar, et al., 2013). Overall, these data suggest that there is not one key determinant or source of social support that impacts on health. It may be the case that support from different sources is interchangeable as long as one has access to individuals to talk with about intensely important and personal matters (Miller & Ingham, 1976).

Measures of functional support also showed variable links to mortality rates. In prior work, the concepts of perceived and received support have been used interchangeably with the assumption that individuals high in perceived support also received more support (Barrera, 1986; Dunkel-Schetter & Bennett, 1990; Uchino, 2009). However, measures of perceived and received support are only moderately correlated and hence seem to represent distinct constructs (Haber, Cohen, et al., 2007). In the meta-analysis, perceived support was significantly related to increased survival (OR = 1.35), whereas measures of received support did not predict survival (Holt-Lunstad, Smith, & Layton, 2010). In fact, several epidemiological studies examining received support (especially tangible support) found it to be associated with *higher* subsequent mortality rates (Forster & Stoller, 1992; Krause, 1997). We will return to this important issue later in the review, but these findings parallel a growing literature showing that under some conditions receiving support may be related to negative mental health outcomes (Wills & Shinar, 2000).

The literature linking social support to specific causes of disease is smaller. Although there are numerous studies linking social support to pre-disease biological processes (see next section), specific chronic diseases are determined by multiple factors so research that also shows a direct link to clinically significant outcomes is needed (Barth, Schneider, & von Kanel, 2010; Pinquart & Duberstein, 2010; Tay, Tan, et al., 2013). Preliminary evidence for a role of social support on the development of cardiovascular disease can be found in studies utilizing imaging techniques. Several of these studies have shown that social support predicts less underlying atherosclerosis (Angerer, Siebert, et al., 2000; Wang, Mittleman, & Orth-Gomer, 2005). For instance, women with established coronary artery disease who were low in emotional support showed faster disease progression as indexed by angiography over a subsequent 3-year period (Wang, Mittleman, & Orth-Gomer, 2005).

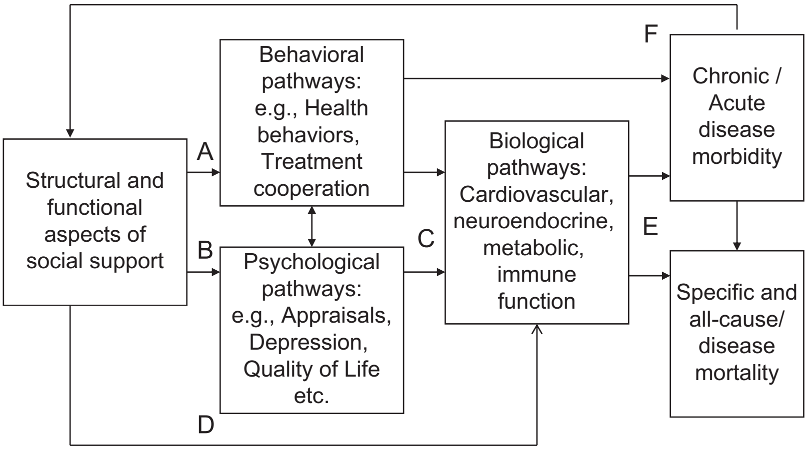
A number of studies have examined survival following the diagnosis of cardiovascular disease and cancer. Results of a meta-analysis focusing on cardiovascular disease found that functional, but not structural, measures of support predicted lower cardiovascular mortality (Barth, Schneider, & von Kanel, 2010). However, both structural and functional measures of support have been linked to lower cancer mortality in another meta-analysis, although these links are moderated by factors such as participant age and type of cancer (Pinquart & Duberstein, 2010). Finally, although we know of no recent meta-analysis linking social support to infectious diseases (e.g., HIV, vaccinations), qualitative reviews suggest that social support has beneficial influences on biologically significant infectious disease outcomes (Uchino, Vaughn, et al., 2012a).

A Broad Multilevel Model Linking Social Support to Physical Health

Although social support predicts significant health outcomes, the testing of a broad theoretical model would be useful to incorporate existing findings and guide relevant interventions. In this section, we focus on an interdisciplinary model highlighting the mechanisms by which social support can influence health outcomes (see Fig. 12.1). There are certainly sub-models (e.g., stress-buffering, direct effect models), and these will be highlighted when relevant. For instance, the stress-buffering model suggests that social support is primarily effective when individuals are under high levels of stress, whereas the direct effect model highlights the role of support regardless of stress (e.g., positive affective experiences). As shown in Fig. 12.1, structural and functional aspects of social support are grouped as indices of the global support construct. By doing so, we assume that structural features of the social environment provide the context by which functional support emerges, is maintained, and changes over time (e.g., family context, Graves, Wang, et al., 1998; Repetti, Taylor, & Seeman, 2002).

Social support is hypothesized to first impact several potential pathways that can influence disease. Path A depicts behavioral processes linking social support to health and includes factors such as health behaviors and cooperation with treatment regimens (DiMatteo, 2004; Shankar, McMunn, et al., 2011). Path B depicts psychological pathways including stress appraisals, depression, and quality of life (Berkman, Glass, et al., 2000). Although depicted as mediators, these psychological and mental health processes are also important outcomes in their own right (e.g., Diener & Chan, 2011). However, given the focus of this chapter is

Fig. 12.1 Broad model highlighting major mechanisms linking social support to physical health



on physical health outcomes, we primarily discuss their role as potential mediators. It is also important to note that the psychological and behavioral pathways are related to each other as stress appraisals can negatively influence health behaviors and health behaviors such as exercise can positively influence psychological processes (Ng & Jeffery, 2003; Stathopoulou & Powers, 2006).

Behavioral and psychological processes may also influence disease through relevant biological alterations (Path C). For instance, exercise is associated with lower blood pressure and greater cardiovascular efficiency (Smith & Kampine, 1990). We also postulate that there may be a direct link between social support and biological processes which in turn influence disease (Path D) as will be discussed below. The main biological pathways include cardiovascular, neuroendocrine, metabolic, and immune function. These biological processes in turn influence disease development and mortality as they play a role in the leading causes of death including cardiovascular disease, metabolic disorders, cancer, and infectious disease (Path E, Timiras, 1994). Finally, once individuals are diagnosed and undergoing treatment for chronic conditions, it can have direct links to social support by influencing support seeking from family and friends, disease-related adjustment, and in some cases support "erosion" due to distress over the adherence or health status of a close other (Path F, Reed, Butler, & Kenny, 2013).

Evidence for the Broad Model

In the following section we focus on a representative review of links between social support and the specific mechanisms highlighted in Fig. 12.1 (Paths A, B, D, & F). There is a large literature linking behavioral (e.g., exercise) and psychological (e.g., depression) pathways to biological and disease outcomes (Paths C and E, see Miller, Chen, & Cole, 2009; Rozanski, Blumenthal, & Kaplan, 1999; Smith & Ruiz, 2002), but here we will focus on the social support influences on pathways related to disease.

Path A: Social Support and Behavioral Pathways There is strong evidence linking social support to beneficial health practices. Perceived support has been associated with greater physical activity, less smoking/alcohol consumption, and better sleep quality (Ailshire & Burgard, 2012; Courneya, Plotnikoff, et al., 2000; Kouvonen, De Vogli, et al., 2011; Steptoe, Wardle, et al., 1996; Reininger, Perez, et al., 2012; Stewart, Gabriele, & Fisher, 2012; Yuan, Weng, et al., 2011). Although many of these studies were conducted in the United States, these associations have also been documented in Mexico, Taiwan, England, and Canada (Courneya, Plotnikoff, et al., 2000; Kouvonen, De Vogli, et al., 2011; Reininger, Perez, et al., 2012; Yuan, Weng, et al., 2011).

Social support is also related to better patient cooperation with treatment regimens in chronic disease populations. DiMatteo (2004) conducted a meta-analysis of 122 studies examining links between structural and functional support with patient's medical adherence (e.g., diabetes, cardiovascular, arthritis). Structural measures such as marital status (RR = 1.17) and living with others (RR = 1.41) predicted greater adherence. However, functional measures were generally stronger predictors of better adherence (RR = 1.90 for practical support, RR = 1.35 for emotional support, RR = 1.54 for general perceptions of support).

The data linking social support to behavioral pathways are consistent with several existing theoretical perspectives (Cohen, 2004; Lewis & Rook, 1999; Umberson, 1987). Social control models of support highlight both an indirect (e.g., life meaning) and direct (e.g., requests by spouse) role of others on health behaviors (Umberson, 1987). This model also makes the unique prediction that although social network members can influence us to behave in healthier ways, they may also be a source of psychological distress (Hughes & Gove, 1981). This distress can occur because people resent being directly controlled by others. Consistent with this prediction, when social control was measured from specific network members, it predicted both greater distress and healthier behaviors (Lewis & Rook, 1999).

The process of social control is often linked to the direct effect model which historically highlighted the role of structural measures of support in fostering lifestyle factors and well-being regardless of stress (Cohen & Wills, 1985). However, it is clear that functional measures of support are also linked to better lifestyle and behavioral factors (Kouvonen, De Vogli, et al., 2011; Stewart, Gabriele, & Fisher, 2012). There are also stress-related links between social support and health behaviors (i.e., stress prevention and stress-buffering models; Gore, 1981; Lin, 1986). These models are particularly important to consider because high stress has been linked to less healthy behaviors including poorer diet, less exercise, and sleep quality, as well as greater alcohol consumption and smoking (Cohen & Lichtenstein, 1990; Hall, Thayer, et al., 2007; Ng & Jeffrey, 2003). Consistent with this pathway, researchers found that tangible support decreased the association between financial stress and alcohol involvement (Peirce, Frone, et al., 1996; also see Wills & Cleary, 1996).

As highlighted by the model in Fig. 12.1, there has also been research examining if behavioral pathways are responsible for links between social support and biological/physical health outcomes (Uchino, 2004). These studies suggest that social support effects are reduced, although still significant, when considering health behaviors (Kaplan, Wilson, et al., 1994; Penninx et al., 1997; Seeman, Kaplan, et al., 1987). Controlling for health behaviors enables one to directly model its overlap with social support and health outcomes. Thus, a reduction in explanatory power as a result of controlling for health behaviors suggests that part of the link between social support and health is due to its association with health behaviors. For instance, one study found that statistical adjustments for risk factors including smoking, alcohol intake, coffee intake, physical activity, body mass, lipoprotein levels, and income reduced the mortality risk for low organizational activities by about 16% (Kaplan, Wilson, et al., 1994). Using data from the Stockholm Heart Epidemiological Program and Västernorrland Heart Epidemiological Program, it was found that disturbed sleep reduced the link between social support and myocardial infarctions in women (Nordin, Knotsson, & Sundbom, 2008). Although these studies did not use more current recommendations for mediational analyses (Rucker, Preacher, et al., 2011), they surely suggest the possibility and should receive further investigation.

Path B: Social Support and Psychological Pathways Most major theories of social support and health argue that psychological mechanisms are partly responsible for such links (Berkman, Glass, et al., 2000; Cohen, 2004; Thoits, 2011; Uchino, 2004). The stress-buffering model of support hypothesizes that social support should (a) reduce stress appraisals or (b) weaken the link between stress and adverse outcomes. The direct effect model also highlights the role of social support in fostering a sense of connection, self-esteem, and control over life due to knowing that you are cared for and supported by others (Lakey & Orehek, 2011; Thoits, 2011; Uchino, 2004). Broader perspectives also highlight psychological mechanisms that have been linked to both support and physical health outcomes in prior work (e.g., depression, quality of life, Uchino, 2004).

There is strong evidence that social support has beneficial influences on psychological and mental health outcomes. Social support has been linked to beneficial appraisal patterns (Dunkel-Schetter, Folkman, & Lazarus, 1987), as well as greater feelings of control, self-efficacy, and self-esteem (Atienza, Collins, & King, 2001; Shaw, Krause, et al., 2004; Symister & Friend, 2003). High levels of social support are also related to lower perceptions of stress, less stress exposure, and lower depression (Sarason, Sarason, & Pierce, 1990; Russell & Cutrona, 1991). Of particular interest is research linking social support to higher quality of life as this is an important indicator of adjustment to chronic conditions and life challenges more generally (Diener & Chan, 2011). To this point, social support has been related to higher quality of life among individuals with cancer (Waters, Liu, et al., 2013), HIV (Bekele, Rourke, et al., 2013), or diabetes (Glasgow, Barrera, et al., 1999).

According to Fig. 12.1, these psychological processes should partially mediate links between social support and biological/physical health outcomes. Such models were tested explicitly in the late 1990s. For instance, one study examined age-related differences in resting blood pressure as a function of perceived social support (Uchino, Holt-Lunstad, et al., 1999). These authors found that social support was associated with lower resting blood pressure in older adults, an effect that was not statistically mediated by perceived stress, depression, or satisfaction with life. Lutgendorf and colleagues (2000) also directly tested the possibility that mood states might be responsible for links between receiving social support and IL-6 in cancer patients. They found no evidence that alterations in mood were responsible for such links. In general, the available literature provides little evidence that the influence of social support on health-relevant outcomes is statistically mediated by anxiety, life stress, subjective distress, or depression (see Uchino, Bowen, et al., 2012b for a review). Although these data are inconsistent with theoretical models, we discuss later (see Emerging Perspectives and Issues) important factors that need consideration when examining this pathway.

Path C: Social Support and Biological Pathways Although behavioral and psychological factors remain the dominant mechanisms postulated to account for the social support – physical health link, there is evidence that there may also be a direct link between social support and health-relevant central and peripheral biological processes (Uchino, Cacioppo, & Kiecolt-Glaser, 1996). As noted earlier, the inclusion in statistical models of neither behavioral nor psychological factors eliminates the link between social support and health-relevant outcomes. This provides evidence for a potential direct effect.

Much work bearing on the pathways linking social support with biological outcomes has focused on the autonomic nervous system especially cardiovascular function. According to the reactivity hypothesis, individuals or situations characterized by high levels of cardiovascular reactivity (usually indexed by blood pressure or heart rate) may be related to higher risk for the development and exacerbation of cardiovascular disease (Chida & Steptoe, 2010). Thus, social support may be beneficial because it "buffers" the potentially harmful influences of stress-induced cardiovascular reactivity (Cohen & Wills, 1985). Indeed, studies that directly manipulate the supportive function of relationships appear to provide evidence for this stress-buffering hypothesis (Cosley, McCoy, et al., 2010; O'Donovan & Hughes, 2008; Thorsteinsson & James, 1999).

Social support may also be beneficial because it is associated with lower resting blood pressure or ambulatory blood pressure (ABP) during everyday life. ABP has emerged as an important outcome because it measures one's real life blood pressure over an extended period of time and has been linked to cardiovascular risk even after considering clinic blood pressure readings (Pickering, Shimbo, & Haas, 2006). One community study found that age was associated with increases in resting blood pressure. Further analysis, however, showed this was only true of individuals low in social support. Individuals high in support showed low and stable blood pressure across age categories (Uchino, Holt-Lunstad, et al., 1999). Existing studies are also consistent with a link between social support and lower ABP during daily life (Gump, Polk, et al., 2001; Rodriguez, Burg, et al., 2008; Steptoe, Lundwall, & Cropley, 2000), especially emotional support (Bowen, Birmingham, et al., 2013). Consistent with the buffering model of support, several studies also suggest that social support can buffer the link between stress and daily life ABP (Bowen, Uchino, et al., 2014; Steptoe, Lundwall, & Cropley, 2000).

In comparison to cardiovascular function, there is much less work linking social support to neuroendocrine function. The relative lack of such data is noteworthy because hormones and neurotransmitters mediate aspects of cardiovascular and immune function (Ader, Felton, & Cohen, 2001) and thus may shed light on how these diverse physiological systems are coordinated as a function of social support. There is some evidence that social support is associated with lower catecholamine levels (Seeman, Berkman, et al., 1994; Grewen, Girdler, et al., 2005) which is consistent with the beneficial effects of social support on cardiovascular function. In addition, social support is related to lower cortisol levels which is important due to its well-documented immunosuppressive effects (Floyd, Mikkelson, et al., 2007; Grant, Hamer, & Steptoe, 2009; Heinrichs, Baumgartner, et al., 2003).

One hormone of particular interest is oxytocin due to its hypothesized links with social support and with stress indicators across multiple biological systems (Knox & Uvnas-Moberg, 1998). For instance, oxytocin has anti-stress effects in both the brain and more peripheral physiological systems (Taylor, Klein, et al., 2000). In one of the few human studies, perceptions of partner support were uniformly associated with higher oxytocin levels (Grewen et al., 2005; but see Smith, Uchino, et al., 2013). Heinrichs and colleagues (2003) also manipulated social support (via a friend) and oxytocin levels (via a nasal spray) in men undergoing acute psychological stress. Consistent with the stress-buffering hypothesis, social support was associated with lower cortisol responses. These support effects were especially evident if combined with the oxytocin manipulation as such individuals showed the smallest increases in cortisol during stress. These data suggest that social support has influences above and beyond oxytocin which is testament to its powerful link across bodily systems. It is important to note that rather than being specific to trust or support in relationships, recent theoretical models suggest that oxytocin may set one's sensitivity to social stimuli – good or bad (Campbell, 2010). Thus, oxytocin can increase interpersonal trust or decrease it depending on the situational cues such as cooperation or competition (Bartz, Zaki, et al., 2011).

Most of the work linking social support to metabolic pathways has focused on diabetics. Importantly, there is evidence linking social support to better metabolic control in adolescents with diabetes (Burroughs, Harris, et al., 1997). A recent longitudinal study of adolescent diabetics also showed that the combination of high family restrictiveness and low parental support was related to poorer metabolic control (Seiffge-Krenke, Laursen, et al., 2013). Of course, metabolic pathways are complex, and more work will be needed linking social support to other patient populations and outcomes (e.g., restorative processes, Robles & Carroll, 2011).

A final physiological pathway by which social support may influence physical health is via the immune system (Uchino, Cacioppo, & Kiecolt-Glaser, 1996). Much recent work in this area has focused on linking social support to inflammation (Costanzo, Lutgendorf, et al., 2005; Friedman, Hayney, et al., 2005; Lutgendorf, Anderson, et al., 2000; McDade, Hawkley, & Cacioppo, 2006; Wirtz, Redwine, et al., 2009). Of these studies, most have examined IL-6 which has both pro- and anti-inflammatory influences (Papanicolaou, Wilder, et al., 1998; Hawkley, Bosch, et al., 2007) and is related to a number of disease processes such as diabetes, cardiovascular disease, osteoporosis, and some cancers (Barton, 2005). The existing data are consistent with a link between social support and lower levels of IL-6 implicating this as one potential inflammatory pathway involved in the health benefits of support (Costanzo, Lutgendorf, et al., 2005; Friedman, Hayney, et al., 2005). However, the links between social support and other inflammatory cytokines have not been investigated in sufficient numbers of studies to draw firm conclusions. For instance, the association between social support and C-reactive protein (CRP) levels has only been examined in a few studies and shows weak or no associations with support (Coussons-Read, Okun, & Nettles, 2007; Loucks, Sullivan, et al., 2006; McDade, Hawkley, & Cacioppo, 2006). These data are surprising in light of links between support and IL-6 which is a potent stimulator of CRP release. However, it is possible that IL-6 may have independent links to disease processes beyond that of CRP (Ridker, Rifai, et al., 2000).

There has also been a systematic effort to link social support to more biologically relevant immune outcomes. In one of the first studies in this area, Glaser, Kiecolt-Glaser, et al., (1992) found that social support was associated with higher antibody (Ab) titers and T-lymphocyte responses to a hepatitis B vaccine. Subsequent work has shown that social support is related to clinical standards for seroconversion rates (e.g., fourfold increase in Ab titers, Glaser, Kiecolt-Glaser, et al., 1992; Phillips, Burns, et al., 2005), although social support has not been related to some vaccines (Gallagher, Phillips, et al., 2008).

There are also links between social support and aspects of immune function in cancer patients. A systematic and innovative program of research by Lutgendorf and colleagues found that perceived support was related to higher natural killer cell activity in both blood and the tumor microenvironment (Lutgendorf, Sood, et al., 2005). In addition, perceived support has been related to lower levels of growth factors (e.g., vascular endothelial growth factor, matrix metalloproteinase) in the blood and tumors of ovarian cancer patients (Lutgendorf, Johnsen, et al., 2002, Lutgendorf, Lamkin, et al., 2008). These findings are important because such growth factors play a role in tumor angiogenesis (Kerbel, 2000).

There have been a number of studies that have tested the stress-buffering model of support on immunity (Bosch, Fischer, & Fischer, 2009; Kang, Coe, et al., 1998; Kiecolt-Glaser, Dura, et al., 1991; Turner-Cobb, Koopman, et al., 2004). Cohen and Wills (1985) argued that one methodological requirement for an adequate test of the buffering model is to show a main effect of stress on the outcome; all of these studies showed such an effect. Importantly, a majority of these studies found some evidence for a buffering effect of support for individuals high in life stress on measures of immunity (Bosch, Fischer, & Fischer, 2009; Kang, Coe, et al., 1998; Kiecolt-Glaser, Dura, et al., 1991; Turner-Cobb, Koopman, et al., 2004; but see Marsland, Sathanoori, et al., 2007).

Finally, recent work is highlighting the central brain mechanisms that may be responsible for coordinating links to peripheral physiological pathways (Coan, Schaefer, & Davidson, 2006; Eisenberger, Taylor, et al., 2007; Eisenberger, Master, et al., 2011; Onoda, Okamoto, et al., 2009). Studies are heterogeneous in terms of their design and manipulations, but social support appears to attenuate responses in the anterior cingulate cortex (ACC). Studies differ in terms of findings in the ventral ACC (Coan, Schaefer, & Davidson, 2006; Onoda, Okamoto, et al., 2009) or the dorsal ACC (Eisenberger, Taylor, et al., 2007; Eisenberger, Master, et al., 2011). Nevertheless, the ACC is linked to greater blood pressure reactivity (Critchley, Mathias, et al., 2003; Gianaros, Derbyshire, et al., 2005) which provides evidence for how these diverse systems are coordinated as a function of support.

There are several neural mechanisms by which social support may attenuate activity in the ACC. Several studies suggest that increased activity in the dorsolateral prefrontal cortex (DLPFC) and ventral medial prefrontal cortex (vmPFC) may be associated with lower activity in the ACC (Coan, Schaefer, & Davidson, 2006; Eisenberger, Master, et al., 2011; Onoda, Okamoto, et al., 2009). In a recent well-controlled laboratory study, Eisenberger, Master, et al. (2011) exposed participants to pain stimuli (heat) while viewing either pictures of a romantic attachment figure, a stranger, or neutral objects. Viewing pictures of the attachment figure were associated with lower pain ratings and greater vmPFC activity which was stronger for longer relationships. In addition, activity in the vmPFC was negatively correlated with activity in the dACC. On a theoretical level, the emerging neuroimaging evidence is thus highlighting how the brain is influencing critical peripheral pathways linking social support to physical health outcomes. Across these biological systems, it should be clear that social support is having direct impacts on our bodies which may translate to health problems. Besides its theoretical value, potential applications of this biological modeling might include: (a) the tracking of pre-disease and chronic disease populations who benefit most from support interventions based on these health-relevant pathways, (b) the comparison of different support intervention approaches that might differ in their ease of implementation and cost-effectiveness, and (c) the identification of support-related biological pathways that might be amenable to pharmacological intervention. Finally, biological modeling can advance a better conceptual understanding of the conditions under which support, in all its different forms, has measureable benefits or costs. In this regard, basic laboratory research can supplement existing work by examining more precise manipulations of support and its causal links to physiological outcomes.

Path F: Changes in Support as a Function of Chronic Disease This is a relatively unique pathway as most models of social support and health do not consider such feedback loops. However, it is well known that stressors can influence the expression of both positive and negative behaviors within families (Randall & Bodenmann, 2009; Repetti, Wang, & Saxbe, 2009). For instance, husbands and wives report more marital anger and withdrawal at home following negative social interactions at work (Story & Repetti, 2006). These findings are important because coping with chronic conditions has been characterized as an interpersonal process that has cascading influences on stress and coping (Berg & Upchurch, 2007).

More generally, coping with chronic diseases can also be conceptualized as a significant stressor given the multiple treatment, lifestyle, and social/psychological issues faced by patients (Nicassio & Smith, 1995). Consistent with the stress-buffering model, social support should be helpful in fostering adjustment and cooperation with medical regimens during the course of chronic disease. Indeed, social support has been linked to beneficial mental and physical health outcomes across chronic conditions including cardiovascular disease and diabetes (Barth, Schneider, & von Kanel, 2010; Fisher, La Greca, et al., 1997; Penninx et al., 1996, Kriegsman, et al., 1996). In addition, these stressors influence not only the patient but their close relationships and hence can have a direct impact on the support process (Berg & Upchurch, 2007; Coyne & Smith, 1991). In one study, researchers directly tested this possibility by examining how support was influenced when couples attempted to cope with the diagnosis and treatment of breast cancer (Bolger, Foster, et al., 1996). These researchers found that although support was initially mobilized in response to the diagnosis, the patients' distress was related to an erosion of received support from the spouse over time (also see Alferi, Carver, et al., 2001; Northouse, Templin, et al., 1998). In theory there are additional places in the model where feedback processes might occur (e.g., behavioral processes influencing support as might be predicted by social control theorist). However, because chronic conditions influence the entire family (e.g., routines, concern over person), it is a good starting point for testing and incorporating more dynamic feedback processes that can influence the pathways depicted in Fig. 12.1.

Emerging Perspectives and Issues

The model depicted in Fig. 12.1 provides a starting point for examining broad but salient pathways based on prior work. It integrates existing work on social support and health by including mechanisms and outcomes at different levels of analysis including psychological, behavioral, and physiological processes. Most work focuses on one or two of these pathways, but the model highlights the importance of modeling their interconnections, as well as potential reciprocal pathways that exist given the complexity of links between social support and health. Although integrative, there are a number of emerging issues that will warrant increased attention in order to maximize the theoretical and applied implications of the model.

Discrepant Health Influences of Perceived and Received Support One important issue has to do with incorporating the discrepancies sometimes found between measures of perceived and received support (Kaplan, Wilson, et al., 1994; Penninx et al., 1996; Seidman, Shrout, & Bolger, 2006). We should note that the same psychological and behavioral pathways are implicated as depicted in Fig. 12.1 although their influence may be opposing in nature (e.g., received support in some cases increasing stress compared to perceived support decreasing stress). It is also important to mention that some studies do find received support to have positive influences, and so we need to be appropriately cautious in accepting this proposition too generally. For instance, received support can be of several types (e.g., informational, belonging, emotional), and few studies have looked at how specific dimensions of received support predict adjustment during stress. There is good reason to take a closer look at specific dimensions because research suggests that the receipt of informational and tangible support tend to be viewed as less nurturant and more controlling than either emotional or belonging support (Trobst, 2000). Consistent with this possibility, one study examining patients with chronic conditions found a detrimental influence of received tangible support on depression but a beneficial influence of received emotional support (Penninx, van Tilburg, et al., 1998).

When received support does have negative influences, it has been argued that contextual issues are important to consider because received support directly involves the exchange of important social resources (Uchino, 2009). As a result, stressor, provider, and recipient factors become important (Barbee, Gulley, & Cunningham, 1990; Dunkel-Schetter & Skokan, 1990; Wills & Shinar, 2000). Stressor-related factors that can influence the efficacy of received support include the type of stress and support received. As highlighted by the matching hypothesis (Cutrona & Russell, 1990), individuals may not receive the optimal type of support to cope with their stress. As a result, the support might be frustrating and/or ineffective to the recipient. For instance, receiving informational support for uncontrollable stressors (e.g., how to "move on" following the loss of a loved one) can be seen as insensitive and unhelpful. There are also some stressors that are perceived as embarrassing/stigmatizing (e.g., sexually transmitted diseases) or evaluative (e.g., important job interview), and if close others attempt to provide unwanted support, this might be associated with negative outcomes.

There are also provider-related factors that can influence whether receiving support is detrimental (Canevello & Crocker, 2011; Gottlieb, 2000). One such factor is anxiety on the part of the support provider that may interfere with the retrieval of effective support skills (Gottlieb, 2000). In addition, the type and quality of the relationship can influence such links. In a controlled test of such differences, Christenfeld, Gerin, et al., (1997) trained friends and strangers to provide the same type of support to participants. Results during a subsequent laboratory stress assessment revealed that friends had a stronger stress-buffering effect on cardiovascular reactivity compared to strangers despite providing what was objectively the same support. These findings are consistent with prior work on the quality of the relationship as those who are viewed primarily as a source of positivity are more effective support providers compared to those who are viewed as simultaneous sources of both positivity and negativity (i.e., ambivalent, Holt-Lunstad, Uchino, et al., 2007).

Another important provider characteristic is the manner in which support is provided. A distinction can be made between support that is provided in a directive (e.g., tells you what to do) or a nondirective (e.g., cooperates with you to make decisions) way (Fisher, La Greca, et al., 1997). This distinction is important because receiving nondirective support has been associated with beneficial influences across a number of domains, whereas the links between directive support and beneficial outcomes appear more contextual (Fisher, La Greca, et al., 1997; Gabriele, Carpenter, et al., 2011; Stewart, Gabriele, & Fisher, 2012). For instance, Fisher, La Greca, et al. (1997) found that nondirective support was related to better metabolic control in younger diabetics, whereas directive support was related to worse mood in older diabetics. In a weight management program delivered by email, however, directive support was more effective than nondirective, suggesting that the most effective type of support may vary by task and setting (Gabriele, Carpenter, et al., 2011).

Finally, there are several recipient-related processes that appear important. One important factor is whether support is actually chosen by the recipient (Bolger & Amarel, 2007). It has been argued that received support is more likely to be beneficial once the choice to seek support has been made (Bolger & Amarel, 2007). In the absence of the decision to seek support, simply providing an individual with it may threaten their sense of esteem by producing feelings of inefficacy, guilt, or indebtedness (Bolger & Amarel, 2007; Martire & Stephens, 2011). As a result, Bolger and colleagues (2000); Bolger & Amarel (2007) have argued that "invisible support" (i.e., support given that is not noticed as such) may be especially beneficial because it does not result in negative psychological reactions that can override support. We should note that although this is given as an example of a recipient factor, invisible support also reflects provider characteristics related to the skillful provision of nonintrusive support (Howland & Simpson, 2010).

Recipients may also differ in their preferences or goals for receiving support. Men appear more likely to benefit from informational support (Craig & Deichert, 2002; Wilson, Kliewer, et al., 1999). In addition, Phillips, Gallagher, and Carroll (2009) found that women had lower cardiovascular reactivity when receiving emotional support from male friends, but higher reactivity when receiving emotional support from female friends. These results were interpreted as reflecting heightened evaluation from a close, similar other (Phillips, Gallagher, & Carroll, 2009). More generally, these studies are consistent with contextual influences of social support due to the importance of socialization on gender-appropriate support behaviors (Flaherty & Richman, 1989; Rosario, Shinn, et al., 1988).

The fact that received support has less consistent influences on outcomes suggests that there may be crucial moderators at work. One important moderator appears to be perceptions of responsiveness by the recipient (Maisel & Gable, 2009). Perceived responsiveness reflects an appraisal that others are being supportive of one's important values, goals, and preferences (Reis, 2007). A recent study from the Midlife in the United States Study (MIDUS) found that receiving emotional support was related to greater mortality only if it was perceived as not responsive to the individual (Selcuk & Ong, 2013). As such, perceptions of responsiveness could reflect the fact that the optimal conditions for receiving support were met (e.g., support that is a good match to stressor). It is also possible that responsiveness may reflect an appraisal of intent which could override any of the problems associated with stress, provider, and recipient factors (e.g., intention was good although misguided).

The issues surrounding received support also beg the question of why perceived support is so beneficial for health outcomes (Uchino, 2009). Interestingly, perceived support is remarkably stable over time, and hence researchers have argued that such perceptions have their origins in early family environments that are caring and nurturant (Sarason, Sarason, & Pierce, 1990). Studies do suggest that individual's perceptions of their early familial experiences are related to their subsequent perceptions of support (Flaherty & Richman, 1986; Mallinckrodt, 1992). Such family contexts may operate via the development of basic social competencies that facilitate the formation of supportive social networks (Cohen, Sherrod, & Clark, 1986; Repetti, Taylor, & Seeman, 2002). Consistent with this possibility, several longitudinal studies have now found that warm family environments predict better relationship function over time (Ackerman, Kashy, et al., 2013; Graves, Wang, et al., 1998).

There are several reasons why perceived support is consistently beneficial to health. First, individuals high in perceived support can use those perceptions as a "safety net" and hence eliminate the possibility of receiving support that may be unhelpful, intrusive, or insensitive (Uchino, 2009). Having the perceptions that others are there for you if needed also fosters feelings of personal control which may be beneficial to health (Shaw, Krause, et al., 2004). Given the early family contributions to perceived support, it has been further argued that such individuals codevelop positive psychosocial profiles which include better social skills, lower hostility, and secure attachment styles which can produce cumulative benefits over time (Uchino, 2009). Future research will be needed to test these possibilities which will inform the pathways depicted in Fig. 12.1.

Antecedent Processes Influencing Social Support The model in Fig. 12.1 is process-oriented but does not designate the antecedent processes that give rise to structural and functional aspects of support. As noted above, perceived social support can be established early in life and highlights the importance of the family environment as one important antecedent process (Flaherty & Richman, 1986; Graves, Wang, et al., 1998). In addition, given the contextual nature of received support, different antecedent processes including the anxiety level or social skills of the support provider, the cultural orientation or personality of the support recipient, and evaluation potential of the stressor context will be important to consider.

The field of relationship science is particularly relevant to addressing questions related to antecedent processes because it is interested in the factors that influence the development, maintenance, and dissolution of social ties. In fact, there are several constructs from relationship science that are particularly promising as antecedent processes for social support. First, individual differences in attachment style appear to arise from early interactions with a primary caretaker (Bowlby, 1982). If these interactions are positive, infants can come to rely on the caretaker as a reliable source of protection and support and hence develop a secure attachment style. However if these interactions are inconsistent or negative, infants may develop more less secure attachment systems (Ainsworth, Blehar, et al., 1978). Consistent with this perspective, attachment styles appear important to support and conflict negotiation in adulthood (Pietromonaco, Uchino, & Dunkel-Schetter, 2013). Securely attached individuals provide responsive support and are better at managing negativity in their close relationships that can interfere with support compared to less securely attached individuals (Kane, Jaremka, et al., 2007).

Several additional concepts from relationship science may also be important as antecedent processes to good quality support. Although often neglected in relationships and health research, sexual behavior also has an important influence on support processes (Diamond & Huebner, 2012). Sexual behavior (e.g., frequency of intercourse) is linked to relationship positivity and maintenance, as well as lower risk for physical health problems (Diamond & Huebner, 2012). Finally, the knowledge that partners have about each other's preferences can help them provide more responsive support. In one study, the more familiar a person was with their partner's attitudes, the more responsive they were toward them and the lower their daily life ambulatory blood pressure (Sanbonmatsu, Uchino, & Birmingham, 2011).

It may not be the case that all antecedent processes associated with social support will prove to be health relevant. However, in the absence of a clear understanding of the factors that influence support to begin with, we will not know if the aspects of support that predict health outcomes are simply more proximal factors in the chain of events (Cohen, Sherrod, & Clark, 1986). For instance, social skills may influence one's ability to effectively mobilize one's network by influencing the choice of support providers and appropriate disclosure. Ultimately it may be the receipt of emotional support that proves health relevant, but the role of social skills should not be ignored in our thinking about social support processes or in developing interventions. Our ability to model these processes, however, will be dependent on our understanding of the antecedent processes influencing the development and maintenance of social support over time.

Direct Evidence for Mediational Pathways Prior research has focused primarily on linking social support to physical health outcomes, especially biological (e.g., blood pressure) and disease-related (e.g., mortality) endpoints (Holt-Lunstad, Smith, & Layton, 2010; Uchino, 2004). There is also strong evidence linking social support to behavioral and psychological processes implicated in health (Stewart, Gabriele, & Fisher, 2012; Lakey & Orehek, 2011). However, such links are necessary but not sufficient for establishing causal models. Finding a link between (a) social support and depression and (b) social support and cardiovascular disease does not logically imply that depression is a causal pathway because both depression and cardiovascular disease are multiply determined by factors other than social support. Causal inferences are best made via appropriate design considerations, but there have been recent advances in statistical mediational analyses that can guide the modeling of mechanisms in this area. (e.g., Rucker, Preacher, et al., 2011). These mechanistic issues are important to address due to the relatively large body of epidemiological research available compared to the dearth of studies formally modeling pathways.

Although there is some evidence suggesting that health behaviors partially mediate links between social support and health outcomes, there is very little evidence for relevant psychological pathways. There are a number of methodological, statistical, and conceptual reasons that might explain this lack of evidence (Uchino et al., 2012b). We do not know of any studies that have included more recent and powerful tests for mediation (e.g., bootstrapping, Rucker, Preacher, et al., 2011). Given the complexity of social support and health links, stronger evidence for mediation might also be obtained by modeling multiple psychological processes simultaneously (e.g., covariance structural modeling). Finally, conceptual issues include the need to consider contextual processes (e.g., sources of support and match to support needed; Thoits, 2011) as well as an extended set of psychological processes linked to relationships (Pietromonaco, Uchino, & Dunkel-Schetter, 2013). Alternative tests of psychological mechanisms that do not rely on self-reported psychological states may also be important such as brain imaging methodologies (Eisenberger, Master, et al., 2011) and paradigms that tap into less conscious relationship representations (Carlisle, Uchino, et al., 2012; Smith, Ruiz, & Uchino, 2004).

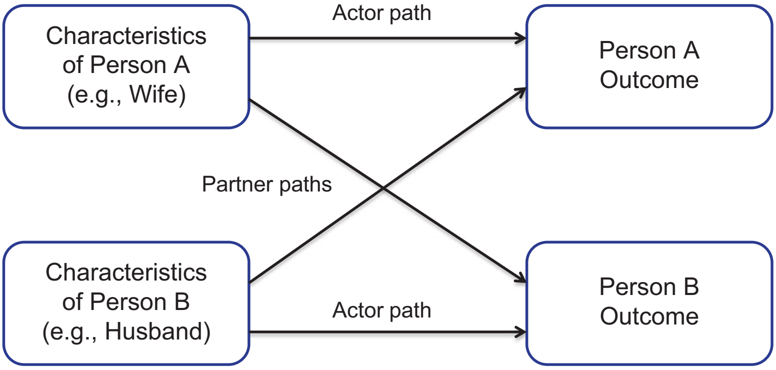
Modeling Dynamic Changes/Pathways Over Time Most models of social support highlight the direct influence it has on health. However, chronic conditions develop over significant periods of time. Testing dynamic/reciprocal influences in the model may thus be important for future work in the area. For instance, decreases in functional support in women over a 9-year period were subsequently associated with the development of hypertension (Raikkonen, Matthews, & Kuller, 2001). Such studies raise the question of where these dynamic processes occur in the model depicted in Fig. 12.1. Although one such pathway is depicted (e.g., Path F), there is very little direct work on this issue which has hindered its incorporation into health-relevant support models.

The importance of dynamic processes over time can also be seen in work on the stress prevention model (Gore, 1981). According to this model, supportive others may actually lower one’s exposure to stressors (in contrast to dampening stress reactions) which can have cumulative benefits over the lifespan (Gore, 1981; Lin, 1986). The stress prevention model is the least tested of all social support models in the health domain despite the fact that existing longitudinal studies are consistent with its basic premise. For instance, the combination of community level and individual support was associated with less exposure to negative life events during a 1-year study period (Lin, 1986; also see Russell & Cutrona, 1991).

There are a number of intriguing ways by which social support may reduce stress exposure over time. First, social support may act to influence cognitive processes such that benign appraisals occur (Cohen, 1988). Second, social support (e.g., informational support on planning for a rainy day) can help individuals make informed decisions that minimize their subsequent stress exposure via proactive coping (Aspinwall & Taylor, 1997). Finally, adequate social support may help decrease exposure to “secondary stressors” (Pearlin, 1989). For instance, stress at work can lead to conflict at home (Repetti, Wang, & Saxbe, 2009). However, if spousal support buffers worksite stressors, it may effectively eliminate potential spillover into marital interactions (Pearlin, 1989). Future direct work testing the stress preventative functions of support on health-relevant processes can thus inform more dynamic models of social support and health.

Finally, social support is often viewed as an individual level factor representing either the perception or receipt of support (Uchino, 2004). More dynamic (and accurate) views of social sup-

Fig. 12.2 Conceptual representation of actor-partner interdependence models



port should conceptualize it as an interpersonal process that involves at least dyadic level processes. An important framework for examining such dyadic processes is the actor-partner models developed by Kenny, Kashy, and Cook (2006). A conceptual representation of actor-partner influences is depicted in Fig. 12.2. Given appropriate data collection, this framework can test if one's own characteristics (actor paths) or a partner's characteristics (partner paths) predict one's outcomes. In addition, one can model actor X partner influences which highlight how a dyad's characteristics combined influence one's health outcomes. For instance, a recent application of this model in married couples showed that partner supportive ties were linked to lower levels of one's own ambulatory blood pressure independent of one's own supportive ties. In addition, couples who had more socially supportive ties combined showed the lowest levels of ambulatory blood pressure (Uchino, et al., 2013a). In general, incorporating dyadic processes when studying links between relationships and health promises conceptual insights that will inform models and interventions (Pietromonaco, Uchino, & Dunkel-Schetter, 2013).

Cross-Cultural Influences on Social Support It is also evident that the links between social support and outcomes may depend on the cultural context (Chen, Kim, et al., 2012; Dressler & Bindon, 2000; Dutton, 2012; Litwin, 2009; Taylor, Welch, et al., 2009). At a broad level, research on cultural differences in support highlights the importance of culturally appropriate forms of support (Brannan, Biswas-Diener, et al., 2013; Dressler & Bindon, 2000). For instance, familial sources of social support may be more directly relied upon and hence more important than friend support in many collective cultures (i.e., where one's identity significantly overlaps with close others as is often the case for Asian, African, and Latin American cultures) compared to individualistic cultures (i.e., where one's identity is viewed as distinct from others as is often the case for American and Western European cultures).

Most of the work on culture and support has focused on differences between individualistic and collective (especially Asian) cultures. Some research suggests that individualistic cultures show a weaker relationship between social support and psychological outcomes compared to collective cultures (Park, Kitayama, et al., 2013; Uchida, Kitayama, et al., 2008). One important distinction in this area is between explicit (i.e., seeking and using support) and implicit (i.e., the comfort of simply having close relationships) support (Taylor, Welch, et al., 2007). Due to relational concerns (e.g., concern about placing a burden on family who are obligated to be helpful), individuals from more collective cultures may benefit more from implicit forms of support during stress in which they simply feel more connected with others (Taylor, Welch, et al., 2009). Such cultural processes may also interact with genetic indicators of social interactions (i.e., oxytocin receptor polymorphism) to influence support seeking (Kim, Sherman, et al., 2010). One study found that, among Americans under stress, those who also had the oxytocin receptor polymorphism reported seeking more social support, whereas no such link was found in Koreans (Kim, Sherman, et al., 2010). One limitation of prior work, however, is that it has mostly focused on Asian cultures, and whether the same pattern would be found in other collective cultures is less clear. For instance, evidence indicates that African Americans indeed benefit from receiving explicit social support (Ford, Tilley, & MacDonald, 1998; Norbeck, DeJoseph, & Smith, 1996).

There is also some cultural work focusing on support differences between Eastern European and European American samples. Dutton (2012) argues that directive social support may be viewed positively in Russian culture which places an emphasis on mutual responsibility in problem-solving. As a result, "butting in" is not seen as threatening a person's sense of autonomy as might be the case for European Americans. In a test of this, nondirective support was interpreted positively by both Russian and European American participants. However, Russian participants were more satisfied with directive support compared to European Americans. These data highlight the importance of looking at more specific cultural groups based on their unique sociocultural history.

Technology and Social Support Technology is changing the way in which social support is communicated. Most homes in the United States now have Internet access, and smart phones are a primary communication device, especially for adolescents and young adults. As a result, many individuals have easy 24/7 access to social networking sites and instant messaging. Early conceptualizations of online social support mostly focused on the deficiencies of computer-mediated communication relative to direct support exchanges, suggesting that the lack of physical presence and emotional cues might negatively impact relationship processes (Jones, 1999; Rice, 1987). However, recent research is now exploring both equivalencies with face-to-face communication and the potential unique benefits of connectivity in increasing support transactions and reducing stress.

There are a number of advantages of online, compared to face-to-face support. For example, while seeking direct support for stigmatized conditions can be embarrassing, Internet-mediated support allows users to seek support anonymously (Malik & Coulson, 2008; Walther, 2002). Internet support may also circumvent social anxiety that otherwise may keep some from seeking or accepting social support. The exchange of support may be perceived as burdensome to the support provider or may require the observation of social obligations on the part of the support recipient (Bolger & Amarel, 2007). However, online forums allow users to search through old posts for informational and emotional support around a specific topic thereby reducing the burden for both provider and recipient (Wright & Bell, 2003). Linking individuals across geographic distance also allows users to create support networks around specific support needs, rather than simple geographic proximity thereby increasing the match between support needs and support availability (Rainie & Wellman, 2012). Finally, the lack of extratextual cues allows the Internet to effectively break down social and communicative barriers that may exist in face-to-face communication due to status, language, or cultural difference (Mikal, 2012; Wellman, Hasse, et al., 2001).

Given these potential advantages, studies now suggest that online support can decrease stress and /or increase psychological well-being. Most universally accepted within the literature on Internet-mediated support is the utility of communicating informational and emotional support (Dare & Green, 2011; Dutta-Bergman, 2004; Leung, 2003; Morgan & Cotten, 2003). More recently, evidence has emerged that simple participation in the broader social network available online can promote well-being and provide a buffering effect during times of stress (Dutta-Bergman, 2004; Nicholas, Picone, et al., 2009). While the majority of studies linking technology and social support have focused on the activation of support networks in the presence of a stressor, empirical studies have also demonstrated that having access to the Internet, and thus a link to physically distant networks of support, can increase the perception of available support (Mikal & Grace, 2011). Of course, there is the potential for Internet-mediated support to undermine health given the issues previously discussed for received support. Future research that directly examines the links between perceived/received Internet-mediated support and physical health outcomes will be needed to make this final link.

The Contextual Nature of Support Finally, a theme that cuts across many of these emerging research directions is that social support is not a monolithic concept and that the context can play a major role in how support is perceived and received and ultimately influences health. These contextual processes can operate early in life (e.g., family) and potentially set the sensitivity of stress-related biological systems. For instance, in a seminal program of research, Michael Meaney and colleagues have shown that pups who were exposed to more licking and grooming from their mothers showed lower adrenocorticotropin and corticosterone levels, increased glucocorticoid messenger RNA expression and receptor sensitivity, as well as epigenetic changes in DNA methylation (Liu, Diorio, et al., 1997; Zhang, Labonte, et al., 2013). Importantly, these differences were reversible by exposing pups of low-licking and low-grooming mothers to high-licking and high-grooming mothers (Weaver, Cervoni, et al., 2004). Thus, social interactions that arise early in life can be an important context for the development of biological vulnerability or resilience. The contextual role of social processes on health-relevant biological systems is also highlighted by recent theoretical arguments that the hormone oxytocin is not specific to positive relationship processes but sensitive to the valence of social situations (Campbell, 2010).

The literature on received support and health also highlights the role of contextual factors. These contextual factors include stressor (e.g., type of stress), provider (e.g., nondirective support), and recipient (e.g., preferences for support type) characteristics. Dyadic level processes also provide a specific context for understanding support processes as it involves a consideration of both actor and partner characteristics that may influence the efficacy of support transactions. At a broader level of analysis, cultural factors appear to influence the efficacy of support (Dressler & Bindon, 2000, Dutton, 2012; Taylor, Welch, et al., 2007; Uchida, Kitayama, et al., 2008). Chief among these are differences that might emerge between more collective and individualistic cultures (Taylor, Welch, et al., 2007); however, there appears to be value in focusing on more specific cultural groups that may differ in their reactions to support based on their unique history (Dutton, 2012). Finally, technology places support processes in a unique context (e.g., relatively anonymous, less geographical barriers) and hence may be an effective means by which to mobilize and receive support.

More generally, the emerging focus on contextual factors is theoretically important because it can influence the more specific antecedent processes and mechanisms that link social support to health outcomes. In the absence of this understanding, our support interventions may be ineffective or perhaps even harmful. These contextual issues can thus highlight multiple points for entry depending on the intervention goals (e.g., primary or secondary prevention).

Intervention, Practice, and Policy Implications

Given the reliable links between social support and physical health outcomes, it is no surprise that much work has been done to test its applied implications. Most of this applied work has focused on interventions aimed at altering social support to promote positive outcomes (Hogan, Linden, & Najarian, 2002; Martire, Schulz, et al., 2010). However, these findings also raise important practice and public policy issues that need consideration given the evidence to date. Although there is a growing literature on interventions using community health workers, many of which provide support functions, we will not review this literature given it is covered elsewhere in this volume (see Intervention chapter).

Intervention Approaches There is a relatively large literature examining support interventions (Allen & Dennison, 2010; Hogan, Linden, & Najarian, 2002). These interventions have mostly been conducted in North America and Europe, with a few studies conducted in Asia. They have included a range of different outcomes indicative of mental (e.g., loneliness) and/or physical (e.g., blood pressure) health. These support interventions take several forms including support from professionals or peers, as well as efforts to mobilize existing network support (e.g., skills training, Gottlieb, 1988).

One of the most common support interventions from professionals is some form of educational intervention by formal support sources such as physicians, nurses, dieticians, and physical therapists (Allen & Dennison, 2010; Helgeson & Cohen, 1996). Such educational interventions serve as a form of informational support and provide the patient with greater knowledge regarding the disease, its symptoms, and subsequent treatment. Such interventions may also address the stress-buffering and prevention aspects of support as patients diagnosed with a chronic condition may need help coping with the accompanying feelings of uncertainty and loss of control (Frasure-Smith & Prince, 1985). A review of such interventions suggests that they were effective in increasing patient knowledge and fostering adjustment to cancer. In fact, such interventions appear at least as effective as peer support groups (Helgeson & Cohen, 1996; Helgeson, Cohen, et al., 2000). These beneficial effects of educational interventions with professional sources of support have also been demonstrated with specific health-related behaviors and outcomes, including exercise patterns, diet, and body mass in at-risk populations (Allen & Dennison, 2010). In fact, this is one intervention context in which directive support appears especially effective given the combination of an expert source and an individual's willingness to change (Gabriele, Carpenter, et al., 2011).

Even more general professional intervention sources can be important support resources to help individual cope with stress. For instance, it has been argued that psychotherapists engaged in formal helping behavior are also important sources of support. Similar characteristics (e.g., honest, warm, open) are associated with good quality relationships in therapy as in other informal relationship contexts (Ackerman & Hilsenroth, 2003). Although the literature on therapeutic support and social support have progressed relatively independent of each other (Barker & Pistrang, 2002), integrating their different emphases can lead to a better understanding of how both formal and informal support interventions work (e.g., process questions related to disclosure, alliance-building, Barker & Pistrang, 2002).

Many interventions have also focused on peers and developing friendships as important support sources. Simply mobilizing peers as a support intervention is related to less consistent influences on outcomes (Heller, Thompson, et al., 1991). Greater attention to factors that increase the quality of the relationship may thus be important for such interventions (Harris, Brown, & Robinson, 1999; Thoits, 1986). For instance, experiential similarity revolves around having common experiences that can help in the friendship formation process and the communication of empathic emotional support (Suitor, Pillemer, & Keeton, 1995; Thoits, 1986). Such interventions built on this premise are associated with beneficial influences on outcomes (Kulik, Mahler, & Moore, 1996), although they may be more effective when individuals naturally form their own relationships (Thoits, Hohmann, et al., 2000). "Befriending" specifically focuses on the friendship formation processes by recruiting outside relationships to serve as the basis for affirming social support over time (Harris, Brown, & Robinson, 1999). A recent meta-analysis suggests a modest effect for such interventions in improving outcomes in different patient populations (e.g., caregivers, prostate cancer patients, Mead, Lester, et al., 2010).

An important peer intervention is related to support groups. These support groups are now an established part of how many patients attempt to maintain behavioral change or cope with diverse medical conditions (Davison, Pennebaker, & Dickerson, 2000). Although many support groups are facilitated by professionals (e.g., making sure everyone shares their experiences), the primary emphasis is on experiential similarity and what the peer group experience can bring to each individual. Such support groups with peers can serve multiple functions such as reassurances of the person's worth (emotional support), sharing of useful information (informational support), and a place to go and be themselves (belonging support).

Interventions examining peer support groups suggest beneficial effects on adjustment and well-being (Hogan, Linden, & Najarian, 2002). In addition, many of these studies documented that the intervention was successful in altering participants' levels of support. These positive findings have been observed with older adults (Andersson, 1985), HIV patients (Kelly, Murphy, et al., 1993), and breast cancer patients (Goodwin, Leszca, et al., 2001). Support groups among cancer patients had beneficial effects (Hogan, Linden, & Najarian, 2002), although this might depend on the extent of existing support (Helgeson, Cohen, et al., 2000). Researchers have also found that participation in support groups seems to influence the size and composition of one's social network. For instance, studies of individuals with substance abuse problems suggest that self-help groups result in decreased contact with drug-using network members and increased contact with support group friends (Humphreys & Noke, 1997). These network members then become crucial sources of support in offering advice and guidance to help individuals remain abstinent (Humphreys, Mankowski, et al., 1999).

Finally, many support interventions attempt to mobilize existing network members by: (a) teaching participants the skills to acquire support from their network, (b) bringing a significant other to treatment to help in the adjustment process, or (c) teaching social network members how to be supportive. Overall, these strategies appear promising in fostering adjustment and outcomes across a variety of patient populations (Hogan, Linden, & Najarian, 2002). Teaching individuals the skills to elicit support from their network has been successfully conducted with adolescents, psychiatric patients, and individuals with chronic diseases (Cutrona & Cole, 2000; Hogan, Linden, & Najarian, 2002). In one intervention, adolescents were assigned to enroll in a semester long course that focused on friendship development and positive peer and teacher relationships (Eggert, Thompson, et al., 1994). Students also learned how to elicit support regarding personal problems. Results of this study showed that individuals in the intervention had an increase in their friendships and in self-esteem. Moreover, compared to adolescents not provided with the intervention, individuals with social skills training showed a trend toward less drug use, a decrease in drug-related problems, and an increase in their grade point average.

One of the most comprehensive social support interventions focusing on skills for acquiring support from participants' networks was the multisite Enhancing Recovery in Coronary Heart Disease (ENRICHD) clinical trial (The ENRICHD Investigators, 2003). In this intervention, myocardial infarction patients with low social support and/or depression were randomized to cognitive-behavioral therapy that individually addressed problems related to depression/social support. Results of this study revealed a statistically significant increase in social support after 6 months for participants given the intervention. However, after about 29 months, there were no differences in survival between the support and usual care groups. There were several potential explanations for these findings (The ENRICHD Investigators, 2003). At the 6-month period, there was approximately a 9% difference in support changes that favored the intervention. However, there was no longer a significant difference between the intervention and usual care groups at the 42-month follow-up (due mostly to unexpected improvements in social support for the usual care group). Overall, the initial support differences may have been too small or not maintained over a long enough period of time to influence the main cardiovascular outcomes. It may thus be necessary to increase the effect size associated with support interventions on such disease outcomes by directly incorporating close others into the intervention (see below). It should be noted that post hoc analyses of these data have shown beneficial influences for some patient subgroups (Burg, Barefoot, et al., 2005; Schneiderman et al., 2004).

Interventions with existing network members have also reached out and directly mobilized the person's network. The challenge here is providing the network members with the understanding and skills to be supportive (Thoits, 2011). The "training" of network members to provide support in many cases focuses on family members and more specifically the spouse as they are an important source of support for married individuals (although friends can also play a role in the support process and facilitate healthy behaviors, Wing & Jeffrey, 1999). Early interventions with hypertensive patients successfully utilized spouses by increasing their understanding of hypertension and how to better manage the patient's condition (Levine, Green, et al., 1979). A recent meta-analysis found that couple-oriented interventions were associated with beneficial patient outcomes (e.g., lower depression, Martire, Schulz, et al., 2010). It is also important to note that spouses experience a considerable amount of anxiety and stress in such situations and interventions focusing on the needs of a spouse also appear promising (Bultz, Speca, et al., 2000; Gottlieb, 1988). One intervention specifically focused on spouses of cancer patients and provided them with a 6-week psychoeducational intervention (Bultz, Speca, et al., 2000). As a result of the intervention, spouses showed improved coping 3 months later. Importantly, the patients themselves also reported greater support and marital satisfaction. A more recent couple-based intervention for women with breast cancer also found that relationship enhancement for coping with cancer (e.g., communication, sharing feelings) was associated with better relationship functioning and less medical symptoms over a 1-year period (Baucom, Porter, et al., 2009).

The fact that existing network members have a rich history with the person needing support also needs to be addressed. In some cases, the history may be overwhelmingly positive and thus presents little problem in that person being a support provider. In other cases, network members may be a source of ambivalence and contain a mix of both positive and negative experiences and feelings which have been linked to poorer quality support and negative health outcomes (Reblin, Uchino, & Smith, 2010; Uchino et al., 2012c). The important implication here is that under some circumstances, dyadic counseling may be needed to help individuals resolve ambivalence in their relationships so that they may provide more effective support to each other.

Future Intervention and Practice Directions Although the results of support interventions are promising, there is certainly room for improvement. For instance, existing interventions are heterogeneous in terms of altering support and some studies did not include manipulation checks to verify that social support was indeed improved (Hogan, Linden, & Najarian, 2002). One general area where much more work is needed is on the efficacy of support interventions for primary prevention. Most interventions focus on individuals who already have health problems. These are often referred to as secondary prevention efforts which stand in contrast to primary prevention that focuses on healthy individuals. In a compelling analysis, Robert Kaplan (2000) argued for the promise of primary prevention efforts, especially in light of the more limited public health benefits that seem to arise from secondary prevention.

An alternative way of thinking about support interventions is thus as a form of primary prevention that reduces the incidence of health problems by providing a greater sense of connection and control and/or reducing the number or impact of stressful events (see Paths B of Fig. 12.1). For instance, increasing feelings of control in adolescents might lower stress appraisals such that certain events are no longer seen as stressful. Rena Repetti, Shelley Taylor, and their colleagues (2002) have argued that early familial interventions are an important starting point and may pay large dividends in the long term. A focus on primary prevention also raises the interesting possibility that support interventions aimed at improving relationship functioning may be useful if applied early on with children and adolescents to place them on healthier trajectories. Preliminary evidence suggests that such interventions result in more positive adolescent social, academic, and mental health outcomes (Dirks, Treat, & Weersing, 2007; Waddell, Hua, et al., 2010).

As research on support interventions progress, it will be extremely important to document the aspects of social support that are most beneficial, for which populations, on what particular outcomes, and for how long. A more thorough future framework for support interventions can be described by asking the question: "Who is providing what to whom and with what effect?" The "who" aspect of this statement is meant to characterize the identity of the provider, their existing support skills, and also the nature of the relationship between the provider and recipient of support. It can range from relatively new relationships such as between patients and practitioners to already established support members such as family and friends. The second aspect of this statement concerns "what" is being provided. It may be the provision of emotional support or the acquisition of new social skills to obtain needed support based on a contextual analysis of the challenges facing a person. The "whom" aspect refers to the recipient or target population of the intervention and can be healthy individuals or specific groups (e.g., depressed or chronic disease patients) and also considers the needs of the support recipient (e.g., their objectives) and other sources of support available. Finally, "with what effect" has to do with the pathways and outcomes that the intervention is attempting to modify. More generally, this framework highlights the key points that support interventions should try to address in order to heed the important support doctrine to "Do no harm" because poorly planned support intervention may result in individuals receiving ineffective help, feeling let down by the support provider, and greater perceptions of stress (Cutrona & Cole, 2000).

An important practice issue is should healthcare professionals screen to identify people who are low in support or socially isolated to facilitate treatment outcomes (Lett, Blumenthal, et al., 2007)? Critics of such an approach would argue that we do not know enough regarding what screening measures to use, what would be an appropriate cutoff score, and perhaps more importantly what exactly we can do to help them (Bucholz & Krumholz, 2012; Thombs, 2008). Proponents, on the other hand, argue that there are scales based on the available epidemiological evidence that could be developed for such purposes and promising treatment protocols (e.g., cognitive-behavioral therapy, Butler, Chapman, et al., 2006; Lett, Blumenthal, et al., 2008; The ENRICHD Investigators, 2003). Even if we might have difficulty treating low support, it can still be assessed for prognostic or predictive purposes along with other factors like age, sex, and family history (Lett, Blumenthal, et al., 2008). In fact, regardless of its treatment, such information might be used to inform individualized treatment protocols such as more intensive monitoring or follow-ups.

We do not know any current guidelines for assessing low general support or social isolation in clinical settings. However, there are several issues that will need strong consideration. First of all, the links between social support and health outcomes are strongest for general perceived support and composite measures of social isolation, so such scales should be used to identify people. There are several questionnaires that are good candidates including the 7-item ENRICHD social support instrument (Mitchell, Powell, et al., 2003), the 16-item version of the interpersonal support evaluation list (Payne, Andrew, et al., 2012), the recently developed 16-item NIH toolbox social relationship scales (support items, Cryanowski, Zill, et al., 2013), as well as the social network index (Berkman & Syme, 1979). Focusing on specific scales that contain items that have been related to physical health outcomes can inform potential diagnostic cutoff points that likely vary as a function of age, gender, and culture. Even simply asking if individuals lack a confidant that they can speak to about personal and health-related problems may prove useful for identifying individuals who are at risk for negative outcomes after the diagnosis of a chronic condition (Williams, Barefoot, et al., 1992).

In many cases, the focus of screening might be on specific relationships that we know to be important in the management of chronic conditions (e.g, spouses, Robles, Slatcher, et al., 2014; Rohrbaugh, Shoham, & Coyne, 2006). There are clinical cutoff scores for validated marital satisfaction measures that distinguish distressed marriages and could prove useful in identifying at-risk couples following chronic disease diagnosis (Crane, Middleton, & Bean, 2000). Although not developed as a screening instrument, we have utilized the social relationships index (Campo, Uchino, et al., 2009) to examine positivity and negativity from any specific relationship (e.g., spouse, friend, coworker). Moreover, we have consistently used specific cutoff points to separate supportive (supportive only) from ambivalent (supportive and upsetting) ties which is important as ambivalent ties predict a range of negative biological outcomes such as higher daily life ambulatory blood pressure, greater inflammation, and even increased cellular aging (Holt-Lunstad, Uchino, et al., 2003; Uchino et al., 2012c; Uchino et al., 2013b). Pending more work, the evidence from the social relationships index suggests some promise as a general relationship-specific assessment device that could be developed into a screening instrument (Campo, Uchino, et al., 2009).

Given the evidence to date, it might even be argued that it would be unethical to not screen for low support or social isolation as has been argued in the case for depression (Sheehan & McGee, 2013). In fact, the literature on screening for depression has a longer history and might be used to inform future work in this area. As recommended for depression, given that some degree of error will likely exist in any diagnostic criteria, individuals who initially screen low in support or high in isolation can be referred for more detailed screening and evaluation. In the case of depression, it also appears that screening is beneficial primarily when there is adequate staff available for treatment (O'Connor, Whitlock, et al., 2009). In fact, it has been argued that in the absence of collaborative care involving integrated services (i.e., medical and mental health), it is difficult to justify depression screening as it might lead to harmful labeling, as well as inappropriate additional testing and treatment (Nimalasuriya, Compton, & Guillory, 2009). Future work addressing these important practice issues deserve immediate attention because according to Holt-Lunstad, Smith, and Layton (2010) low social support appears to be as important a risk factor as cigarette smoking and a lack of exercise. Of course these health behaviors are standard assessments in medical settings which underscore the need to also develop and test relevant support screening instruments.

Policy Implications It is also important to point out that the research on social support may carry important policy implications (Umberson & Montez, 2010). Relevant policy can help escalate much needed funding priorities, bolster public perception, and increase dialogue on future policy implementation. These health policy implications are made salient by the work reviewed above, as well as the potential cost-effectiveness of social support interventions. For instance, a combined 1-year educational and support group intervention for osteoarthritis patients yielded an average cost savings during the subsequent 2 years of $1279 per participant a year compared to a control condition (Cronan, Hay, et al., 1998). This difference was primarily due to a lower number of days spent in hospitalization for the intervention groups. In fact, it has been estimated that if support groups participation was at 3% among the 32 million arthritis sufferers, the 4-year cost savings would be around 650 million dollars (Davison, Pennebaker, & Dickerson, 2000)! With increasing emphasis on medical cost containment, the health-care policy implications of social support may be considerable if future work can clearly document such savings across a number of chronic conditions (but see Wilson, Thalanany, et al., 2009).

Public policies can thus be aimed at increasing funding for understanding the more specific nature of such links or at fostering better interpersonal functioning (Brownell & Shumaker, 1985; Umberson & Montez, 2010). As an example, the Deficit Reduction Act of 2005 devoted significant funds to the Healthy Marriage Initiative (HMI) to help build stronger, stable marriages. The HMI focuses on research and demonstration projects regarding relationship education and skill building (e.g., listening, problem-solving) which have thus far yielded promising effects on relationship quality and communication patterns. Most recently, the importance of social relationships was acknowledged explicitly in Healthy People 2020 which is a nationwide health promotion plan as well as the Affordable Care Act which highlights the role of community health workers in disease prevention and treatment.

Another important policy implication of research on social support and health is the need to anticipate policies that might disrupt social support and plan/allocate funds for their amelioration or at least minimizing its potential influences (e.g., urban renewal projects that may result in gentrification, Brownell & Shumaker, 1985). More generally, it would be important to evaluate future policies in terms of their impact on support processes or the quality of people's social relationships as these are important determinants of stress management and health outcomes. For instance, end of life planning issues may influence not just the stress of the dying person but also the survivors (Carr, 2012).

A general policy implication goes back to the early pages of this chapter: *social support has very real influences on health*. It has enormous impacts on life and quality of life, comparable to those of cigarette smoking. Its association with morbidity/mortality is not because it is accidentally or coincidentally associated with the "real causes." Rather, the aggregate of evidence reviewed here shows that social support has an important influence on behavior, biology, risk factors, social interactions, and disease management, all of which have major impacts on health and illness. At the same time, social support is not simple. The paradoxical role of received support in sometimes being associated with worse outcomes makes clear that good intentions are not sufficient to guarantee good support. Thus, social support is worthy of serious investment by our culture, investment in research to enhance our understanding of this very important area of human behavior and experience, and investment in high quality interventions to enhance it.

Conclusions

It is clear that social support is a strong predictor of physical health outcomes (Holt-Lunstad, Smith, & Layton, 2010). These links are often independent of traditional demographic, lifestyle, and biological risk factors (Berkman, Glass, et al., 2000; Cohen, 2004). The mechanisms responsible for such links at different levels of analysis are being elucidated through interdisciplinary work, including psychological, behavioral, and biological pathways. It is likely that social support will play a major role in behavioral medicine over the next 20 years as it is one of the most well-documented psychosocial risk factors with over 35 years of epidemiological research in North America, Europe, Asia, and Australia (Holt-Lunstad, Smith, & Layton, 2010).

There are several reasons why social support research will continue to play a major role in behavioral medicine. First, risk factor models must continue to examine this construct and associated pathways given the evidence to date. Despite the tremendous body of work, we know very little about mechanisms which will be critical for designing cost-effective interventions. Second, social support may be part of a positive psychosocial profile that includes other important constructs in behavioral medicine such as optimism, attachment, and hostility (Uchino, 2009). Many of these factors have their origins in the early family environment which is being increasingly appreciated as an important protective or risk factor in itself (Repetti, Taylor, & Seeman, 2002; Taylor, 2010). Third and relatedly, social support may be an important mediator of other psychosocial risk factors such as early-life experience (Taylor, 2010), socioeconomic status (Cohen, Kaplan, & Salonen, 1999), or personality (Smith, 1992). Finally, the emphasis on patient-centered care will only increase the importance of social support for medical treatment across the health-care (e.g., physicians) and family (e.g., spouses) systems.

As a final parting shot, we sometimes assume that there is nothing we can do to encourage good relationships and the support they provide; they either happen or they don't. We sometimes assume that support will happen automatically if people have family or friends available to them. We sometimes assume that good support is common sense so that volunteers don't need training, supervision, or help to be good at providing it. We may also assume that it is none of our business to interfere in other people's social relationships. All these assumptions are wrong. Rather, if we take the data and its impact across individuals, families, and society seriously, we must find ways to identify those who lack it, take affirmative steps to get them the support they need, and do so in high quality, adequately funded programs to make the support as effective as it can be. Doing so will help our society realize the full potential of social support to help individuals live healthier and happier lives.

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13

Social and Cultural Context: Healthy Eating and Physical Activity

Linda C. Baumann and Betty L. Kaiser

Introduction

In any place and time, cultural practices reflect the complex interplay between broad social phenomena and values, norms, and customs. When one of us (Baumann) first visited Vietnam in 1989, available foods were primarily local due to poor transportation systems and primarily seasonal because of limited food storage options. Traditional tea breaks included fresh green tea and seasonal fruits. At that time, most Vietnamese walked or used bicycles, and the bicycle was a national symbol of Vietnam. By 2003, the tea break at a diabetes training session for nurses consisted of prepackaged tea with sugar, prepackaged coffee with sugar and whitener, and little sweet pastries made in a local factory. The hosts were quite proud of the convenience and expanded consumer choices these foods represented. Bicycles are now scarce in the large cities and are overpowered by motorcycles and automobiles on congested roads that threaten pedestrian safety.

Worldwide, sweeping social and economic changes associated with globalization have precipitated changes in cultural norms related to dietary practices and physical activity behaviors. Across nations, food and physical activity environments are becoming more homogeneous, characterized by widespread access to calorie-rich but nutrient-poor foods, built environments that pose barriers to active modes of transportation, and occupational trends toward sedentary work (World Health Organization, 2003). Within nations and communities, these broad social and economic trends interact with local culture to create unique and dynamic contexts for health behaviors.

Culture shapes illness (Kleinman, Eisenberg, & Good, 1978); it also shapes health and health behaviors. The concept of "healthy lifestyle behaviors," widely embraced by public health practitioners and researchers, is a social construct that may have limited meaning within some cultures. In many low- and middle-income settings, "healthy" is not the absence of disease but the ability to work. Or it may be the ability to reproduce and to live long enough to raise one's children. In many cultures, eating practices are foremost important for promoting acceptance, kinship, socialization, and solidarity, rather than for promoting health or preventing disease (Purnell & Paulanka, 2008). The notion of physical activity as a purposive, regular health practice is prominent in Western, high-income countries, but not elsewhere. To design effective interventions that address the underlying behavioral determinants of health, it is essential to understand the cultural context of health behaviors.

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Numerous definitions of culture exist, but they all imply a dynamic process (Andrews & Boyle, 2008). Moreover, there is agreement that defining culture too narrowly or too broadly makes it lose much of its significance. Giger and Davidhizar (2008) provide a useful definition, identifying culture as a meta-communication system based on values, beliefs, attitudes, customs, language, and behaviors that are shared by a group of people and passed down to generations through formal communication and imitation. Health beliefs and practices arise from collective cultural values that interact with an individual's unique experiences, beliefs, and values that have been learned and adapted to a particular context. Although health beliefs and practices of subgroups within a culture may be somewhat distinct, overarching cultural characteristics such as language, traditions, and sociopolitical experiences provide a shared and common experience.

Two predominant models used to explain beliefs and health-related behaviors within diverse cultural contexts are the self-regulation model (Leventhal, Meyer, & Nerenz, 1980) and the explanatory model (Kleinman, Eisenberg, & Good, 1978). Both of these models identify strategies for assessing beliefs about health and how beliefs influence behaviors. In self-regulation, beliefs about health concerns or conditions are assessed within the following dimensions: identity (symptoms, labels), cause, timeline, consequences/seriousness, control and/or cure, and coherence (overall understanding).

The explanatory model uses situated discourse to elicit illness stories about how people interpret the somatic, psychological, and social experience of an illness, as told within a "culture system." Explanatory models reflect social class, cultural beliefs, religious beliefs, and past experience. Lay explanatory models begin with an awareness of body sensations and feelings and are elicited by a series of questions (Harwood, 1981):

1. What do you think caused your problem?
2. Why do you think it started when it did?
3. What does your sickness do to you? How does it work?
4. How severe is your sickness? Will it have a long or short duration?
5. What kind of treatment do you think you should receive?
6. What are the most important results you hope to receive from this treatment?
7. What are the chief problems your sickness has caused you?
8. What do you fear most about your sickness?

Examination of explanatory models held by distinct social groups within a community can be revealing. In a classic study by Blumhagen (1980), explanatory models of hypertension were elicited from both lay people (mostly white, middle-aged men) and health experts. The lay group believed that the cause of hypertension was chronic stress, anxiety, and worry, while the experts acknowledged that the cause of hypertension is largely unknown, e.g., essential hypertension, but that the condition is probably exacerbated by chronic stress. Baumann and Leventhal (1985) conducted a worksite study in which healthy adults participated in twice-daily blood pressure monitoring and symptom reports for 2 weeks. Most participants held beliefs that blood pressure changes were associated with symptoms such as anxiety and stress, despite information they received that high blood pressure was not a condition with symptoms and evidence presented to them at the end of the trial that blood pressure fluctuations were not associated with these symptoms.

Theories of illness causation vary across cultures (Baumann, 2003). Folk systems classify disease as natural or unnatural, with natural illness the result of environmental exposure and unnatural conditions resulting from divine punishment. Latino cultures share common "labels" for certain illnesses, such as "mal ojo" or evil eye, reflecting a shared belief in magical causation and the impact of social disharmony on the physical health of an individual (Winkelman, 2009). Further, many disparate cultures, including Latinos and Asians, believe in the hot/cold theory of disease that explains cause of illness as well as appropriate treatments aimed at creating a balance of forces (Spector, 2009). In contrast, the focus of Western medicine is diagnosis by finding the causative organism, cure, and prevention. However, within the biomedical system, little is known about physiological variability across populations, including such characteristics as nutritional needs, physiological responses, and digestive capabilities (Giger & Davidhizar, 2008).

Most belief systems across cultures address the principles of harmony, balance, and moderation. Health as a balance between the individual and the environment is a bidirectional relationship. Practices such as healthy eating and being physically active are believed to have a positive effect on the individual, who in turn has a positive effect on the environment (Spector, 2009). A widespread cultural belief of health as achieving a balance in life allows one to engage in multiple belief systems, e.g., folk and Western medicine, most of the time, without negative consequence (Giger & Davidhizar, 2008).

Some aspects of culture are not specifically related to health behaviors but nonetheless influence them. Temporal orientation can influence how people regard health behaviors. Although many people in the USA tend to be oriented toward the future, many cultural groups are oriented to the present. Preventive behaviors to affect a long-term outcome may be incompatible with a present-time orientation (Purnell & Paulanka, 2008). Fatalism is the belief that powers greater than oneself control individual destiny. In cultures where fatalism is prominent, people may feel no sense of personal control over their health status and thus no imperative to engage in recommended health behaviors. In sociocentric cultures, as compared with individualistic cultures, people are not conceived as autonomous selves but rather as part of a family or community unit (Landrine & Klonoff, 2001). Obligations to the family supersede individual needs; thus, self-care practices such as personal health behaviors may not be a cultural norm.

As the intersections between diverse world cultures increase, recognition of cultural influences on health behavior becomes more critical to our understanding of processes that guide health behavior. By failing to adequately acknowledge culture, healthcare practitioners as well as researchers decontextualize social problems and objectify them as individual problems. Researchers often do not assess the culture of participants beyond their affiliation to a specific community or race/ethnicity, making it difficult to determine the impact of culture on behaviors (MacLachlan, 2006). However, this approach may be reasonable when the social, economic, and political contexts of communities may overshadow cultural differences. For example, in the USA, the condition of poverty may be a more powerful determinant of eating behaviors than race/ethnicity and cultural traditions.

The following overview focuses on two health behaviors: healthy eating and physical activity. As major underlying determinants of noncommunicable diseases (NCDs), these behaviors represent key targets for improving global health (Fineberg, 2011, February). The overview is grounded in an ecological framework (see Fig. 13.1) that proposes that social and physical environments as well as individual factors influence health behaviors (Baker, Brennan, et al., 2000; Booth, Sallis, et al., 2001). There is substantial overlap between research that addresses environmental influences on healthy eating and physical activity and research that specifically addresses environmental influences on obesity. In general, we focus on research that has addressed behaviors rather than the distal outcome of obesity and refer the reader elsewhere (Hu, 2008) for a thorough discussion of obesity determinants. A subsequent search at the time this volume was readied for publication (January, 2015) indicated no substantial changes from the conclusions here. We conclude with a discussion of issues related to research designs for studying the sociocultural context for physical activity and healthy eating as well as recommendations for further research.

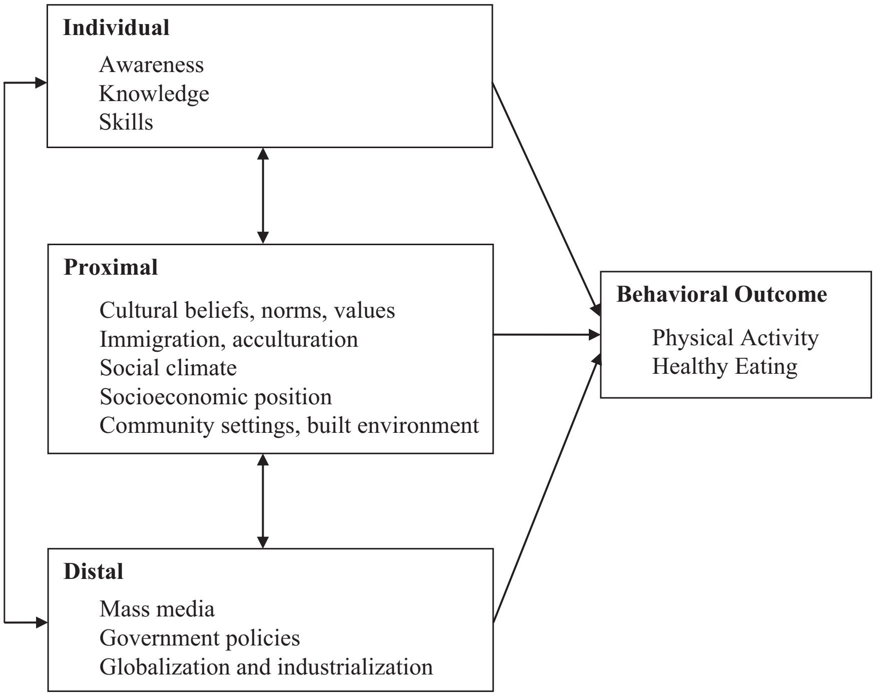

Fig. 13.1 Ecological framework of influences on physical activity and healthy eating (Adapted from Baker, Brennan, et al., 2000; Booth, Sallis, et al., 2001)

The Context for Healthy Eating and Physical Activity

Almost 20 years ago, Geoffrey Rose succinctly described the power of the social environment in shaping personal behaviors, stating:

> Personal life-style is socially conditioned . . . Individuals are unlikely to eat very differently from the rest of their families and social circle. . . It makes little sense to expect individuals to behavior differently than their peers; it is more appropriate to seek a general change in behavioural norms and in the circumstances which facilitate their adoption. (Rose, 1992, p. 135)

Rose's comments highlights proximal factors such as social and cultural norms as well as distal "circumstances" in the social environment that can support, or hinder, health-supporting behaviors. Increasingly, research on diet and physical activity behaviors is grounded in ecological frameworks that depict individuals and their behaviors at the center of a nested or interlocking structure of proximal and distal influences (Booth, Sallis, et al., 2001; Sallis, Owen, & Fisher, 2006; Story, Kaphingst, et al., 2008). Proximal influences on healthy eating and physical activity include cultural beliefs, norms, and values, immigration and acculturation, social support, socioeconomic position, and community settings and the built environment. Distal influences on healthy eating and physical activity include mass media and marketing, government policies, and globalization and industrialization. We present key concepts and evidence from studies conducted in developed and developing countries, drawing on both descriptive and intervention research.

Proximal Influences

Cultural Beliefs, Norms, and Values

In the course of clinical practice, one of us (Baumann) provided diabetes education to an African-American male and suggested that he substitute baked, skinless chicken for fried chicken. He shared that he had never in his life eaten chicken that had not been fried and that his family would not tolerate eating "diabetic food." This example suggests how eating practices are shaped by cultural preferences and perceptions that operate at multiple levels (Larson & Story, 2009). In a study on diabetes self-care behaviors of Ugandan adults (Baumann, Opio, et al., 2010), participants indicated that the word "food" refers to any carbohydrate in a carbohydrate-rich diet. These "foods" include matooke (steamed plantains), posho (cornmeal mush), millet, rice, Irish potatoes, sweet potato, and cassava. Participants expressed beliefs that green vegetables are for animals and that fruit is for children or when someone is sick. Meat and fish are not considered "food" and are eaten in small amounts and not with most meals.

Dietary practices may be influenced by cultural attitudes toward optimal body weight. Some cultures, particularly subsistence-oriented societies that experience food scarcity and poverty, view overweight as the norm or as desirable because it conveys good health (Adams, Quinn, & Prince, 2005; Marlowe & Wetsman, 2001). In sub-Saharan Africa, large body size signifies wealth and power. The consumption of luxury foods that promote weight gain, such as meat, butter, and fried foods, is a means of attaining respect and status in the community. Thinness is associated with malnourishment, disease, and poverty, and foods that are affordable to poor people, such as vegetables and legumes, have a pejorative connotation of survival food (Renzaho, 2004). Research with Latinas indicates that they prefer plumpness in children, and these preferences may affect their child feeding practices (Contento, Basch, & Zybert, 2003). In a focus group study of women from diverse cultures, African-American and American Indian women contrasted the accepting attitude in their cultures toward heavier female bodies with attitudes in white culture that establish thinness as the standard for women (Eyler, Matson-Koffman, et al., 2002). However, the women also attributed the larger body size of African-American and American Indian women to traditional diets containing high-fat foods.

In many African cultures, men prefer women with large body size (Swami, 2006). A tribe in eastern Uganda fattens a bride for a month before the wedding by force-feeding milk, often resulting a weight gain of 30 to 40 pounds. Recent research suggests that traditional non-Western attitudes favoring heavier figures, especially for women, may be changing. A study of Ghanaian women found that women were willing to change their weight if they knew of negative health consequences associated with being overweight or if requested by their spouse (Duda, Jumah, et al., 2006). Furthermore, for women willing to change their weight to comply with a spouse's request, 92% indicated they would choose to reduce their body size, suggesting a perception that husbands prefer a smaller body size. A study that examined cross-cultural differences in attitudes toward female body weight (Swami, Frederick, et al., 2010) included 7434 adults from 26 countries. Participants completed a visual rating scale for different sizes of females and items that assessed exposure to Western media. The authors concluded that cross-cultural differences in preferred female body weight were small compared to differences by rural/urban location, with heavier female figures preferred by people in rural settings. Lifetime exposure to Western media was a significant predictor of preferences for a lower female body weight, and the authors concluded that the ideal of thinness for women is becoming international due to global exposure to Western media messages (Swami, Frederick, et al., 2010).

Cultural norms and beliefs can pose a barrier to physical activity. Walking is the default form of transportation for poor people; consequently, walking may be viewed as undesirable because it denotes poverty or idleness (Kiawi, Edwards, et al., 2006). Women face unique barriers to physical activity related to cultural beliefs and norms. Normal responses to physical activity, such as sweating or fatigue, may be perceived as unhealthy (Caperchione, Kolt, & Mummery, 2009) or unwomanly by some cultures. Gender norms and gender inequity have a substantial impact on women's ability to be physically active, limiting options because of concerns about appropriateness of dress, safety of certain locations, and practical challenges, such as concerns about childcare. A practical issue that is very salient for African-American women is hair care. For African-American women, concerns about the effects of physical activity on their hair can pose a major barrier to exercise, because well-groomed hair represents a substantial investment of time and money (Brown, 2009; Railey, 2000). For some women, physical activity is not a cultural norm. Latina and African-American women report that being physically active is not a norm for girls in their cultures, making it difficult to establish a habit of physical activity in adulthood (Evenson, Sarmiento, et al., 2003; Sanderson, Littleton, & Pulley, 2002).

Overeating and physical inactivity have not historically been public health issues in subsistence societies, so that many individuals may not have well-developed personal representations or understandings of what constitutes healthy eating and physical activity. Even in cultures with traditional diets that are healthier than the Western diet, such as Vietnam, rates of overweight and obesity are increasing. The traditional Vietnamese diet consists of fresh vegetables and fruits, and steaming and boiling are common cooking methods. However, people are highly dependent on refined rice as a dietary staple. Rice is a food with a high glycemic index and contributes to an increased risk of diabetes (Baumann, Blobner, et al., 2006). The carbohydrate-rich diet, coupled with less physical activity as the society transitions from an agricultural economy to one based on industry and manufacturing, creates a potential for energy surplus. Vietnam is also an example of how even traditional foods, such as *pho* (beef or chicken soup), have been supersized and contain more kilocalories per serving than 10 years ago (Ho Chi Minh City Nutrition Centre, 2002). In Uganda, the carbohydrate-rich diet reflects local food availability and limited economic resources. Reliance on carbohydrates, as well as dietary customs such as only tea for breakfast and dinner at 10 p.m., presents a challenge to healthy eating.

Social Climate

The social climate for healthy eating and physical activity is constituted by specific interpersonal relationships that confer support as well as a more generalized sense of community (McMillan & Chavis, 1986). Within families, peer networks, and other social groups, supportive relationships help to establish positive behavioral norms and link individuals to resources that can support healthy behaviors (Heaney & Israel, 2002; McNeill, Kreuter, & Subramanian, 2006). Social support entails behaviors that convey caring, give affirmation, provide role modeling, or offer resources. Numerous primary studies have identified social support as a positive correlate of adult physical activity (Anderson, Wojcik, et al., 2006; Emmons, Barbeau, et al., 2007; Wendel-Vos, Droomers, et al., 2007). Stahl et al. (2001) examined the relationship between self-reported physical activity and perceived environmental support for exercise in a study of health promotion policies in six European countries with established market economies. Major variables corresponded to concepts in social cognitive theory (Bandura, 1986) and included direct and indirect social support, community opportunities for physical activity, and health policies. Social support emerged as the strongest environmental correlate of physical activity; participants who reported low levels of social support were twice as likely to be sedentary as those with high social support.

Several recent reviews have examined the relationship of social support to physical activity in youth and adults. Ferreira and others conducted a systematic review of environmental influences on youth physical activity, drawing on 66 observational studies conducted in established market economies, primarily in North America (Ferreira, van der Horst, et al., 2006). They reported mixed findings for the influence of social support on physical activity. Support and encouragement from parents, friends, and significant others were not related to youth physical activity. However, modeling of physical activity by fathers appeared to be an important influence on children. In most studies in which mother's and father's level of physical activity were measured separately, levels of youth and father physical activity were positively associated.

In its systematic review of interventions to increase physical activity, the Task Force on Community Preventive Services reviewed nine studies on social support interventions in diverse adult populations (Kahn, Ramsey, et al., 2002). Most of the studies were conducted in the USA and used experimental designs. Typical intervention components included motivational and problem-solving telephone support from research staff or participants, discussion groups, and group walking or exercise opportunities. Strong evidence was provided that social support interventions in community settings are effective at increasing adult physical activity.

Social support is also associated with healthy dietary habits. In a comprehensive review of environmental influences on food choices, Larson and Story (2009) summarized findings from research examining the relationship of family environments and social networks to dietary practices. Family and group norms and attitudes influence food choices; in particular, youth and adults are more likely to eat fruits and vegetables when their peers eat them (Larson & Story, 2009). Similarly, results from a narrative summary of six systematic reviews on the determinants of healthy eating and physical activity indicated that social support and modeling were important influences on healthy eating behaviors, particularly in youth (Brug, 2008).

Most research on the social climate for health behaviors has focused on social support. Sense of community is a broader concept that encompasses belonging, trust, feeling important, and emotional connection to others in the community (McMillan & Chavis, 1986). A sense of community may influence healthy eating and physical activity behaviors and may be particularly important for health promotion with people in sociocentric cultures (Bathum & Baumann, 2007), where collectivism rather than individualism is a principal value. Hystad and Carpiano (2010) examined the relationship of belonging to community and adoption of health behaviors using data from 119,693 participants in the Canadian Community Health Survey. They identified a dose-response relationship between sense of belonging and more exercise, change toward a healthier diet, or weight loss during the previous year. These authors suggested that initiatives to enhance community belonging could be an important component of population-wide health promotion initiatives. In our research with low-income, rural adults, the community social climate emerged as an important influence on physical activity and eating behaviors (Kaiser & Baumann, 2010). Participants described how mistrust of neighbors or feeling like an outsider disinclined them to engage in physical activity. However, they also described how sharing cooked meals or home-grown produce and participating in potlucks supported healthy eating and connected them to other people in the community. When we conducted community forums to share results from this research, people attending the forums, particularly Latinas, requested regular events that would bring community members together to discuss issues related to healthy lifestyles and to support and learn from one another. One Latina talked about how grateful she was to be in a setting where she could share with others; she offered the poignant comment "We didn't think anyone cared what we think."

Immigration and Acculturation

Immigration promotes both cultural change and cultural homogeneity—societies incorporate and adapt new practices, while immigrants, to various degrees, acculturate to the practices of their new country of residence (Larson & Story, 2009). Acculturation is influenced by numerous contextual factors, making generalizability of results from diverse immigrant populations difficult (Ayala, Baquero, & Klinger, 2008). Some immigrants arrive in their new country in good health due to past employment in physically demanding occupations, reliance on active transportation, and use of low-fat, high-fiber foods in their country of origin. Others may be in poor health due to malnourishment and inactive lifestyles (Caperchione, Kolt, & Mummery, 2009). The independent effects of acculturation on health behaviors are unclear since effects of acculturation are often confounded with the effects of socioeconomic position (Satia-Abouta, 2003).

The availability, expense, and convenience of foods in the new country of residence influence dietary acculturation, a process by which immigrants adopt and adapt the dietary practices of the host country (Satia-Abouta, 2003; Satia, 2010). The process involves adding new foods to the diet, excluding some traditional foods, or finding new ways to use traditional foods. Although dietary acculturation may improve the nutritional profile of diets, acculturation to societies that are more urbanized than the country of origin typically results in diets that increase the risk for NCDs (Satia, 2010). Among Latino immigrants to the USA, greater acculturation is associated with lower consumption of fruits and vegetables, legumes, and rice and higher intake of fast foods (Ayala, Baquero, & Klinger, 2008).

New immigrants face social barriers to physical activity. Immigrant neighborhoods are often located in high-crime urban areas. Poor language skills create social isolation, discrimination or fear of discrimination, loss of social capital, lack of access to resources, and unfamiliarity with their new neighborhoods (Caperchione, Kolt, & Mummery, 2009; Satia-Abouta, 2003). When we offered a weekly physical activity and nutrition program in a low-income neighborhood in the USA, we publicized the program in Spanish and English. Many of the Latino participants told us that if our advertising had been only in English, they would have understood the information, but they would not have felt welcome to participate in the program.

Socioeconomic Position

Socioeconomic position is a powerful determinant of health and health behaviors, structuring opportunities as well as exposure to risk factors (Marmot, 2002). For 8 years, we have led a weekly exercise, health education, and social support program in a low-income neighborhood and have heard participants describe the challenges they and their family members face in developing healthier behaviors. A program participant who had been homeless described living in her car with her four children and subsisting exclusively on fast food meals for a week. In her words, “It was the most food we could get for the money we had.” A Latino adult, who accompanied program sessions with his overweight adolescent son, described how he and his wife both worked two jobs. Their schedules limited their ability to model and participate in physical activity with their son. With his parents frequently out of the home, the boy spent most of his time watching television. These scenarios highlight some of the complex interactions between proximal factors such as socioeconomic position, food resources in the local environment, and social support for health behaviors.

Socioeconomic position influences the amount of money people can spend on food and physical activity resources, the amount of time people can invest in food preparation and exercise, and the neighborhood in which people can afford to reside (Caprio, Daniels, et al., 2008). Indicators of socioeconomic position include income, educational level, occupation, and poverty status, and these indicators may be measured at the individual or geographic level (Bennett, Wolin, & Duncan, 2008). Lower household income is consistently associated with lower prevalence of moderate or vigorous physical activity (National Center for Health Statistics, 2007) and less healthy diets (Drewnowski, 2004). Authors of a systematic review on environmental determinants of fruit and vegetable consumption, drawing on results from 24 studies conducted in the USA, the UK, Australia, and Europe, concluded that both household and community income are positively related to fruit and vegetable intake (Kamphuis, Giskes, et al., 2006). Limited financial resources may preclude adherence to a diet emphasizing whole grains, fruits and vegetables, lean meats, and fish (Darmon & Drewnowski, 2008), and the lowest-cost diets are those prominently featuring foods such as refined grains, added sugars, and added fats (Drewnowski, 2009). Lower socioeconomic position may limit access to healthcare providers and services that support healthy behaviors.

Community Settings and the Built Environment

Key settings in communities that influence healthy eating and physical activity include parks and recreational facilities, workplaces, schools, and places of worship (Booth, Sallis, et al., 2001). Religious institutions can play an important role in supporting the health of communities, particularly in disadvantaged communities (Peterson, Sorensen, et al., 2002). *Project Joy* investigated the effects of a 1-year church-based program on cardiovascular risk profiles of African-American women age 40 and older (Yanek, Becker, et al., 2001). Sixteen African-American churches in Baltimore were randomized to a standard behavioral intervention, an intervention incorporating spiritual strategies, and a control intervention consisting of standard self-help strategies. Over the course of the project, women in the standard behavioral arm instituted their own spiritual strategies. Compared to the self-help group, the combined intervention groups showed statistically significant improvement in daily energy intake, body weight, waist circumference, systolic blood pressure, and fat and sodium intake. There is consistent evidence from studies conducted in the USA that interventions in African-American churches are effective in improving dietary habits and increasing physical activity. However, there are very few studies that examine interventions in other types of religious institutions or other countries (World Health Organization, 2009).

A systematic review of worksite health promotion programs examined results from 13 randomized controlled trials. The authors found strong evidence for the effectiveness of worksite programs in increasing fruit and vegetable intake and decreasing fat intake. However, the distinct effects of workplace environmental interventions such as food labeling and increasing availability of healthy foods could not be distinguished from the educational elements of the intervention, such as counseling and group education (Engbers, van Poppel, et al., 2005). This review found inconclusive evidence for the effect of workplace interventions on physical activity.

Growing evidence addresses features of the built environment that influence healthy eating and physical activity that include access to sources of fruits and vegetables (Zenk, Lachance, et al., 2009) and amenities such as sidewalks, paths, parks, and trails (Frumkin, Frank, & Jackson, 2004). Neighborhoods characterized by high residential density, mixed land use typified by a combination of housing units and retail sites, and short blocks are consistently associated with walking and cycling (Cervero & Duncan, 2003; Saelens, Sallis, et al., 2003; Saelens, Sallis, & Frank, 2003). Results from a meta-analysis of 16 studies on perceived environmental correlates of physical activity indicated that the perceived environment has a modest but significant association with physical activity. Environmental features significantly associated with physical activity included the presence of sidewalks, low levels of vehicle traffic, physical activity facilities, and retail shops and services. However, the authors note that in all of the included studies, the possibility of participant self-selection into "more supportive" environments cannot be ruled out (Duncan, Spence, & Mummery, 2005). A "review of reviews" examined 13 review papers on the relationship of physical activity and the built environment. Characteristics of the built environment that had consistent associations with physical activity included access to physical activity facilities, access to destinations, residential density, "walkability," perceived safety, access to exercise equipment, and footpaths. Several features of the built environment had inconsistent associations with physical activity, including aesthetic features of the environment, topographic features such as hills, and perceived crime (Bauman & Bull, 2007).

To summarize this section, we have presented proximal influences on healthy eating and physical activity. Although the ecological approach emphasizes the need to consider variables that reflect multiple contextual levels, these levels are highly interconnected. An ecological system is dynamic and synergistic and a means of explaining complex, nonlinear processes (Stillman, Hartman, et al., 1999). For example, evidence shows that collaborative goal setting facilitates positive behavior change. However, to support patient-provider goal setting requires a healthcare provider who is skilled in supporting behavioral change efforts and a healthcare system that provides continuity of care (Glasgow & Emmons, 2007). Cultural traditions interact with local environment to influence behaviors. In Vietnam, a sociocentric culture, it is common for groups of men and women to exercise in parks and open spaces early in the morning before the pedestrian, motorbike, and automobile traffic dominate the space. Exercise is a cultural tradition taught in schools. Modern forms of morning exercise, such as aerobic exercise classes incorporating music, are increasingly popular. By contrast, in Uganda there is not a tradition of exercise, and it is rare to see men or women jogging or exercising outdoors; a solo runner is typically a *muzungu* (white person or foreigner). Modes of transportation such as walking, taking a minibus, or riding on a motorbike reflect one's socioeconomic position more than one's commitment to physical activity.

The dynamic nature of globalization fuels more intermingling of cultures worldwide. Cultural beliefs, norms, and values will continue to evolve as people encounter new barriers and facilitators to healthy lifestyle behaviors. Evidence shows that changes in nutrition and physical activity patterns are occurring rapidly and will especially impact economic development in poorer countries (Popkin & Gordon-Larsen, 2004). Finally, the built environment and community institutions such as churches, schools, and workplaces, as well as features of healthcare systems, represent important individual and family resources for supporting positive behavior change. Many of these features of the built environment are determined in large part by local, regional, and global policies and trends. Strategies to improve health need to take into account the diversity of determinants and contexts as well as the dynamic nature of the systems within which behaviors occur.

Distal Influences

Globalization, Urbanization, and Industrialization

Globalization, urbanization, and industrialization are global phenomena with similar and overlapping effects. Urbanization increases exposure to mass media, adoption of work technologies that require low levels of physical activity, and access to an increased variety of foods (Mendez & Popkin, 2004). Many developing countries are undergoing chaotic urbanization. Air pollution, traffic congestion, and urban design favoring motorized transport have created environments that discourage active forms of transportation.

Globalization is the process by which distinctive social and cultural characteristics of diverse geographic areas recede over time (Caprio, Daniels, et al., 2008). The forces of globalization are pervasive and include the reduction of trade barriers, broad penetration of international corporations into national economies, access to Western media, and uptake of advanced technologies in manufacturing and agriculture (Popkin, 2004). These forces have far-reaching influence on human behavior. Globalization exerts direct effects on behavioral choices via marketing of energy-dense foods and indirect effects due to transitions to occupational structures that require less physical activity (Beaglehole & Yach, 2003; Mendez & Popkin, 2004).

There are benefits to globalization. Globalization can improve dietary sufficiency in areas with food scarcity and increases access to healthy food (Mendez & Popkin, 2004). However, one of the most recognizable consequences of globalization is its impact on the availability of energy-dense foods worldwide, including "fast foods." Globalization has created a worldwide culture of international food such a McDonalds and KFC. Hawkes (2006) presented a case study of increasing snack consumption in Thailand. She described how global free trade agreements have interacted in Thailand with national policies that are favorable to foreign investment to create a booming market in sweet and savory snacks; between 1999 and 2004, the value of snack sales increased 75% (Hawkes, 2006). In settings such as Uganda, intensive marketing of sugar drinks makes them the most available beverages, even more available than safe water. As we have worked in Uganda in recent years, we have been struck by the strong preference Ugandans have developed for high-calorie soft drinks, favoring the full-calorie version over low-calorie versions. In fact, a non-calorie cola beverage produced by an industry giant has been withdrawn from the country due to poor sales.

Mass Media and Marketing

Several years ago, we conducted key informant interviews with health and social service professionals as part of a project to assess influences on physical activity and healthy eating in a low-income, rural population. One of the informants was a public health nurse who described how the parents she worked with struggled with their children's constant requests for heavily marketed high-fat or high-sugar products. From her perspective, an essential parental skill was establishing a plan for responding to children's requests for junk foods or "how to say no to McDonald's."

The influence of mass media, and particularly its influence on children's food preferences, has drawn increasing attention from researchers and policy makers. Mass media can influence physical activity and diet behaviors through multiple mechanisms. Watching television or using the Internet may supplant recreational physical activities, and television watching is associated with increased consumption of food (Strasburger, Jordan, & Donnerstein, 2010). Perhaps the most powerful and pervasive effect of mass media is its effect on food preferences and purchases. In a synthesis of research on food marketing to children and youth, The Institute of Medicine (2006) found strong evidence that television advertising influences the preferences, purchase requests, and short-term food consumption of children ages 2–11 years but insufficient evidence to support similar effects on youth 12–18 years. While much of the attention on food marketing has focused on its effect on children, adults' consumption of energy-dense foods may also be influenced by advertising (Thomson, Spence, et al., 2008). In a cross-sectional study of 1495 Australian adults, more time watching television was significantly associated with consumption of fast food for dinner and snacks (Scully, Dixon, & Wakefield, 2008).

Most television advertising that targets children and youth promotes high-calorie, low-nutrient products (Harris et al., 2009). Because interventions to decrease television viewing are impractical at a population level, regulation of television marketing to children represents the most promising strategy for decreasing the influence of advertising (Swinburn & Shelly, 2008). Results from an experiment with children and youth attending a summer camp demonstrated that children will eat low-sugar ready-to-eat cereals and those children who eat low-sugar cereals tend to eat less cereal and more fruit than children who eat high-sugar cereals (Harris et al., 2011). These results have implications not only for parents but also for policy makers. For example, a requirement that manufacturers of ready-to-eat cereals devote a proportion of their cereal advertising to low-sugar cereals may be a promising policy intervention to decrease sugar consumption in children and youth.

Policy

Policy operates at a broad societal level to structure physical activity and diet behaviors. Because policy-making, particularly at the national and international levels, is distant from the daily lives of most people, its effects are not generally obvious to individuals. Policies related to road construction, public transportation, and pedestrian and bicycle access ultimately affect personal choices about using active modes of transportation. Decisions to walk or bicycle are affected by urban design and land-use policies (Heath, Brownson, et al., 2006). At a community level, effective interventions to increase walking and bicycling include zoning regulations that provide convenient access to retail and investments that improve the quality and connectivity of sidewalks.

At a street-scale level, active forms of transportation are supported by improved street lighting, traffic calming measures, and landscaping that enhances the aesthetic quality (Heath, Brownson, et al., 2006). In Bogotá, the urban environment has been transformed through policies that discourage private vehicle use, improve public transportation, promote nonmotorized transportation, and convert parking areas to attractive public spaces (Wright & Montezuma, 2004). A weekly car-free day, *Ciclovía*, was established through a city referendum, and women who participate in the event are more likely to engage in leisure-time physical activity than those who do not (Gomez, Mateus, & Cabrera, 2004).

Public policies broadly determine the type and costs of foods available to individuals. A large and complex array of agricultural, industrial, and economic policies have created the contemporary food environment in the USA and other nations. The agriculture sector represents a substantial part of the US economy; government policies support this sector through subsidies, farm credits, commodity programs, trade policies, marketing assistance programs, and sponsorship of agricultural research (Tillotson, 2004). During an era when nutrient deficiencies were common, policies to increase the food supply played an important role in improving public health. However, at the present time, these same agricultural policies support the proliferation of processed foods and conflict with national nutritional policies that guide Americans to eat more fruits and vegetables, less processed food, and a smaller volume of food (US Department of Agriculture, 2010). Tillotson (2004) questions whether targeted policy initiatives such as taxes on high-fat or high-sugar products or limits on food advertising can affect American eating habits in the absence of changes to broad agricultural policies. Similar questions can be raised for other high- and middle-income nations where national policies encourage a surplus food supply.

Until recently, distal influences on health behavior such as policies, mass media and marketing, and globalization have not been a routine area of investigation for behavioral scientists. However, it is these distal influences that have radically and pervasively changed the environment in which individuals worldwide make choices regarding food and physical activity. The development of ecological models of healthy eating and active living has helped to broaden the scope of behavioral research to the larger social and political arena and has set the stage for an era when interdisciplinary collaboration is not a rarity but an absolute requirement for conducting relevant and contextualized behavioral research.

Synthesis of Research Issues

The number of studies on environmental influences on healthy eating and physical activity has increased enormously in recent years, making it a challenge to synthesize and make sense of the evidence. Numerous narrative and systematic reviews in this area have been conducted, such that "reviews of reviews" are appearing (Bauman & Bull, 2007), and more work is needed to combine and reconcile the disparate findings in these many reviews. Systematic reviews are highly selective, and studies with sufficient rigor for inclusion in systematic reviews are most often conducted in high-income countries. Contextual evidence, such as local evaluations of community-based health promotion programs, is barred from most evidence hierarchies yet constitutes the bulk of evidence for health promotion in the developing world (McQueen, 2001). Few systematic reviews have rigorously integrated results from qualitative and quantitative studies. However, this type of methodological strategy may provide a sounder evidence summary and a more appropriate base for policy decisions related to healthy eating and physical activity than overreliance on one type of study.

There is a great need for more "contextualized" research that examines unique processes, environments, and behavioral outcomes in a wide variety of settings; there is a corresponding need for greater diversity in the design of research in this area. Randomized controlled trials in community settings are expensive, difficult to implement, and probably inadequate for measuring population-level change (Victora, Habicht, &

Bryce, 2004). "Rather than efficacy in the purposefully limited context of experimental design, more timely questions surround reach, success in engaging high priority population, or robustness and replicability of impacts" (Fisher, 2008, p. 16). The great majority of studies on the environmental context for healthy eating and physical activity are correlational in design and examine a very limited range of environmental influences; few apply multilevel modeling techniques. Most studies using an ecological framework do not address the nested nature of behavioral influences (Glasgow & Emmons, 2007). However, studies examining multiple factors at multiple levels of influence present substantial challenges to researchers, such as developing measures at multiple levels, building interdisciplinary research teams, applying advanced statistical analyses, and engaging in the political processes that lead to policy and environmental change (Sallis, Owen, & Fisher, 2008). More research on sustainability and cost-effectiveness in diverse settings is also needed (World Health Organization, 2009). Researchers should consider developing studies related to the process, output, and outcome indicators developed by the World Health Organization (2008) to monitor and evaluate environmental and policy changes related to healthy eating and physical activity. Rigorous evaluation of community-based healthy lifestyle programs is especially needed in developing countries. Finally, working closely with diverse community partners is an absolute prerequisite to designing studies that are culturally appropriate and suit the local context (Baumann, 2011; World Health Organization, 2009).

Conclusion

Decades of research on individual-level approaches to promoting healthy eating and physical activity have had no demonstrable effect on improving population levels of these behaviors. The burgeoning rates of NCDs that threaten global public health are concurrent with dramatic changes in the environmental context for healthy eating and physical activity. To counter the broad forces that predispose individuals around the world to sedentary behaviors and unhealthy diets, the World Health Organization (2004) has recommended the development of environments that enable populations and individuals to achieve energy balance, shift to unsaturated fats, increase fruits and vegetables, limit free sugars and salts, and engage in developmentally appropriate amounts of moderate and vigorous physical activity. Prevention-focused, population-based policies and programs for physical activity and dietary behaviors will be needed to achieve improved and have the best potential to substantially reduce the predicted growth of the global burden of noncommunicable disease. This climate of change provides an opportunity for behavioral scientists to make a recognizable impact on public health. As environments change and new policies are enacted, opportunities abound for natural experiments, quasi-experiments, comparative case studies, and longitudinal research. The pandemic nature of NCDs demands strategic behavioral research that is timely, moving quickly from design to dissemination of results, and targeted, reaching the opinion leaders and policy makers who lead change efforts (Brownell, 2010, August). Timely and targeted research that takes place in community settings that reach large numbers of participants will provide the best evidence for practices, programs, and policies that create a more supportive context for healthy eating and physical activity for people worldwide.

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14

The Fundamental Role of Socioeconomic Resources for Health and Health Behaviors

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Introduction

History suggests to us – with the most intuitive interpretation – that over the past several hundred years, as the world and its inhabitants have become more economically prosperous, their social prosperity – including their health status – has also advanced in meaningful ways. While, in many respects, this describes the overall health-wealth relationship, it is far from being a fulsome account of the dependencies between the health of individuals and populations, their economic resources, and those of the societies in which they are embedded.

Through scientific inquiry, we have learned that (a) for both people and societies, incremental improvements in economic resources (and, more completely, *socioeconomic* resources, described below) are associated with incremental improvements in health and health behaviors (HHBs), though, after a point, there are diminishing returns to greater resources; (b) while there are important "absolute" aspects of economic resources which matter for HHBs, an abundance of evidence suggests that one's relative resources – that is, resources compared to others in society – are influential above and beyond any absolute level; (c) as economic resources have grown, their distribution between individuals and societies has been increasingly unequal, which has had consequences for the distribution of HHBs; (d) growing economic prosperity has also been accompanied by other societal changes which carry health effects of their own; and (e) the mechanisms – both social and biological – through which economic resources are tied to HHBs are many and varied; the influence of economic resources on health via their effects on health behaviors is certain, but also extends well beyond.

In this chapter, we first provide a working definition of *socioeconomic resources*, a broader and more complete construct which acknowledges the interdependence of economic resources and the social or relational resources which accompany them. Next, we review the current state of evidence on the relationship between socioeconomic

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Clyde Hertzman passed away during the writing of this chapter.

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resources and HHBs at the three main levels of society for which we have systematic evidence from around the world: individuals and families, communities/neighborhoods, and nations. Our review concentrates on the overarching understandings which have emerged from the scientific literature in this area and presents an emergent model to synthesize these findings. We then describe two case studies which provide a more in-depth perspective on the importance of examining the interdependencies of socioeconomic resources at each of these three levels and the ways in which the interplays have consequences for HHBs. In the first case study, we explore how, in two economically advanced countries with many societal similarities – the United States and Canada – differences in the health status of their respective populations are significant and are largely explained by differences in resource distribution at the national level and its effects on other aspects of the national context, and on the resources of neighborhoods and those of individuals and families. In the second case study, we examine changes in population health status which occurred in a set of middle-income countries – those of Central and Eastern Europe – during the late 1980s'/early 1990s' transition from a communist political-economic orientation, to a capitalist (market) orientation, a shift which altered many economic and social aspects of these societies and thus changed the resources available to individuals and families.

Concepts and Measurement of Socioeconomic Resources

Individual Socioeconomic Resources

A long tradition of sociological inquiry has guided thinking about the importance of economic resources in many aspects of daily life. Scholars have long argued about the precise characterization of resources, particularly in terms of the means through which they were acquired, distributed, and valued (Lynch & Kaplan, 2000; Marx, 1894, 1991; Weber, 1922). Overall, however, there are two particularly significant and consistent findings which have emerged from this literature: (1) there is an inextricable link between education, occupation, and income as the principal inputs or indicators of an individual's economic resources; and (2) there is an inextricable link between economic resources and social resources – namely, social status and prestige – which are also strongly implicated in the quality of everyday lived experiences. In fact, the aforementioned inputs of economic resources also contribute to social status and prestige. Collectively, this constellation of economic and social resources is widely referred to as "socioeconomic resources," though there are slight deviations, depending on the nuance one brings to the construct (e.g., socioeconomic status, socioeconomic position) (Lynch & Kaplan, 2000). Moreover, not only are economic and social resources inextricable, their association is reciprocal; while higher education, occupational position, and income result in higher levels of status and prestige, it is precisely status and prestige which beget these higher economic resources, because they open doors to opportunities (particularly for future generations) for acquiring these resources (Breen, 2004; Duncan & Brooks-Gunn, 1999; Hauser, Warren, et al., 2000; Ishida, Muller, & Ridge, 1995; Solon, 2004).

Over a long history of inquiry into the causes of health and illness the contribution of socioeconomic resources has been widely investigated. In the process of adapting this construct to the investigation of HHBs, the interpretation and measurement of socioeconomic resources has been broad and varied. At the individual and family level, the translation has been fairly direct, with the idea that both material- and status- or prestige-based aspects of resources may have implications for health status (Krieger, Williams, & Moss, 1997). As such, measures of socioeconomic resources include both material assets, such as income and wealth, and social resources, which provide prestige, such as educational attainment and occupation (Krieger, Williams, & Moss, 1997).

On the one hand, as these different indicators attempt to measure the same overall construct, there is some overlap between them, both conceptually and empirically. On the other hand, the health literature has demonstrated that each indicator has a unique pathway through which it is hypothesized to influence HHBs (Lynch & Kaplan, 2000). As such, the working theory is that each indicator represents a unique dimension of socioeconomic resources. There is now abundant evidence that considering multiple measures of socioeconomic resources is necessary to capture the full association between this construct and HHBs (Braveman, Cubbin, et al., 2005).

Communities/Neighborhood Socioeconomic Resources

As research on the influence of socioeconomic resources has progressed, a major insight has been that, above and beyond the socioeconomic resources of individuals and families, HHBs are also a function of the socioeconomic resources of the communities or neighborhoods in which individuals and families are embedded. While, as we will see later in the chapter, the conceptualization and measurement of individual/family socioeconomic resources in relation to HHBs has been a global phenomenon, most of the thinking and empirical work in this regard has been based in the United States, with some evidence coming from other OECD (Organisation for Economic Co-operation and Development) nations.

As such, most of the understandings which have developed are primarily rooted in the neighborhood dynamics found in the United States, though many aspects of this literature are more broadly applicable. In the context of the United States, a long history of economic, political, and social forces has led to a high degree of residential segregation – the "sorting" or "concentration" of individuals and families in accordance with their socioeconomic resources, such that US neighborhoods are marked by a high degree of socioeconomic homogeneity within neighborhoods and a high degree of heterogeneity across neighborhoods (Massey & Denton, 1993).

Not surprisingly, neighborhoods with more socioeconomic resources are often more desirable places to live, offering more services and less stressful living. Resource-poor neighborhoods often offer fewer services and often have higher crime rates, more abandoned housing, more limited access to healthy foods, and other markers of worsened quality of life (Sampson, 2003b). As such, then, residential segregation is strongly linked to inequalities in socioeconomic resource distribution, with a reinforcing mechanism whereby the most disadvantaged individuals are differentially concentrated in cheaper and less resource-dense neighborhoods (Diez Roux & Mair, 2010).

Of note, these institutional forces have also evolved to create residential segregation based on not only socioeconomic resources but also race (Massey & Denton, 1993). Racial minorities in the United States (particularly African Americans) then experience the highest degree of segregation, owing principally to two forces: historical and present-day racism which has diminished their opportunities to acquire individual and family socioeconomic resources and, historical and present-day racism which prevents them from purchasing or renting housing in neighborhoods characterized by high resource levels, which tend to have large proportions of white residents (Williams & Collins, 2001).

Relying heavily on census data to approximate neighborhood boundaries and obtain socioeconomic measures, early studies on neighborhoods and health primarily defined neighborhoods as census tracts and the socioeconomic resources of neighborhood were proxied by the socioeconomic characteristics of the residents in a census tract (e.g., average or median household income in a neighborhood (census tract)) (Diez Roux & Mair, 2010).

A second generation of neighborhood effects studies has focused on characterizing the socioeconomic resources of neighborhoods from a structural perspective: that is, a characterization of "true" neighborhood attributes rather than solely an aggregation of the socioeconomic resources of a neighborhood's residents (Sampson, 2003a). Similar to the construct of socioeconomic resources, these attributes include both physical and social factors (Diez Roux & Mair, 2010). The physical environment refers to what materially constitutes a given neighborhood. Some examples, but not an exhaustive list, of these attributes include environmental exposures (e.g., air pollution), aspects of the built environment (e.g., housing, urban design and public spaces), and access to health-related resources (e.g., health foods and places for physical activity) within the neighborhood (Diez Roux & Mair, 2010). The social environment is defined as the social organization of the neighborhood; it includes, but is not limited to, social interaction and cohesiveness, social capital, levels of safety or violence, and the presence of social norms (Diez Roux & Mair, 2010; Kawachi & Berkman, 2003).

Societal/National Socioeconomic Resources

The third main level at which socioeconomic resources have been considered in relation to their consequences for HHBs is at the level of society, more specifically, the nation. Socioeconomic resources of nations have primarily been conceptualized and measured in terms of the per capita economic production of a nation (most commonly measured as per capita gross domestic product (GDP)) (Preston, 1975; Rodgers, 1979; Sampson, 2003a). Later literature began to focus not only on the role of per capita or average economic resources in health, but also on the role of the distribution of economic resources, most often referred to as the degree of income inequality (Kawachi, 2000).

Unlike the neighborhoods literature, which has greatly evolved in terms of its conceptualization and measurement of socioeconomic resources, literature on national socioeconomic resources has largely remained focused on income and income-like measures. Other national indicators which have strayed from this pattern still largely measure aggregate characteristics of the population. A key example in this respect is the Human Development Index, which combines per capita gross national income, mean and expected years of schooling, and a measure of health, life expectancy at birth. Increasingly, the economics literature is suggesting "gross national happiness" – determined principally through surveying population perceptions of various aspects of national wellness – as a metric of a nation's socioeconomic well-being (Anand & Sen, 1994; Kahneman & Krueger, 2006).

With few exceptions, the literature has not well elucidated nor empirically tested more structural conceptions of socioeconomic resources at the national level – such as overall infrastructure, service provisions (e.g., health care, transportation, education), safety net (e.g., unemployment insurance, welfare) – which aren't only aggregations of population characteristics (Muntaner, Borrell, et al., 2011; Navarro, Borrell, et al., 2003; Siddiqi & Hertzman, 2007). Even the World Bank's often-used categories are based solely on income (as in the designations of low-, middle-, and high-income nations) or on the compositional characteristics of citizens (as in the designations of "developed" and "developing" which draw on the Human Development Index (Stanton, 2007; UNDP, 2014)). Later in the chapter, we will take a closer look at two key examples of how a wide range of national socioeconomic factors shape the population's HHBs.

Socioeconomic Resources and Their Influence on Health

Individual/Family Socioeconomic Resources and Health

Socioeconomic resources have been strongly linked to opportunities in countless spheres of life. Their association with HHBs is profound. In fact, the persistent and ubiquitous nature of this association is perhaps one of the most striking of all epidemiologic findings about HHBs. Historically, documentation first began during the nineteenth century with the work of Villerme and Virchow (Berkman & Kawachi, 2000; Krieger, 1992). In the modern era, much of the early work on this topic arose during the early 1990s from the analysis of the Whitehall study in which investigators observed a striking relationship between the employment grade of British civil servants and a variety of HHB outcomes (Marmot, Smith, et al., 1991). These studies suggested that, with each additional increase in employment grade, HHBs (such as risk of cardiovascular disease, smoking, and alcohol use) also improved.

Take, for example, the rich literature on smoking. Low levels of socioeconomic resources in childhood and adulthood are associated with higher smoking rates in adulthood in middle- and high- income countries, with some evidence of this association in poor nations (Gilman, Martin, et al., 2008; Hiscock, Bauld, et al., 2012; Jefferis, Power, et al., 2004; Lawlor, Batty, et al., 2005; Power, Graham, et al., 2005). The link between socioeconomic resources and smoking includes the influence of resources on a variety of specific aspects of smoking behavior, including initiation, prevalence and consumption, quit attempts, and cessation rates. Differences across socioeconomic groups in initiation has been linked to family characteristics (parental smoking status, decreased ability to resist peer pressure, lower awareness and underestimation of tobacco's harm, behavior problems, and poorer educational performance) during childhood and adolescence (Galea, Nandi, & Vlahov, 2004; Hiscock, Bauld, et al., 2012). While the number of cigarettes smoked is more variable (in high-income countries, lower socioeconomic status is associated with less cigarette consumption among smokers but, in most low-income settings, with greater cigarette consumption), socioeconomically disadvantaged individuals smoke each cigarette "harder" – a process that extracts more nicotine while increasing exposure to other risky components of tobacco smoke (Hiscock, Bauld, et al., 2012). There is also evidence to suggest that individuals in lower socioeconomic strata are less successful in attempts to quit smoking (Hiscock, Bauld, et al., 2012).

Similar to smoking, type of alcohol consumption is socioeconomically patterned, with lower resourced individuals consuming higher amounts of alcohol, though higher resourced individuals drink more frequently (Huckle, You, & Casswell, 2010; Kuntsche, Rehm, & Gmel, 2004). Fewer socioeconomic resources are also associated with poorer nutritional consumption, less leisure time physical activity, and more sedentarism (Beenackers, Kamphuis, et al., 2012).

These well-documented relationships between socioeconomic resources and HHBs demonstrate a graded association. That is, incremental changes in socioeconomic resources lead to incremental changes in HHBs; the relationship is one of a gradient, not of a threshold (Adler, Boyce, et al., 1994; Siddiqi & Hertzman, 2007). NB: there are, however, some studies which suggest that the "steepness" of the gradient is greater at lower socioeconomic levels and lesser at higher socioeconomic levels (Rehkopf, Berkman, et al., 2008; Rehkopf, Krieger, et al., 2010).

The pattern has thus widely come to be known as the "gradient effect" or the "socioeconomic gradient in health." There are several related implications of this finding. The first, that there seems to be no level of socioeconomic above which an individual is certain to be protected against ill-health, because the significance of one's resources is a relative matter. The second, that health is a function of the socioeconomic resources an individual possesses compared to those possessed by others in society (Adler, Boyce, et al., 1994). Put differently, for a given individual, it is difficult to predict a level of health that corresponds to a level of socioeconomic resources, because what matters in large part is the value of one's socioeconomic resources relative to others in a given time, place, or other relevant context. This notion has been reinforced through cross-national studies which have demonstrated that the quality of life and health outcomes of low-income workers – those with similar absolute resource levels – is superior in Canada, where the relative position of these workers is higher, compared to the United States, where their position is lower (owing to lower levels of socioeconomic inequality in Canada than in the United States) (Siddiqi & Hertzman, 2007; Siddiqi & Nguyen, 2010; Zuberi, 2006). Third for a population, there are two ways to characterize health differences across socioeconomic groups: on an absolute scale (the difference in health status between high and low socioeconomic groups) and the relative scale (the ratio of health status between low and high socioeconomic groups). For instance, by some accounts, the ratio of ill-health between low and high occupational categories is less favorable in Scandinavian nations than in the United States; however, the absolute levels of ill-health for both low and high occupational groups is much lower than those of the United States (Kaufman, 2009; Lynch, Smith, et al., 2006).

At one time, it was thought that socioeconomic differences in health outcomes were mainly attributable to socioeconomic differences in health behaviors. Research had rather definitively established both that behaviors are a function of socioeconomic resources (as described above, for example with smoking, alcohol use, and diet) and that health behaviors are associated with a variety of health outcomes such as cardiovascular disease, cancers, and other leading causes of morbidity and mortality (McGinnis & Foege, 1993; Mokdad, Marks, et al., 2004). However, more recent studies have provided more mixed results with some suggesting that, in fact, the role of health behaviors may be rather modest for explaining socioeconomic disparities in health, a rather counterintuitive finding indeed. Collectively health behaviors have been shown to explain between 12% and 54% of the social inequities in mortality (Stringhini, Sabia, et al., 2010). Today, we know that socioeconomic differences in health outcomes are a function of not only behaviors, but multiple other biological mechanisms, which we describe later in the chapter.

To be sure, however, many of these studies only considered prevalence of health behaviors measured at one point in time and therefore may underestimate the contribution of health behaviors to social inequalities in health (Stringhini, Sabia, et al., 2010). Moreover, as mentioned earlier, to understand the contribution of health behaviors to the social gradient in health, it is important to consider inequalities on both absolute and relative scales. For example, a study of social inequalities in coronary heart disease (CHD) found conventional risk factors (including some health behaviors such as smoking) explained 72% of the relationship between socioeconomic position and CHD on the absolute scale, but only a modest 24% on the relative scale, suggesting that there are high levels of such risk factors in every socioeconomic group, but few differences between groups (Lynch, Davey Smith, et al., 2006). Therefore, the true contribution of health behaviors to social inequalities in health may be underestimated in many contexts.

Neighborhood Socioeconomic Resources and Health

Beyond personal socioeconomic resources, those of neighborhoods are an important context in which HHBs develop. As discussed earlier in the chapter, the neighborhoods in which individuals live and work are important factors in both constraining and enhancing HHBs (Diez Roux & Mair, 2010). Neighborhood characteristics have been shown to be associated with a variety of smoking related behaviors. Compared to neighborhoods with higher socioeconomic resources, those with fewer resources are associated with higher number of retail outlets and higher rates of cigarette advertising and promotion (Hiscock, Bauld, et al., 2012). Moreover, the well-established mood-elevating and anxiolytic effects of nicotine may make those in low-income neighborhoods especially susceptible to that advertising and promotion (Services, 1998). International studies show associations between lower educational status and greater nicotine dependence (Siahpush, McNeill, et al., 2006). That greater distress among low-socioeconomic status (SES) groups may make them more susceptible to nicotine dependence is suggested by studies linking distress and dependence, for example, associations between nicotine dependence and mood and anxiety disorders (Grant, Hasin, et al., 2004). Thus, greater likelihood of dependence due to varied stressors among residents of low-income neighborhoods may reinforce greater marketing of nicotine products, which, in turn increases use and dependence.

Neighborhoods with lower socioeconomic resources also have a greater density of alcohol outlets, which is associated with greater alcohol use. Neighborhood socioeconomic resources also affect (or are correlated with) other aspects of neighborhood context, which in turn influence health behaviors. The food environments within neighborhoods have been linked to quality of diets for its residents. For example, access to retail outlets with healthy food options (e.g., supermarkets) was associated with having healthier food intake (Larson, Story, & Nelson, 2009). Moreover, the number of and proximity to fast food outlets are associated with a poorer quality diet (Moore, Diez Roux, et al., 2009). Lower levels of stress and even lower levels of asthma have been observed in individuals living in neighborhoods with increased presence of physical activity resources in parks and recreational settings (Kaczynski & Henderson, 2008) and increased neighborhood safety (Diez Roux & Mair, 2010; Wright, Mitchell, et al., 2004). There is now building evidence that neighborhood characteristics are linked to health conditions, such as obesity (Black & Macinko, 2008; Papas, Alberg, et al., 2007) and diabetes (Auchincloss, Diez Roux, et al., 2009; Ludwig, Sanbonmatsu, et al., 2011) in large part through cumulative exposures to negative health behaviors.

Societal (National) Socioeconomic Resources and Health

Socioeconomic resources of societies – in particular, of nations – also have a strong association with HHBs. At the national level, both the overall level of socioeconomic resources and the distribution of these resources have received considerable attention. Moreover, these aspects of resources have been investigated in terms of both overall population levels of HHBs and the distribution of HHBs within and across societies. For the most part, national level studies have focused on the most commonly gathered and widely available measures of population health, life expectancy, and its close correlate, mortality rates, as their metric of health. As described earlier, perhaps the most common metric of overall resources is often per capita gross domestic product (GDP).

Influence of Societal Resources on Overall Population Health

The association between per capita GDP and metrics of population health demonstrates two major phenomena (see Fig. 14.1). First, one can observe the same general pattern as the individual association between socioeconomic resources and HHBs; incremental increases in GDP result in incremental increases in life expectancy; however, at a certain point, the health returns to additional GDP diminish and then level off entirely (Rodgers, 1979). Interestingly, this leveling off at the population level appears to be much sharper and con-

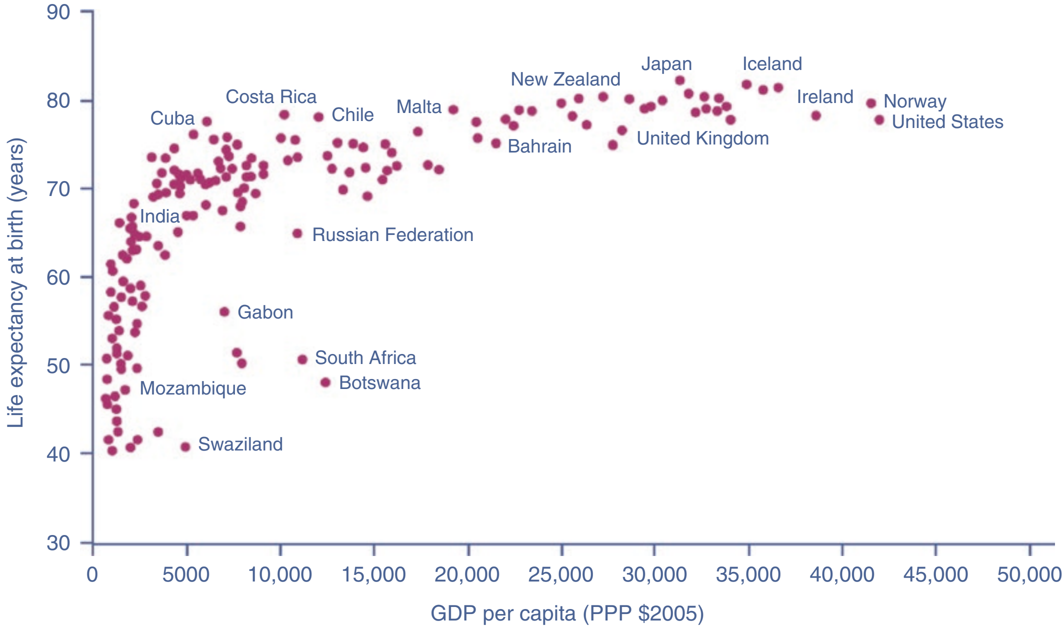

Fig. 14.1 Life expectancy at birth versus average annual income in GDP (Source: http://underpoint05.wordpress.com/category/inequality/)

sistent than that at the individual level, where nonlinearities in the socioeconomic gradient have only begun to be explored. Countries such as those of sub-Saharan Africa benefit tremendously from improvements in their national income, but by the time societies reach the level of wealth of countries such as Sweden, the United Kingdom, Canada, and the United States, there are no ostensible health benefits to becoming richer.

The initial part of this pattern – the rise in health status associated with increased resources – is largely explained by the improvements in basic health resources such as sanitation, drinking water, food security, and medical care (Preston, 1975). The latter part of this pattern – diminishing returns to life expectancy of increased national income – occurs among those countries which have a long history of basic health infrastructure, and thus have undergone an epidemiologic transition away from infectious diseases and low life expectancies to a dominance of chronic diseases which occur in later decades of life (Omran, 1971).

Among these wealthier countries then, rather than differences in absolute levels of wealth (and thus differences in basic infrastructure), variations in life expectancy are thought to be a function of the distribution of wealth and also of co-occurring societal phenomena. For instance, recent studies are beginning to show that the health outcomes of the advanced capitalist democracies (the so-called welfare state nations) are patterned by the type of social policy regime they exhibit, with more generous welfare states demonstrating stronger population health outcomes (Eikemo, Huisman, et al., 2008; Muntaner, Borrell, et al., 2011).

Second, at any given level of national resources, there is also quite a significant spread in terms of population health status; South Africa and Croatia are similar in terms of their per capita national income (South Africa, $10,700; Croatia, $10,600 according to 2003 purchasing power adjusted figures), but maintain a nearly 30-year difference in life expectancy (South Africa, 26.6 years, Croatia, 74.37 years). Moreover, the health of many poorer nations matches or surpasses that of much richer nations. Cuba's 2003 per capita GDP was $2900 and its average life expectancy was 76.8 years. By contrast, the Czech Republic with a GDP of $15,700 had a lower life expectancy, 75.2 years, and the United States at $37,800 had a life expectancy only marginally better, 77.1 years. Though not yet thoroughly investigated, these "diversions from the line of regression" are thought to be due to the provision of health resources in some countries (like Croatia and Cuba) which outpaces their level of wealth (data obtained from World Bank World Development Indicators) and sociopolitical upheaval in others, such as the epidemic of HIV/AIDS in South Africa and the postcommunist transition in the Czech Republic.

Influence of Societal Resources on Health Disparities

Evidence is also beginning to accumulate which suggests that in addition to affecting overall population health, these national characteristics (most notably, income inequality and social policy) also affect the distribution of health – health inequalities or the socioeconomic gradient – *within* a population. In fact, one hypothesis which has been forwarded suggests that health inequalities underlie the statistics on average population health; low average levels of population health are driven by large socioeconomic inequalities in health (Siddiqi, Kawachi, et al., 2007; Siddiqi, Kawachi, et al., 2013). Among the wealthy countries, those such as the Scandinavian cluster, which demonstrate lower levels of socioeconomic inequality have a correspondingly "shallower" socioeconomic gradient in health and also the highest average health status, while the United States, whose income inequality is the most pronounced among these nations, has a remarkably steep gradient effect and the lowest average health status of these nations (Mackenbach, Kunst, et al., 1997; Mackenbach, Stirbu, et al., 2008).

While the pattern of steepness (i.e., strength) in the socioeconomic gradient in health appears to be correlated with the distribution of income, it seems it is also attributable to the distribution of health resources such as education, neighborhood/living conditions, working conditions, and the like (Siddiqi & Hertzman, 2007). In some nations, where the socioeconomic gradient is shallower, policies work to provide equitable access to these resources, while in others, where the gradient is quite steep, policies to provide resource equity are either absent, weak, or even work to concentrate among the wealthiest members of society. These propositions are only beginning to be investigated.

Later in the chapter, we provide two cross-national comparative case study examples which highlight how in countries that are similar in many respects there are, nonetheless, marked differences in socioeconomic health inequalities and in average levels of population health, and which investigate the role of individual resources and societal distribution of resources in explaining these differences.

Mediating Pathways/Mechanisms Linking Socioeconomic Resources and HHBs

Over time, the bulk of research has focused on establishing the associations between socioeconomic resources and HHBs rather than deconstructing the mechanisms through which these associations arise. This may partly have been driven by the initial assumption that health behaviors were the overwhelming means through which health status was patterned along socioeconomic lines and also resulted in little emphasis was placed on exploring alternative mechanisms. Over time, as discussed above, research began to demonstrate that health behaviors explained some, but not all (maybe not even most), of the association between socioeconomic resources and health. For instance, after accounting for socioeconomic differences in smoking, drinking, and body mass index (as a proxy for diet and exercise), large socioeconomic inequalities in mortality still remain (Lantz, House, et al., 1998). More recently, then, scientific investigations have explored other major mechanisms through which socioeconomic resources are, literally, embodied and expressed as HHBs.

In the following section, we explore the now strong set of findings which suggest that, aside from affecting health behaviors, socioeconomic resources affect two additional pathways involved in shaping health (which operate distinctly, but may also be interconnected): the degree of physiological stress experienced by the body (McEwen & Seeman, 1999; Miller, Chen, & Parker, 2011) and epigenetic mechanisms (Borghol, Suderman, et al., 2012; Hertzman & Boyce, 2010).

The Role of Physiological Stress

Individuals with fewer socioeconomic resources experience both increased frequency and intensity of exposure to stress across the life course. Stressful environments in childhood, conceptualized as exposure to risky early family environment (e.g., early maltreatment, familial conflict, neglect, and cold, nonnurturing behavior (Matthews, Gallo, & Taylor, 2010; Miller, Chen, & Parker, 2011)) as well as stressful life experiences and adverse physical and social conditions in adulthood (e.g., economic hardship (Braveman, Marchi, et al., 2010)), racial discrimination (Williams & Mohammed, 2009), and low job control have been linked to poor health outcomes later in life. Individuals with few resources not only experience more of stress but also report higher levels of emotional distress compared to their more resourced counterparts when exposed to similar levels of stress (Matthews, Gallo, & Taylor, 2010). Individuals with few socioeconomic resources often lack the reserve capacity (e.g., protective resources) to deal with stressful environments. Two potential mechanisms have been proposed for this diminished reserve capacity. Relating to the stressful environment often accompanied by low levels of resources, (1) individuals may use resources more often and (2) social environment may prevent the development and replenishment of resources (Matthews, Gallo, & Taylor, 2010).

Exposure to repeated stressful experiences in low levels of socioeconomic resources can lead to physiological and behavioral dysregulations, leading to social inequalities in health getting “under the skin.” The brain plays an important role in managing stress. Exposure to stressful environments during development and aging can alter the structure and function of the areas of the brain that manage stress (e.g., hippocampus, amygdala, and areas of the prefrontal cortex) (McEwen & Gianaros, 2010). Changes in these areas of the brain, referred to as neuroplasticity, can modify the regulation, reactivity, and recovery, in both the short and long term, from physiological and behavioral stress processes, causing corresponding effects in the autonomic, cardiovascular, and immune systems (McEwen & Gianaros, 2010). Under chronic stress conditions, long-term disruptions of these systems can lead to wear and tear on the body and brain or "allostatic load."

The origins of our insights into social hierarchies and physiological dysregulation come from work done on primates (Sapolsky, 2005). Studies of baboons have clearly demonstrated that the social hierarchy in this species is associated with differential secretion of cortisol, a stress hormone; as one moves (incrementally) to baboons that have a higher social ranking, cortisol secretion in response to stressful stimuli decreases (McEwen & Seeman, 1999). These findings have now been replicated in human beings as well; individuals with greater socioeconomic resources secrete less cortisol in their stress response when compared to their lower resourced counterparts. The same is true for other aspects of the physiological stress response such as increased blood pressure (Colhoun, Hemingway, & Poulter, 1998; Loucks, Abrahamowicz, et al., 2011). In evolutionary terms, the physiological stress response is an effective means of dealing with immediate, life-threatening stressors. However, when the stress response is chronically triggered by the worries and anxieties of daily life or the vicissitudes of low social status within the group, over time, this can result in disease states such as diabetes and high blood pressure. The notion is that the stressors of everyday life are socioeconomically patterned, and so is the stress response.

The Role of Epigenetic Processes

Compelling evidence is beginning to emerge that socioeconomic resources fundamentally alter the structure of the DNA and its associated proteins, which then leads to differential long-term gene expression, and thus differential health outcomes. This process is known as epigenesis (Feinberg, 2008). Evidence among human suggests 1252 loci (i.e., "points") on the DNA molecule whose pattern of methylation (a particular type of protein alternation) is correlated with childhood socioeconomic resources. In animal models, the findings are much more robust. In mice, both prenatal and postnatal experiences affect epigenetic processes which change the health status of offspring across their life course (Diorio & Meaney, 2007; Szyf, 2003; Weaver, Cervoni, et al., 2004). For instance, maternal licking and suckling of newborn mice has been associated with decreased physiological stress response of these mice in their adulthood. The hypothesized mechanism is that epigenetic processes affect the main systems involved with the stress responses (such as the Hypothalamic-Pituitary-Adrenal axis) (Hertzman & Boyce, 2010). Epigenetic processes are also thought to affect the functioning of the autonomic nervous system and the immune system. Though these areas of research are only now beginning to gain momentum, the pool of studies conducted so far are promising.

In sum, there are three primarily distinct but interdependent ways in which socioeconomic resources affect health status: through behaviors, through physiological stress, and through epigenetic mechanisms. At the population level, socioeconomic disparities in health are created by differential vulnerability of lower socioeconomic groups to health-harming behaviors, high stress conditions, and genetic changes which lead to ill-health. At the root of these disparities, however, are the socioeconomic resources themselves. Evidence suggests that tackling any of the mechanisms we have described without addressing the distribution of socioeconomic resources and of the "life conditions" that accompany these resources will result in the persistence of the socioeconomic gradient in HHBs. As we will see later in the chapter, societies vary tremendously in the extent to which they distribute and redistribute resources across socioeconomic groups.

A Life Course Perspective on Socioeconomic Resources and HHBs

A key finding in the literature has been that the influence of socioeconomic resources on each of these mechanisms – health behaviors, physiological stress, and epigenetic processes – occurs also in the context of another dimension, that of time. Life course epidemiology is the study of the long-term effects of physical or social exposures during gestation, childhood, adolescence, young adulthood, and later adult life, which impact the development of health and disease (Kuh, Ben-Shlomo, et al., 2003). Life course studies acknowledge that individuals and environments change over time, and therefore attempt to quantify both the timing (at what period in the life course) as well as the duration of exposures (the total amount) and their corresponding risk on disease outcomes (Hertzman & Power, 2003). Individually, measures such as education, occupation, and income reflect socioeconomic resources experienced at specific periods in the life course. Using a life course perspective and combining more than one of these socioeconomic measures incorporates information on both the timing and duration of exposure and the corresponding influence on HHBs and health overall.

Three life course frameworks have been proposed to conceptualize life course socioeconomic resources (Kuh, Ben-Shlomo, et al., 2003). The "accumulation of risk" model represents the summation of effects of socioeconomic resources across the life course that accrue to increase risk for disease (Kuh & Ben-Shlomo, 2004). In contrast, the "critical/sensitive periods" model acknowledges that individuals could have heightened vulnerability to exposure to low socioeconomic resources at specific periods in the life course – many of which occur in early childhood – resulting in changes in disease risk (Kuh & Ben-Shlomo, 2004; Lynch & Smith, 2005). Finally, the "social mobility" model reflects that an individual's socioeconomic resources are dynamic throughout the life course, and incorporates the trajectory of socioeconomic mobility across a person's life (e.g., from low socioeconomic resources in childhood to high socioeconomic resources in adulthood) in determining disease risk (Pollitt, Rose, & Kaufman, 2005).

A Fundamental Cause Perspective on Socioeconomic Resources and HHBs

As the mountain of evidence has accumulated supporting the link between socioeconomic resources and HHBs, socioeconomic resources alas have come to be considered a "fundamental cause" of HHBs. In a rather influential conceptual paper, Link and Phelan identified three primary reasons for ascribing "fundamental causation" to SES (Link & Phelan, 1995).

First, the association seems to present for almost every HHB: infectious and chronic diseases; physical and mental illnesses; conditions afflicting the entire life course, from birth through death. The few illnesses that do not seem to demonstrate a gradient effect are strongly associated with a single-gene mutation, such as Down's syndrome. Others, which may show a "reverse gradient" with higher SES associated with worse health status, seem to show a flip in the gradient over time. An example is cardiovascular disease which, several decades ago, was a disease of affluence. Over time, this trend now exhibits the opposite patterning, with highest rates of disease occurring in the poorest segments of society in the wealthier nations, and evidence of the flip presently occurring in economically developing nations (Ezzati, Vander Hoorn, et al., 2005).

Second, the general gradient pattern of the association – incremental improvements in SES leading to incremental improvements in HHBs – is present in every society and every historical time period in which it has been measured. Socioeconomic gradients have overwhelmingly been studied in the context of the advanced capitalist societies where, to repeat, they are present for virtually all diseases with the aforementioned caveat. Among the middle- and low-income countries, socioeconomic gradients are apparent in the expected direction for infectious disease such as Malaria, HIV/AIDS, diarrheal diseases, and the like. For chronic conditions and their proxies (such as obesity), the middle- and low-income countries are currently in the process of a transition from reverse gradients to those which mirror the pattern of the association with infectious diseases in these countries.

Third, as earlier discussed, it is difficult to "block" the association between SES and HHBs by acting on any singular intervening mechanism. The basis for this insight is that many of the resources which accompany SES – money, knowledge, power, prestige, social support, and social network(s) – are tied to HHBs through *multiple* mechanisms. This is, perhaps, the essence of the notion that socioeconomic resources are a fundamental cause of HHBs; they lie at the origin of so many paths which lead to disease and its correlates. Interventions to date have tended to focus on intervening mechanisms (particularly on health behaviors). But, in isolation, this is largely ineffective, as socioeconomic resources simply "find" alternative pathway(s) – stress, epigenetics – through which to influence HHBs, and the socioeconomic gradient reasserts itself. That is, socioeconomic resources set forth a cascade of influences that may substitute or complement each other in ways that are only altered by altering the resources themselves. It is perhaps because public health has not addressed the fundamental (root) causes of socioeconomic gradients in HHBs – socioeconomic resources – that these gradients remain persistent and pervasive over time and space.

Next, we examine two cross-national case studies which elucidate the notion of socioeconomic resources as fundamental causes, and of the broader societal contexts which shape them and thus shape HHBs.

Case Study 1: Equity in Resource Distribution Trumps Overall Economic Prosperity

In the first case study, we examine population health in two economically advanced societies – Canada and the United States – whose many economic, political, and social similarities provide a basis for isolating and contrasting their differences. The analysis is taken primarily from Siddiqi and Hertzman (2007) and Siddiqi, Kawachi et al. (2013). In this case study, we establish that (i) differences in average levels of population health have corresponding differences in socioeconomic inequalities in health, (ii) more wealth and spending on health care does not yield better health outcomes, (iii) public provision and income redistribution have greater effects on population health, and (iv) the gradual development of public provision represents the buildup of social infrastructure that has long-lasting effects on health status. We proceed by comparing Canada and the United States on basic health outcomes and a range of determinants of health for which routine data have been collected for all or most of the period between 1950 and the present.

Health Status

Figure 14.2 depicts secular trends in life expectancy by gender (and race, which we will address later) in the United States and Canada. As of 1950, the life expectancy of Canadians and Americans was similar, with a slight American advantage for women and a small Canadian advantage for men. During the 1950s and 1960s a gap opened up, such that both male and female life expectancy in Canada increased faster than in the United States. In the late 1970s the gap narrowed considerably but starting around 1980 it opened again and continued to widen until it reached approximately 2 years by the end of the twentieth century. Although differences in infant mortality contribute to the gap, it is driven, primarily, by differences in adult mortality. A 2-year life expectancy gap may not sound like a lot, but during ages 25–64 it translates into mortality rates 30–50% per year higher in the United States compared to Canada.

A significant part of the explanation for higher average levels of health in Canada seems to be connected to lower levels of social and economic inequalities in health status. Though neither country makes data widely available from systematic

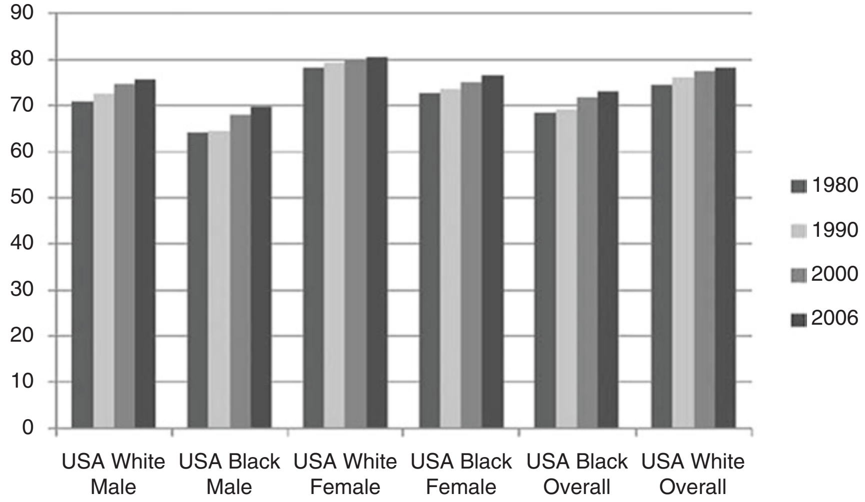

Fig. 14.2 Life expectancy by gender and race: Canada and the United States compared

monitoring of national health inequalities, studies using nationally representative samples from the 1990s and early 2000s demonstrate that the United States showed significant health disparities based on social class (Eng & Feeny, 2007), race (Siddiqi & Nguyen, 2010), and immigrant status (Prus, Tfaily, & Lin, 2010), while those differences in Canada were comparatively muted. In particular, this seems to be driven by superior health in Canada of those in more resource disadvantaged groups. For example, those in the lowest income quintile and with the lowest levels of education in Canada report a higher level of health status and health-related quality of life (as measured by the Health Utilities Index) than their US counterparts (Eng & Feeny, 2007). Other analyses have shown that the poorest 20% of Canadians enjoy the same life expectancy as Americans of average income (Singh & Siahpush, 2002; Wilkins, Berthelot, & Ng, 2002).

In both countries, people belonging to Aboriginal communities (First Nations in Canada and American Indian in the United States) are among the most disadvantaged subgroups. In relative terms, Canada and the United States show similar differentials in overall life expectancy between Aboriginal and non-Aboriginal populations (female life expectancy has a differential of 0.94 years expected life in Canada and 0.93 in the United States while the differential in male life expectancy is 0.90 in Canada and 0.91 in the United States). Interestingly, while the differentials are similar across countries, the life expectancies of both Aboriginals and non-Aboriginals is higher in Canada than in the United States, indicating better overall health in Canada among both groups. On the other hand, for several specific causes of mortality (prostate, cervical, and colorectal cancer, intentional self-harm, pneumonia, and assault), Canada demonstrates a higher relative risk for Aboriginals compared to non-Aboriginals than that observed in the United States (Bramley, Hebert, et al., 2004).

The one exception to the dearth of population-based social inequality data is the collection of life expectancy statistics by race in the United States (see Fig. 14.2) (Xu, Kochanek, et al., 2010). Indeed, these statistics demonstrate startling disparities. In 1980, the black-white female life expectancy differential was approximately 5.3 years (white female life expectancy 78.2 vs. black female life expectancy of 72.9), which increased to 5.7 years in 1990, declined to 4.9 years by 2000, and declined further to 4.1 years by 2006. The black-white male life expectancy gap in the United States was larger at all time points. In 1980, the racial gap for men was 6.7 years (white male life expectancy of

70.8 years vs. black male life expectancy of 64.1). By 1990, this gap had increased to over 8 years. In 2000, it had declined to 1980 levels and by 2006 the gap was, at 6 years, still very large. Though no directly comparable Canadian trend data are available, analysis from a 2003/2004 nationally representative survey demonstrate no significant disparities in health between whites and non-whites in Canada (Siddiqi & Nguyen, 2010).

And so the question becomes how in two countries with many similarities – both are economically advanced, democratic, have high proportions of immigrants, and are racially/ethnically diverse – are health outcomes so divergent. We next examine possible explanations. We start with the factors most traditionally associated with population health, overall economic well-being, and unemployment rates, and then move to factors that have been more recently elucidated as important correlates of population health, including the distribution of income, level of public spending, and neighborhood conditions.

Potential Explanatory Variables

Economy/Labor Market Characteristics

Purchasing-Power-Adjusted Per Capita Gross Domestic Product Gross domestic product (GDP) is an indicator of a nation's overall level of economic well-being. Adjustment for purchasing power equalizes differences across countries in the "value" of currency and expressing GDP on a per capita basis equalizes for differences in population size. From 1975 to 1988, GDP per capita adjusted for purchasing power (Purchasing Power Parity adjusted GDP) grew in Canada and the United States and tracked closely through business cycles. Throughout this period, the United States remained approximately 10% higher than Canada but from 1988 to 1993 this pattern was broken. PPP adjusted GDP per capita continued to grow in the United States, but did not grow in Canada. From 1994 to 2002, growth in Canada and the United States was, once again, in parallel, but because of the 5-year period of stagnation in Canada, its PPP-adjusted GDP per capita remained approximately 20% lower than the United States. Thus, unlike metrics of population health, overall economic well-being during this period seems to favor the United States and suggest that this variable does not explain why health of Canadians outpaced that of its American neighbors.

Unemployment Rate From the end of the Second World War until 1982, unemployment rates in Canada and the United States overlapped with each other from business cycle to business cycle, such that no systematic trend can be detected. From 1982 until 2000 unemployment rates have been consistently 2–4% higher in Canada than in the United States. Similar to GDP, unemployment trends also favored the United States, indicating that this factor is inadequate for understanding the Canadian health advantage.

Trends in Distribution of Income

Gini Coefficient In the 1970s, the Gini coefficient of income inequality, post tax and transfer, was approximately 2 points lower (i.e., more "egalitarian") in Canada than in the United States, with Gini coefficients in the "high 20s" in Canada and the "low 30s" in the United States. From then until the late 1990s the Gini stayed in the same range in Canada but increased (i.e., became more unequal) in the United States, such that there was a 5-point gap by the late 1980s and a gap of approximately 7 points by the late 1990s. In other words, over this time, the United States became an increasingly more income unequal society than Canada. Moreover, the relative redistributive work of the Canadian policies rose compared to American policies from the late 1980s to the late 1990s. The differences in redistributive policies between the countries were particularly marked in their success at poverty reduction (Zuberi, 2001). In 1974/75, taxes and transfers reduced poverty by approximately 11% in both countries. By 1994, poverty reduction had risen to 24% in Canada, but only to 13% in the United States. As indicated by prior literature, the smaller gap in income in Canada compared to the United States is consistent with higher levels of population health.

Public Spending

National Expenditure on Health During the 1960s, Canada spent approximately 0.5% of GDP more on health care than the United States. Canada's universal, single payer medicare plan was fully in place by 1971, while the United States was putting in place a plan that was universal only for seniors. Health care spending in the two countries tracked closely from 1970 to 1973, at approximately 7% of GDP. From 1973 to 1993, spending on health care in Canada rose to 10% of GDP and stayed between 9% and 10% until 2002. In the United States, spending on health care rose to 13.5% by 1993, and further to 14% by 2002. Thus, the 30-year period of universal medicare in Canada, but not the United States, has been one during which the level of spending on health between the countries diverged. Now, Canada spends 4% of GDP less than the United States. Thus, Canada's health was superior even in the face of lower health care expenditures. At the individual level, analyses of racial, immigrant, and class-based disparities have demonstrated that health insurance coverage does not explain why Canada's health is superior; higher disparities in the United States persist even after controlling for health insurance (Prus 2011; Siddiqi & Nguyen, 2010; Siddiqi, Ornelas, et al., 2013).

Public Social Expenditure In 1980 public social expenditures consumed approximately 13% of GDP in both Canada and the United States. By 1990, a large gap had opened, such that Canada was spending more than 4% of GDP more than the United States (>18% and <14%, respectively). By 1998 this difference had largely persisted, with Canada spending 18% and the United States spending slightly more than 14%. This suggests that social spending trends correlate well with population health trends in the two countries.

Neighborhood Conditions

Just as the social welfare policies differentiated the United States and Canada in terms of the extent to which basic resources for health were linked to individual/family income, so too were these nations disparate in the organization of communities and their institutions. The differences were primarily driven by two interrelated factors. First, these nations differed drastically in terms of the degree of economic and racial residential segregation. Data from the late 1980s demonstrates that both blacks and Asians in Canadian cities experienced segregation that has been described as minimal compared to the pervasive and often extreme segregation which characterized the United States (White, Fong, & Cai, 2003). Second, compared to the United States, urban planning policies of provinces and municipalities assured that key community infrastructure such as schools, community centers, parks, and transportation were maintained at a high level across all neighborhoods, not just the wealthier neighborhoods (Zuberi, 2001). Thus, the combination in Canada of greater explicit attention in local policies to equality of resources, and more economically and racially mixed neighborhoods, meant that more people had access to high-level resources irrespective of their individual characteristics or their neighborhood of residence.

Analysis

Over time, among two comparable high-income nations, trends in national-level indicators suggest that maintaining a narrower distribution of income and providing greater publicly available resources yields higher levels of population health than can be achieved through high levels of overall economic growth and investments in health care systems.

The period during which Canadian life expectancy increasingly surpassed the United States was a time when Canada's levels of public spending on social programs, the redistributive work of its social safety net, levels of maintained income equity, and levels of access to education were all surpassing the United States. Indeed, despite periods of relatively high unemployment, Canadian health status did not suffer.

The point of unemployment is especially useful for illustrating Canada-US differences. Where the labor market intersects with the social safety net, Canada's ability to support population health becomes particularly evident. Canada scores higher on the indexes of unemployment protection, labor relations, and corporate governance, constructed during the 1990s, which are designed to distinguish "liberal" from "coordinated" market economies (Estevez-Abe, Iversen, & Soskice, 2001). Unemployment protection (in part) represents the extent to which wages and benefits accrue to individuals, even in times of unemployment. The higher the unemployment protection score, the greater the wages and benefits afforded to unemployed workers. As such, unemployment protection represents a set of social policies that are designed to *transfer* income from the wealthiest members of society to the unemployed. In turn, to fund this aspect of welfare policy requires the presence of taxation policies that are progressive in nature; withholding larger amounts (as a percentage of one's income) from the rich compared with the poor. Corporate governance refers to the extent to which the state has a role in determining and enforcing the rights and responsibilities of corporations. Higher scores on this index suggest greater government input. Compared with the United States, Canada features lower wages of chief executive officers and other upper management and higher tax rates (and fewer loopholes) for large corporations.

On the other hand, Canadian health status increasingly surpassed that of the United States in a period in which economic growth in the United States moved increasingly ahead of Canada, and American unemployment rates, for the first time since the Second World War, were consistently lower, *a result that is somewhat* counterintuitive (though is consistent with their placement on the health/wealth trajectory displayed in Fig. 14.1). As mentioned earlier, research on other social processes in relation to population health came about only after cross-sectional studies showed little association between GDP per capita, health care expenditures, and measures of population health. Moreover, our data demonstrate that, even when a long view on wealth, spending on health care, and health are taken, the association is nonexistent. Even health insurance coverage seems to do little to abate cross-national differences in population health. Spending on health care in the United States increasingly surpassed Canada, during a time in which Canada had a national medicare scheme and the United States did not. (It should be noted that total government spending *per capita* on health care is greater in the United States than in Canada, despite the fact that coverage is not universal in the former.)

The Canada-US comparison is one of public provision and redistribution trumping traditional economic growth and direct health spending in producing population health. This conclusion is reinforced by the observation that, from the early 1970s to the late 1990s, socioeconomic gradients in health status did not get steeper in Canada. Over the 25-year period from 1971 to 1996, each of the income quintile groups in Canada gained equitably in terms of rising life expectancy (Wilkins, Berthelot, & Ng, 2002). The same was not true in the United States, where the highest income quintiles gained life expectancy at a faster pace than the lowest quintile (Singh & Siahpush, 2002).

Case Study 2: Health During Times of Economic, Political, and Social Transition

Our second case study examines determinants of health in the set of middle-income nations in Central and Eastern Europe (CEE) following the major (and relatively sudden) societal transition there in the late 1980s and early 1990s. It is taken primarily from an analysis conducted by Siddiqi, Bobak, and Hertzman (2009). The overall context is that, during this time, in much of the CEE, a change of guard occurred from "hardline" Soviet-style communist regimes to equally "hardline" capitalist (free market) economic approaches, a phenomenon described as "shock therapy" that was marked by a breakdown in the trade relationships among the Warsaw Pact countries, rapid economic decline, and high rates of unemployment and inflation (Brainerd, 1997; Klein & Pomer, 2001).

Health Status

Population health statistics suggest that during the first 4 years of the transition period, there were dramatic increases in mortality among males and females of working age. Among males aged 30–49, mortality rose as much as 70–80% in Russia, 30–50% in Ukraine, and 10–20% in Hungary, Bulgaria, and Romania. Among females, mortality in the same age range rose 30–60% in Russia, 20–30% in Ukraine, and more modestly in Hungary, Bulgaria, and Romania (UNICEF, 1994).

The conditions leading to this mortality increase were primarily cardiovascular disease and injuries (UNICEF, 1994). However, these were also the most prevalent conditions in working age persons at the beginning of the transition period; mortality due to these two causes was increasing even before the end of the Soviet period. Thus the working premise for this case study is that the vulnerability in this group was general: that is, a crisis in health status that simply expressed itself through the principal causes of mortality for its age group. This suggests, then, that explaining the health crisis in CEE must go beyond understanding the determinants of these conditions, and address the factors that created general risk of mortality, in particular among the working age population.

Analysis

In the analysis we present below, CEE represents a case study in which the collapse of government institutions and of civil society created for citizens conditions of economic deprivation, social isolation, and loss of control over life that, in turn, undermined the health status of the population.

Prior to rapid transformation out of communism, societies in CEE (in particular, Russia) had been depicted as having the character of an "hourglass" (Rose, 1995). This was intended to evoke the image of a society with an elite top which controlled the available economic political structures; a weak civil society in the middle (to varying degrees, depending on the country), whose capacity to buffer the stresses of daily living was limited; and at the bottom, the masses of individuals and families most of whom relied on multiple sources of support – from intimate associations to the state. During communist times, the relationship between the top and the bottom of the hourglass was stable, with a modicum of mutual obligation between the state and the individual.

Both empirical and observational accounts of the effect of the transformation yield important insights. Observationally, it has been noted that, after capitalist reforms began to be instituted in 1989, the twin ideologies of individualism and free market created unprecedented prosperity for those at the top of the hourglass and widening the social and economic distance between these elites and the masses. These new societal philosophies allowed those at the highest levels to abandon their responsibilities to those at the bottom, exposing the vulnerability of the common person – who had neither the aid of civil society nor the economic and political clout on which to depend.

In an analysis of the Russian Barometer survey, we found that people reporting higher levels of material deprivation (measured by the frequency with which people reporting going without food, heat, or necessary clothes and shoes) were more likely to report poor self-rated health (Table 14.1). Such material insecurity was rampant at the time. Polarization of the labor market had dramatically increased, as noted by a decline in the proportion of the population who were economically active simultaneous with an increase in wages for those who remained active (Forster & Toth 1998). According to sample surveys of ten countries in the region, conducted in the winter of 1993–1994, between 20% and 53% of households reported that they could not cope economically; even when resources gleaned from the informal economy were considered (Rose, 1995; Rose & Haerpfer, 1994).

For the most vulnerable members of society, this left only the intimate realm of family and informal social supports to compensate for a lack of support structures at the higher levels of social aggregation. In the same survey in Russia, respondents who reported relying exclusively on formal

Table 14.1 Odds of poor self-rated health among Russians after the collapse of communism

	OR (95% CI)	OR (95% CI)
	Men	Women
Education		
Primary	1.0	1.0
Vocational	0.66 (0.31–1.42)	0.55 (0.29–1.03)
Secondary	0.39 (0.17–0.88)	0.35 (0.17–0.70)
University	0.50 (0.17–1.40)	0.43 (0.18–1.03)
Material deprivation (quartile)		
1 (least)	1.0	1.0
2	1.56 (0.74–3.38)	1.32 (0.68–2.55)
3	3.17 (1.56–6.41)	1.87 (1.04–3.36)
4 (most)	2.70 (1.25–5.83)	2.37 (1.29–4.33)
Coping with economic circumstances		
Yes	1.0	1.0
No	1.55 (0.93–2.58)	1.17 (0.77–1.77)
View on civil society (quartile)		
1 (most traditional)	1.0	1.0
2	0.61 (0.31–1.20)	0.81 (0.47–1.37)
3	0.67 (0.35–1.27)	0.47 (0.26–0.84)
4 (least traditional)	0.68 (0.32–1.47)	0.84 (0.45–1.54)
Reliance on formal institutions only		
No	1.0	1.0
Yes	2.83 (1.47–5.43)	1.89 (1.05–3.41)
Married		
No	1.0	1.0
Yes	1.35 (0.67–2.73)	1.05 (0.69–1.64)
Control (quartile)		
1 (lowest)	1.0	1.0
2	1.02 (0.5–1.95)	0.63 (0.37–1.09)
3	0.39 (0.20–0.76)	0.44 (0.25–0.75)
4 (highest)	0.39 (0.18–0.83)	0.46 (0.24–0.88)

institutions (employer, state, public organizations, charities, or church) were more likely to report being in poor health than those who could also rely on informal sources of support (Table 14.1). We also measured whether respondents had trust in "traditional" institutions of Russian society (e.g., police, courts, army) or in those of the "new" Russia. Those more likely to place trust in traditional institutions had poorer self-rated health. There is also supportive evidence from past research which suggests that those who were left to rely *only* on formal social capital were more likely to rate themselves as having poor health status (Abramson & Inglehart, 1995). The variations in country-level mortality support the thesis that, in those parts of CEE which had stronger civic traditions going back over the past several centuries, this tendency was less pronounced than in those places where civic traditions had never been strong. In these latter regions, life became, in Hobbesian terms, nastier, more brutish, and, for some, a great deal shorter than before.

Our analysis also revealed that these factors had a more pronounced effect on men than women, and that men who were unmarried were much more likely to report being in poor health (Table 14.1). This is consistent with earlier findings that single people were more vulnerable to declines in health status than married people during the political transition (Hertzman, Kelly, & Bobak, 1996). We interpret this result as an indication of further social disconnectedness and isolation. Taken in the context of the other results, the combination of an inadequate personal social network, and inability to rely on formal civil society (that essentially wasn't functioning) had detrimental health effects for individuals and, the fact that this was happening on a mass scale lead to detrimental population-level health outcomes.

This case study illustrates the effects on population health induced by swift and massive transformation of economic, political, and social aspects of society following the transition out of communism in Central and Eastern Europe. The dismantling of communist institutions and the rapid rise of market-based institutions brought with it both suddenly diminished national income and a drastic increase in income inequality. These new economic conditions in turn led to deleterious effects on the social fabric of society. Specifically, two (related) social shifts were induced: (1) for the majority of citizens, particularly those at the lower end of the socioeconomic spectrum, "material" security was severely compromised; and (2) social security – both that afforded by intimate relations and that by broader society – had drastically eroded. Our analyses suggest that, together, the deterioration in these factors played a major role in the decline of health status in this region.

The principal causes of death in this time period seem to point away from explanations that link this societal atmosphere to health solely through "material deprivation." This would be supported, for instance, by illness that could be traced primarily to nutritional deficiencies (e.g., wasting). Rather, our study suggests that one major way in which changes in macro-features of society led to ill-health was through the stress brought on by the rapidly changing conditions. We submit, in other words, that both material and social insecurity led to conditions such as cardiovascular disease through the well-documented physiological sequelae of stressful societal circumstances.

Based on the insights gathered from our analyses, we conclude that the root causes of major shifts in population health lie primarily at the policy level – in the case of CEE, it was the rapid economic reforms that ushered in new societal conditions – and that these policies set forth a cascade of changes at all levels of society, from national to one's most intimate connections. Our analyses also indicate that, during a time of transition to free market principles, population health is best protected by policies that maintain relative equality in income through the regulation of market institutions and systems of social protection and welfare.

A Framework for the Interdependencies Between Socioeconomic Conditions and Health and Health Behaviors

As the review and case studies we have presented illustrate, the relationship between socioeconomic resources and health status transpires – and is modified – in multiple ways and at multiple levels of society. Of course, we have not made the observations outlined in this chapter *de novo*. We build not only on the body of literature that we have reviewed and on our own contributions to this field of study, but also on preceding conceptual frameworks that have summarized the interdependencies between socioeconomic conditions and HHBs (Solar & Irwin, 2010). Sallis, Owen, and Fisher (2008) provide an excellent review of models that have been particularly influential in the study of health behavior (Sallis, Owen, & Fisher, 2008). However, such models have not fully embraced the multiple contexts – those geographically based and otherwise – nor have they incorporated the temporal dynamics – both those of individuals across their life course as well as of societies across historical time.

In Fig. 14.3, we provide an updated social-ecological model which we have modified from our earlier work (Irwin, Siddiqi, & Hertzman, 2007; Siddiqi, Vaghri, et al., 2012). Like others, the model depicts the individual as the center of a system that is affected and affects the contexts surrounding her. Also like others, each part of the system reflects many different characteristics which, for the sake of brevity we will not elaborate on. However, our model makes three primary additional contributions. First, our model portrays the development of an individual over the lifespan as a means for depicting the influence of context on the biologically and socially developing person over their life course that, as our review suggests, has been well established. Second, our model, like others before, also depicts several "nested" levels of societal aggregation. The shading and overlapping of the environments depicts their interdependencies. Moreover, the arrow through the model is intended to capture the element of historical time and thus, the accumulation of changes in societies (e.g., changes in policies) that also influence individuals. The notion is that just as individuals' life course trajectories matter, so too do the historical trajectories of societies. Finally, our model adds contexts that have previously been discussed, but not well integrated into the dominant frameworks and models in the field: the "environment" of health and other social services and the "environment" of relational communities – communities defined by social relations, such as those based on culture, religion, and even by illness status (Berkman & Glass, 2000; Fisher, La Greca, et al., 1997). While space prevents us from elaborating extensively, on these associations, both of these environments have been found to be associated with health status and socioeconomic resources (Berkman & Glass, 2000; Smedley,

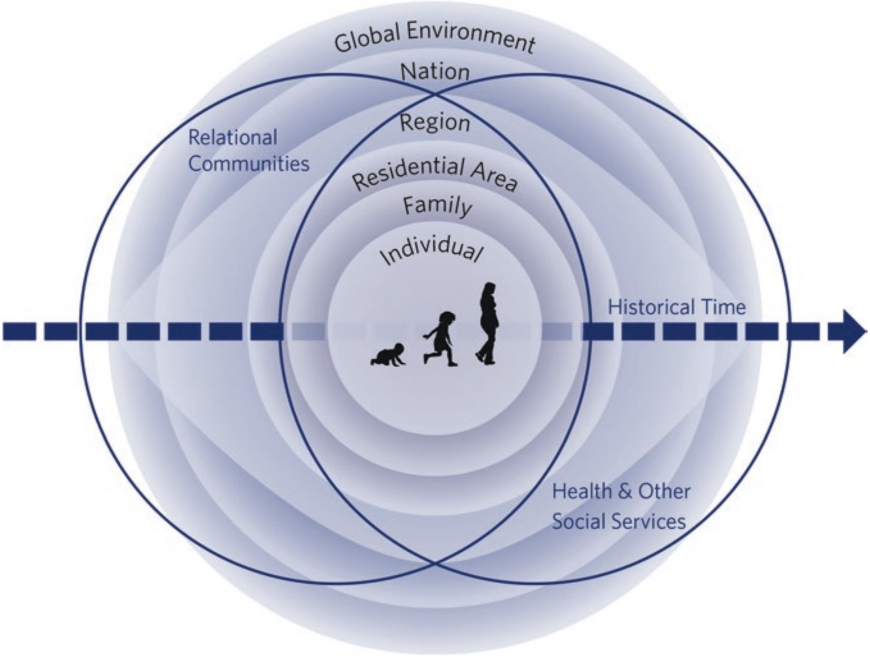

Fig. 14.3 An updated social-ecological model

Stith, & Nelson, 2003). Yet, these are not environments which are neatly subsumed by the other geographic levels described in our framework and previous frameworks. Instead, we overlay these "environments" across the geographic contexts which they touch. Our model thus depicts a broader set of contexts than has previously been captured and incorporates important dimensions of time, both of individuals and of societies. In doing so, we more fully represent the body of evidence that has thus far accumulated on the production of health for individuals.

Discussion

This chapter highlights the centrality of economic resources – and, more accurately, the cluster of socioeconomic resources – for HHBs. In fact, socioeconomic resources have come to be known as *fundamental causes* of HHBs. That is, they are tied to most every pathway through which the health of the human body is affected. They are most certainly tied to the manifestation and expression of health behaviors, but also to a variety of other biological pathways, including affecting physiological stress systems and epigenetic processes. On the other hand, the degree to which and ways in which socioeconomic resources matter seems to vary across communities and societies – socioeconomic gradients are less "steep" in some societies than others – which has led to the hypothesis that it is possible to mute or modify the effects of socioeconomic resources on health by changing resource distribution itself, or by changing the extent to which individual socioeconomic resources are needed to "purchase" opportunities for healthy living (vs. having these opportunities universally provided, e.g., by governments). We have also seen that both the community (neighborhood) and national contexts are critically important in this regard. Of note, eliminating the role of socioeconomic resources entirely seems unlikely, given that, in large part, it is the value of a particular set of resources *relative* to those of others across the socioeconomic spectrum that has importance for health status; as long as there is a socioeconomic spectrum of any span, there are likely to be health inequalities across this spectrum.

The work presented in this chapter leads to a key set of questions which will be important to further investigate: How do the socioeconomic resources of individuals/families, communities, and societies interact to produce well-being and mitigate health inequalities? How do societal level decisions about resource distribution work to address multiple aspects of human and societal well-being, including health but also extending to human development (education), a qualified work force, social cohesion, and the like? Finally, what kinds of factors allow citizens and their representatives to work toward the kinds of family, community, and societal supports that are optimal for health and well-being? Now, knowing the importance of socioeconomic resources, the future of the science in this area and of designing sound policy lies greatly in solving these complex dilemmas.

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15

Improving Health and Tackling Health Inequities Through the Non-health Sector

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Introduction: Setting the Agenda

The basic message of this chapter is if you wish to markedly improve population health in an equitable way, it will be necessary to orient policy toward the non-health sector such as housing, and to take into account the environment, and especially the built environment, in which people live, work, and play. Even though some recurrent arguments can be identified in the contemporaneous public health literature about the importance of ecological factors, there is now a certain agreement among epidemiologists that the environment plays a critical role in individual and population health. Overall, the observable divergences among studies may be attributed to a large extent to the existence of competing definitions of the concept of “environment,” as some authors include social factors that affect human health while others do not. We will argue strongly in this chapter that the social, economic, and cultural conditions should be considered as a significant part of our environments. This echoes the well-known definition of social determinants of health – “the circumstances in which people are born, grow up, live, work and age” (WHO, 2008, 2010a). This comes as no surprise since the bulk of evidence from social determinant research and informed practice suggests that in order to improve health and reduce health inequalities, it is necessary to act on areas of life and activity lying beyond the health sector (Kelly, Morgan, et al., 2007; WHO, 2008, 2010a; Marmot, 2010). This also necessarily favors a broad way of defining health such as that put forward by the International Union for Health Promotion and Education, namely, *Health is a basic human need. It is fundamental to the successful functioning of individuals and of societies. (…/…) The main determinants of health are people’s cultural, social, economic and environmental living conditions, and the social and personal behaviors that are strongly influenced by those conditions* (IUHPE, 2007 as cited by Abel & McQueen, 2013). Empirically, these various factors have consistently been found to contribute to the formation and maintenance of social inequalities in health. Health inequalities, or preferably health inequities, have been classically defined by Whitehead as differences in health which are *avoidable*, *unnecessary*, and *unjust* (Whitehead, 1991).

At this stage, it is important to be clear about what we mean by health inequalities and what is

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at stake for policy makers, public health practitioners, urban planners, and other non-health sector stakeholders. There will always be differences in health and indeed other differences such as educational success between individuals and groups. Beyond such personal differences, differences in environmental exposures and resources may also be found between individuals and between social groups within the population.

Crucially some differences matter more than others in that they occur systematically between different social groups or populations and may be related to loss of potential and social injustice. These are at the heart of the impact of the non-health sector and policy on health. Understanding and tackling these will offer a shape and rationale to the contents of this chapter which we will now outline.

Scope of the Chapter

First, let us give a *working definition for the non-health sector*. A working definition of a *health system*, as proposed by the World Health Organization (2000a), is a system "whose primary purpose is to promote, restore, or maintain health." We will mirror this definition and suggest pragmatically and conversely that non-health policies are policies that lie outside the health system domain (i.e., in the non-health sector) and *do not have as their primary aim to promote, restore, or maintain health*, even though, as we will argue, policies in the non-health sector may have the potential to prevent disease and improve health greatly. The case of environmental protection and environmental health lies on the borderline of such a definition, but we have chosen to examine this since it has a key role to play, and in practical terms, it is almost impossible to separate non-health areas such as housing and urban development from environmental health and protection.

Once one accepts this view, it makes a good sense to focus on what is underlying persistent good health in certain groups and persistent bad health in others, i.e., social determinants of health. Since it is obvious that people pursue their lives on the whole, with some notable exceptions, outside the health system (as usually defined), it is crucial to take into account sectors beyond the health sector itself. As Ollila (2011), citing Rose[1] (1958), states "The fact that health is largely constructed outside the health sector has been known not only for decades but even for centuries." To stress this point, one may cite René Villermé, a French physician working during the first half of the nineteenth century in Paris *Thus however one looks at it, the same result stands out; that is mortality in the different quarters of Paris is in general inversely related to the degree of 'how comfortably off' their inhabitants are*[2] (our translation, Villermé, 1830, p. 322).

We will first examine in some detail a key question which has great relevance when designing and thinking through non-health sector policies and interventions, namely, "When does a difference in health become a health inequity?" Notably, we will suggest seven principles which should be considered when addressing health differences and potential health inequities (Harpet, 2011, 2015). Following this, we will examine findings on the social gradient in health and how health and health inequities are determined, including the health inequality synthesis of the World Health Organization Commission on Social Determinants of Health. We will then go on to put forward a model of non-health sector action incorporating both structure and agency (Frohlich & Abel, Bourdieu, Sen) but also drawing on insights from environmental science, a life course perspective (Ben-Shlomo, Kuh), ecosocial theory, sociobiological embodiment (Krieger/Hertzman), and salutogenesis (Antonovsky/Lindstrom). The role of intersectoral working will be crucial for tackling health inequities and not without challenges. We turn then to examine critically the contribution of the health sector to health and briefly pause to explore why until fairly recently, the non-health sector has been

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[1] "The fact that health is largely constructed outside the health sector has been known not only for decades but even for centuries" Rose G. A history of public health. Expanded edition. First edition 1958. Baltimore: The John Hopkins University Press; 1993.

[2] "Ainsi donc de quelque manière que l'on s'y prenne, le même résultat surgit toujours; c'est. que la mortalité dans les divers arrondissements de Paris, est. en général, en raison inverse de l'aisance de leurs habitants."

somewhat neglected. We will then go on to give an extensive range of examples drawn from the social science literature to emphasize the range of policies; the different levels of action (macro, meso, micro); the complexity of interactions, involving both social and cultural dimensions; and the role that both structure and agency may play in the impact of the non-health sector and policy on human health. Links among the economy (including the impact of globalization and recessions), labor market, employment, unemployment, work conditions, and health are explored. Particular accent is placed on how the degree of inequality in a society may itself be a factor influencing health and other social issues (Wilkinson & Pickett, 2010).

The aim of our review is to be illustrative rather than systematically exhaustive.[3] To this end we have highlighted a number of sectors and social policy issues. These include inclusive policy for disabled people and the impact of culture and religion. We will offer examples from the education sector and show how discrimination and territorial segregation may add further disadvantage to other social and environmental difficulties. We will then go on to discuss critically how contexts may determine health and health inequities. This will include work in environmental health but will go on to consider the impact of context on health, health inequities, and health behaviors within neighborhood studies. We will explore the concepts of space and place to understand context and the reciprocal relationship between the population and its neighborhood, including the argument that "people make neighborhoods and neighborhoods make people." We will review research and experimental approaches to studying space and place, including examining how people living in a community define their own community rather than only relying on objective geographical boundaries. We will focus particularly on the impact of urban life, housing, and urban planning, sectors that are particularly illustrative of non-health policy, and of how environments may impact human health and behavior. This will examine risks but also the resources available within urban environments. We will review how health practices, such as smoking, involve interactions between structure and agency such as individual capabilities, different resources, and the possibility they have to mobilize health-giving resources.

We will look at Health in All Policies and health impact assessment (Kickbusch, McCann, & Sherbon, 2008; Roundtable on Population Health Improvement, Board on Population Health and Public Health Practice, & Institute of Medicine, 2014; Kemm, 2006). In this, we will examine methodological challenges and suggest that it will be important in the future for scientists to move beyond seeking causality to embrace complexity and a science of solutions (Potvin, Petticrew, & Cohen, 2014). We will go on to sketch different strategies founded on theories of social justice that could be put forward in an attempt to improve the health of the population while at the same time taking health inequities into account. Lastly, we will further reflect and draw conclusions on the future role of non-health policy in its impact on health. It is convenient to divide such policy into different sectors since this is how the world views it and how much research on non-health policy is structured. It is, however, illusory as social determinant research shows to make a sharp separation between so-called health policy and non-health policy. Policy makers seeking lasting and long-term impact on population health should rethink the question of responsibility and health protection, promotion, and improvement to include participation, complexity, and intersectionality between the health sector and other policy areas.

What Do We Mean by "Inequity"?: Differences and Inequities in Health

A difference may be apprehended objectively or subjectively. We will consider in this chapter that a difference is a degree of dissimilarity between two states or processes. This may be expressed as

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[3] Furthermore, we are very conscious that it is largely based on European and North American experience. For a wider perspective on worldwide urban health incorporating experience from India, South America, and Africa, readers are recommended to consult the Lancet Commission findings: Rydin et al., 2012.

either a qualitative or quantitative value. An objective measurement of this allows us to compare two states or processes. This should be contrasted with the idea of an inequality, or preferably an inequity, which is a matter of moral judgment or/and a question of social justice. So an important question for non-health sector policy and social and environmental justice is "When does a difference in health become an inequality or an inequity in health?" Recent philosophical work in environmental health justice by Harpet (2015) suggests that inequities (or unjust inequalities) which impact on freedom and the capacity to live in dignified and healthy conditions may be characterized through reference to seven principles, namely:

1. A sentiment of injustice
2. The existence of excessive differences or gaps between individuals and groups
3. Unacceptable degree of harm and prejudice undergone
4. The principle of clearly established causes and their legitimacy
5. The presence or participation of at least one third party witness
6. Infringement of dignity
7. Accumulation of burdens, inequalities and vulnerability

These seven principles offer a framework for social justice advocates and policy makers when approaching questions of health inequities since they offer a range of factors which could be referred to determine whether injustice has occurred and, if this be the case, the degree of injustice to which people are subjected.

1. *A sentiment of injustice*: From an anthropological perspective for inequities to be perceived as such, first and foremost, there must be recognition by the people concerned that alternative existences are imaginable and may be achieved through change. Life is not just a matter of preordained fate. Comparison of living conditions (notably material living conditions) of persons of different status may lead to the recognition of injustice. Injustice highlights need and foregrounds a call for justice. Absence and lacks may be considered as being as real as presences. Crucially, justice is to be seen as being one of a series of legitimate ideals and as taking the form of an unending quest rather than simply being taken for granted. Justice should not be seen as equivalent to equality since fighting injustice by imposing the norm of strict equality would not take into account diversity. Furthermore, we would run the danger of being left with a society made up of interchangeable individuals or a collective lacking singularity. In contrast to such absolute equality, Rawls's principle of justice as fairness highlights that formal equality in the eyes of the law implies that everyone enjoys the same right to exercise their freedom and the same duty to respect the same civil laws (Rawls, 1971).
2. *Excessive differences*: Secondly, the idea of injustice highlights that some degrees of difference between people may be considered to be excessive. This may result in the emergence of a feeling of guilt. The privileged members of society may feel they are partly responsible for the privation of others. Symmetrically, the underprivileged may experience feelings of envy and seek to right this. This heralds so-called distributive justice which attempts to right unequal sharing of burdens and goods. Primary inequalities are righted through ensuring that fair proportions are distributed. However, is fair distribution of social goods in itself sufficient to establish justice? The notion of capabilities teaches us that justice may not necessarily be achieved through the mere attribution of means (Sen, 2009). Thus, two individuals with different constitutions may not act in the same way even when they find themselves in similar conditions with similar resources at their disposal. Aristotle in his *Nicomachean Ethics* explicitly stresses the idea of just proportion (fair shares) as being a condition for justice and that injustice involves having too little or too much. Unfair shares are easily visible and easily measurable since they represent a deviation from the just medium. The size of the gap clearly matters.

Nevertheless, as we have previously stated, differences per se are measurable in terms of a heuristic process, while inequalities involve questions of morality and ethics. Rawls's "difference principle" in his theory of justice (Rawls, 1971) argues strongly that the greatest benefit should be attributed to the least-advantaged members of society.

3. *Inacceptable harm*: Thirdly, injustice arises with the recognition of the suffering being inflicted and perceived as inacceptable to persons of sensibility. Such suffering can be attributed to destiny, divine, or diabolic works or as a result of the actions of men. Such suffering resists objectivation. How can external environmental causes be related to a degree of personal suffering? Such self-perceived impact on one's individual physical, psychological, or moral state is eminently subjective. Within environmental health, such questions arise in the case of so-called ultra-sensitive individuals or groups, e.g., in connection with perceived impact of telephone masts and high-tension electricity pylons (SCENIHR, 2009). Nevertheless, one must be wary of dismissing out of hand such self-perceived "unscientific" suffering as being nonexistent.
4. *Establishing causes and their legitimacy*: Fourthly, to speak legitimately of injustice in the case of misfortune or suffering necessarily entails that any differences that may occur between individuals and groups must be explained through reference to clear definable causes. Furthermore, there are no contextual reasons which render such differences legitimate. Thus, if the risk of injury is greater in population (A) of young men than in another population (B) of young men of similar characteristics, it would be reasonable to seek causes of this difference and declare that a health inequity was at work. But if one takes into consideration that the first group has freely chosen to go skiing while the other group has not, then the idea of inequity would no longer be tenable (Whitehead, 1991). To establish a health inequity, the causes must be clearly established. In the case of urban health, for instance, large differences in life expectancy may occur between two city areas. There is notably a difference of 28 years in life expectancy between two areas within the City of Glasgow (WHO, 2011a). These may be considered as health inequities if one is able to show what causes these differences and that these differences can be avoided. If such differences are due to high alcohol consumption, smoking, and drug use, is it legitimate to speak of health inequities? Here another factor comes into play: the idea of responsibility. In deontic egalitarian ethics, injustice is not deemed to have occurred if no wrongdoing can be attributed to others (Parfit, 1997). Wrongdoing is generally more easily established and attributed to individuals than to organizations, institutions, corporations, and government.

Here views within the public health domain may differ between advocates of individual responsibility associated with proximal explanations and those favoring more distal explanations. The latter recognizes that the socioeconomic environments and cultural mores have great impact on people's practices and aspirations. Of course in all such agency-structure debates, the truth of the matter will lie in the interaction of people's lives with their physical and social environment. In the case of teenage pregnancies, these will occur in all strata of society (Wilkinson & Pickett, 2010). The important scientific question is not "Why do they occur?" but rather "Why do they occur more frequently in certain urban populations than others?" The answer logically lies not in some personal flaw within individuals but the different social conditions in which those individuals have developed and lived. Since in the case of Glasgow it is possible to link social inequality with health inequality, we are justified in speaking of health inequities. As Link and Phelan (1995) would suggest, the fundamental cause, "the cause of the causes," is not alcohol, smoking, or drug use but the unequal distribution of income, social conditions, and life chances. To argue otherwise would lead to becoming a "prisoner of the proximate" (McMichael, 1999).

5. *Third-party witnessing*: Fifthly, the idea of injustice will emerge if the person or group concerned can take a step back and distance themselves from their own situation. Often, such distancing will be facilitated or require a third-party witness. The witness can then offer an independent appraisal of how one group is faring in relation to another comparable population. This bearing of witness is crucial in creating and permitting a sense of injustice to emerge and crystalize, thus achieving greater legitimacy. Public health authorities and institutions have the duty to play this role of third-party witnessing thereby distinguishing legitimate differences from unacceptable differences or, in other words, inequities.
6. *Infringement of human dignity*: The sixth principle is related to the nonrecognition or infringement of human dignity. This may be due to negligence, ignorance, or deliberate oppression of others. Treating all humans with dignity ultimately implies treating them as an end in themselves rather than as a means, as in Kant’s categorical imperative. Differences in health may occur due to oppression or discriminatory practices. Under the European nondiscrimination directives, protection is offered against discrimination on grounds of sex, racial or ethnic origin, age, disability, religion, and sexual orientation. In addition other grounds such as “language,” “social origin, birth, and property” and “political or other opinions’ are featured in European court of human rights rulings (EUAFR, ECHR, & CE, 2011). Discrimination and oppression have much in common, although the latter is probably more extreme in degree. Oppression may be considered as being systemic and structural phenomenon permeating a whole society in which one group dominates another group and treats them as being less than human (Young, 1990). “No matter which definition you use, oppression is when people reduce the potential for other people to be fully human. In other words, oppression is when people make other people less human” (Young, 2004). Oppression may take several forms and not all of which involve violence or harsh treatment. Perhaps, it is at its most insidious when the people who are oppressed do not realize this, having no voice or will to change their condition. Such hegemony may also be tied to Seligman’s “learned helplessness” (Peterson, Maier, & Seligman, 1993). It is of course legitimate to speak of health inequities when it may be demonstrated that differences in health have arose due to oppression or non-respect of human rights and equal citizenship.
7. *Accumulation of inequalities and vulnerability*: The seventh principle is central to our treatment of non-health sector policy, namely, the accumulation of inequalities. One inequality is exacerbated by another, increasing the risk of further inequalities. Just as it is possible to recognize overabundance, it is also similarly possible to recognize vulnerability and the duty to act, to support, or to compensate vulnerable and disabled people. This involves a sharing or redistribution of resources from those with to those without or in need. Such acts of sharing or redistribution express and recognize our human empathy.

Inequities in Health

Differences in health may thus be seen between individuals, groups, populations, or neighborhoods. Explanations of differences between individuals may be linked to physical or psychological characteristics or individual behavioral practices. It is important to make a distinction between such individual level explanations based on comparison between individuals where responsibility is more often than not lodged in behavioral or essentialist terms and population level explanations arising from comparison and analysis of groups or populations and the impact of their living and working conditions on health (Marmot, 2000). In the former, answers are sought in behavior or individual psychological and physical makeup. This may lead to interesting and valid solutions but often neglects the impact of non-health sector policy and factors associated with the environment and the neighborhood in particular. In the latter case where differences are seen between groups, the differences in health that matter are systematic and tend to cumulate with other inequalities. More often than not, they are associated with what resources are available within the environment and the capacity of the people to access and mobilize such resources to cope with health threats and to favor and foster health-promoting practices. A study of differences between groups will not tell us who, in the groups, will fall ill, or die early, or why any particular person falls ill or dies early. It will however give us information on what factors within the physical and sociocultural environment (and this includes non-health sector policies and urban infrastructure) will favor or harm health and how these factors are distributed differently between social groups. Furthermore, through answering these questions, it will suggest solutions based on righting inequalities of resources or access. Such solutions will necessarily be systemic. They will inevitably involve not just actions and interventions located in each individual sector but also the joining together and interactions between different non-health sectors and indeed the health sector itself.

A Social Gradient in Health

Differences in health may be revealed and characterized through statistical analysis linking health and illness, disease and death, and to latent variables of social inequality such as income, education, and socioeconomic status. Typically, an inverse social gradient emerges. Increases in income, education, or socioeconomic status are associated with improved health status and decreases in mortality and morbidity across a range of diseases. Reduction in income, education, and socioeconomic status is associated with worse health and increases in mortality and morbidity across a range of diseases. Causality may occur in both directions, i.e., poor health may also lead to lower socioeconomic status, income, or education, so-called health selection. Or socioeconomic status, education, or income may lead to health status. Nevertheless, the overriding tendency and bulk of evidence tend to show that social position determines population health status, and for this reason, we may speak of social determinants of health and health inequalities (Marmot, 2010; WHO, 2010a). Three remarks may be made. Firstly, it is not just a question of those with high levels of morbidity and mortality and low economic status being solely involved, since there is a systematic relationship between health and the entire range of socioeconomic status resulting in a social gradient. Social gradients seen throughout the world in different societies are difficult to explain through evoking health selection. Secondly, where health selection does occur, this will lead to diminishing, rather than increasing, the social gradient. People of higher socioeconomic status with poor health moving down the social ladder nevertheless will tend to have better health than those further down the social gradient, and similarly upwardly socially mobile people will tend to have worse health than those within the groups they join. A smoothing out of the gradient would occur (Marmot, 2005).

Thirdly, although within the public health literature the term health inequality has become the standard, in the United States, the term "health disparities" is often employed and frequently refers to questions of access to health services. Furthermore, this term is traditionally associated with health differences found between different ethnic groups. In Europe vital statistics of social class are habitually found in censuses and surveys, whereas the situation regarding ethnic information varies, the French constitution notably outlawing the collecting of nationwide ethnic statistics. Policy will often depend on what we can count or not, within the public statistics information system (Trostle, 2005). As Frohlich and Abel (2014) maintain, health inequities should be the preferred term[4] as it places a moral emphasis on "the inequitable processes leading to these health inequalities." These may also

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[4] The WHO website gives the following definition through answering the question "What are health inequities or inequalities?" *Health inequities are avoidable inequalities in health between groups of people within countries and between countries*. See http://www.who.int/social_determinants/thecommission/finalreport/key_concepts/en/ consulted 20 September 2015.

include discrimination of ethnic groups leading to poorer life chances and poorer health. As Tawney's writing in the 1930s, cited by Bickenbach (2009), stresses *inequality* per se, involving the endowment of different talents to different individuals is not what matters, unless it can be shown that such inequalities have their root in social and political organization.[5]

We will thus consider health inequalities/disparities, or preferably health inequities, to be systematic and concern groups and lead to lost potential of people as Braveman (2006) stresses "Health disparities/inequalities are potentially avoidable differences in health (or in health risks policy can influence) between groups or people who are more or less advantaged socially; these differences systematically place socially disadvantaged groups at further disadvantage on health."

Models

Several different models have been put forward to explain how social determinants in constant interaction are linked to health status and how they produce a social gradient of health. Certain approaches underline the importance of proximal factors (lifestyles and behaviors), while others place greater emphasis on distal fundamental or structural determinants such as socioeconomic conditions and "the causes of the causes" of health and disease (Link & Phelan, 1995). Dahlgren and Whitehead (1991), for instance, famously represent "the main determinants of health as a set of concentric arcs around the individual." Health is represented as "the outcome of a web of social influences" (Graham, 2004a). One may consider the most distal factor to be the social structure of society.

One useful way of thinking about structure is it constitutes the objective features of social life which preexist individuals, i.e., before they are born, and which typically are reproduced and outlive them. Such features include the power structures, organization of a society, and how the resources of a society are distributed (Layder, 2005). Social position may be considered as being embedded within social structure and "usually refers to an individual's location in the social hierarchies around which his or her society is built. This includes such dimensions as socioeconomic position, gender, and ethnicity" (Graham, 2004a). Gender may be of increasing importance to take into account as recent reflexion in urban health suggests (Frye, Putnam, & O'Campo, 2008). Importantly as Graham explains, social position may be considered to be "the point at which the social structure affects, and affects unequally, people's access to key resources for health" (Graham, 2004a).

The structural perspective is especially relevant to non-health sector policy, and it may be strengthened and complimented by research on developmental life course factors impacting favorably or unfavorably on future health (Ben-Shlomo & Kuh, 2002), biosocial embodiment (Krieger, 2005), agency, and salutogenesis (Antonovsky, 1996; Lindstrom & Eriksson, 2005; Lindström & Eriksson, 2009). A life course approach shows how the human organism is subject to both benefits and insults from conception to death, impact of which translates into health status and disease. The existence of different critical stages within this life course has the potential to magnify effects (Ben-Shlomo & Kuh, 2002). Thus, impacts on the developing fetus, babies, and young children should assume great importance. Firstly, these are especially vulnerable during development, but it is also during this critical period of life where the foundations of good or bad health are laid down (Hertzman & Boyce, 2010). Since we are profoundly social beings throughout our life, we are subject not only to stressors from the physicochemical environment but also from our interactions within social relationships and social situations. Calling on Durkheim's seminal work

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[5] To criticize inequality and to desire equality are not, as is sometimes suggested, to cherish the romantic illusion that people are equal in character and intelligence. It is to hold that, while their natural endowments differ profoundly, it is the mark of a civilized society to aim at eliminating such inequalities as having their source, not in individual differences but in social and political organization Tawney (1931).

on social integration and Bowlby on attachment, Berkman, Glass, Brissette, and Seeman (2000) have conceptualized, from the macro-social to interpersonal behavior and intrapersonal biological functioning, the different mechanisms involved in the impact of social networks on health with the possibility of both positive and negative effects are arising. Complex interactions that may occur include our own perceptions and feelings about social situations and others. These may act positively or negatively on our well-being and future health prospects. As research suggests on primates, we may consider that in many ways such experience becomes embodied in our very biology (Krieger & Davey Smith, 2004; Krieger, 2005). Research on epigenesis may cast further light on important mechanisms involved (Hertzman & Boyce, 2010). As Bonnefoy, Morgan, et al. (2007) of the Measurement and Evidence Knowledge Network (MEKN) of the WHO Commission on Social Determinants of Health highlight through referring to Schutz‘s phenomenological approach, we are all unique individuals with unique life experiences. These different experiences impact on our health and well-being throughout the life course. It will be a vital part of the social determinants of health paradigm to produce evidence showing how social structuration impacts on agency and impacts on biological mechanisms translating these effects into health gains and losses (Kelly, Bonnefoy, et al., 2006).

It is important also to consider health beyond the prevention of disease and incorporate salutogenesis and resources for health and well-being favoring a sense of coherence and quality of life. Lindstrom and Eriksson (2005) renewing Antonovsky (1996) have proposed a salutogenic framework to explain the production of well-being and health and factors that favor coping and resilience to disease. More radically, Abel and McQueen (2013) and Frohlich and Abel (2014) have proposed an agenda where the starting point is the study of social context, and the outcomes considered are not just health outcomes. Such an approach emphasizes the role of social structure and agency, and how different groups and individuals have different access to capitals determining resources and are subject to different health risks.

Abel and Frohlich (2012) draw on Bourdieu’s conceptualization of different capitals at work in producing and reproducing social structure, namely, economic, social, and cultural capitals, etc. and combine this with Amartya Sen’s Capability Approach (Sen, 1999). In this second approach, the freedom and the opportunity for choice are highlighted. The combination of the two theoretical perspectives provides a powerful framework to understand how the social gradient in health is produced. Taking into account that theories of social structure generally make little accommodation for including change, Abel and Frohlich (following Hayes) distinguish between reproductive agency and transformative agency. The latter is crucial for health promotion and tackling health inequalities where health is not merely viewed as a result of choice but also as the result of a possibility of choice and availability of resources, enabling choice, or a lack of availability of resources, hampering choice. Healthy choices flying against antagonistic and unfavorable social structure will always be possible and indeed should be encouraged, but their probability from a public policy perspective will be increased, where access to health-giving resources is possible through the possession and possibility of transformation of economic, social, and cultural capitals. In our view, this is the key to understanding how different determinants of health systematically exert their effect differentially throughout the population and produce a social gradient, i.e., health inequities.

The World Health Organization Commission on Social Determinants of Health chaired by Sir Michael Marmot (WHO, 2008) has put forward a synthesis of the different models. This distinguishes three main components:

- The political and socioeconomic context (governance, macroeconomic policy, social, policy, culture, and values).
- Structural determinants linked to socioeconomic position of individuals (social stratification measured by income, education and training, employment, gender, and ethnicity).

– Intermediate determinants (material circumstances, psychosocial factors, environmental factors, behaviors, biological factors including early development, life course factors, and the health system itself). The inclusion of the health system as among the intermediate determinants that are shaped by political and socioeconomic contexts and structural determinants merits particular attention. It will also allow us to examine evidence on the respective contribution of the health and non-health sectors to health, how the health system as it exists for different groups is shaped by broader contexts and structures, and that, contrary to popular belief, the health sector is not the sole determinant of our health.

A number of frameworks and research methodologies have been proposed to explain more specifically the complex relationships of urban components and health (Whitehead & Dahlgren, 1991; Northridge, Sclar, & Biswas, 2003; Barton & Tsourou, 2004; Barton, 2009). Methodologies include a mix of research methods comprising not only ecological and multilevel analyses but also case studies and other sociopolitical methodology (De Leeuw, 2010; Gibson, Petticrew, et al., 2011). A number of models integrate social determinants of health and mirror Whitehead and Dahlgren (1991); Northridge, Sclar, and Biswas (2003); Barton (2009); and Barton and Tsourou (2004).

There is clear evidence suggesting that specific urban components at the neighborhood and city level have an impact on several determinants of health which in turn have a direct or indirect influence on the development of specific diseases or on general health and well-being (Barton, 2009, Grant, Braubach, et al., 2010, De Leeuw, 2009). Schulz and Northridge (2004) have notably put forward a model pertaining to the urban physical environment and environmental health inequalities incorporating (1) fundamental (macrolevel), (2) intermediate (meso-/community level), (3) proximate (micro-/interpersonal level), and (4) health and well-being at the individual or population level. They apply their model to four case studies involving diesel exhaust fumes, lead pollution, unintended injuries, and chronic stress. They stress the dynamic and often bidirectional nature of the phenomena modeled and the importance of fundamental factors, stressing that "environmental health promotion efforts must include the creation of structures and processes that actively work to dismantle existing inequalities and to create economic, political, and social equality." We shall echo and further illustrate their model throughout this chapter.

A Model for Framing Non-health Sector Impacts

We are now in the position to put forward a model taking into account three essential dimensions of non-health sector determinants of population health, namely, (1) environmental and sociocultural, (2) personal attributes, and (3) individual and societal development. The model draws upon a wide range of conceptual thought and thus echoes other models in the area of health promotion, health anthropology, and disability studies. More specifically, the model has been constructed from four main existing models, namely,

- The well-known model of concentric arcs of influence of Dahlgren and Whitehead (1991)
- The environmental risk analysis model, also named Driving Force-Pressure-State-Exposure-Effect-Action (DPSEEA) (Corvalán, Briggs & Kjellström, 1996)
- The burden and capacity model of the National Research Council (2009), pertaining to the work setting and the balancing point between work demands and capacities after Dempsey (1998)
- The model of Abel and Frohlich (2012) proposing a synthesis of Bourdieu's habitus and different capital theories, with Amartya Sen's Capability Approach.

We believe that our model has a number of distinctive features. Firstly, while echoing Dahlgren and Whitehead (1991) (as do other authors, such as Barton and Grant (2006)), it places great emphasis on how on one hand the physical environment and on the other hand both material and immaterial cultures constitute a heritage which can potentially impact on health. Viewed horizontally, the schema with its arrows of time highlights the fact that individuals have developmental life courses nested in societal development. Of particular importance are the transmission of values, social practices, and lifestyles. These constitute along with the physical environment a preexisting heritage into which members of the population are born and develop and bequeath in turn to subsequent generations. Viewed vertically, the nested circles highlight the different levels of organization through which health and well-being may be influenced. These range from the intrapersonal to the micro-, meso-, macro- and institutional environment. Secondly, the model portrays and emphasizes that different elements make up our environment. This goes beyond the physical environment, to include the sociocultural and economic environment, and may be declined as *constraints or freedoms* and operate symmetrically but with potentially ambivalent impacts on health. Thus, the same element or factor may constitute risks or opportunities (life chances) for human health and development, e.g., water. The sphere of constraints may be considered to be engendered by the physical, sociocultural, political, and economic environment and preexist individuals being born into the world. This represents a physical, sociocultural, political, and economic heritage. As we stress throughout the chapter, this heritage however is socially structured and is not equal. This largely explains how social inequalities persist across generations fueling health inequities. Nevertheless, the past of course not only offers constraints but also resources from which we have developed our societies and which we inherit as individuals. The past cannot be changed, although its unequal legacy may be taken into account. Nevertheless, people in the present potentially have the possibility of wroughting change in their physical, sociocultural, economic, and political environments for the current and future good. The sphere of freedoms highlights this and how individuals and groups may respond and adapt to constraints and associated pressures on human health and well-being through having access to resources for carrying out projects that have reason to value, including the mitigation of negative risks for health and the mobilization of resources for the promotion of positive health and human development. This explains why optimistically we have highlighted freedoms on the right of the schema linking this to collective and individual agency which may be theorized through capability and allied theories. Through access and use of resources, this may lead to the production of values impinging positively on the human health and environment and outcomes such as health, well-being, quality of life, sustainable development, social justice, and participation. Constraints, of course, and barriers to health may also continue to exist. Thirdly our model includes the idea that it is useful to consider this ensemble as sources of health and disease. It thus refers to *sources of health* rather than determinants. This has a double advantage. It recognizes that it may be misleading to suggest that determinants determine our health in some absolute way and that the same element may represent a source of health or disease for the population and different individuals within the population. Our world may at times be more ambivalent than we sometimes like to admit.

Although it is challenging to display graphically, we insist on the fact that the environment whether it be sociocultural or physical acts on us throughout our existence. This is the foundation of population health. Individuals from their conception onward are subjected to the negative or positive influences, but the distribution of these influences is structured socially and is unequal (Graham, 2004a). Furthermore, individuals themselves are relatively powerless to mold this environment. Burdens on health exert their force throughout the life course. Positive and negative influences act on health and are mediated through different levels of societal organization from the micro- and meso- to the macrolevels. As the nested circles attempt to portray, individuals are subject to influences from their personal attributes, their biological and genetic heritage, and their immediate surroundings and relationships. These include family, neighbors, friends, their wider sociocultural environment with its wealth or dearth of social relationships and support from social group membership or isolation, and indeed wider societal norms, rules, and regulations within a macro-socioeconomic and political context. Of course such influences impinge on individuals, but individuals and their social groups can also exert influence on their environment and the norms and policy through social and political processes in turn. However, power is not shared evenly. Government, institutions, and their apparatuses, including public health, powerful enterprises, and members of the civil society, may exert particular influence to uphold, protect, or transform both the physical and sociocultural environment in which we live (Fig. 15.1).

Central to this framework is that there are multiple determinants of health and that they may be declined as "constraints" or "freedoms." At times it would seem easy to isolate health hazards, e.g., radon, Ebola, and asbestos and treat them as purely physical, biological, or chemical hazards. These may engender risks to human populations and individuals. Nevertheless, many constituents of our world may be declined negatively as constraints creating pressures on individuals and populations or positively as freedoms creating resources available to individuals and populations. Although risk intrinsically is synonymous with chance or probability, here risk is being viewed as in the sense of a probability of an event occurring associated with deleterious consequences for health. Furthermore, we may consider that hazards become "socialized." Thus, if noise represents a physical hazard to human health Goines and Hagler (2007), exposure to noise is a profoundly social phenomenon. Individuals and populations are profoundly social beings. They occupy social positions within society and are subject to the influence of social structure. These may reproduce constraints on individuals' agency negatively influencing health and reinforcing health inequalities through leading to differential exposures to risk of disease and injury. Nevertheless, it must be recognized symmetrically that social structure and social position also may provide access for the deployment of individual and collective human agency giving access to opportunities and resources for the maintenance and promotion of health as well as resources for the mitigating risk. Furthermore, from a psychosocial perspective, pressures, such as stress at work, can also be exacerbated or

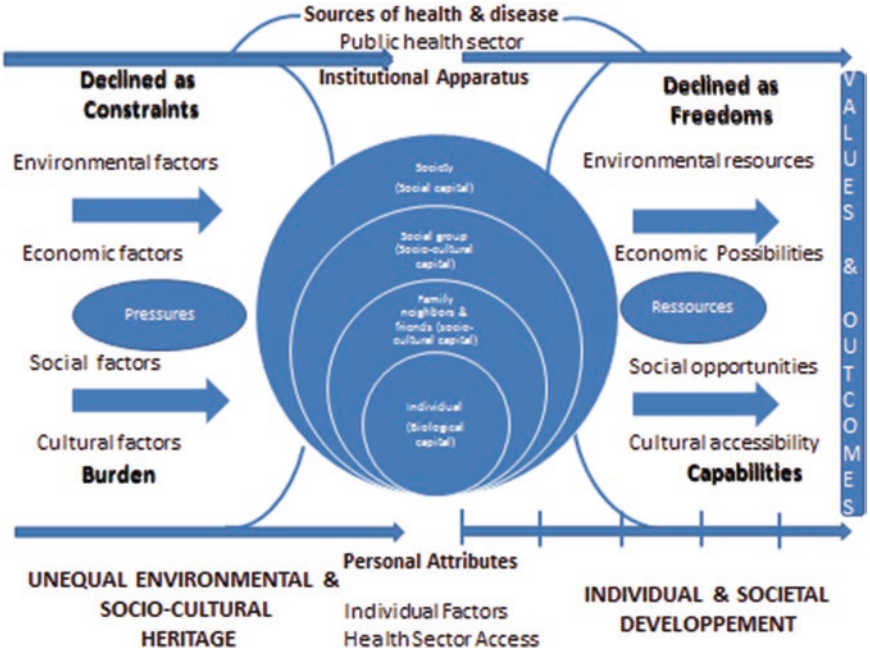

Fig. 15.1 A model for framing non-health sector impacts on health

created through overcompensation or overinvestment by the person. In response to personal ambition or of one's management, coupled often inextricably with the societal norm of individual performance or entrepreneurship, the self-setting and imposition of goals may go beyond what would normally be considered reasonable and may thus constitute a risk to health and well-being. Repeated psychosocial demands on oneself may become embodied leading to the production of chronic conditions including mental health problems.

We are confident that our model gives a good idea of how the non-health sector (such as housing and the urban environment) may impact on health. It offers insights for the design of policies and strategies ranging from acting on constraints and pressures reducing burdens, to acting on freedoms and resources promoting individual and collective agency. It allows us to consider a range of risks from the apparently "purely" physical (radon), heat waves, mold (clearly linked to income inequalities and housing status) to the deeply socialized lack of accessibility, unemployment (see Moller, 2011), health practices, smoking, drinking, etc. As may be easily appreciated, the different constraints and freedoms presented in the model together with potential resources involve a diversity of non-health sectors and stakeholders whose main activity and goals may not necessarily include health. We will now examine the particular challenges that policy makers promoting an intersectoral approach will need to face.

Emergence of the Intersectoral Health Agenda and Its Challenges

The emergence of an intersectoral Health in All Policies agenda founded on the paradigm of social determinants and health inequalities will thus necessarily involve many new non-health sector stakeholders having to work together (Kickbusch, McCann, & Sherbon, 2008). Intersectoral action on social determinants of health and the health inequity agenda coupled to implied responsibility represent a considerable challenge for policy makers and stakeholders (Exworthy, 2008). Indeed, the very attempt to link non-health sectors such as transport, industry, urban planning, education, agriculture, economy, and work with health, thus broadening the remit and responsibilities of the professionals and their services involved, may easily be greeted with a degree of astonishment, skepticism, or outright rejection. Rather than insist narrowly on health as the appropriate outcome, it will be necessary to broaden traditional indicators to take into account the environment and lived experience of the population and especially the marginalized population (Masuda, Poland, & Baxter, 2010). Thus, it may make more sense to highlight the importance of equitable services and environments adapted to all citizens. (The underlying idea for this is that services and environments that ensure social justice are most likely also to impact favorably on health, since there is much evidence that increased social justice and respect and equality are linked to well-being and less-damaging health behaviors (Wilkinson & Pickett, 2010).) Furthermore, links with the community-based participatory research, the empowerment of marginalized groups (Masuda, Poland, & Baxter, 2010), and the social participation of people with disabilities and the human rights based on the Convention on the Rights of persons with disabilities (United Nations, 2006) may be articulated.

Such an intersectoral agenda may involve both private and public enterprises and organizations. Signing up to "Health in All Policies" implies that each sector must not only analyze how its policies will impact on health, well-being, and health inequalities but also analyze how different sectors will interact with impact on health. This needs to be taken into account within policy formulation, implementation, and practice (WHO, 2010d). This goes beyond the recognition that non-health sectors can have important impacts on health and well-being and that health is not the sole concern of the health sector. Indeed ultimately it calls for the recognition that fundamentally, as, for instance, in the case of noncommunicable disease (NCDs), the conditions which determine the degree of health of population are social. As Abel and McQueen (2013) maintain "the conditions and distribution patterns, the perception of the problem, and actions taken by a society all indicate that population health issues including those on NCDs are inherently social in nature." In relation to the social determinants of health more specifically, we may speak of a "dual agenda" (Graham, 2004a). As Graham stresses "the social factors influencing health and the social processes shaping their unequal social distribution are not the same." In other words, there is an important conceptual distinction to be made between "health determinants" and "health inequality determinants" (Graham, 2004a).

Thus, in designing policies to tackle risks and behaviors, for instance, it will be necessary to demonstrate population health improvement *and* reduction or, at the very least, non-exacerbation of health inequalities. Since the latter is fueled through deep-set structural social inequalities which determine the distribution of exposure to risk and salutogenic assets, this represents a considerable political and policy challenge (Phelan, Link, & Tehranifar, 2010; Cerdá, Tracy, et al., 2014.) As the Whitehall studies demonstrated, smokers coming from higher socioeconomic groups have better health than smokers from lower socioeconomic groups. This also applies to nonsmokers. The quality of the environment such as housing, air, and water affects all people, but with rare exceptions, which argues well for keeping the above distinction in mind; the greatest risks will impact on lower socioeconomic status groups who will also tend to cumulate environmental risks and other risks as Graham (2004a) argues "…despite better health and improvement in health determinants, social disparities persist … more emphasis on social inequalities is required for a determinants-oriented approach to be able to inform policies to address health inequalities." What is more is that since policies in different sectors interact, overlap, may be in synergy, or suffer from contradictions, extensive intersectoral collaboration and policy regulation will be necessary to improve population health while at the same time to tackle health inequities. This last point in our view is crucial since experience has shown that it is all too easy to improve the health of the population while widening health inequalities. Furthermore, as we shall argue, population health should not be seen as being synonymous to health care.

Determinants of Social Gradient

The Role of the Health Sector

The inclusion of health systems within models of health determinants is in fact relatively recent. Indeed, according to Graham (2004a), in earlier models of social determinants of health, the health-care sector rarely featured prominently. Different complementary explanations may be offered. Firstly, as the bulk of research suggests, health systems do not in themselves constitute a major influence on health (Marmot & Bell, 2009). Thus, with respect to the United States, Schroeder (2007) – citing Mcginnis et al. (2002, 1993) – maintains that the health-care system has a "relatively minor role" in preventing premature deaths (10%) when considered alongside the influence of other health determinants linked to non-health policy. Similar conclusions have recently been drawn by the IOM report "For the public's health. Investing in a healthier future" (2012). (see Kaplan et al. *infra*.)

Secondly, as many have remarked, health systems are more suitably characterized as being "disease treatment systems" since they largely may be considered to be organized and designed to treat disease and repair bodies. This is a role that they often perform admirably. Nevertheless, they focus on the "negative pole" of health rather than highlighting a positive idea of health as epitomized in the WHO definition (1948). This statement may easily be substantiated through a cursory look at resources given over to prevention and health promotion. For instance, in 2006 this represented 6.4% of health expenditure in France (Fénina, Geffroy, et al., 2006). Health promotion as defined by the Ottawa Charter, and indeed in more recent health policy documents from around the world, can be properly considered in many respects to go beyond the negative pole and foster a positive vision of health and well-being.

Finally, and importantly, the social determinants paradigm linked to the health promotion movement epitomized by the Ottawa Charter emerged to counterbalance biomedical and clinically based curative approaches to health through advancing the case that the determinants of health are to be found in wider society and especially the structural inequalities within society. Hence, health-care systems simply were, rightly in our view, not considered to be a major driver of people's health (Graham, 2004a). Such a position may also be seen against the backdrop of the well-known pioneering work of Thomas Mckeown who offered evidence drawn from the analysis of historical demographic data to argue powerfully that health improvement over the last centuries was better explained by improvement of economic, social, and living conditions than by the contribution of medicine and public health and health-care services (Mckeown, 1976a, 1976b). However, the methodology and data on which the thesis was based received severe criticism and have claimed to be discredited (Colgrove, 2002; Szreter, 2002). Furthermore public health was defined rather narrowly (sanitary reforms, vaccination, quarantine) in contrast to more recent social determinants of health thinking. However, the debate is far from closed. Link and Phelan (2002) point out that social conditions are themselves linked closely to individual health-enhancing actions carried out by members of the population themselves, such as to seek good housing and go hand in hand with improvement in socioeconomic conditions. They continue to support the fundamental idea implicit in Mckeown's thesis that the contribution of medicine to population health cannot explain its dramatic improvement. Social and economic factors are the fundamental causes of health, the key to explaining population health and health inequalities (Link & Phelan, 1995; Phelan, Link, & Tehranifar, 2010). (Even if risks change over historical time, the same people at the bottom of the social ladder are those affected and who cumulate different risks.)

After perusal of the evidence, Nolte and Mckee (2004) suggest that health care may assume greater importance in more modern times since more possibilities for improving health through technology and medicines are now on offer. Nevertheless, the case of the United States would seem to present a conundrum. The United States spends more on health care than any other country and has one of the most advanced health systems in the world. As a recent IOM report reminds us "The United States is among the wealthiest nations in the world, but it is far from the healthiest. For many years, Americans have been dying at younger ages than people in almost all other high-income countries" (Committee on Public Health Strategies to Improve Health, & Institute of Medicine, 2012). Marmot and Bell (2009) offer an explanation of why the United States has poor health in spite of high health expenditure; suggesting the answer to this conundrum lies in taking into account social determinants of health. In spite of the Mckeown thesis being reevaluated and the difficulty of establishing causal relationships between percentages of GDP spent on health-care and health outcomes (Nixon & Ulmann, 2006), inequalities in health are difficult to explain by mere reference to health-care access quality and performance. In the WHO Commission on Social Determinants of Health (CSDH) framework (WHO, 2010a), the health-care sector is considered to be one of the intermediate determinants of health[6] and is put alongside material circumstances, social cohesion, psychosocial factors, and individual behavior.

Role of Non-health Sector

Non-health Sector, Policies, and Health Inequities

We believe that highlighting health inequities and their relationship to the non-health sector and policies matter. Firstly, as we have stressed, they are a concern for social justice. Indeed, health may be considered to have special moral status

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[6] It is interesting to reflect on the Cuba paradox which suggests that combining *community health approaches* (highlighting the role of social determinants and health promotion) *with modern clinical medicine* may be the ideal mix for achieving good health outcomes (Evans, 2008).

over other goods, since it has both intrinsic and instrumental values being vital resources enabling people to carry out their life projects. Secondly, but equally importantly, health inequities and the fact that they are associated systematically with a social gradient indicate clearly where the sources of disease and good health lie: substantially outside the health sector within the fabric of society.

The view that health is largely determined by factors from outside health systems is well known and has been emphasized within the pioneering work of the Lalonde report and Ottawa Charter and indeed the WHO Healthy Cities project. More recently, official recognition in concrete policy terms of the impact of non-health sector policy on health has been forthcoming. The Adelaide Statement (WHO, 2010c; Government of South Australia & WHO, 2010) notably has argued strongly for Intersectoral Action for Health (IAH), and the logical policy follow-up to such initiatives' "Health in All Policies" highlights the necessity for intersectoral initiatives including the health sector (Baeza, Lim, et al., 2011). More pragmatically the general acceptance of environmental and health impacts assessments. Kemm (2006) also bears witness to this trend.

Non-health sectors and policy impact on people's living and working conditions through different mechanisms acting at the macro-, meso-, and microlevel (Loewenson, 2013). Lurie (2002) singles out which federal government departments may have a role to play in acting on the nonmedical determinants of health. Figure 15.2, adapted from a World Bank report of Meiro-Lorenzo, Villafana, et al. (2011), indicates how different sectors such as education, finance, urban planning, agriculture, industry, transport, and health itself may have a significant role to play in reducing risk factors for NCDs.

Addressing risk factors is important but should not blind us to the possibility of moving beyond a risk factor and lifestyle agenda to encompass a broader social and salutogenic view of health which recognizes both structure and agency and how these may interact to produce health. As recognized increasingly by such initiatives as "Health in All Policies," the non-health sector and action between non-health sectors and the health sector do not only consist of dealing with risk factors but should include an asset-based approach to health at all levels (Morgan & Ziglio, 2007). Assets for health may be found at the individual, community, and organizational level (Glasgow Centre for Population Health, 2011). Eriksson and Lindström (2007) have outlined an asset approach to healthy public policy based on salutogenesis and a quality of life perspective.

Let us now offer some illustrations of how the non-health sector and policies instigated and implemented at different levels may impact on the health of the populations and individuals through different mechanisms involving sociopolitical and political context, structure, social position and agency, and the possibility or not to have access to different capitals. We have chosen a range of examples from many different sectors whose influences on health are mediated through

	Tobacco	Poor Diet, Nutrition	Physical Inactivity	Alcohol	Unhealthy Environment	Pathogens	Injuries & Violence
Health	✓	✓	✓	✓		✓	
Education	✓	✓	✓	✓		✓	✓
Finance	✓	✓		✓	✓		
Urban Planning			✓	✓	✓		✓
Agriculture	✓	✓			✓		
Industry	✓	✓		✓	✓		
Transport			✓		✓		✓

Fig. 15.2 Sectors in which actions can be taken to reduce key risk factors for NDCs (Adapted from Fig. 6 in Meiro-Lorenzo, Villafana, et al., 2011)

different pathways. These illustrations could be easily multiplied. They range from identified environmental risks (and how such risks may accumulate with others in the case of vulnerable populations) to the impact of peoples' representations and beliefs on health outcomes and behaviors. The aim is not to be exhaustive but to be explanatory, demonstrating that whether the impact of the non-health sector and policy is conceived at a macro-, meso-, or microlevel, its effects, both anticipated and unanticipated, are likely to be mediated through social structure and position and more often than not involve interactions between levels and the accumulation of disadvantage or advantage.

Illustrations of How the Non-health Sector and Policies May Impact on Health

Macroeconomic, Political, and Contextual Influences

The relationship between the economic situation and health is complex. (See also the chapter devoted to socioeconomic influences by Siddiqi, Hertzman, and Smith, *infra*.) Often the assumption is made that economic growth = improved population health. However, Szreter argues "the human record in fact shows no necessary, direct relationship between economic advance and population health, rather a more ambivalent and contingent relationship." Increase in wealth can potentially improve population health but that will largely depend on how that wealth is used and shared (Szreter, 2003). Most often strident economic growth and great social change have had negative impacts on mortality. Indeed Szreter (2003) speaks of the four D's associated with the rapid economic and social changes of the industrial revolution – "disruption, deprivation, disease, and death" (Szreter, 1997). Such ideas are important to bear in mind when examining how worldwide macroeconomic policy and globalization in particular can impact on health.

With respect to economic globalization, it is also important to note that views may vary according to the evidence available, the countries studied, and the context, and especially economic context in which they were voiced. Thus, it has been argued that globalization has both positive and negative impacts on health (Feachem, 2001) (Dollar, 2001) (Cornia, 2001). In 2001 Feacham claimed that "Globalisation is good for your health, mostly." Dollar writing in the same year before successive financial crises and the reports of the Commission on Social Determinants of Health maintained that "the higher growth that accompanies globalization in developing countries generally benefits poor people." Furthermore that in all probability, "globalization has indirect positive effects on nutrition, infant mortality and other health issues related to income." Among negative aspects cited were the spread of disease (AIDS) due to increased migration and travel and the impact of tobacco through free trade. (Dollar, 2001). Cornia (2001) suggests that the impacts of globalization are complex but if well managed may produce positive effects on health in conditions where markets are competitive, open, and well regulated, and social safety net protection is available. Cornia states "However, the domestic and international conditions for successful globalization have been met in relatively few countries." Thus, globalization affected some countries, such as Asian countries, more positively than others (African, Latin American, and Eastern European countries). Economic development in such economies was dependent on the state of the domestic market, unequal foreign investment as well as new rules limiting access to markets of the Organisation for Economic Co-operation and Development. Furthermore globalization had particular impacts on the poor population. On the one hand, slow and uneven growth was associated with stagnation in health indicators, and on the other hand, as we will see later in more detail, economic crises in middle-income countries such as the former Soviet Union produced economic instability, sharp rises in unemployment, and dramatic effects on health and life expectancy. Of particular interest with respect to health and inequality is the observation that "high income inequality reduces the pace of growth and of poverty reduction."

Attempts have been made to model the complex effects of globalization (Woodward, Drager, et al., 2001; Huynen, Martens, & Hilderink, 2005). Huynen, Martens, and Hilderink (2005) put forward a framework for studying globalization and health which incorporates sociocultural, economic, environmental, and institutional factors intervening at different contextual, proximal, or distal levels. They point out the importance of contextual and institutional factors such as structures of global governance, global markets, global communication, and diffusion of information, mobility, and environmental change. Notably they suggest, citing Fidler (2002), that the World Trade Organization has more influence on the governance of global health than the WHO and that it is unclear whether World Trade Organization agreements may protect health.

A series of three articles by Labonte and Schreker (2007a, 2007b, 2007c) have studied the impact of globalization through a social determinants of health lens founded on work by Diderichsen, Evans, and Whitehead (2001) and have reached more negative conclusions claiming that globalization has had deleterious impacts on health and health inequities, especially in poor developing countries and among the poor households. The gains and losses due to globalization across a range of domains are not evenly distributed and tend to favor those with preexisting capital, power, and resources. This fundamentally asymmetric character of globalization does not just apply to economic development but also to the impacts of financial crises which exacerbate social disadvantage and vulnerability, for example, to environmental hazards. Different pathways involving the non-health sector leading to such asymmetric effects are singled out such as the trade liberalization, global reorganization of production and labor, debt crises and economic restructuring, financial liberalization, urban settings, and influences that operate by way of the physical environment. They conclude their three article investigation bleakly claiming that "redistributive policies of various kinds are likely to be needed to reduce health inequities within and between countries" and that "globalization tends to be associated with a long-term trend toward increasing economic inequality and increasing attachment to markets as a mechanism for allocating resources and setting policy priorities" Labonté and Schreker (2007c).

Within the developed world, the impact of economic crises and recession and the compensatory measures undertaken by governments highlight the particular importance of macroeconomic factors for health. Nevertheless these impacts are largely ignored in policy documents (e.g., *Economic Crisis in Europe: Causes, Consequences and Responses* European Commission (2009)). Recent work on austerity shows that recessions can impact on people's health negatively, as one would intuitively suspect, but also positively (Suhrcke & Stuckler, 2012). This may largely depend on whether support from social protection systems is maintained or cut. Ironically however recession in itself may have less effect than the austerity measures taken to combat it (Stuckler & Basu, 2013). Stuckler and Basu also argue powerfully that austerity measures are bad for health and can kill massively. The size of effects on health may also depend on whether a rich developed country or poorer country is concerned. Impacts of the economic situation may be masked by wider positive trends on population health. Thus, overall mortality may fall. Within the American depression, an increase in suicides was dissimulated by a bigger decrease in road accident deaths. People drove less since they could not afford cars and fuel: there was less traffic (Stuckler & Basu, 2013).

Policy matters. Different policies more often than not produce different impacts (Van de Bosch & Cantillon, 2006). Making different economic choices has implications for health and well-being. Thus, when Roosevelt's New Deal was adopted in the United States, its eventual impact very much depended on whether the policy was wholeheartedly implemented, as in certain left-leaning states, or resisted in more conservative states. Cornia, (2001) and Stuckler, King, and Mckee (2009) have highlighted the impact on health of the dramatic political and economic upheavals involving rapid privatization in Russia and certain Eastern and Central European countries in the decades following the collapse of the Soviet Union. Again where social protection system mechanisms were maintained and introduction of economic changes associated with privatization was more gradual, the negative impact on health was less pronounced. This speaks volumes in favor of the hypothesis that how economies flourish, are regulated, and buffer the possible negative effects of their functioning through social safety nets, and thereby diminish inequities, have great influence on health.

In complement to the above findings, Wilkinson and Pickett (2010) have examined how the degree of inequality within societies may impact on health and other social issues. They graphically illustrate that when comparisons are made between wealthier nations, no discernable relationship between national income per head and life expectancy is to be found. However, when one comes to examine the degree of income inequality within a wealthier country, this tends to correlate with people's health (and indeed a large range of indicators of social problems within countries). It is worth pointing out that Wilkinson and Pickett (2010) consider that income inequality is a measure, and perhaps the best measure that we currently have of how hierarchial a society is, the bigger the differences in income, the bigger the social distance and more important the social stratification. Health and a host of other social problem indicators follow a social gradient clearly related to income and social position. To quote Wilkinson and Pickett (2009): "Population health tends to be better in societies where income is more equally distributed. Recent evidence suggests that many other social problems, including mental illness, violence, imprisonment, lack of trust, teenage births, obesity, drug abuse, and poor educational performance of schoolchildren, are also more common in more unequal societies." The measure of inequality taken is how much richer the top 20 percent than the bottom 20 percent are in each country. Significantly in richer countries, what counts is not absolute wealth but whether the wealth is distributed more or less equally. As Wilkinson has stressed, it makes little difference on how a degree of equality is achieved. Countries such as Sweden and Japan are vastly different in many respects and have different social protection and fiscal systems, but their relatively low degree of income inequality correlates well with health and may be contrasted with the situation in less-equal societies. The situation with respect to inequality and health and other social indicators seen between countries is also mirrored among states in the United States. States with the highest degree of inequality (measured through Gini coefficients) also have high levels of poor social outcomes including health.

One explanation for the impact of income inequality is that status competition and status anxiety thrive in more unequal societies where social position tends to usurp social identity and common humanity. The latter receives greater recognition in more equal and more trustful societies. Humans are peculiarly sensitive to being evaluated socially, and when such social evaluative threats undermine identity and self-esteem, this leads to psychological and indeed biological stress. Such chronic social stress triggers the release of stress hormones such as cortisol with its deleterious effects on the cardiovascular and other physiological systems (Brunner, 1997). Thus, this provides one very plausible mechanism through which greater inequality within societies has impact on health and life expectancy (Wilkinson & Pickett, 2010). We would maintain that people's health is sensitive to economic forces and policies, governance, the labor market, and the degree of social and income inequality associated with social evaluative threats and stress this may engender.

Of particular importance is the labor market. Bambra (2011) reminds us that "work (paid wage labor) and worklessness (lack of paid work) are not the discreet activities of individuals, but are essential parts of the way in which the totality of society is politically, socially and economically organized." Furthermore, "the effects of work and worklessness on health and health inequalities are … mediated by political, economic and social organizations and by the welfare state regime." Health inequities are engendered by state political and economic policy which may also through social protection play a part in buffering the impact of social inequality on health. Being in work is an important condition for health, having an income and for social inclusion, but can also lead to bad health through the impact of an adverse physical or indeed psychosocial working environment. These risks follow a social gradient: lower paid workers being more vulnerable to work place hazards and accidents as well as having less control over their work and related stress in the work place. Interestingly effects especially of psychosocial working environments may differ between countries having different welfare regimes (Dragano, Siegrist, & Wahrendorf, 2011; Bambra, 2011).

Unemployment has a complex relationship with health (Bartley, 1994). Unemployment may lead to bad physical and mental health, and bad health may be related to unemployment or withdrawal from the labor market (economic inactivity). Unemployment is associated with poverty and social exclusion, and it has also been associated to greater risk of death and is linked to poor mental and physical health (Dorling, 2009; Urban Institute: Nichols, Mitchell, & Lindner, 2013). Poor health and disability also impact on the likelihood to suffer from long-term worklessness (Bambra, 2011). The effects of such worklessness are socially patterned and may lead to further social exclusion and poverty which in turn precipitate further health problems leading to a vicious circle (Whitehead, Clayton, et al., 2009).

With respect to disability, the occurrence of health problems and impairment may not only impact on social trajectories and lead to sliding down of the social gradient, but importantly and inversely, the social position of individuals and families has consequences for health. Impairments are more frequently associated with low social position, and the impact of disability on social participation is greater for the poorest and cumulative with other social disadvantages. Thus, in France not only is the unemployment rate of disabled people (15–64 years) twice that of the general population (DARES, 2012), but disabled children of working class families are seven times more likely to be cared for in full-time residential centers in France than children from professional class families (Ravaud & Mormiche, 2003). We will be examining how social policy may impact on the inclusion of people with disabilities in some detail later in this chapter.

The Impact of Supranational Policy

It is clear that economic and social policy at the national level is clearly subject to supranational and transnational influences and that these may have negative impacts on health especially in the developing world for economies in transition or crisis. Nevertheless, in spite of such conclusions, it is also clear that supranational bodies such as the European Union can also set standards and positively frame how national policy is exerted. This may have important knock-on effects in different sectors of economic and social activity. In the European Union, free movement of labor, goods, services, and persons is guaranteed under its treaty obligations. Such non-health policy has impact on the health field (notwithstanding that health falls under the principle of subsidiarity being considered to be a matter under the aegis of national governments) and has been figured as the subject of famous European jurisprudence. Since the free movement of labor, goods, services, and persons operates as the paramount principle on which European Union policy is founded, it has important effects on the health and other sectors. Notably the Kohll and Dekker cases established patients' rights to travel and be treated in different countries and to be reimbursed for treatment (Mossialos, Permanand, et al., 1996). Interestingly such a possibility was never envisaged by policy makers.

The influence of European policy on national policy is well documented, extensively studied, and permeated the national policy agenda. One example is the European Union's (EU) regulatory context on urban planning and environmental health. This includes several charters, strategies, strategic papers, and directives. In 2006, the EU adopted the Thematic Strategy on the Urban Environment in which it recognizes the problems faced in urban areas and attempts to provide guidance for better implementation of existing policies and long-term action plans. This has been followed up by the Green Paper and the Leipzig Charter which put forward an integrated sustainable urban development to overcome demographic, social, and environmental problems in European cities. Two EU directives have been implemented to address the issues related to ambient air quality (2008/50/EC) and environmental noise (2002/49/EC). The Parma Declaration (Fifth Ministerial Conference on Environment and Health in 2010) described the way forward in the work of environment and health in Europe. It sets out concrete targets to tackle the key urban environmental risk factors, paying special attention to children's health, inequalities, and emerging environmental health challenges (WHO, 2010b).

The influence of supranational policy agendas sets the scene for national legislation and implementation and can have both positive and negative effects on health. This can easily be seen in another important non-health field within Europe, namely, agriculture and food policy. The Common Agricultural Policy provides a strict regulatory framework and subsidies for farmers in Europe. This has important impacts on land use, the form of agriculture practiced, its impact on employment, the environment, and the type and price of food available favoring either health or disease (NIPH, 1996). Thus, on one hand, subsidizing beef and dairy production favors high saturated fat intake and associated disease throughout society, and on the other hand, the lack of support for fruit and vegetables favors comparatively high prices and lower consumption with obvious implications for health. Consequently, recommendations have been made for public health policy and agricultural policy goals to be aligned, matching subsidies to public health nutritional goals thus favoring higher and more equitable consumption of fruit and vegetables and less sugar, dairy produce, and meat (Birt, Faculty of Public Health, 2007; NIPH, 1996).

Similar conclusions can be drawn with respect to US farming subsidies which would also seem to conflict with US nutritional policy (PCRM, 2014). Nevertheless, sweeping changes in farming practice such as a transition from animal husbandry to the production of healthier food crops may not only lead to changes in consumption of foods with possible improvement in diet and positive impact on health but would necessarily be accompanied by huge structural and cultural changes in how agriculture and farm labors were pursued with possible negative impact on the number of people employed within agriculture and its support services and industries. For instance, according to one estimate, one man is able to cultivate 200 hectares of arable crops, but three men will be required to look after a herd on a farm of a similar acreage. Although calculating such effects is hugely complex (Whitehead & Nordgren, NIPH, 1996) and fraught with uncertainty, they may not be entirely positive for community health. Such examples demonstrate that whether it is recognized or not, macroeconomic and trade policy impact deeply on health either directly or indirectly throughout our world.

Social Policy and Inclusion

Beyond economic-related policy, social policy exerts a large impact on people's welfare and health. The macroenvironment will shape how people and families at a microlevel are represented and treated. Governments may introduce policies favoring equality between the sexes and equal rights irrespective of ethnicity, sex, and religion. Equality of this sort is often written into constitutions and documents such as *The Universal Declaration of Human Rights*. However, the straightforward monitoring of such policy involving the collection of nationwide ethnic statistics may be routine in some countries but unconstitutional in others such as France (Cédiey, Desprès, & L'Horty, 2007).

Including Disabled People in Society

Bearing in mind the relationship between inequality and disability previously mentioned, we will now consider in some detail policy aimed at favoring the inclusion of disabled people. This has been at the heart of European policy for some time but has fairly recently entered into French national policy. This illustrates well how policy, which both reflects and structures society, can have a deep influence on people's lives.

With respect to disability policy, European policy has had particular influence on national policy. In the case of France, this has led to the official taking up of nondiscrimination within French policy, notably in its landmark legislation of 2005 in favor of social participation, equal opportunities, and citizenship for disabled people.[7] Traditionally France, despite its firm belief in Republican universalism, has tended to favor affirmative action and specific treatment policies in favor of disabled people. The trend toward nondiscrimination and social inclusion of disabled people has been reinforced recently also by the adoption and ratification of the United Nations' Convention on Rights for Persons with Disabilities (United Nations, 2006). This lays down the principle of equal rights for people with disabilities in all walks of life.

One may consider that policy-promoting diversity and the rights of people with disabilities may be shaped differently to conform to two main paradigms of either favoring (a) specific treatment or (b) nondiscrimination. In the former, specific treatment or affirmative action (traditionally embedded in French practice) is designed to right (compensate) wrongs and disadvantage and lead to greater equity within the population. This may involve compensatory measures in favor of the disabled, e.g., in the provision of specific parking spaces and, within the labor market, the setting up of quota for disabled employees, e.g., 6% of the workforce in France.

Employment of disabled people is often informed by a more biomedical individual model, where the person is assessed and adaptations are made piecemeal or case by case. Furthermore, the setting up of sheltered workshops is frequent, so employment becomes very much a question for social work professionals. However, in line with European practices and the philosophy expressed in the United Nations' Convention on the Rights of Persons with Disabilities (United Nations, 2006), disability policy may alternatively be informed and built around nondiscrimination coupled to universal design and mainstream provision. Here employment of people with disability becomes primarily a question of inclusive employment rights (similar rights for all). This may involve adapting workstations, but the key principle is everyone has an equal right to work. In universal design, the idea is to render all environments and work situations open to anyone (Green, 2011); thus, toilets (rest rooms) and lifts/elevators are designed to be able to cater for all those with wheelchairs or non-wheelchair users and are equipped for all people including people with visual and hearing impairments and will incorporate auditive signals as well as Braille information and visual information. They may also attempt to cater to people with intellectual deficiency in using Makaton-type symbols. Parking spaces are not specifically designated as being for the disabled but are all made wider allowing people with wheelchairs and families with baby carriages and children to use them. Universal design also attempts to satisfy the needs of the neediest and through that process be adapted to all people. Of course in practice, the two policy paradigms are not exclusive and will frequently interact and be in tension or perhaps complement each other.

Disability policy aimed at granting disabled people with the same rights as other people may also be broadly divided into policy-shaping services and resources and the physical environment and policy impacting on the attitudes of the society toward people with disabilities. The latter has considerable importance since not only is there direct impact of attitudes on the opportunities made available to disabled people, but the very expectations of the disabled person herself and of her family, friends, neighbors, and society will tend to be integrated into the psyche and soma of the disabled person. We may make a distinction between "indifferent kinds" and "interactive kinds." In the former, a description made of an object has no impact on the structure of the described object. Hacking (2000) terms such objects as being "indifferent." The latter, termed "interactive kinds" by Hacking, is on the contrary affected by the way we describe or conceptualize. Thus, how we describe people matters. The labeling and classificatory theories we wield may become embodied by the very people being described through negative or positive feedback

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[7] *Loi* n° *2005*–102 du 11 février *2005* pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées.

loops. A positive enabling environment will empower disabled people to take their rightful place within society, whereas a hostile discriminatory environment will lead to low self-esteem and exclusion.

Of course, physical environments and adaptations also have great importance and may be enabling or disabling. The physical environment here is defined broadly to include urban planning and architectural design. The impacts of environment may result from interactions between dimensions which go beyond the impact of the sum of each individual dimension. Substantial and important work, leading to the "*Processus de production du handicap*" (PPH) Classification (Disability Creation Process) carried out in Canada by Patrick Fougeyrollas and colleagues, has resulted in increased understanding of how environments in all their different dimensions may impact on people living with impairment (Fougeyrollas, Noreau, et al., 1998).

The production of disability situations and indeed of situations in which humans are involved as developing beings may be considered to be an interaction between environmental factors, personal factors, and life habits. In principle the same schema applied to those with disabilities may be applied to all humans, their environments, and lives. The World Health Organization has drawn up the International Classification of Functioning, Disability, and Health (2001). This also considers that disability, and indeed healthy functioning, may be related to interactions between the person, her health condition, her body functions and structures, and her physical, social, and cultural environmental factors enabling or hindering the carrying out of activities and participation thus producing disablement. A situation of disability may often come about through the impact of planning and urban design informed and thought out through considering the needs of a standardized "normal" man without impairments and thus failing singularly to be adapted to a large number of humans with other needs. Architectural, physical, and environmental barriers make it impossible or difficult for people with reduced mobility to fully participate as citizens within society. Disability situations thus frequently arise due to a mismatch of the environment with the needs of people with disabilities. Environments, including sociocultural environments with their norms, may be truly disabling, e.g., lack of signing interpreters for deaf people, which may hamper their full participation or the lack of trained teaching assistants to help disabled children in schools. Thus, a well-adapted environment may bring about a huge improvement in social participation and well-being.

The mismatch between environment and ability erects barriers and obstacles toward disabled people, hampering and rendering impossible the achievement of goals which they have reason to value (Sen, 1999). These would be considered as being perfectly reasonable goals for an ordinary member of the population. Notably the United Nations Convention offers disabled people an instrument in order to pursue their rights. The convention calls upon employers and organizations open to members of the general public such as cinemas, theaters, stores, and public services to make "reasonable accommodation" so that disabled people may exert the same rights and participate equally in society. Not to do so is considered discriminatory, and organizations in breach of their obligations may be taken to court. Two points may be made. Firstly, "reasonable accommodation" is a legal, technical, and political matter. There may be tensions between the adaptations provided for different impairment groups. So, trade-offs may have to occur. Secondly, "reasonable accommodation" nevertheless should not be used as a pretext for failing to implement the principles of universal and inclusive design to the greatest extent possible. Indeed what might be the implications of more widespread promotion of inclusive environments rather than environments suited to the "normal," dutifully adjusted to accommodate others?

The United Nations Convention also has important implications for urban design and architecture and illustrates well how change in law can potentially be a powerful macroenvironmental influence on attitudes and practice. This again is well conceptualized by the Disability Creation Process (Fougeyrollas, Noreau, et al., 1998). With respect to discrimination, it is worth pointing out that specific treatment of disabled people with special needs under the convention is not considered as being discriminatory (article 5) if it favors the person's inclusion and participation in society. To such policy, especially relevant to how disabled people can thrive or have their opportunities restricted, we can add the importance of the media and the representations and discourse which structure how people behave and react toward society and others. Furthermore, representations are not just cognitive and individual, they are social and live through the norms, laws, taken-for-granted practice, physical facilities, and care and educational provision on offer. The existence of large institutional residential centers for disabled people in France will tend to structure the social protection benefit system and how disability professionals and social service workers represent and envisage life, employment, and education for people with disabilities (Sherlaw, Lucas, et al., 2014). We may consider that the representations are crystalized "in the very walls" of the residential care homes. This may militate against disabled people being accepted in society's ordinary services and facilities. Thus, it may not be a high priority for the inclusion of disabled pupils in mainstream education in spite of the existence of legislation offering disabled children the right to education in ordinary schools. Similarly, employment of disabled people paradoxically is not necessarily favored by the existence of substantial sheltered employment provision, nor is living in ordinary housing within the community, given the taken-for-granted idea, often championed by disability associations and families, that the state should provide disabled people with special residential care.

There are important vested interests at stake. Often the state or local authorities will provide funding while reaping the political advantage of delegating on the ground operational responsibilities to Disabled People's Organizations (DPO). Since a huge number of health and social service professionals are employed in DPO-managed centers, both employers and employees have a vested interest in maintaining current institutionalized practice. It is thus difficult for more inclusive policy to make headway in the face of such vested interests and alliances, despite the emergence of new paradigms and attitudes. Nevertheless, change will inevitably occur since there has been a substantial paradigm shift toward inclusive approaches throughout Europe and the world. Families through Internet and the media are also becoming more and more aware of other more inclusive possibilities on offer in other countries for their children.

Going Beyond the Social Gradient

We may speak of social structure, social stratification, and class, but we should not forget that different societies may be structured not only through social economic status but through cultural- or religious-based norms. The impact of culture is well illustrated through the example of the well-known Latino paradox (Abraído-Lanza, Chao, & Flórez, 2005). In opposition to the taken-for-granted idea that poor socioeconomic status is systematically associated with poor health, it has paradoxically been shown that recent Latino migrants to the United states have better health status in spite of their comparatively poor socioeconomic status than other more prosperous members of the Latino community who have lived much longer in the United States. It is suggested that this may be explained by the fact that recent arrivals possess better dietary habits and healthier lifestyles coupled to a greater sense of community than those Latinos that have lived in the United States much longer and who have taken on board the lifestyles and the diet of the ordinary American. Structural determinants, which may include also cultural- or religious-based norms, will determine social position, which results from the unequal distribution and use of resources.

Religion

There are many well-known examples of how religious norms of a minority community may be in tension with majority secular societal norms, e.g., the banning of wearing religiously connoted clothing or religious signs in French schools (Liogier, 2009). Another good example of how religion and norms may interact with social policy is provided by the case of school meals in France. Through offering subsidized school meals to school children, the intention is to make sure that all children eat healthily and have sufficient to eat. Poor nutrition is associated with poor health but can also lead to poor academic achievement (CDC, 2014). Policy on school meals will also largely determine whether school children return home to eat or not and favor or hinder mothers having employment. Different societies and authorities may choose to adapt menus to religious food taboos or not. An interesting study by Hermet on schools in the Parisian area illustrates how policy toward diversity may impact not only on whether subsidized or free school meals are actually taken up by children and young people from minority communities but also have unexpected knock-on effects with wider implications for social integration. It was found that meals in certain schools were not deemed culturally acceptable, and children of Moslem faith often chose to return home to eat in their families. Interestingly previous adult eating habits conforming to French norms could be modified under the pressure of their children and Moslem families readopting traditional Halal food, which had previously been forsaken, through reverse socialization (Hermet, 2001). Such overarching policy on how diversity is handled within a society although instituted at the macrolevel, including the norms associated with the policies, will impact at a microlevel on individuals and their families, their lives, and the projects that they have reason to value and that they can envisage and realize.

Further Illustrations from Education

Education provides a concrete example of how social position may be a determinant for the future life course of individuals lacking social, economic, and cultural capitals. The example is from education, which may also be considered as a structural determinant, but it illustrates well how structure and agency or rather lack of agency combine to produce their effects. Compulsory schooling in certain cantons in Switzerland is fixed at 6 years counting from May 1 or 6 years and 3 months counting from 31 August. The school year starts in September. Generally, children go to nursery school for 2 years before entering their compulsory schooling. The youngest children born in April, March, and February on entry to primary school may be less mature and hence be at a disadvantage with respect to more mature children as regards with what is considered to be an appropriate behavior and development. The influence of the birth date one would expect to be taken into account in assessments and orientations. However, as recent Swiss research has shown, some children and their families are more equal than others (Grémion, 2013). Middle professional class parents understanding the danger of a poor assessment due to a relative lack of maturity on leaving nursery school have devised strategies to protect their children from the possibility of being oriented into a special education class or *being obliged to redo* a year in the nursery school which is potentially highly stigmatizing. They postpone their children's entry into nursery school, and when their children have reached the obligatory age for primary schooling, they manage to ensure that their children, with the support of their family pediatrician who provides the seal of approval, do a second year in nursery school (doing 2 years in nursery school is considered as a right and not considered as redoing a year), so when finally they enter primary school proper, they are among the most mature children. But foreign and frequently families of lower socioeconomic status may not have access to such a fine understanding of how the educational system works. This militates against their children, who find themselves simply due to being born in the "wrong month" (April, March, or February) and thus less mature, being drawn into a downward spiral. This may end in an orientation for special schooling or institutionalization which coincidentally allows primary school teachers to be free of children from diverse backgrounds needing more attention than the others.

In this above example, we have a perfectly normal biological difference of maturity which gathers great significance due to the existence of administrative criteria and rules about how starting age for schools should be determined. This biological difference is quickly mitigated through the strategic action of middle-class parents. These parents with the welfare of their children and possessing good knowledge of the institutional system are able, through the operation of social network and economic and cultural capitals, to provide improved life chances for their children. However, parents from working class or of immigrant backgrounds may not possess such knowledge nor may they have privileged access to institutional resources or health professional allies and thus are unable to take prophylactic measures against the possible impact of a lack of maturity. Such an initial lack of maturity is quickly forgotten for the children from privileged backgrounds but may assume great importance with the intentional or unintentional complicity of the primary school teaching professionals for the life chances of children from less-privileged or immigrant background. Biology is expressed through and moderated by the social. Similarly to the case of environmental health which we will examine further, we have an apparently biological, physical, or chemical phenomenon which again may be reduced or exacerbated through the impact of social position. Furthermore, as we shall now examine, such phenomena and social position may also be impacted by territorial segregation and discrimination.

Discrimination and Segregation: Adding Further to Social Disadvantage

Discrimination may take different forms relating to gender, age, sexual orientation, disability, religion, or ethnic origin. It may frequently exacerbate health inequality. Such discrimination may be revealed within different sectors such as work, housing, and leisure activities (e.g., acceptation in restaurants, discos, or night clubs). Mirna and Simon (2014) consider that discrimination may be studied within practices, social actions, and their consequences. This is especially relevant in connection to ethnicity. One may also, as work on stigmatization of people with mental health problems has shown, make a distinction between problems of knowledge (ignorance), problems of attitudes (prejudice), and problems of behavior (discrimination) (Thornicroft, 2006). Discrimination in the last sense is linked to actions which affect individuals and groups negatively and unjustly. At first sight, such distinctions are useful but fail to appreciate that the line between attitudes and actions is a very narrow one, since attitudes tend to impact on ambient norms and people's well-being and self-esteem and as we shall see may become embodied.[8] Nevertheless, practically with respect to discrimination, the major problem is how can discriminatory behavior be characterized objectively, since, for example, unequal treatment is extremely difficult to measure (e.g., in equal employment opportunities and treatment of candidates or for patients having safety net insurance in receiving medical treatment). It should also be noted in countries supposedly "color blind," such as France, where the collection of ethnic statistics is strictly controlled, such objectivation of discrimination is peculiarly challenging (Cédiey, Després, et al., 2007).

Inequalities may also be related to the spatial distribution of the population which lives, works, and pursues leisure activities within a territorial area. Territorial segregation is at the focus of a number of significant studies carried out in sociology, urban planning, development, and geography. One of the principle findings suggests that population groups/clusters tend to cumulate disadvantage involving multiple exposures related to socioeconomic, cultural, and ethnic discrimination coupled with territorial segregation in enclaves or ghettos. Leaving aside why population clusters tend to form between people sharing features of identity, it is important to highlight in the context of discrimination the importance of the accumulation of disadvantage. This includes the lack of easily accessible neighborhood social and health services

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[8] Furthermore, it should not be considered unjust if those who have previously be subjected to unfair treatment or oppression receive benefits and privileged treatment as a righting mechanism to favor social justice.

and from an environmental health perspective living close to potentially hazardous industrial sites, being exposed to high noise levels, air pollution, and zones liable to flooding.

A particularly important and well-documented example of segregation is that of African-American residential segregation. It is well known that there are important health disparities between African-Americans and whites. Williams and Collins (2001) powerfully argue that “racial residential segregation is the cornerstone on which black-white disparities in health status have been built in the US. Segregation is a fundamental cause of differences in health status between African Americans and whites because it shapes socioeconomic conditions for blacks not only at the individual and household levels but also at the neighborhood and community levels.” Despite methodological issues such as how one measures and defines segregation among others White and Borrell (2011), some criticism of this position and examples where segregation may protect health, the overall effect of such residential segregation is deleterious to health and in particular black pregnancy outcomes (Kramer & Hogue, 2009).

Factors linked to residency that may contribute to health inequities include educational opportunity, poverty, employment opportunities and thus income, and accumulation of disadvantage. Mismatch of work opportunities, re-siting of companies, and isolation of blacks in segregated communities takes their toll. A lack of positive role models and social networks linked to employment opportunities engenders cultures where work ethic and civic ethics are undermined and academic success undervalued, all within a context of enduring poverty. If it is clear that health disparities are primarily linked to socioeconomic status (SES), it is equally clear that such segregation usually tends to exacerbate disparities in SES and, hence, health inequities. It is important to tackle this issue since the majority of African-Americans live in urban settings and many of which remain highly segregated (Kramer & Hogue, 2009).

From a methodological perspective, additional distinctions may be drawn between spatial geographical segregations linked to the localization of habitations, work, and leisure. The fact that people may live and work and play in different geographical areas may lessen the impact of residing in an unhealthy environment favoring smoking, for example. Shareck, Frohlich, and Kestens (2014) have conceptualized and suggested people possess mobility potential which will transform into actual mobility through agency. Such mobility potential however is likely to be distributed unevenly across SES groups leading to different contextual influences on health inequalities. Mobility could buffer the effects of unhealthy residential environments, but probably the degree of conversion of mobility potential will be subject to influences such as norms and resources at people’s disposal which will be socially patterned. Nevertheless individuals, even if suffering discrimination, may be able to access resources across different urban environments, even if having an address within an urban area with a poor reputation may in itself be associated with discrimination.

There is however a crucial difference between territorial segregation and discrimination. Discrimination involves rejection and exclusion with respect to personal characteristics which may not be modified or exchanged or negotiated (one cannot change the color of one’s skin, sexual orientation, country of origin, mother tongue, etc.). Age, sex and gender, health status, accent, and mother tongue are the very characteristics which contribute toward the formation of identity and in many ways can be considered as being embodied. Discrimination thus may be defined as being an insult to such identity and human dignity. Unequal treatment is unjust since it implies domination and oppression. In order to consolidate equal rights and fight unfair discriminations, there is no question of changing and transforming individuals, but rather tackling such discrimination at a structural level implies political will and social and cultural changes in how institutions and organizations are governed and managed.

As health inequities are the biological expression of social inequities, social disadvantage related to race has a long social and political history that is sedimented in the places people dwell and the bodies, hearts, and minds of both those who suffer discrimination and those who have participated – actively or passively – in discrimination. Krieger (2012a) in putting forward an ecosocial model of embodiment has argued that it is important to study the multi-level effects of such discrimination rigorously in order to combat it and denounce it but also to give evidence of its devastating effects on people's health and lives.

We close this section on discrimination by describing a provocative study that illustrates the many complexities of the relationships among social structure and its embodiment, all as moderated by the contexts in which people live. The mean level of blood pressure in populations has been shown to vary according to different societies and social contexts. Furthermore, as has been graphically demonstrated by Gravlee (2002), cited by Russell Bernard (2006), a relation between self-perceived skin color among Puerto Ricans and blood pressure may be seen. But this is no straightforward relationship. As Gravlee has dramatically demonstrated, such effects may vary according to the socioeconomic situation of the individual and their self-esteem and pride. Gravlee measured skin color in two ways: an emic (self-perceived) rating and an etic (objective) rating with a photospectrometer. The difference between etic skin color and what people say their skin color (emic) was strongly related with blood pressure. Poor individuals in southeastern Puerto Rico who rated themselves as having a darker skin color than they really had are likely to have a higher blood pressure. For successful middle-class individuals, the relationship was inversed. They are more likely to have lower blood pressure when they rate their skin color darker than it really is. Such findings suggest that the impacts of our sociocultural environments on individuals are complex and are far from being just skin deep[9] (Gravlee, 2009). It also suggests that through changing social contexts and the socioeconomic circumstances of individuals, we may impact favorably on health and well-being.

Complex Interactions Among Contextual Determinants

In the course of the previous sections, we have identified a wide variety of determinants of health across the environment and arising from the health and non-health sectors. We now turn to a central point of our model and of most writing in these areas, the fact that different environmental or contextual determinants often interact in their influences on health.

We will take as our starting point the physical characteristics of the environment and its related exposures (Desai, Mehta, & Smith, 2004). This offers a baseline approach to considering how non-health policy impacting on and shaping environments may be explored and analyzed. In the case of ambient air quality, Deguen and Zmirou (2010) citing evidence from their extensive literature review suggest two mechanisms may be involved, namely, differential exposures to environmental agents and differential susceptibility to them. Both of these differences may be related to socioeconomic status. Firstly, populations with less resources, such as income, tend to end up living and working in unhealthier environments than other populations. However, illustrating the general point of the importance of interacting elements of context, in some settings,

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[9] In tackling this sensitive issue, Gravlee (2009) takes the "opportunity to refine the critique of race in three ways: (1) to reiterate why the race concept is inconsistent with patterns of global human genetic diversity; (2) to refocus attention on the complex, environmental influences on human biology at multiple levels of analysis and across the life course; and (3) to revise the claim that race is a cultural construct and expand research on the sociocultural reality of race and racism." One may add however that biology of course should not be used as the one and only yardstick to measure discrimination and the impact of inequality. Other indicators may of course be used. But beyond this idea in principle, all forms of oppression and discrimination are wrong and should be fought against. Measuring them is one means to achieve that end. However, it is important to bear in mind the words of Simon Weil,

> Equality is a vital [human need]. It consists in recognition, at once public, general, effective and genuinely expressed in institutions and customs, that the same amount of respect and consideration is due to every human being because this respect is due to the human being as such and is not a matter of degree. (Weil, 1949, p. 26)

e.g., Rome, people having higher socioeconomic status have higher exposures to pollutants than poorer populations. Nevertheless, irrespective of the levels of exposure, there is a correlation between being poor and the resultant harmful effects of pollution. This would seem to be related to the second mechanism of differential susceptibility. In other words, poorer populations may, through having been exposed to repeated insults of their environment during certain periods of their life (windows of exposure) (Deguen, Petit, et al., 2015), have developed a greater susceptibility to the resultant health effects. Such susceptibility may be linked to poorer health status and developmental life course factors. As Deguen and Zmirou conclude, in the case of ambient air quality, long-term multipolar urban planning and diversity-sensitive housing policy may be the best way to tackle the environmental and social inequities and to mitigate differential health impacts.

The interactions among contextual determinants are especially apparent in research on urban areas that investigates the effect of neighborhoods on health. For example, evidence shows that obesity rates will vary between neighborhoods within cities such as New York. A range of factors would seem to be involved including the presence of supermarkets and food stores and the area income (Black, Macinko, et al., 2010). With respect to smoking, it is well known, as shown in research from Scotland and France (Lawlor, Frankel, et al., 2003; Perreti-Watel, Constance, et al., 2009), how people at the lower end of the social gradient are more likely to smoke and smoke longer than those from higher up on the social gradient. Consistent with this, better economic and social prospects and associated better health, increased life expectancy and security that goes with them will lead people not to take up smoking or to forsake tobacco (Lawlor, Frankel, et al., 2003). However, it is not only social position that will determine whether one becomes a smoker and one's smoking habits. These will also depend on which neighborhood one lives in. It has been shown that the practice of smoking is favored by the proximity and density of points of sale for tobacco (Henriksen, Feighery, et al., 2008, McCarthy, Mistry, et al., 2009, Cantrell, Anesetti-Rothermel, et al., 2015). These have often found to be concentrated in deprived areas. Van Lenthe and Mackenbach (2006) have also found that people from deprived communities are more likely to smoke but even more so if they live in stressful neighborhoods. Stressors included "physical quality (decay), required police attention, noise pollution from traffic, and population density in neighborhoods." Similarly, objective and perceived measures of neighborhood crime have also been correlated with smoking. Nevertheless, the picture is even more complex than one may suppose. Mirroring findings from a well-known qualitative study from Scotland (Stead, MacAskill, et al., 2001), Ahern, Galea, et al. (2009) demonstrate that neighborhoods with "higher collective efficacy" may either discourage smoking or favor it depending on the presence of pro- or anti-smoking norms. They point out that it will be important when intervening in neighborhoods to bear in mind such findings since increasing social cohesion, seen as being generally favorable for health, may also, depending on the norms at work within the community, lead to favoring unhealthy practices and consequent bad health.

Neighborhood effects may also depend on national contexts. Recent research by Wilson, Eyles, et al. (2010) has compared living in four different neighborhoods in Hamilton (Canada) and Glasgow. They showed that certain effects on health behaviors were shared between the two cities such as living in a low SES neighborhood impacted on likelihood to smoke or being physically inactive. However, living in a poor neighborhood favored being overweight or obesity in Glasgow but not in Hamilton. On the other hand, there were strong associations with mental health (emotional distress) seen in Hamilton but absent in Glasgow.

All such neighborhood studies of the urban environment and populations pose key questions concerning geographical space and place (Burton, Kemp, et al., (2011). In the former, effects on health may be explained through the physical characteristics of the environment and exposures occurring within that geographical space. In the latter, different spaces can have different effects on health which may not be explained completely by reference to physicochemical and biological parameters. Space may become place. Ecob and Jones (1998) citing Macintyre and colleagues suggest that place may have impacts on health through different mechanisms and distinguish between compositional, collective, and contextual effects. Compositional refers to the idea that differences between the sociodemographic characteristics of the population living in different places explain the effect; in other terms, the effect of place on health may be explained "away" through the different characteristics of the population living in the places studied (with respect to health, spaces become places, only through the fact that different populations live in them). The second refers to the possible normative social contagion ("social miasma") between people living in the same place and the last invokes the direct impact of the context. Thus, the question *do people of similar characteristics experience different health outcomes in different types of places?* may be posed. Recently, however, Oakes (2004) has raised important theoretical and methodological questions about causal inference and the possibility to neatly separate social and environmental contexts from the people who live in them. Paraphrasing Macintyre and Ellaway (2003), Oakes, Andrade, Biyoow, and Cowan (2015) remind us that "the fact is neighborhoods make people and people make neighborhoods. It is not composition *or* context, but composition *and* contexts" (authors italics).

Oakes et al. remaining fully committed to investigating rigorously the impact of social contexts on health have called for more experiments, including natural experiments, rather than observational studies. According to Oakes, Andrade, et al. (2015), such experiments are of two types: people are moved from one neighborhood to another or the neighborhoods in which people live are changed. The first category of people being moved from one neighborhood to another includes programs that give people housing vouchers to change home and neighborhood. "Moving to Opportunity" permitted families to move from public housing in high poverty neighborhoods to private housing in lower poverty or nonpoor New York neighborhoods. Moving out of the public housing/high poverty neighborhoods was associated with lower distress among parents and lower anxious/depressive and dependency problems among their sons (Leventhal & Brookes-Gunn, 2003). Similarly, a randomized environmental experimental intervention carried out in Chicago (Ludwig, Sanbonmatsu, et al., 2011) has shown that obesity and diabetes risk may be reduced by moving to different neighborhoods. Three groups were constituted. One group was offered housing vouchers provided they changed address and moved to another neighborhood. Another group was offered the equivalent sum but was given no instructions or advice on moving, and third, control group was offered neither advice nor money. Over a 7-year period, there was no significant difference between the latter two groups, but the objectively measured risks of developing obesity and diabetes were reduced in the group who moved home. Positive effects[10] were seen 10–15 years later in prevalence of obesity and diabetes (Ludwig, Sanbonmatsu, et al., 2011). Nevertheless, such programs are costly, and moving home may be no simple affair as people may identify strongly with the place they live in spite of social and economic difficulties. As Popay, Thomas, et al. (2003) have shown through comparing two Northern England towns, Salford and Lancaster, each with a high- and low-income area, there will be complex interactions involving the interplay of structure and agency and meaning of place. People will react differently depending on their socioeconomic status, biographical and narrative history, and capacity to reconcile the dissonance between "normative guidelines" of what a "proper place" to live in should be like and their own actual "lived experience of place" and the people living there. Thus, when faced with criminality, different individuals and families may take different stances, such as combatting criminal behavior through individual action and mobilizing the community or, on the contrary, protecting and shutting themselves off in their own "privatized space" from the outside world. Such realities

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[10] See also http://www.nber.org/mtopublic/.

are important to take into account as they may structure the possibility of collective community action and social cohesion, both important for promoting health. Being aware of these issues and sociological work, such as Williams (2003), Frohlich and Abel (2014) have put forward a substantial framework founded on a synthesis of Bourdieu's theory on capital and Sen's Capabilities theory, thus combining structure and agency. They suggest that rather than study individual health-related behavior, it is more fruitful to study contextualized health practices. As we shall see, they have applied this framework to inequities in smoking. Evidence from neighborhood studies such as these implies that some neighborhoods are healthier places than others, and ultimately environments should be considered as places with both objective and subjective realties in which representations circulate rather than mere geographical space. Indeed, in line with our model, communities may be thought as having both a geographical and historical dimension.

The historical dimension of communities is illustrated well by research on lay epidemiological understandings of breast cancer (Salant & Gehlert, 2008). Focus group interviews guided by grounded theory showed that collective memory, including nostalgia for simpler lifestyles and environments, fear and social stigma of cancer, and distrust of doctors, is fed by a historical heritage of injustice and discrimination. This suggests that breast cancer-related survival and recourse to early diagnosis and treatment may be related to how black women represent the illness and how they and their families have been treated in the past. Here is a good illustration of how health may be impacted through the representations circulating within a community stemming from explicit or implicit discrimination. As Salant and Gehert suggest, research and interventions on health disparities may need not just to consider easily quantifiable indicators of belonging to a geographical community defined by objective boundaries but may need also to explore "imagined communities", that is, how the community members themselves define their own community. Imagined communities may not correspond to usual geographical definitions. Furthermore, collective representations of community can be used to "interpret the health landscape" and impact on health behaviors. This is in contrast to individual models of health responsibility (Salant & Gehert, 2008).

We suggest *in fine* that exposures to health risks and the possibility to mobilize health-giving resources by individuals and populations are socially and culturally structured. Environments are not equal for all. On the contrary, they are stratified and structured socially and culturally. Thus, conceptualizing a sharp division between risks and health behaviors depending on individual choice and passive exposure to risks is untenable. As MacIntyre (2000) suggests, the inverse care law formulated by Tudor Hart may also be usefully applied to health-promoting resources and facilities available within cities. Poor people will generally have the least resources for improving their health, whereas the richer and healthier members of the community will have the most. What is more is that hazards and risks are unevenly shared, as are the opportunities for people to extract themselves from the source of such risks. People being exposed to high levels of environmental noise linked to harmful effects on health in general will have little opportunity to choose to move home due to lack of economic, social, and cultural capitals. Such "passive" long-term exposure to sources of ill-health is generally not a question of individual choice. Public policy can of course attempt to protect habitations from high noise levels by screens or reduce noise levels through legislating for quieter motor vehicles or more radically and intelligently distancing of habitations from the proximity of major road systems. Furthermore, as we will maintain, often people from a population and specific urban district will be exposed to a accumulation of several adverse risks associated with physical agents, such as poor-quality air and noise potentially deleterious for health. These different risks will also be exacerbated, maintained, or mitigated through the sociocultural and physical environment, i.e., the conditions in which people live, work, and play.

Examples and Progress: Housing and Urban Life

We will now take a more detailed look at two of the most important non-health sector areas, housing and urban planning and development and how these impact on people's lives.

Social determinants of health have been famously defined as "the circumstances in which people are born, grow up, live, work and age." These circumstances may vary starkly from living as a rough sleeper on the city streets without a home to enjoying the luxury of a comfortable mansion. Those who are homeless suffer the highest rates of premature death (Wilkinson & Marmot, 2003). This single fact highlights the crucial importance of having a home and living conditions for health. Shaw in her 2004 review of the impact of housing on health highlights both material and immaterial attributes that are associated with having a home. We will review principal harms and benefits associated with housing in detail later. If it is reasonable to adopt a Maslowian approach to human needs by stressing the "hard" impacts of the physical housing environment as a starting point to study impact on health, it is insufficient. Impact of housing on health and well-being must also take into account psychosocial and cultural dimensions. Citing Dupuis, Shaw discusses the importance of the ontological aspects which bring the meaning of having a home to the fore. This is recognized by the WHO (2007) in their recent definition of housing as "the conjunction of dwelling, home, immediate environment and community." One should never forget that housing (if one has the chance to have a home, be it a house, an apartment, or less well-appointed dwelling) is not just a shelter where one sleeps but constitutes the daily and often yearly environment for children's play and study and adult leisure, study, and often work. Increasingly and importantly, it is well recognized that good and bad housing and living conditions are important determinants of health (Wilkinson & Marmot, 2003; Bonnefoy, 2007). Thus, access to decent housing and the type of housing policy pursued have important effects on population health (WHO, 2006a).

Housing supply may include rented social housing through the public sector or housing associations or providing rented property through private landlords or private ownership. National and local government policy with respect to issues such as mortgages, local housing taxes (rates), and rent fixing will largely determine whether the supply of social housing is high or low. Access to social housing (housing owned and rented out by local authorities to people with low incomes or specific needs) will for the most part be determined by residence in the community and recognized need such as being a lone woman with children. Since supply is restricted, competition to get on the housing register is fierce, and this in itself creates considerable tension within society among those on housing waiting lists, creating the conditions in which stigmatization and discrimination thrive especially on ethnic grounds. In France, a country with a tradition of strong social policies, it is estimated that more than 500,000 people do not have a home, and among those, 133,000 are actually homeless; others are living on sofas of friends, hostels, squats, etc. (Fondation Abbé Pierre, 2011). If the number of people living in a very "difficult housing" situation is added, the number rises to 3.6 million, more than 5% of the French population. The term "difficult housing" situation refers to those living in chronic overpopulation and dangerous buildings, with a lack of basic amenities. Moreover, another 5 million people are considered to have a very fragile housing situation (lack of house maintenance, large unpaid rents, etc.), and nearly 3.5 million face fuel poverty (Fondation Abbé Pierre, 2011). These estimates are likely to underestimate the real problem given the present economic crisis. The rehabilitation of substandard housing, both public and private owned, is a key area of intervention among French city councils (Heritage, Garchitorena-Garcia, 2013).

Even if appropriate and affordable housing has been heralded as a fundamental human right, it remains as one which is far from being upheld in many developing and developed countries alike. Homelessness has increased in many countries, including the richest, and these populations suffer the highest rates of premature death (Wilkinson & Marmot, 2003). The WHO "Closing the gap in a generation" report warns that "One of the biggest challenges facing cities is access to adequate shelter for all. Not only is the provision of shelter essential but the quality of the shelter (…). This crisis (of housing) will worsen social inequities in general, and in health in particular" (WHO, 2008). The US Surgeon General's Call to Action (2009) says that "To improve the nation's overall health, we must improve the health of the nation's homes and ensure that safe, healthy, affordable, accessible and environmentally friendly homes are available to everyone" (Meyer, 2010).

The Home Environment: A Crucible for Health and Disease

People spend the majority of their lifetime inside their homes, and therefore exposure to housing-related factors represents a considerable threat. Illustrating our earlier discussion of the roles of both exposure and susceptibility, the most vulnerable populations such as the sick, the elderly, the children, the unemployed, and the poor are also the ones who spend the largest proportion of time at home, further exacerbating the impacts of household exposures (WHO, 2007). Lower household income is associated with inadequate housing which is linked to many risk factors such as mold growth, crowding, indoor pollution, and noise (Braubach & Fairburn, 2010). Fuel poverty is also disproportionately higher in low-income groups (Braubach & Fairburn, 2010) and associated with excess winter and summer deaths due to thermal stress (Kuholski, Tohn, & Morley, 2010). Furthermore, exposure to traffic-related noise, proximity to industrial pollution sources, lack of green spaces, and lack of perceived safety due to deprived neighborhoods (litter, graffiti, etc.) are also experienced more frequently by lower income groups.

Housing Conditions and Health

Many links have been identified between housing conditions and health (see Fig. 15.3). The presence of safety devices, structural characteristics of the house, the materials used for construction, interior decoration, and neighborhood configuration can all have an influence on health. The most significant housing hazards have been quantified by the WHO Health Evidence Network (WHO-HEN). The ranking is the following: poor air quality; poor hygrothermal conditions; radon; slips, trips, and falls; noise; house dust mites; tobacco smoke; and fires (Thomson & Petticrew, 2005).

Chemical and Biological Hazards

Air pollution causes premature deaths and is associated to increased risk of coronary heart disease and many respiratory diseases such as asthma and chronic obstructive pulmonary disease, with increased susceptibility in low-income groups (Deguen & Zmirou-Navier, 2010). Indoor sources of air pollution can be caused by both chemical and biological sources.

Exposure of children to hazardous levels of lead may result in long-term effects on the brain and cognitive development among others (US EPA, 2004). Measures to reduce lead exposure have great cost-benefit ratios and result in actual savings in medical care, education, and productivity for those who are protected (Thomson & Petticrew, 2005). For instance, lead hazard control in the United States has shown to be a very effective intervention, decreasing dust lead levels by 78% over a 3-year period (Sandel, Baeder, et al., 2010).

In France, exposure to radon is the second leading cause of lung cancer after tobacco causing up to 2900 deaths per year (Ministère du travail de l'emploi et de la santé, 2008). Radon mitigation is effective in reducing individuals' risk of lung cancer and is cost-effective compared to other health-care and environmental interventions (Sandel, Baeder, et al., 2010; National Collaborating Centre for Environmental Health, 2008). Other common sources of indoor chemical air pollutants like residential secondhand smoke, pesticides used in the house, and volatile

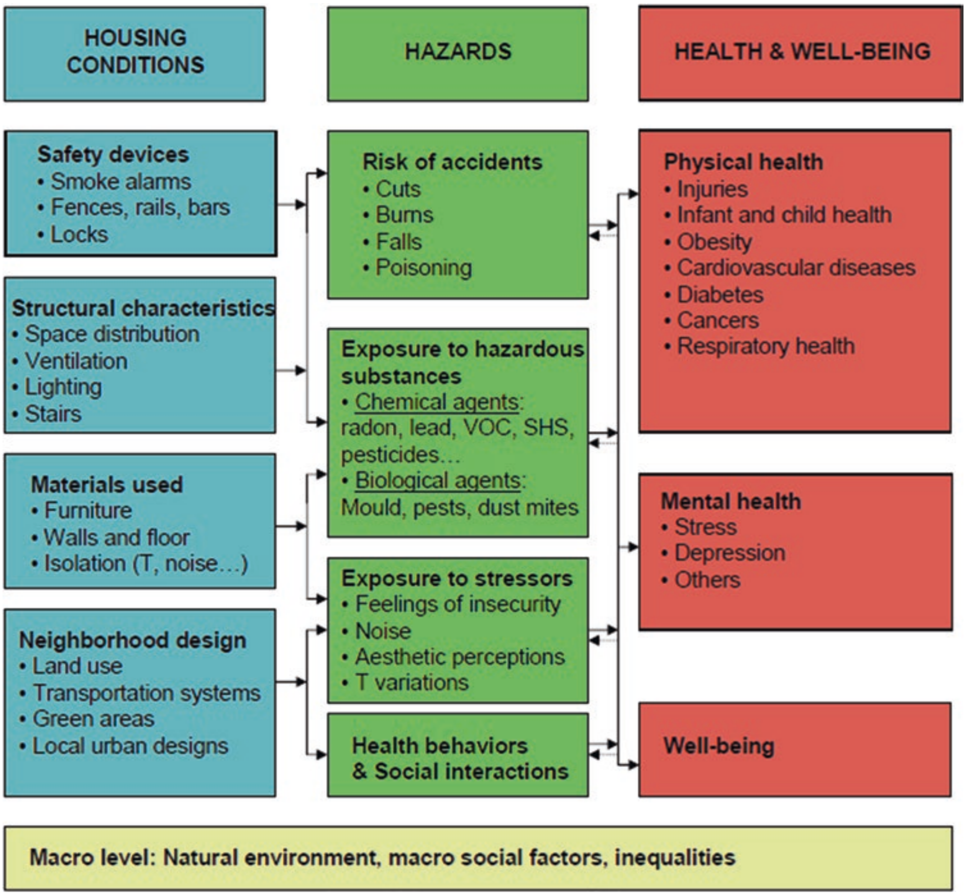

Fig. 15.3 Summary of the links between housing conditions and health outcomes (Garchitorena Garcia, 2011 adapted from Northridge, Sclar, & Biswas, 2003)

organic compounds released by many household items may result in respiratory problems and development of cancers (Sandel, Baeder, et al., 2010; WHO, 2000b).

Housing conditions may also create a favorable environment for the presence and levels of house dust mites, mold growth, cockroaches, and other pests. Overall, they represent the most common source of domestic allergens, and some of the fungal cell wall components can also irritate the respiratory tract through nonallergic mechanisms (Krieger, Jacobs, et al., 2010). They are associated with asthma development and exacerbation and other respiratory problems (WHO, 2009a). Leaks, plumbing problems, or inadequate ventilation can lead to excess moisture which attracts pests and supports mold growth (Krieger, Jacobs, et al., 2010, WHO, 2009a).

Psychosocial Influence of Housing

Housing conditions can impact not only directly on physical health but also through their influence on psychosocial factors and mental health (WHO, 2007; Grant, Braubach, & Krzyzanowski, 2010; Krieger & Higgins, 2002). They are not only associated to specific health outcomes but also to self-reported health status, well-being, and quality of life (WHO, 2007). For instance, neighborhood noise is the most frequent complaint lodged to the French municipal services (Centre d'information et de documentation sur le bruit, 2009), and it can induce stress, annoyance, sleep disturbances (WHO, 2009b), and changes in social behavior (Passchier-Vermeer & Passchier, 2000; WHO, 2011b). Other sources of stress are exposure to dampness or lack of indoor daylight (Aylin, Morris, et al., 2001). To sum up, the evidence of the link between adequate housing and both mental and physical health is irrefutable (Thomson, Thomas, et al., 2009; Jacobs & Brown, et al. 2010). Housing polices to increase the supply of affordable housing and also to improve the quality of the existing housing stock will reduce morbidity. We will now look at urban planning and development.

Urban Environmental Impacts, Planning, and Development

More than half of the human population worldwide lives nowadays in towns and cities. This is likely to increase to 60% by the year 2030. In the developing world, this is likely to lead to megacities in Asia and other large cities in Africa and 2 billion people living in slum conditions worldwide. Thus, it is important to draw lessons from the healthy cities movement to prepare for an increasingly urban world (Rydin, Bleahu, et al., 2012). In Europe and the United States, 75% and 80% of people, respectively, live in urban areas (EEA, 2011, Northridge, Sclar, & Biswas, 2003). Megapoles, cities, and other built and planned urban environments may be considered as a set of unequally structured spaces in which human populations are subject to constraints and possibilities. The existence of varied infrastructure parking lots, industrial zones, shopping areas, office blocks, road, and transport systems unequally structures the urban environment leading to health opportunities and risks. The road network and public transport systems facilitate movement but also numerous conditions that increase the likelihood of disease transmission. They also may form veritable barriers and enclaves. Cities are “plastic,” since they provide opportunities and constraints with respect to health (Raban, 2008).

Some of the challenges of the urban environment are especially pronounced for those with disabilities. Brzustowski and Jourdain (2003) found through comparing non-disabled people and physically disabled people, the latter go to the cinema 17% less than the general public. This is more than likely due to lack of accessibility of cinemas than some inherent preferences specific to disabled people. Additionally, accessibility is multidimensional and involves not just accessibility to public facilities, houses, and apartments but also the paths and roads between facilities and other dwellings as well as whether accessible transport is available and the points at which such transport services may be accessed or left (Bodin, 1999). Furthermore, provision should take into account multiple forms of impairment, each with their own particular needs.

Software is now available for analyzing accessibility (Bodin, 2005). Apps on smartphones have also been produced where disabled people may signal that a particular facility is truly accessible, thus mapping their city at low cost and to the benefit of all.[11] What is at stake in urban environments for disabled people is the possibility to benefit from the same facilities with the same rights and access as any other citizen and to carry out social activities and practices of their choosing. This has immediate implications for their health and well-being. If they cannot easily access stores and markets selling healthy food, then their health may suffer.

Disability may be a special area of interest, but its lessons hold true for other health practices with both positive and negative impacts. Frohlich and Abel (2014) suggest that urban environments and neighborhoods in particular should be thought as spaces providing resources for practices either enhancing health or harming health. Access and availability to resources are considered to be governed by four sets of rules, namely, proximity, price, rights, and informal reciprocity, e.g., gift transactions (after Godbout, 2000, 2003). Health practices, such as smoking, will occur as the result of the interaction of individuals possessing different social, economic, and cultural capitals (Bourdieu) with the resources within different domains. These domains include the physical (proximity), economic (price), institutional (rights), local sociability in community and organizational domains (informal reciprocity), and variations in how these domains are configured and in which these rules act.

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[11] See, for instance, the collaborative initiative of Jacedde http://www.jaccede.com.

How different local configurations of domains within local neighborhoods influence health is illustrated by considering will "the local production of inequities in smoking" (Frohlich & Abel, 2014). How close are tobacco outlets? How much do cigarettes cost? Who is allowed to buy cigarettes? Who is allowed to smoke by law? And at what age? Is smoking banned in public spaces? What information resources on smoking exist? Is smoking a way to handle stress stemming from living or working conditions? What social norms are at play in relation to smoking, is it encouraged or frowned upon? Does smoking furnish a way of setting up and fostering relationships? Is smoking a way of marking out one's identity and community belonging? Are there alternative possibilities to achieve such goals within the neighborhood? Do community resources such as smoking cessation clinics exist and are they accessible to those who wish to use them? Do school-based programs exist within the community? What attitudes are taken by the school authorities to smoking? Do informal support programs set up by volunteers from the community exist? As can be easily appreciated, the above questions highlight the different domains and degree of complexity at play. Thus, physical proximity, market, institutions, and informal reciprocity involving social ties have their role to play.

Access to resources is important but insufficient to explain health practices. Depending on the neighborhood, resources will be more or lesser available, and this is not just a question of quantity. It is also a question of the capitals (social, economic, and cultural) that individuals may deploy. Although resources may be available, the ability of individuals to access these will vary. Thus, in two neighborhoods, equal health-enhancing resources may be available but their actual use may differ. Thus, mapping resources statistically is insufficient to characterize health inequities between neighborhoods. As Frohlich and Abel propose, inequities will arise at three different levels, namely, in the resources that are present in the environment, in the capitals and how these capitals relate to each other and may be deployed by individuals synergistically to access resources, and in the interaction of these levels in terms of capabilities (Abel & Frohlich, 2012). Capabilities go beyond achieving a set goal to encompass the idea that what matters is possessing the freedom to envisage and choose from a range of possibilities in relation to the projects and life plans that people have reason to value. Neighborhoods structure the health practices that people engage in, notably through the unequal distribution of resources. The idea of resources may be widened to include not just physical resources but also intangible resources which may be seen as relational processes. Neighborhoods are not just passive geographical spaces but living dialectics of structure and agency where people adapt to constraints and embrace freedoms in different domains over time and places where individuals and communities engage in practices producing health on a daily basis (Bernard, Charafeddine, et al., 2007).

Engaging in physical activity to promote health is also largely, but as our previous analysis suggests, not totally dependent on the resources within the environment. Are there safe footpaths with street lighting, green spaces, cycle tracks, gymnasium, and sports facilities? (One may have the cultural capital to engage in physical activity, but if the area is unsafe or cycle lanes inexistent, this is insufficient. Conversely, cycle lanes may exist, but cycling may be contrary to the social norms of the community, or economic capital to buy a cycle is lacking.) Is the environment isolated from the road system? Is the air clean? Are noise levels acceptable? Such matters are of course matters for local government and should be pursued actively (WHO, 2006b). (An example of the importance of the institutional domain.) Similarly, healthy eating may be seen as a health practice which is complex and favored by many factors such as personal history, education, and norms but is also very obviously dependent on the proximity, availability, and price of healthy food and unhealthy food in the local environment (Larson, Story, & Nelson, 2009; Hilmers, Hilmers, & Dave, 2012) as well as many of the neighborhood level social influences identified for smoking.

From a more physical perspective, the urban environment has also assumed considerable importance in public health terms notably due to its high population density, the size of buildings, and the existence of a considerable technical infrastructure coupled with diverse industries having high potential for different kinds of environmental pollution impacting on human health. These may aggregate or intensify the chemical and biological hazards associated with housing described above. As in our earlier mention of the diverse harms associated with noise, the degree of health impact is strongly related to the proximity of the population concerned and the source of noise emission. Thus, an increase of 10 dB of sound intensity corresponds to an increase in prescribed sleeping pills and cardiovascular disease medications (Franssen, Wiechen, et al., 2004).

The Chicago, 1996, and French, 2003, heatwaves illustrate how the urban environment may also exacerbate risks to health. Built-up environments lacking trees, hedges, bushes, and other plants tend to conserve heat (or cold). The impact of such events on mortality and morbidity is exacerbated, vulnerable isolated members of the population being trapped in veritable islands of heat within the urban environment (Klinenberg, 2003). We may also mention more extreme events such as terrorist attacks, earthquakes and other natural disasters, industrial catastrophes associated with high levels of death and injury, and chronic health problems, all of which are intensified in the densely populated urban setting. Additionally, and as noted previously, those most vulnerable are likely to have greatest exposure. In the case of industrial sites, "insult is added to injury," as very often disadvantaged populations are more likely to live close to industrial sites. Such exposed populations suffer from accumulation of long-term chronic emissions impacting on health throughout life and acute risks due to explosions and environmental contamination which may affect a large perimeter around the industrial site. Beyond the acute, immediate, traumatic injuries and deaths, disasters may also bring in their wake psychosocial consequences, such as depression. This has been seen following the major explosion of the AZF plant in the French city of Toulouse (Rivière, Albessard, et al., 2010).

The urban environment not only has direct physical impacts on health due to physicochemical risks on the human organism or as we have seen through the exacerbation of such risks but also can have indirect impacts in the form of social and behavioral effects (Whitehead, & Dahlgren, 1991; Barton, 2009). The existence of good public service provision may also contribute to mitigating such effects as indeed poor, or absent service provision may exacerbate the situation. As we have seen, people's perceptions can intensify health risks or alternatively promote healthy behaviors through reinforcing feedback loops impacting on many of today's most relevant health problems (asthma, diabetes, cancer, cardiovascular disease, depression, etc.) (Grant, Braubach, et al., 2010).

The distance to daily destinations and therefore the levels of active travel and physical activity are partly determined by the choice in urban planning of either separated or integrated land uses, the city development density, or the type of street network. Mixed land uses together with investments in good quality, accessible public transport, and reductions in the capacity of motorized transport in residential areas can reduce air pollution and traffic noise and might lead to increases in active travel and better mental health. In addition, lower speed limits in neighborhoods are associated to decreases in noise, traffic-related injuries, and fatalities (Grant, Braubach, et al., 2010).

The design of the neighborhood and the provision of urban green spaces have an impact on health risks, influencing aesthetic perceptions and physical constraints and determining the degree of social mixing. Poorly maintained and deteriorated urban environments lacking of green areas are associated with lower levels of physical activity and increased rates of overweight, partly explained through people's perception as a reaction to the aesthetic impression, which also affect mental health and social isolation. The presence of accessible municipal services, public gathering places, and green areas can counteract some of these effects. In addition, environments mimicking natural conditions (green corridors, parks, etc.) help by reducing ambient air pollution, cooling urban areas, providing a barrier against noise, and may even have an influence on preventing the development of some forms of cancer (Grant, Braubach, et al., 2010).

Given that low-income populations are disproportionately found in environments with worse urban features (less green spaces, poor urban design, etc.), many different approaches have been developed in the last decades to address health inequalities by changing the neighborhood characteristics of low-income people. For instance, programs have addressed area characteristics by moving people from high- to low-poverty neighborhoods. As we have discussed, moving to a new neighborhood can improve mental health, reduce obesity, and impact positively on some wider determinants of health (Gibson, Petticrew, et al., 2011). However, urban regeneration programs, aiming at the whole neighborhood level, are argued to be more cost-effective than the movement of individuals to better areas, since it benefits the community as a whole (Bond, Sautkina, & Keams, 2011). Yet the evidence supporting this idea is still weak. A systematic review in the UK (Gibson, Petticrew, et al., 2011) found small positive impacts on socioeconomic determinants of health but potential negative impacts as well. Mixed tenure has also been promoted in many European countries as a means to tackle social exclusion and create sustainable communities. However, the evidence is inconclusive on whether it actually promotes social cohesion and residential sustainability or improves people's perceptions of the neighborhood nor has it been found to provide better job opportunities or changes in income mix (Bond, Sautkina, & Keams, 2011).

Other interventions that have the potential to improve health and health inequalities include the demolition of distressed housing and relocation of residents, universal design standards to favor the elderly and people with disabilities, crime prevention through environmental design, smart growth and connectivity designs, zoning (regulating how a land or a site may be or not used for certain purposes, e.g., prohibiting alcohol outlets near schools), and interventions concerning green space around housing (Lindberg, Shenassa, et al., 2010).

We have presented a range of ways non-health sector factors and policies may impact on human health. We have also sketched a number of different policies that may reduce or mitigate deleterious health impacts. We have also stressed that health should be seen positively and that physical and sociocultural environments have the potential to promote and improve health. Increasingly non-health policy is taking up the gauntlet and addressing a number of these issues at the macro- and microlevel. At the macrolevel, this has been tackled notably through adapting recommendations from Health in All Policies within national and supranational government policy agendas. At the micro- or local level, numerous initiatives tackle proximal lifestyle issues. These are increasingly being proposed in tandem with more projects oriented toward distal health determinants and health inequities which recognize the impact of environments on people's practices and health. At the local level, the practice of carrying out systematically health impact assessments on new infrastructure development projects has also largely been accepted and built into law on urban renewal and industrial developments. We will briefly outline these trends giving examples of projects which recognize and reflect the importance of social determinants of health in their design.

Policies and Values

Health in All Policies and Health Impact Assessment

The idea of Health in All Policies (HIAP) is not new. The first article of the Alma-Ata declaration proclaims after defining health as a human right that

> "… the attainment of the highest possible level of health is a most important world-wide social goal whose realization requires the action of many other social and economic sectors in addition to the health sector."

The Ottawa Charter on health promotion highlights the area "Build healthy policies," "including legislation, fiscal measures, taxation and the adoption of healthy policies in non-health sectors and the development of ways to remove them."

Healthy public policy and its natural partners HIAP and Health Impact Assessment in many ways are the tool embodying the principles of healthy public policy figure prominently in WHO (2010c) and European Union policy (Ståhl, Kemm, et al., 2006). Within Europe they are also at the heart of the Healthy Cities Network. This was established at the end of the 1980s and now has around 1300 member cities. Currently the Healthy Cities Network objectives reflect a HIAP agenda incorporating both health and tackling health inequities (RFVS, 2010). Furthermore, they encompass the idea of nondiscrimination and stress a city is for all citizens. The Healthy Cities Network also recognizes that health depends on both healthy lifestyles and the living and working conditions provided to people. Good urban planning and services provide safe and healthy environments and promote health through, for example, decreasing pollution and providing opportunities for physical activity and social participation thus leading to increased well-being. Different cities and their municipal councils fix priorities and initiate projects in a wide range of environmental and health domains. In France these include projects on radon and indoor air pollution, physical and sporting activities to tackle obesity, school transport schemes encouraging walking to school or environmentally friendly vehicles, healthy nutrition, and carrying out a Health Impact Assessment in order to inform decisions about the setting up of a new crèche in an urban area.

On a global basis, the principles of Health in All Policies have also been enshrined in WHO policy by the Adelaide Statement (2010c). This stressed how cross-sector collaboration and joined up government were not only keys to better health and equity but may also be linked to sustainable development, citizen participation, and more efficient economies. The Adelaide Statement also explicitly recognizes that “the causes of health and well-being lie outside the health sector and are socially and economically formed.” The statement concludes with non-health sector examples of joined up government and its capacity to improve health and well-being (including both individual and societal well-being). The following non-health sector areas and issues are singled out: economy and employment, security and justice, education and early life, agriculture and food, infrastructure, planning and transport, environments and sustainability, housing and community services, and land and culture. As can be easily appreciated, all these areas are related to social determinants of health and tackling inequities. It is clear that the problem of introducing Health in All Policies is not for want of unclear objectives and means, since these are clearly stated, but rather lies in the fact, recognized in the Adelaide Statement, that considerable tension exists between different goals of public policy. To resolve such tension will require patience and new forms of governance and politics. As has been remarked, one measure of the success of a social innovation is whether it has managed to incorporate its most dear principles within tangible instruments or tools used routinely which become taken for granted and diffused among a wider public. As Kemm (2006) notes, “the idea of Health in All Policies is difficult to imagine without its counterpart and ally Health Impact Assessment.” In our view, Health Impact Assessment has effectively managed to incorporate a number of the key features of the Health in All Policies agenda into project design, evolution, and evaluation. As Kemm stresses however Health Impact Assessment can never be a substitute for political decision. It will give evidence on the possible consequences of policies, but it will never resolve dilemmas and tensions between different policy goals. This remains the task of policy makers who through Health Impact Assessment will be better informed about possible outcomes of their decisions affecting people’s lives. Nevertheless, there will always remain uncertainties.

Since non-health sectors largely constitute the economic and social fabric of society and non-health policies involve or impact on the people living in society, it will be necessary for all those concerned to weave common purpose in their aim to protect, maintain, improve, and address health inequities. Note that there should be no question of “us” and “them” in this, since the factors producing the social gradient in health do not only impact on those at the bottom of the gradient but act along the entire gradient. This should be done through setting up mechanisms for participation especially at the local and community level. (See chapter by Ramanadhan and Viswanath, *infra*.) This is no pious pipe dream but is based on the essential idea that humans share common needs and aspirations which go beyond culture, private, and corporate interests. In order to live in peace and prosperity in a sustainable way, it will be necessary to set up such mechanisms.

The government will need to place more emphasis on non-health policy in order to address population health. This flies in face of taken-for-granted representations of health in the general population. Health is often reduced to health care, and this is how governments and citizens traditionally represent health, dividing up the world into health and non-health. Nevertheless, recent initial French findings (You, Simons, et al., 2015) suggest that local stakeholders involved in a community project may perceive health more broadly than previously envisaged, "as a global resource for life, determined by a large number of factors (behaviors, social life, work conditions, education, transportation, etc.) and for which every local actor has a responsibility." A background paper on social determinants of health (Commission on Social Determinants of Health, 2005) highlighted the political and scientific challenges of intersectoral working and implementing policy grounded in social determinants of health agenda. Such stakeholder perceptions of health are welcome support for the idea that a robust health policy may be legitimately seen to include interventions and policies from beyond the health-care sector (Roundtable on Population Health Improvement, Board on Population Health and Public Health Practice, & Institute of Medicine 2014).

Scientific Challenges Ahead

Through engaging in work examining the impact of policies and the development of infrastructure, environmental and public health scientists have increasingly recognized that huge scientific and epistemological challenges are posed with respect to establishing causality between non-health sector factors and policies and their impacts. On the one hand, the challenges are related to the necessity for gathering high-quality data systematically. This is no easy task due to different standards, to different information systems, and to different items of information gathered in different ways, in different regions and countries, and with different degrees of priority. This last point is crucial since we are faced with a paradox. The health sector for obvious reasons gathers data about health from health sector sources. Such data frequently lacks crucial information on the circumstances of people's lives and living conditions relating to non-health policy and non-health sectors. This is almost by definition not the concern of the health sector. On the other hand, even if the non-health sector gathers data on many facets of its activities, information on health all too often will be difficult to obtain, since health, by definition again, is not a primary objective pursued by non-health policy. Thus, correlations may be difficult to establish. Geocoding by neighborhood of residence offers one approach to linking health data with other data characterizing the kinds of neighborhood and community determinants emphasized throughout this chapter. However, fundamentally gathering of such information is feasible and necessary. If it is lacking, little headway may be made and much evidence will be easy to dispute.

But even bigger challenges await researchers and policy makers. For beyond the necessity of gathering high-quality data, researchers and policy makers are confronted with the challenges of complexity and multiple pathways and feedback loops inherent within the non-health sector. It is a relatively simple matter to establish whether poor-quality or insalubrious housing can have direct proximal effects on health through, for example, dampness and associated mold increasing the risk of respiratory disease (But even here there is some degree of controversy as to the degree of impact.). However, if one attempts to further link housing to health status through studying its more indirect influence, it is immediately obvious that there are many confounding factors such as income, employment, and geographical area associated with its environmental characteristics which are challenging and difficult to unravel. As Shaw states in her 2004 review:

> Housing, health, and poverty are still empirically related and conceptually interconnected. We often become tangled in circular explanations as we attribute the effects of poverty on health to poor housing, and the effects of poor housing on health to general poverty. … This difficulty of disentangling and proving causal links is inherent to the study of social determinants of health, which tend to be multifaceted and confounded. No single factor can be identified whereby housing affects health (as with social class or socioeconomic position, gender, or ethnicity); housing is best viewed as a catch-all term for the myriad and multidimensional ways in which our conditions of living—physical, proximate, emotional, and social—can affect health. (Shaw, 2004)

Similarly Oakes and colleagues with respect to neighborhood effects stress that "Efforts to disentangle mutually constitutive, inextricably linked, synergistic, and coevolving elements are doomed to fail" (Oakes, Andrade, et al., 2015). They suggest social epidemiologists should look to solutions in ecological approaches as described by Macintyre and Ellaway (2000) and McLaren and Hawe (2005). Qualitative research may also have a significant role to play. It is perhaps illusory and ill founded to believe that such factors may be totally unraveled notwithstanding good study designs and new methodological trends in social epidemiology (Kawachi 2013, Muntaner, 2013, Galea & Link, 2013) Recent work on public health intervention research recognizes this and takes into account social theory (Hawe & Potvin, 2009). This will imply in some cases a rejection of linear logic, such as in the standard sequence of clinical medicine, that is, diagnosis, intervention, outcome, and its assessment, in favor of other models which incorporate participation, actor reflexivity, systems thinking, and complexity theory (Potvin, Gendron, et al., 2005, Livingood, Allegrante, et al., 2011).

The example of Penwerris, in Falmouth, Cornwall, UK, may be cited as a model for thinking about these issues. This socially deprived area in 1995 had the highest number of poor households, the highest proportion of children in households with no wage earners and the second highest number of lone parents. More than 50% of homes lacked central heating, and the illness rate was 18% above the national average (Durie & Wyatt, 2007). Five years on through community action initiated by two local health visitors, but carried forward by the community itself, the situation had undergone a spectacular radical transformation. Improvements of a whole series of community indicators had occurred including a 50% drop in crimes, a 42% fall in child protection registrations, and a drop of 70% in postnatal depression. Furthermore, there were no unwanted teenage pregnancies, educational achievement had hugely improved, and the unemployment rate had fallen by 71% in both men and women (Durie & Wyatt, 2007).

Durie and Wyatt carried out qualitative interviews and two focus groups to understand the process of change with its facilitators and obstacles. They suggest, through referring to complexity theory, that the downward spiral of social deprivation and urban decline was reversed through acting at a critical point, developing trust and self-confidence, favoring self-organization within the community, and leading to a reconfiguring of social relationships between those residents living in the Penwerris community, different statutory agencies, and new actors. The health visitors pinpointed 20 residents who they felt could work constructively on the estate's problems with the authorities. Five agreed to participate. The health visitors went on to initiate intersectoral action inviting the representatives of health, social services, education, local government, and the police to a series of meetings. Most importantly, in parallel with an injection of funds following a successful application for an energy improvement grant for the area, a shift in power was granted by the authorities to allow the community partnership to fix priorities and take decisions about their own community and lives. Crucially, problems were discussed and "discovered" between the actors and different solutions being explored. This was not based on classical needs analysis carried out from above but emerged and relied on local knowledge, ideas, and initiative. Regeneration was not planned from outside but emerged from within (Durie & Wyatt, 2007). This success has led to similar initiatives with other deprived communities based on similar principles of trust and self-organization being set up in other urban areas in the UK.[12] Such interventions may provide viable and effective alternatives to more traditionally planned interventions with fixed objectives based on needs analysis. It will be important to carry out intervention research to further explore and seek confirmation of this possibility.

In terms of policy outcomes, what matters is to protect, maintain, and improve health and reduce inequalities. Rather than vainly seeking complete understanding of the complex relationship between, say, housing and health, it makes more sense to humbly accept the possibility that interventions may still be effective, even if our understanding of the mechanisms by which health improvement and the righting of inequality were achieved is imperfect. In terms of population health interventions, what is important is to respect the underlying logic of the intervention and to be able to describe the different aspects of the intervention in a careful manner thus allowing transfer.

Interventions designed from a population health perspective aim to change the distribution of risk in the population in view of long-term sustainable improvements (Rose, 2001, 2008). However, there has been much debate as to whether Rose's population approach may actually widen health inequalities. It has been suggested that this may depend on whether strategies for tackling health inequities are based on structure (approaches seeking to change the context in which people live, work, and play) or agency (individual-targeted behavioral or educational interventions) (Frolich & Potvin, 2008; McLaren, McIntyre, & Kirkpatrick, 2010). The emergent consensus suggests that both agency and structure must be taken into account, and thus it is appropriate that population approaches be associated with vulnerable/high-risk group strategies (Frohlich & Potvin, 2010) and, as we will discuss later, be implemented in a spirit of proportionate universality.

Recent trends in population health intervention research also reflect this calling for a new "science of solutions" (Potvin, Petticrew, & Cohen, 2014). We may even suggest that the implicit philosophy underlying "Health in All Policies" recognizes the unpalatable fact that causality is far from easy to establish. As research on social determinants of health is increasingly demonstrating, inequality is long acting and long lasting, being embodied within individuals, its roots often being laid down early in the life course. The web of causation is complex. To tackle real-world non-health sector problems such as how housing in its wider dimensions affects health, it may well be necessary to adopt different models and forms of evaluation such as realistic evaluation (Pawson, 2006; Pawson & Tilley, 1997).

Political and Strategic Challenges Ahead

Not only are there considerable scientific challenges, there are also difficult strategic and political decisions tied up with different strategies for improving health while tackling health inequities. Firstly, it is important to revisit what we mean by a health inequity. At the beginning of this chapter, we have suggested seven principles to consider in order to determine whether we are dealing with a trivial difference in health or a health inequity. Notably it is the duty of public health professionals and academics to play a role of third-party witnessing to determine whether or not we are dealing with a case of health inequity. Secondly, policy makers and public health professionals must recognize that much health improvement and righting of health inequities is only achievable through non-health sector policies and actions since these not only impact at the heart of the conditions in which people live, work, and play but provide the resources and opportunities for access to conditions favoring health and

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[12] See, for example, the work of *C2 Connecting Communities Ltd.* http://blogs.bmj.com/bmj/2015/02/04/jonathan-stead-on-transforming-disadvantaged-communities/.

healthy choices (Braveman, Egerter, Williams, 2011). Thirdly, different non-health sector stakeholders must come to take on board the idea that their actions, often unintendedly, have important impacts on health and well-being of the surrounding population. Fourthly, non-health sector stakeholders must realize that a social gradient in health amounts to clear evidence that everyone's health, to a greater or lesser extent, including their own is affected by their activities, and thus health becomes another dimension that needs to be considered in their policy.

How then can and should social policies aim to improve health and tackle health inequities?

Forms of Social Justice

As abovementioned, it is now clear that health inequities are frequently linked to social inequalities. In principle these may be addressed by different means involving different kinds of social justice and public health population strategies. Three main types of social justice may be singled out.

Universalism of rights. For instance, universal insurance cover may be offered to all people residing in a country, as in France, for example.

Strategies which categorize certain population groups as being at high risk or deemed vulnerable. Policy explicitly prioritizes such vulnerable groups over others thus compensating or providing more resources to the most vulnerable members of the population.

Proportionate universalism. This attempts to address health inequalities by providing more effort or resources according to how the group or individual is placed on the social gradient.

Each approach corresponds to particular public policy logic. Which form of social justice should be preferred?

Universalism of Rights

French universally oriented social policy may be considered as a good illustration of the first principle. This principle of universal coverage of needs and service provision is directly linked to an egalitarian credo. Everyone has equal rights of access to health care and services whatever their particular situation is. However, as Desrosières (2010) in his historical treatise on statistical thought and practice has explained, statistical treatment of data built around the idea of the mean and "the average man" leads to the discarding of exceptional situations and events. This favors a certain "averaging out" and standardization in line with the principle of universality. Since singularity and diversity are absorbed through the statistical mean, this may, somewhat paradoxically, lead to the necessity of deploying a second additional strategy for addressing health improvement and health inequities. Equal treatment for all almost inevitably leads to inequities since certain groups and individuals are less able to access the resources on offer than others.

Strategies for High-Risk or Vulnerable Groups

The second strategy is based on granting priority to certain, often minority, groups deemed to be suffering from deprivation, at particular risk or to be vulnerable. Such specific-targeted approaches are by their nature double edged, since they have to single out people with specific needs to be effective, but also, ultimately, run the risk of being stigmatizing. They may end up blaming the victim rather than the context that fuels inequality and need. In principle, groups at high risk may be taken into account in public policy through characterizing their living conditions in socioeconomic terms, e.g., with respect to minimum income or the poverty threshold. Through exploiting national census information, for instance, extreme situations of poverty can be characterized and classified according to percentiles. Nevertheless, all too often, the most fragile and vulnerable members of society remain "invisible" or "silent" falling outside standard statistical gathering of information. Such individuals "escape" statistical treatment. Only on the ground observation allows specific situations to be taken into account. A well-known example of this phenomenon is the Roma communities. Populations are small, statistically insignificant, poorly represented, often homeless, sleeping rough, with a wide scattering of families, and subject to wide discrimination. In order to take such populations into account, it will almost certainly be necessary to adopt preferential treatment measures in order to grant reparation and compensation for the harms and wrongs undergone by the population in question. Needless to say, such measures may be politically highly controversial but should be considered as a starting point, enabling members of the community to achieve initial successes thus laying the ground for the progressive withdrawal of the affirmative action policy.

Finally, a too simplistic and rapid reading of classical socioeconomic variables (education level, income level, size of household, etc.) gives the impression that there are typical profiles which may be considered as being deprived, even if other more statistically favorable profiles on paper, in fact, may also suffer from many of the same environmental impacts. Clyde Hertzman's work with colleagues in Vancouver on childhood vulnerability[13] illustrates this idea well (Hertzman & Bertrand, 2007). If social and education policy targets only the most vulnerable members of the community, many more families and children exhibiting features of vulnerability according to Educational Development Indicator (EDI) assessments living in apparently more favorable neighborhoods will remain untreated by the targeted policy. This argues volumes for introducing measures based on the third principle of proportionate universalism.

Proportional Universalism

Proportional universalism or proportionate universality has not yet been totally adequately theorized and may be considered to be in emergence. It is based on the idea of taking into account the social gradient and applying effort or resources according to observed need. In simple terms, universal measures are implemented but are tailored to the socially graded needs and characteristics of concern. A good illustration of how such a policy could work is afforded by the practice of providing universal after school help with homework. This is motivated by the observed needs of children disadvantaged in the educational arena. In principle, however, all children may attend. Children from more privileged backgrounds will probably need and receive less help from the homework assistance staff who will be able to focus on the children with greater need. But importantly all children will receive help and no one will be excluded. Such models may be useful for thinking through interventions for all areas of public policy, including health policy.

Scenarios for Tackling Health Inequities and Improving Population Health

Benach, Malmusi, et al. (2013) based on Rose's population health approach and Graham (2004b) has have put forward theoretical scenarios for tackling health inequities and improving population health. Four scenarios are proposed and illustrated with examples relevant for non-health policy interventions:

1. Focusing on targeted interventions and health gap, e.g., targeted neighborhood renewal
2. Universal policy with additional focus on gap, e.g., increasing childcare provision but especially in disadvantaged areas
3. "Redistributive" policy, e.g., social housing provision and decreasing residential segregation through housing vouchers
4. "Proportionate universalism" universal policy with increasing benefits through the gradient, e.g., workplace organizational psychosocial interventions which are potentially beneficial to all but bring greater benefit to lower grade employees

In the case of the environment, it is evident that the foremost policy goal is to protect and improve living conditions through reducing and controlling harmful exposures (noise, air pollution, water quality, and industrial and natural risks). But since urban spaces in particular have been planned and organized unequally leading to the cumulative effects of socioeconomic inequalities combined with environmental inequalities, it is important to

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[13] See http://earlylearning.ubc.ca/.

attempt to right such inequities. However, this is not easily achieved, and effects on health can be insidious and persist long into the future.

Effective plans to address health inequities and improve health of communities will involve different key community players from diverse sectors such as education, housing, schooling, transport, and culture working together and working with the community of health. We believe that the "heyday" of unipolar programs based on the belief that diseases, whether they be social or biological, can be tackled through only focusing on proximal and immediate causes has long passed. Public health policy makers should take on a broader vision accepting that complexity is firmly on the agenda. This has a number of implications well spelled out by Rydin, Bleahu, et al. (2012) describing comprehensive planning of urban environments to take into account their impact on health. Three main principles taking on broad complexity are advanced. First, emphasis is placed on applying a heuristic approach involving localized pilot experimentation which enables context and the resources of local communities to be harnessed effectively. Secondly, mutual learning coupled with "strengthened assessment" involving diverse stakeholders and the community is stressed. Such assessment may be based on different forms of knowledge from statistics through to the experiential baggage of both professionals and lay members of the community. Assessment should not be seen as being imposed through the intervention of external experts. Thirdly, policy makers should recognize that attempts to improve the health of the community and to decrease risks to the urban population are value laden. They will inevitably need discussion and debate of objectives and related ethical issues with those who are concerned, i.e., the community themselves. This will necessitate the organization of forums and paying special attention to involve and sound out potentially marginal and vulnerable groups, for example, people with disabilities. What is more is that such forums will also play a key political role in protecting the interests of such groups from other more powerful vested interests at work in urban development and regeneration.

Concluding Thoughts

Ian Hacking has famously remarked "Names organize our thoughts" (Hacking, 1995). In this chapter, we have taken the decision of making a straightforward and sharp split between the health sector and policy *and* the non-health sector and non-health policy. In line with Health in All Policies, it will become more and more necessary for government, policy makers, and indeed stakeholders to accept, as in environmental health, that we all have a part to play in making the world a healthier and safer place. Such a realization however is also linked to our values and views on the sources of inequality and health. It is clear that inequality is a major source of poor health and disease. It is also abundantly clear from the evidence we have at our disposal that the non-health sector and its related policies could have a substantial role in righting such inequities. In the field of environmental health, a sea change has occurred through the recognition that we all live in the same world with finite resources, and this has opened the way for greater sustainable development and more friendly environmental policy. We believe it will be necessary for a comparable change of representations to occur accepting that the health and welfare of individuals are deeply tied to the circumstances and environments in which they work, live, and play. Indeed as Galea, Rudenstine, and Vlahov (2005) declare "There is little doubt that who we are, what we do, and to an extent even what we think, is shaped by our environment." However, different environments do not offer equal opportunities and access to resources for health. Indeed, they also are associated with different degrees of risk. We now know, but we have known this since at least Villermé's writings of the nineteenth century, that the places we live in are not equal as regards health, well-being, and indeed death. Often health policy and economic policy are construed on the basis of the independent individual, making her or his choices. This view has the merit of allowing responsibility to be allotted simply to the individuals concerned, but it flies in the face of evidence which shows that it does matter where you live, since it is likely to impact on your health and how long you are likely to live. Furthermore, it does matter where you work since similarly conditions of work impact on health and life span. And of course, if you are unlucky to be among the workless, this again has profound implications on your health and when you are likely to die.

The time has perhaps come when it will become habitual to think of people being embedded in sociocultural and economic contexts with habitual practices rather than as decontextualized individuals within statistical populations with free choice of behaviors and free choice of dwelling and neighborhood (Krieger, 2012b). Frohlich and Abel (2014), citing Sen, explain: "Sen distinguishes between two types of freedom; opportunity and process (Sen, 2009). When describing opportunity freedom, Sen draws on the structural constraints and opportunities that people have to make choices. The ability to be a certain way and live a certain life is confined, or not, by the options that are available for people to choose from. The process aspect, on the other hand, focuses on the true agency that people have to make their choices." Choice may be seen as having two components: (a) the conditions which lead to certain choices being possible or not and (b) the actual individual choosing process. It is important not to confuse the two. We now know that at least potentially, our lives are influenced before birth and may depend on what has happened in prior generations. Furthermore, Hertzman's work at Vancouver has shown that the effects of the environment, measured through indicators of educational development, are embodied through epigenetic neurodevelopmental mechanisms leading to vulnerability which varies according to neighborhood area classed by SES in which children develop and live. This vulnerability potentially may have impacts beyond early childhood. Importantly, it also graphically demonstrates that the social gradient not only concerns the children living in the poorer areas of the city but also many other children living in more prosperous areas. Social gradients demonstrate that the same underlying influences impact on people's lives and furthermore show that people's health may potentially improve in different environments with more opportunities and less risks. There are no "them" and "us." It is indeed a brave new world where genes may be switched on and off, and health is subject to influences from previous generations, prenatal, and early development, beyond the control of those they affect (Khan, 2010), but it offers us a possibility of rethinking who bears responsibility for health and health inequities. Through applying Harpet's seven principles identifying inequities, it is likely that the answer that may emerge is that those who can influence the sociocultural and physical environments in which we live, work, and play are indeed responsible. Some of us are, of course, more responsible than others. Notably, this includes our political and business leaders and policy makers, since they are responsible for the physical and sociocultural environments and their upkeep that are on offer to our fellow men, women, and children. Once this has been accepted, then the determining role of the non-health sector and the necessity for different sectors and the health sector itself to work together will be very apparent. Furthermore, the idea that insalubrious, run-down, unhealthy, unsafe, non-accessible, or segregated environments are acceptable will become unthinkable, a thing from the past.

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16

A Life Course Perspective on Behavior and Health

Timothy P. Daaleman and John Preisser

The life course is a framework that provides a way to integrate macro-level factors – social, cultural, environment – with individual-level influences that collectively contribute to health by pointing to the trajectories and transitions of persons (Elder & Johnson, 2002; Elder, Johnson, & Crosnoe, 2003). The importance of this orientation is highlighted by the Patient Protection and Affordable Care Act, which has extended health-care coverage to millions of Americans and has concomitantly focused attention on social and behavioral determinants of health (Institute of Medicine, 2014). The Institute of Medicine (IOM) has responded to this legislation by a recent call to delineate and capture these determinants within emerging electronic health records, information that can ideally be used by individual clinicians, by health-care systems, and by public health officials and researchers (Institute of Medicine, 2014; Adler & Stead, 2015).

Social factors can be attributed at the individual level or larger contextual level (e.g., neighborhood and community), and both have a profound effect on the health and health care of patients. Individual-level social factors, such as race/ethnicity, exert a substantial influence on how people view and rate their health (Gibson, 1991; Kramarow, Lentzer, et al., 1999), in addition to how frequently they use health-care services (Phillips, Hamel, et al., 1996; Greiner, Perera, & Ahluwalia, 2003). Contextual factors are features of the social and physical world (Berkman & Kawachi, 2000), and geographic location and the local distribution of health-care resources are strongly associated with the intensity of services that patients receive (Fisher, Wennberg, et al., 2003a, 2003b). Although much prior work has studied the separate effects of individual-level and contextual determinants (Han, Phillips, et al., 2005; Wen, Cagney, & Christakis, 2005; Covinsky, Eng, et al., 2003), a conceptual framework to examine how these factors jointly contribute to health and health services has not been fully developed.

The recent IOM report recommended a panel of largely individual-level domains and measures, such as race/ethnicity, tobacco and alcohol usage, and social connectedness (Institute of Medicine, 2014). Unfortunately many of these measures do not fully capture or delineate the contributory and differential effects of key social and behavioral determinants on health outcomes (Braveman, Egerter, & Williams, 2011). The report also has a restricted view of contextual factors, such as community-level social and environmental data

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(Bazemore, Cottrell, et al., 2015), a limitation that does not add understanding in how upstream factors contribute longitudinally to the health of populations (Braveman, Egerter, & Williams, 2011). In response, this chapter introduces the life course as a multilevel perspective that can frame how both contextual and individual factors jointly influence the health and health care of patients. This field of inquiry is characterized by locating people longitudinally along trajectories and characterizing their social contexts and situations as pathways in which their lives progress (Elder, Johnson, & Crosnoe, 2003). The life course has already gained wide acceptance across multiple disciplines, such as aging and gerontology, developmental psychology, and social epidemiology (Mortimer & Shanahan, 2003). A life course approach to chronic disease epidemiology, for example, examines the biological, behavioral, and psychosocial pathways that may be paved early in life and operate across an individual's life span, eventually contributing to the risk of developing chronic disease (Ben-Shlomo & Kuh, 2002; Kuh & Ben-Shlomo, 2004; Lynch & Davey, 2005). Conceptual models within life course epidemiology look at how the temporal ordering of exposure variables, such as stress, factor into later life risk of disease (Ben-Shlomo & Kuh, 2002).

Social Factors Contributing to Health and Health Care

The socio-ecologic model is addressed in many chapters throughout this book and underscores the importance of social and environmental influences within the life course perspective. Although individual-level social factors, such as race/ethnicity, are more commonly understood (Gibson, 1991; Kramarow, Lentzer, et al., 1999), contextual factors are less clearly defined features of the social and physical world (Berkman & Kawachi, 2000), but they account for many differences in the health-care experience of patients; geographic location and the local distribution of health-care resources are strongly associated with how much health-care services that patients receive (Fisher, Wennberg, et al., 2003a, 2003b). To illustrate these influences, this chapter will direct attention to the social and behavioral factors as they influence an important part of the life course, older adulthood, and the end of life.

As background, the overall health and health-care experience of older adults with serious chronic illness varies widely depending upon the local social and physical environment (e.g., geographic region, distribution of health-care resources) and individual-level factors (Dartmouth Medical School Center for the Evaluative Clinical Sciences, 1999). There are compositional and contextual explanations for such variation. A compositional explanation attributes area variation to differences in the characteristics of individuals in defined areas (Macintyre & Ellaway, 2000). For example, a larger concentration of frail, older adults in one geographic area would explain a higher rate of health service utilization when compared to another area. Contextual explanations, in contrast, suggest that there are features of the social and physical environment that influence the health of those exposed to it (Macintyre & Ellaway, 2000).

Older adults may be more influenced by their social environments and emotional ties to their communities (Diez-Rouz, 2002; Krause, 1996; Robert & Li, 2001). These place effects play an important role in health outcomes, especially near the end of life. This is illustrated by the finding that the chance of an inhospital death varies more than twofold among hospital referral regions in the United States, from as few as 20% of deaths to more than 50% (Dartmouth Medical School Center for the Evaluative Clinical Sciences, 1999). In addition, for older patients with Medicare, the number of days spent in acute hospitals and the chance of being admitted to an intensive care unit during the last month of life vary by factor of more than five (Dartmouth Medical School Center for the Evaluative Clinical Sciences, 1999). These variations in hospitalizations are associated with the per capita supply of hospital beds and physicians (Wennberg, Freeman, & Culp, 1987; Wennberg, Freeman, et al., 1989; Fisher, Wennberg, et al., 1994), health services that are unfortunately associated with aggressive technical interventions and are frequently undesired and at odds with elders' individual life situations and expressed preferences (Stein, Lynn, et al., 1989).

From an economic perspective, regional differences in Medicare spending are largely explained by more hospital and specialty-based patterns of care (Fisher, Wennberg, et al., 2003b). Intuitively, older adults residing in areas with high concentrations of health-care resources (i.e., hospitals, physicians) would expect better health outcomes than residents in low-resource areas. However Medicare recipients in high-spending areas do not have better quality of care or improved health outcomes, such as decreased mortality or improved functional status, when compared to lower-spending regions (Fisher, Wennberg, et al., 2003a, 2003b). The local supply of specialist physicians and hospital resources is a major driving force to the use of discretionary services – hospitalizations, physician visits – in a geographic area (Fisher, Wennberg, et al., 2003b).

Individual-level factors (e.g., race and ethnicity) also exert a powerful influence on outcomes, including perceived health status (Gibson, 1991; Kramarow, Lentzer, et al., 1999) and health-care utilization (e.g., hospitalization, hospice usage) (Phillips, Hamel, et al., 1996; Greiner, Perera, & Ahluwalia, 2003). Over 60% of African Americans prefer to die in the hospital, opt for more aggressive medical care for terminal illness (Garrett, Harris, et al., 1993; Gramelspacher, Zhou, et al., 1997), and are less likely to use hospice when compared to whites (Greiner, Perera, & Ahluwalia, 2003). In addition to health service utilization, race and ethnicity also exert a powerful influence on self-reported health status in older adults (Gibson, 1991). Among persons 65–74 years of age, non-Hispanic black persons and Hispanics are more likely to report fair or poor health, when compared to non-Hispanic white persons (Kramarow, Lentzer, et al., 1999). Further, self-rated health status and other health-related quality of life indicators have been found to be consistent predictors of how often health service are utilized (Hulka & Wheat, 1985; Wan, 1976; Wolinsky & Arnold, 1988). These global measures are representations of the physical, emotional, and social aspects of health and have been found to be an independent predictor of mortality (Idler & Benyamini, 1997) and life expectancy in older adults (Lubitz, Cai, et al., 2003).

The Life Course Framework

The life course provides a framework for understanding how social and behavioral factors impact health. Life course theory emerged from three intellectual traditions: social relations, age and temporality, and life span development (Elder, Johnson, & Crosnoe, 2003). From a social science perspective, roles are patterns of expected behaviors and attitudes that are commonly held and defined within groups or by social situations (Theodorson & Theodorson, 1979). A foundation for framing such a social and relational dynamic begins with the sociological relationship theories that surfaced in the 1960s and 1970s and continues with the life course theory of today (Kertzer, 1983; Clausen, 1968; Brim & Wheeler, 1966).

Socialization describes how individuals move into and out of social roles (e.g., parent, student) accompanied with a set of proscriptive and prescriptive expectations (Clausen, 1968). Patients may occupy a sick role which can release them from their usual obligations and responsibilities, such as work or parenting (Mechanic, 1978). These social roles, however, are not isolated sets of expected behaviors and attitudes but are often characterized by a graded sequence and transitions across different periods of the life cycle (Antonucci & Akiyama, 1995). Older adults rather than children and adolescents, for example, are more readily recognized and accepted by others in the sick role, although individual members within each group may be afflicted with the same serious illness.

Role-theoretical perspectives – social roles, life cycles – are limited in their ability to conceptualize relationships since they are timeless and fail to locate individuals within their larger social or historical contexts. Life course theory fills this void by incorporating constructs of age and temporality developed from social anthropology (Riley, Hess, & Bond, 1983; Neugarten & Neugarten, 1996). These elements recognize the multiple chronological meanings of age (e.g., historical time, social time, biological time) and the remarkable individual variability in the timing and scheduling of events along a life course (Neugarten & Neugarten, 1996). For example, the health effects of life events and transitions often depend on when they occur (e.g., whether bereavement and widowhood occur early or later in life) (Wortman & Silver, 1990).

A life span concept of development represents the final intellectual strand of the life course, drawing upon contributions from developmental psychology and life course sociology. Life span concepts such as life review and autobiographical memory emphasize the importance of narrative and memoir accounts within lived lives (Thomas & Znaniecki, 1958), while human agency views individuals as central actors and producers of their own development (Clausen, 1993). In the United States, patient-centered movements such as end-of-life care and complementary and alternative medicine can be viewed as attempts by patients to reclaim their own voice and individual human agency within a system of health care that is often depersonalized and grounded in technology (Daaleman, 2004).

Principles of the Life Course

Life course principles focus on individual choice and decision-making, promote an awareness of larger social and historical contexts, and foster an understanding of the timing of events and the various roles that change in a lifetime (Daaleman & Elder, 2007). These principles also think of human lives as embedded in relationships with significant others and help us consider a holistic understanding of lives over time and across changing social contexts (Elder, Johnson, & Crosnoe, 2003). As a whole, the principles are (1) *human development and aging as lifelong processes*, (2) *human agency*, (3) *historical time and place*, (4) *timing*, and (5) *linked lives* (Elder & Johnson, 2002).

The principle of *lifelong development and aging* embraces a longitudinal, often intergenerational, perspective that links earlier life influences with events and outcomes in subsequent years (Amick, McDonough, et al., 2002). Life course epidemiology, which was introduced earlier, is representative of this principle and examines the long-term effects of physical, environmental, or social exposures during childhood on subsequent health or disease risk in later life (Kuh, Ben-Shlomo, et al., 2003). This approach casts light on the behavioral, biological, and psychological processes that are in play across an individual's lifetime, or across generations, and that can contribute to the risk of developing disease or that can help maintain health and functional status (Kuh, Ben-Shlomo, et al., 2003). In its ideal form, life course epidemiology integrates the contributions of well-established risk factors for disease – smoking, obesity, and hypertension, for example – with the social and environmental processes (e.g., lower socioeconomic status) that may be operational. Consider, for example, the prevalence of heart disease, which peaked in the 1960s for a cohort of men born around the turn of the twentieth century (Lynch & Davey, 2005). After this decade there was a marked, progressive decline in heart disease, which reflects both the reduction in smoking and advances in blood pressure control in the general US population (Lynch & Davey, 2005). However the drop-off in heart disease in subsequent years was not uniform for all populations, illustrating the differences across subsequent birth cohorts in how early and later life exposures to smoking and hypertension – as well as to other social and psychological factors – predispose to developing heart disease (Lynch & Davey, 2005).

A life course epidemiologic approach looks at how socially developed and patterned exposures to risk factors in early life may account for marked differences and inequalities –which may not solely be attributable to genetic or biological factors – in later life mortality, disease, and health (Kuh, Ben-Shlomo, et al., 2003). Socioeconomic factors at different periods of the life course can function through an accumulation of risk or via a chain of risk (Kuh, Ben-Shlomo, et al., 2003). The accumulation of risk describes the gradual accrual of multiple behavioral risk factors (e.g., smoking, limited physical activity), adverse environmental conditions (e.g., limited access to clean air and water), and repeated illness or injury episodes that cumulatively cause physiological damage and subsequently increase the risk of disease and mortality (Kuh, Ben-Shlomo, et al., 2003). A chain of risk model, in contrast, is a sequence of linked exposures that raise the risk of disease; different types of social, biological, or psychological chains may mediate or moderate an increased or decreased risk of disease (Kuh, Ben-Shlomo, et al., 2003). In either risk model, there can be a critical period, which is a limited window of time in which an exposure can have a hazardous or protective effect on subsequent outcomes (Kuh, Ben-Shlomo, et al., 2003).

Agency is the second principle in the life course, and this reflects and characterizes the sense of control that people seek to gain over the events in their lives (Bandura, 1997). Human agency views individuals as active participants who construct their own life course through the choices and actions they take, given the opportunities and constraints of their personal history and social circumstances (Clausen, 1993; Bandura, 1997). Human behaviors, particularly health behaviors, are governed by a myriad of factors and individuals contribute to – rather than being the sole influencers of – what they do or what happens to them (Bandura, 1997). Agency is tied to individual actions that are done intentionally, and these actions are driven and guided by a person's personal efficacy (Bandura, 1997).

Self-efficacy beliefs are key in personal agency; if people do not believe that they are capable of executing a given plan of action and that the actions will produce a desired outcome, they will not initiate an activity or see it through to completion (Bandura, 1997). These beliefs can be drawn and developed from several sources: enactive mastery experiences that reinforce capability, vicarious experiences that promote efficacy beliefs through comparison with others, verbal and other types of social persuasion, and physiological and affective states through which people gauge their readiness and potential for change (Bandura, 1997). Personal agency does not operate autonomously and individually but emerges from a network of social structures that have both constraints and opportunities for personal growth and development (Bandura, 1997).

Personal agency and efficacy beliefs have provided the theoretical foundation for many interventions that have promoted health behaviors and enhanced the self-management of chronic disease. These beliefs that people can motivate themselves and regulate their health behaviors impact each phase of the personal change process, the contemplation and consideration of changing health behaviors, garnering the motivation and resources that are needed to be successful, and sustaining the desired change and dealing with setbacks (Bandura, 1997). One effective strategy that draws upon human agency is peer support or mentoring. Peer supporters provide the needed practical and emotional support of behavior change that can potentially facilitate and enliven the efficacy beliefs of people who live with comorbid disease by sharing a personal knowledge and an illness experience in authentic and meaningful ways (Solomon, 2004). There is a substantial evidence base – from patients living with chronic conditions such as diabetes, cancer, cardiovascular disease, mental illness, and HIV/AIDS – that has demonstrated the effectiveness of peer support in sustaining health behavior change (Davidson, Chinman, et al., 1999; Parry & Watt-Watson, 2010).

Peer support strategies offer emotional, social, and practical assistance on how to achieve and sustain complex behaviors that are essential for managing conditions and staying active and healthy (Brownson & Heisler, 2009; Dunn, Steginga, et al., 2003; Fisher, Brownson, et al., 2005). In addition, this approach often complements and adds value to existing health-care services that help people adhere to care management plans in daily life, to stay motivated and cope with the stressors of chronic illness, and to maintain continuity with their health-care providers, often in a cost-effective manner (Whitley, Everhart, & Wright, 2006).

Individual lives are located in a specific *historical time and place*, another core life course principle. The individual life course is embedded in and shaped by the places that a person experiences over a lifetime (Elder & Johnson, 2002). The same historical event may differ in impact and meaning across different countries or regions, as evidenced during the immediate postwar years of World War II which saw widespread devastation in parts of Europe but prosperity in the United States (Elder, Johnson, & Crosnoe, 2003). A more contemporary example is the social and economic effects of the current AIDS epidemic on African children. Homelessness, migration, malnutrition, and reduced access to health care and education are staggering problems which have greatly increased the probability of illiteracy, poverty, and chronic illness in subsequent adulthood for this population (Foster, 2002). These place effects can be viewed as historical and ecologic constraints that limit the range of potential opportunities and choices along the life course.

In health care, there has been longstanding interest in the geographic variations found in the distribution of health-care services and a growing recognition that many social determinants of health may operate at local levels through neighborhoods and communities (Diez-Rouz, 2001). A number of health problems, such as low birth weight and infant mortality, tend to be aggregated and studied at the neighborhood level (i.e., census tract or block) and are tied to the cumulative disadvantage and geographic isolation of many African American populations (Sampson, Morenoff, & Gannon-Rowley, 2002). Here it is important to clearly define the characteristics of geographic boundaries or areas in ways that are applicable to specific health outcomes (Diez-Rouz, 2001). The terms neighborhood, area, and community have frequently been interchangeably used, often referring to an individual's immediate residential environment (Diez-Rouz, 2001). Administrative boundaries (e.g., zip code or census block) have been traditionally used in many studies to operationally define neighborhoods and communities that are situated in a specific geographic location (Diez-Rouz, 2001).

Over the last decade, geographic information systems (GIS) have been increasingly employed as tools that have been more discretely used to define the social and physical environment of individuals, as well as a way to capture the distribution of health-care resources (e.g., physicians, hospitals) in a spatial context (Ricketts, 2003). Geographic software programs can now generate precise area coordinates that reflect more meaningful regions of human activity – rather than by administratively set boundaries – that are marked by commerce (e.g., markets and shopping centers), work locations, places of worship, and the sites of health-care services, such as hospitals and physician practices (McLafferty, 2003).

The life course principle of *timing* acknowledges that the concept of age has several meanings and interpretations (Neugarten & Neugarten, 1996). Similar events and life experiences can impact individuals in different ways depending on when they occur in the life course (George, 1993). For example, the differential experiences of young people who go through very early transitions from adolescence to adulthood (e.g., leaving home, marrying or cohabitating, becoming a parent) have detrimental effects on mental health (Elder, Johnson, & Crosnoe, 2003). Health-care providers commonly limit their understanding of time to strictly biological terms that are marked by developmental or physiological changes, such as childhood language acquisition, puberty, and menopause. However, the life course broadens this view to include other ways of thinking about time. For example, social time looks at how chronologic age (i.e., age in years since birth) distinguishes and differentiates role expectations among individuals, an understanding that is illustrated by ongoing discussions regarding the appropriate age for younger adults to have legal access to alcohol, to vote, or to serve in the military and for older adults to receive Social Security and Medicare benefits (Scanlon, 2006). Subjective time, in contrast, is a person's self-perception of how old they are or how old they wish to be (Neugarten & Neugarten, 1996).

Timing focuses on the assumptions and expectations regarding when life events should occur and are normative in areas such as childbearing and family life. Timing comes into greater play for patients and family members particularly around the beginning and end of life (Lynn, O'Connor, et al., 1999). This principle takes into account the developmental antecedents and consequences of life events and transitions which may vary according to their timing in a person's life (Elder, Johnson, & Crosnoe, 2003). In addition, it recognizes that the same events or experiences may impact individuals in differential ways, depending on when they occur in an individual's life course (George, 1993). For example, the very early transition to adult responsibilities (e.g., getting married or becoming a parent) at a relatively young age has been found to negatively impact subsequent mental health (Elder, Johnson, & Crosnoe, 2003).

The principle of timing also takes into account that individuals may view themselves as synchronous ("on-time") or asynchronous ("off-time") with their expectations regarding their social time (i.e., is the life event concordant with their age) or subjective time (i.e., is the life event concordant with how old they see themselves). This principle is illustrated by variations in the timing of a terminal illness, whether early or later in life. For example, a 35-year-old woman who is unexpectedly diagnosed with an aggressive breast cancer would be considered in a "too early" age group and asynchronous according to the timetable of her birth cohort.

The last principle in the life course, that of *linked lives*, refers to the interdependence and network of shared, social relationships that surround individual lives. Larger social changes can impact individuals through their interpersonal contexts on more microlevel settings, such as family units (Elder, Johnson, & Crosnoe, 2003). For example, economic hardships can negatively impact the mental health of parents, which in turn affects the growth and development of their children. Social relationships can be thought of as the relational ties between individuals (i.e., interindividual) or changes in these connections that take place within one individual over time (i.e., intra-individual) (Elder & Johnson, 2002). There are basic characteristics of social relationships, including the size of the personal network and the varying strengths of the social ties among network members (Antonucci & Akiyama, 1995). These ties and networks serve multiple functions, such as emotional and instrumental support, and often provide resources in the areas of caregiving and personal care services.

Social network is a conceptual approach which recognizes that individuals are embedded in a web of relationships and are influenced by the behaviors and activities of those around them (Christakis & Fowler, 2007). In analyzing social networks, the concept of a node is used to describe people who may or may not be connected to others in the network; the connection between two nodes is termed a tie (Christakis & Fowler, 2007). Social networks acknowledge the human tendency of individuals who choose relationships with others that have comparable attributes and behaviors, and the grouping of nodes – each of which is connected to at least another node – is called a cluster (Christakis & Fowler, 2007). A longitudinal study, for example, examined the linkage between the social network and obesity among 12,000 people who participated in the Framingham Heart Study and found that a person's risk of becoming obese increased by 57% if he or she had a friend who also became obese (Christakis & Fowler, 2007).

The convoy model is another organizing framework of social relationships, one that adds a life course dimension to the concept of networks. The model views relationships as a series of interactive sequences involving significant others (e.g., important family members, longtime friends) that aggregate and disassemble across different periods of the life course (Antonucci & Akiyama, 1995). This way of thinking emphasizes the longitudinal character of relationships and conveys a fluid aspect that is often not captured by social support or family network concepts (Broadhead, Gehlbach, et al., 1988). The social convey model views an individual as moving through their lifetimes surrounded by different groups of people who are close and important to them, an alliance of others who have a critical influence (either positive or negative) on their life and well-being (Antonucci & Akiyama, 1995).

Trajectories and Transitions

The concepts of trajectory and transition are central, unifying themes, and they represent both the long and short perspective of life course principles. Lived lives, for example, take place over an extended span of time, a social trajectory of work or marriage or a developmental trajectory of self-rated health. In contrast, a sense of agency or personal control may be developed within a short time span that is marked by the transition of specific life events, such as graduating from college and getting married. The life course emphasizes the importance of trajectories, as well as transitions and turning points, as core concepts in its framework. Trajectories are sequences or long-term patterns within a given area (e.g., health, family, or work situations) and are formed by linking states (e.g., health status, poverty) and transitions across successive years (Duncan, Brooks-Gunn, et al., 1998; Clipp, Pavalko, & Elder, 1992). Trajectories are not individual events in time, but are embedded in social pathways that are defined by social institutions and relationships that provide social support. That is, they are socially determined. Trajectories reflect the cultures and communities in which they evolve as well as the individuals whose lives they characterized. Transitions are inflections and changes in direction of the trajectory (Elder & Johnson, 2002).

Illness trajectories go beyond the physiological unfolding of disease to encompass the total organization of work done over the course of the illness and take into account the impact that this work has on those involved in the accompanying activities (Strauss, Corbin, et al., 1984). Work here refers to the physical and emotional tasks and activities performed by patients and caregivers. When a trajectory and its transition place people in new environments and alter behavioral and social patterns, they are referred to as turning points (Sampson & Laub, 1993). Turning points are individual or institutional sentinel moments that result in a change of direction along the life course (Clausen, 1998). For example, a seriously chronically ill patient who declines aggressive medical care has reached a turning point. The probable subsequent decline in health and functional status and entry into long-term care or hospice would constitute both a trajectory and a turning point. Trajectories are influenced by and directly impact social relationships (e.g., family caregivers) and provide a way to understand and conceptualize the important factors that potentially affect a patient's experience of health, illness, and well-being.

Trajectories have been mapped out to depict the patient experience of serious chronic illness and are distinguished by variations in their duration and shape (Glaser & Strauss, 1965; Pattison, 1977; McCormick & Conley, 1995). A report from the Institute of Medicine, for example, offered three plausible functional trajectories specific to serious illness and dying: (1) sudden death from unexpected cause, (2) steady decline from a progressive disease with a "terminal" phase, and (3) advanced illness marked by slow decline with periodic crises (Fig. 16.1) (Glaser & Strauss, 1965; Field & Cassel, 1997). A subsequent study of Medicare beneficiaries examined the degree to which these three trajectories accurately characterized

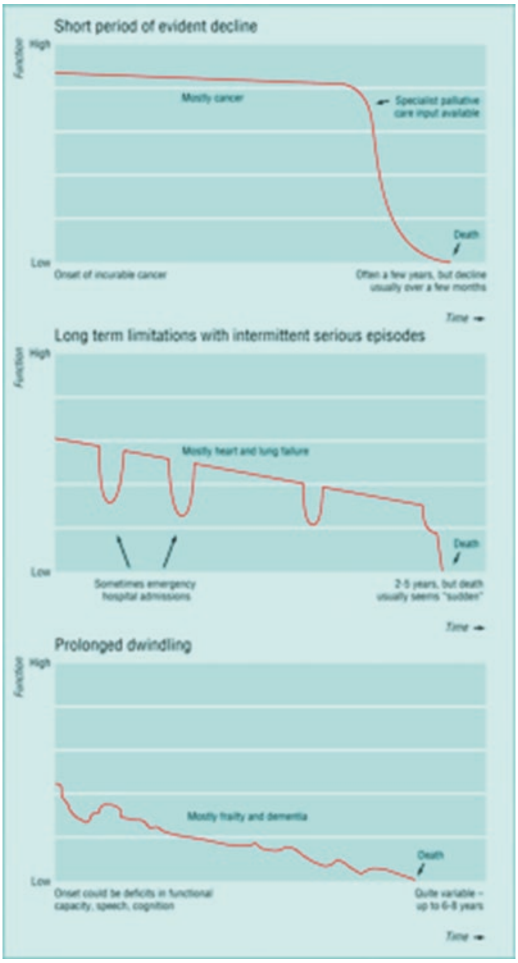

Fig. 16.1 Functional trajectories of serious chronic illness (Murray, Boyd, & Sheikh, 2005; Lynn & Adamson, 2003)

seriously ill and dying patients, and four trajectories were able to characterize 92% of individuals' pathways at the end of life: (1) sudden death, (2) terminal illness, (3) organ failure, and (4) frailty (Lunney, Lynn, & Hogan, 2002).

An Analytic Approach to Determining Trajectories

Statistical methods that integrate repeated observations over time and identify different paths of progression are central to characterizing trajectories. This analytical approach is different than simply using discrete observations at baseline and at one or more points in time. With trajectories, the focus is less on determining the outcome of interest as it is in describing the sequence of events that contribute to and sustain it. Since analytic strategies used in characterizing trajectories may not be commonly understood, the following section describes one approach by illustrating the functional trajectories of older adults with serious chronic illness (i.e., a subset of chronic diseases which are marked by a progressive loss in health and functional status leading to death) (Stein, Lynn, & Stein, 1989).

The primary strategy assumes a continuous-scale outcome and relies on the use of hierarchical linear models (HLM) to account for repeated measures; these are also known as linear mixed models. When the outcome is categorical or discrete, generalized linear mixed models may be used. The methods include: (1) equations for population-averaged trajectories and their corresponding residuals that are used to aggregate individuals into subgroups based on a specific outcome measure (e.g., older adults with a pattern of physical functioning over time), (2) explanatory models that identify factors associated with different outcome pathways, (3) estimating individual trajectories with prediction equations that include random individual-level effects to account for deviation of an individual's trajectory from the population-averaged trajectory for the group to which he/she belongs, and (4) validating the trajectories with respect to conceptually related measures.

Using our example, older adults with serious chronic illness (SCI) might be categorized into the following groups: (1) terminal illness (cancer, solid or hematologic malignancy, or malignant tumor of any type), (2) organ failure (ischemic heart disease, congestive heart failure, chronic kidney disease, chronic obstructive pulmonary disease), and (3) frailty (stroke, cerebrovascular accident). Life course principles, that were described earlier, can inform the selection of data elements to be used in modeling trajectories for specific patient populations and patients. The following section illustrates how analyses might proceed in differentiating and then describing these three groups and the extent to which they provide a representation of the variety of pathways among those with serious chronic illness.

Identifying the Pathways: Population-Averaged Trajectories and Residuals to Identify Resilient or Vulnerable Functioning

For each of the three groups with serious chronic illness, an average trajectory can be estimated by adjusting the intercept for baseline severity (and comorbid conditions, such as depression) and then identifying individuals for whom the model does not have a good fit. For simplicity, an analysis for a single group can be considered, although models can be specified to analyze all three groups simultaneously as this provides improved precision when regression parameters are shared across the three groups. Specifically, a longitudinal data model may be fit with up to a cubic effect of time (i.e., an individual's age is used instead of calendar time (t) in order to address age cohort effects):

$$E\left[Y\left(t\right)\right] = b0 + b1 * t + b2 * t^2 + b3 * t^3$$

In conjunction with this model for the mean value of functional status, an appropriate covariance model can be specified within the context of a hierarchical linear model (Cnaan, Laird, & Slasor, 1997) in the case of a continuous outcome or a generalized linear model (GLM) estimated by generalized estimating equations for a categorical outcome (Liang & Zeger, 1986; Diggle, Heagerty, et al., 2002). Once the regression parameter estimates have been obtained, a set of residuals can be computed, one for each observation that an individual contributes to the analysis. An individual with a particularly large (i.e., positive) residual (e.g., about the estimated mean regression line) is one who has functional status better than expected at that particular age. An individual with a particularly small (i.e., negative) residual is one who has functional status poorer than expected at that particular age. In this way, we can define so-called "resilient" (i.e., those who maintain their functioning) and "vulnerable" (i.e., those with declining functioning) older adults.

Practically, using longitudinal data from electronic health records can inform the categorization of an individual as resilient or vulnerable. This categorization will be time dependent, as an individual may have better functioning than expected at a younger age and subsequently poorer functioning than expected at an older age. At each of several ages, which can be determined based upon the distribution of ages in the data, the upper quartile of residuals can be defined as the resilient older adults, and the lower quartile of residuals as the vulnerable older adults. Two logistic regression analyses can be conducted, the first assessing whether individual factors, such as linked lives and agency, predict resiliency and the second assessing whether these factors predict vulnerability. These analyses (i.e., one for resiliency and one for vulnerability) can provide an assessment of individuals' longitudinal indicators in order to summarize findings across the life course. For example, do stronger social network ties with others explain resiliency across all ages or only for some age groups? To address such questions, modeling approaches for longitudinal binary data such as generalized estimating equations can be used (Liang & Zeger, 1986; Diggle, Heagerty, et al., 2002).

Understanding Differences Among the Pathways: Explanatory Models That Identify Factors Associated with Different Functioning Pathways

This approach, which extends that of the previous section, assesses directly, within the context of an HLM (or GLM, in the case of a categorical outcome), whether or not trajectories of functional status differ by individual characteristics. For simplicity, consider a covariate, X, and the longitudinal data model for a single SCI group:

$$E\left[Y(t)\right] = \left(b0 + a0^{*}X\right) + \left(b1 + a1^{*}X\right)^{*} t + \left(b2 + a2^{*}X\right)^{*} t^{2} + \left(b3 + a3^{*}X\right)^{*} t^{3}$$

If X is equal to 0 or 1, then a test that the regression coefficients, a0, a1, a2, and a3, are simultaneously equal to 0 is a test of whether or not the trajectory of functional status is identical for the two groups determined by X. A fully saturated model including several categorical covariates, informed by life course principles, would estimate intercept, linear, quadratic, and cubic time effects for each group resulting from the cross-classification of the covariates. In accordance with the richness of the data, a sequence of regression models can be fit.

The first set of models can include severity factors retaining main effects in order to adjust the intercept b0 above, but dropping nonsignificant polynomial time effect interactions as more complex but parsimonious models are built to describe varying trajectories. In this regard, the second set of models can additionally include individual factors, and the third set of models can add potentially protective factors, such as social networks. For example, do protective factors alter the group trajectories of functional status after controlling for symptom severity and other individual factors? The focus here is on estimating functional status trajectories for the three SCI groups and determining whether subgroups within those three primary groups have different trajectories.

Identifying Individuals' Pathways: Estimating Individual Trajectories Using Prediction Equations

Hierarchical linear models, also known as random coefficient models in the context of repeated measures, can be used to estimate a trajectory of a continuous outcome for each individual; generalized linear mixed models (e.g., logistic models with random coefficients) (Diggle, Heagerty, et al., 2002) could be used for dichotomous or categorical outcomes. In the parlance of linear mixed models, the individual-level trajectories can be based upon best linear unbiased predictors of model random effects. It would be possible to estimate a trajectory for each individual using only person-specific data, for example, a cubic polynomial curve for an individual with at least four data points. However, these trajectories can be poorly estimated if there is little data. The strength of the HLM approach is that individual trajectories can be estimated by also using information from a comprehensive data set from electronic health records via the particular model that is used. Ideally, random coefficients would be fit for each of the four polynomial terms in the model above. However, this model is very complex and it may not be computationally feasible to test it. Therefore, a simpler model that specifies a random intercept and linear term may be employed. Considering one of the mean models above, the model for the i-th adult at the t-th time is:

$$\mathrm{Y}\left(it\right) = \mathrm{E}\left[\mathrm{Y}\left(\mathrm{t}\right)\right] + bi0 + bi1^{*}\,\mathrm{t} + \mathrm{e}\left(it\right)$$

In the above equation, Y(it) is the observed functional status for the i-th adult at the t-th time, E[Y(t)] is the mean trajectory for a particular SCI group (or subgroups if individual-level factors are included), bi0 and bi1 are individual-level deviations from the overall group mean intercept and slope, and e(it) is a random error term. With the usual zero-mean normality assumptions of these random deviations, empirical Bayes estimation is used to provide estimates of bi0 and bi1 for each individual. Plugging these estimates into the above equation (with zero for e(it)) gives a predicted trajectory for each individual. For each SCI group, the individual trajectories can then be plotted to reveal their variation about the overall group mean trajectory, allowing characterization of variability of trajectories within each SCI group.

The potential contribution of using a life course approach in developing trajectories for older adults with SCI is highly relevant for both policymakers and care providers, since the number of older Americans continues to grow and will be facing disability, functional decline, and reduced quality of life (Merck Institute of Aging & Health, 2002). At the policy level, the striking geographic variation in health service utilization highlights that increasing services and resources do not improve mortality or quality of life, but result in less satisfaction with care for this population (Dartmouth Medical School Center for the Evaluative Clinical Sciences, 2006). And for providers, gaining a richer and longitudinal understanding of how individual-level social and behavioral factors contribute to the health of their patients can improve their care that they provide (Adler & Stead, 2015).

Caring for Patients and Populations Through the Life Course

The US health-care system is in the midst of a transformation to value-based care, which will focus on high-quality, cost-effective, patient-centered care for individual patients. In this new system, health-care providers will also be responsible for managing the care of populations of patients, such as those with type 2 diabetes mellitus, depression, and hypertension. The life course can provide both the intellectual and practical grounding for professionals who will be managing population in a system that seeks to optimize health and reduce disease burden not just in the short term but over the life span (Halfon & Conway, 2013). This orientation will shift the focus away from discrete, unlinked episodes of care, such as office visits, hospitalizations, and treatments for episodic or time-limited problems, to longitudinal trajectories of health and illness. In the foreseeable future, electronic health records and other sources will allow the measurement and creation of longitudinal data across the life course of patients, allowing the categorization of individual trajectories in specific health and wellness domains, such overall health and functional status.

A major challenge of health care in the twenty-first century will be a paradigmatic shift from an acute and largely communicable disease model to one that reflects chronic disease. Over a hundred years ago, communicable diseases –tuberculosis, diphtheria, and influenza – were the leading causes of death that largely contributed to infant and child mortality rates (Brim, Friedman, et al., 1970). The advent of antimicrobial therapy and major public health initiatives, such as vaccinations, have reduced mortality in these early years of life. As a result, chronic diseases – heart disease, cancer, stroke, lung disease – have displaced acute infectious diseases as the major causes of morbidity and mortality today (CDC, 2003; Jemal, Ward, et al., 2005). This shift may be illustrated in considering a 45-year-old woman who is newly diagnosed with diabetes mellitus and will require care over the next three to five decades. From a life course perspective, the biometric goal for her will not be a targeted level of glucose control at the next medical visit but a sustained trajectory of glucose control. The identification of major contributing factors – biological, social, and behavioral – in the early stages of her disease will confer an accumulation of risk providing a way to look at these trajectories that will inform treatment decisions and other interventions that last many years. Life course principles and trajectory analyses offer this way of thinking.

For health-care providers and public health officials, life course health data will allow a more complete understanding of how health is maintained or how disease develops over the life span. Practically, this information will transform the way health promotion and disease prevention programs are designed and implemented (Halfon & Conway, 2013). For example, predictive models using a life course approach may identify patients who are most likely to develop heart disease or diabetes, based on their cumulative individual (e.g., lack of exercise) and larger contextual (e.g., residence in a high-stress community) risk factors, facilitating the creation of targeted preemptive and preventive interventions (Halfon & Conway, 2013). At the same time, modeling pathways will support evaluation not in terms of "snapshots" of current status but of status and change in status over many years.

Health insurers and other payors will have greater incentives to promote health trajectories for populations of patients and to augment the longitudinal integration of health-care services, such as extending coverage and benefits from years to decades, creating incentives to manage risk and assume accountability for specified health outcomes (Halfon & Conway, 2013). An effective and efficient health-care system, as illustrated in Fig. 16.2, would ultimately require not only health-care services that are vertically integrated across medical, educational, and social service sites (e.g., worksites, schools) but also the

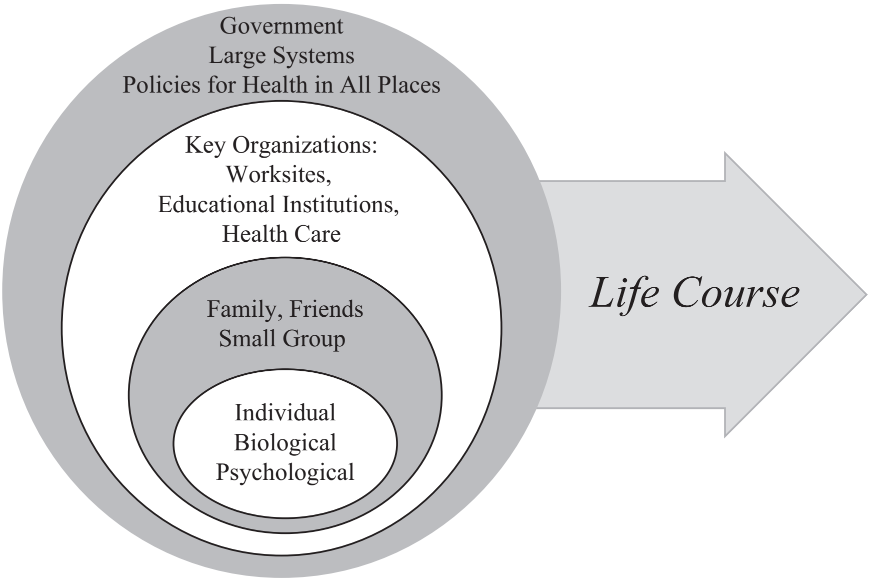

Fig. 16.2 Vertical levels of influence and the life course

horizontal integration across the entirety of the life course (Halfon & Conway, 2013; Halfon & Hochstein, 2002).

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Part IV

Approaches to Changing Behavior Related to Health

17

Health Education and Health Promotion: Key Concepts and Exemplary Evidence to Support Them

Hein de Vries, Stef P. J. Kremers, and Sonia Lippke

The focus of this chapter is to summarize health education aimed at individuals and groups of individuals. We first briefly describe the history of health education. Next, we discuss the importance of identifying and systematically planning the various steps of health education. We then outline the constructs that are used in health education to motivate people to adopt health behaviors. Furthermore, we describe examples of approaches that are used in various settings. We outline the importance of taking a comprehensive and more ecological approach to health education by outlining the health promotion approach and contributions of ecological models for health education and health promotion, health behavioral change models, and diffusion models to illustrate the main concepts relevant for understanding how health education programs are developed, tested, and disseminated. We will also provide examples of programs that have been developed and were successful in various settings, such as mass media approaches, school-based programs, worksite programs, patient education programs, and eHealth and computer-based tailoring interventions.

Health Education

In 1948 the WHO acknowledged that health should be regarded as a state of physical, mental, and social well-being (WHO, [WHO definition of Health], 1946). An essential implication of this description is the fact that health is more than the absence of disease and that physical, social, and mental aspects are of equal importance. This view on health represents, in contrast with the medical disciplines, a more holistic view on health. This holistic principle was affirmed in the *Alma Ata Declaration* in 1978 (WHO, 1978) and the *Ottawa Charter* (WHO, 1986). These two documents outline that health should not be considered in an isolated context but as the result of the interplay between the individual and the context. In other words, health should be regarded as the result of an interaction between individual and environmental factors. Accordingly, the Ottawa Charter defines health promotion as strategy targeting the individuals and its environment.

Health education has a long history that dates before 1948 or 1986. Messages and interventions concerning hygiene were part of several ancient societies including the Roman civilization, where regular bathing was a hallmark. Messages about hygiene can also be found in many documents of several religions, such as the Bible, the Islam, and in Hindu documents. Yet, although issues of

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health have always been a major concern for many civilizations, health education's significance has not always been articulated.

Generally, health education refers to the process of educating people about health and how they can influence their health. Health education methods thus pertain to methods used to educate people about health and how to achieve this. With regard to health education, several definitions can be found in the literature. For instance, health education aims at equipping people to enable them to make sound decisions regarding their health, safety, and welfare (Hochbaum, 1971), bringing about changes in individuals, groups, and larger populations to realize behaviors that are conducive to present and future health (Simonds, 1978).

An important concept in health education is *health behavior*. Health behavior often refers to an action taken by a person to reach and/or maintain good health and to prevent illness. These actions can be individual actions, such as quitting smoking and adopting a lifestyle with sufficient amounts of physical activity. We consider this action at the personal level.

Yet, groups can also undertake actions in order to promote good health or to prevent illness. We can think of parents helping their children to remain healthy but also of companies that start health promotion programs or regional and national governments that implement health-promoting policies. Hence, promoting health behavior can take place at the *micro level* (the personal level), the *meso level* (the organizational level, including e.g. families, schools and worksites) and at the *macro level* (the (inter)national level, including e.g. governments) (de Vries & van Dillen, 2007). This also implies that health education may be needed for several target groups in order to be able to comprehensively address a particular health problem.

Let us illustrate this with an example about the prevention of Lyme disease (de Vries & van Dillen, 2007). With regard to Lyme disease, several target groups can be identified. In the United States, the highest attack rates are in children aged 0–14 years and in persons 30 years of age and older. Several studies suggest a higher risk for children than for adults (de Vries & van Dillen, 2002). If one focuses on the prevention of Lyme disease in children, children are an important target group at the micro level. Target groups at the meso level can be, for instance, parents, siblings, relatives, and teachers but also sports trainers and peers. Examples of target groups at the macro level are institutions responsible for providing health education about Lyme disease. For addressing each target group effectively, it is relevant to know whether they are already engaged in the health education actions and what their motives are for engaging in it or not.

Health education is one of the methods used in health promotion. Health promotion refers to the process of enabling people to increase control over their health and its determinants and thereby improve their health (WHO, 1986). Health promotion implies the utilization of combinations of health education and organizational, political, and economic interventions designed to facilitate behavioral and environmental adaptations that will improve or protect health (USDHHS, 1980). Green and Kreuter define health promotion as the combination of educational and environmental supports for actions and conditions of living conducive to health (Green & Kreuter, 1991).

Green and Kreuter (1991) point out that health education – as a strategy for health promotion – should entail a systematic and planned approach. In achieving such an approach, various models and theories should be used. Different classes of models and theories can be distinguished. *Planning models* aim to outline the steps that can be taken in the process of identification of health problems up to the final stage of solving them. *Behavioral change models* aim to identify the factors that determine the adoption of a particular health behavior and to identify strategies to change these factors. These models are important for developing specific health education interventions. *Diffusion models* aim to describe the steps needed to disseminate effective programs on a larger scale. In the following we outline them in more detail.

Planning Models

One essential step in health education planning models concerns the analysis of the various steps that are important when trying to approach and solve a particular health problem (or sets of health problems), essential steps that need to be taken into account. Basically, the identification of these steps is characteristic for all health promotion planning models: they break down the complex process of health promotion into important steps that can be recognized.

An important conclusion from many of these planning models is that certain types of actions are needed in order to facilitate the conditions for a better health in a person, groups of persons, communities, and nations. Planning models can help to identify which types of health-promoting actions may be needed. The utilization of these models is important, since their application will help us to acknowledge important steps in the health promotion process, steps that we otherwise might have neglected. An important conclusion after investigating a particular health problem will probably be that we need to undertake actions in order to motivate persons to adopt a healthier lifestyle and to change our environment into a healthy environment.

The *PRECEDE–PROCEED Model*. In 1980 Green described the PRECEDE model for health education planning (Green, 1980). The PRECEDE model distinguishes five steps in the planning of health education strategies. The first step entails conducting a social diagnosis to determine people's perceptions of their own needs or quality of life and their aspirations for the common good. The *second step* is the epidemiological diagnosis which is conducted to determine which health problems are important. In the behavioral and environmental diagnosis, the *third step*, the main determinants of the health problem are analyzed. In the educational and organizational diagnosis, an analysis is made of the predisposing, reinforcing, and enabling factors that should be changed to initiate and sustain a process of behavioral and environmental change. These factors will become the immediate targets of a health promotion program (*step four*). The *fifth step* is the administrative and policy diagnosis, focusing on developing health education and health regulation actions.

In 1991 the PRECEDE model was amended and elaborated with a PROCEED part, describing the process that occurred after the development of health promotion interventions, thus describing the implementation of the actions (*step 6*); the changes of these actions on the predisposing, reinforcing, and enabling factors (process evaluation, *step 7*); the changes of the individual's behavior and the environment (impact evaluation, *step 8*); and the outcomes of the health promotion actions on health and the quality of life (outcome evaluation, *step 9*).

The PRECEDE–PROCEED model is still very influential in guiding health education and health promotion research and practice. One of the results of its utilization is the need for a slightly different organization of the planning model. Consequently, other planning models have been formulated which can be seen as various variations of the PRECEDE–PROCEED model, such as PATCH (see, e.g., McKenzie & Smeltzer, 2001, for an overview). In the United States, the *Planned Approach to Community Health (PATCH)* was developed in 1983 by the United States Centers for Disease Control (CDC) together with state and local health departments and community groups. PATCH was also intended to serve as a mechanism to improve links both within communities and between communities and state health departments, universities, and other agencies and organizations. PATCH integrates principles of community participation with the diagnostic steps of applied community-level epidemiology. The PATCH process guides users through five phases: (1) mobilizing the community, (2) collecting and organizing data, (3) choosing health priorities, (4) developing a comprehensive intervention plan, and (5) evaluation.

While applying the PRECEDE–PROCEED model, the Dutch I-Plan model resulted (also called ABC model (de Vries & van Dillen, 2007)). The I-Plan model is based on the three ABC's of the planning process: analysis, behavioral change, and continuation. The first *analysis phase* distinguishes five steps: (1) assessing quality of life, (2) assessing behavioral and environmental factors related to the problem, (3) defining the target groups, (4) analyzing factors that determine a person's behavior, and (5) access points analysis aimed at assessing how to best reach the target group and health intermediaries. The second *behavioral change* step involves (1) developing program goals and objectives, (2) developing the program, and (3) testing the program. The last phase, *continuation*, includes (1) establishing inter-sectoral collaboration and support, (2) developing diffusion strategies, and (3) developing supportive policies.

The *community organization model* by Bracht (1990) did not originate from the PRECEDE–PROCEED model. However, it has also similarities (Bracht, 1990). Since many health education and health promotion goals require active involvement of community citizens, leaders, and organizations, community organization is a central notion in this model. Community organization can be described as a planned process to motivate a community to use own resources and social structures to achieve the community (health) goals. The development of strategically planned interventions in which local groups or organizations are involved is therefore important to be able to realize relevant changes (Bracht, 1999). Community organization also implies community empowerment, capacity building, and partnership development. Bracht's model distinguishes five stages for the development of community programs, which are described in Table 17.1.

Table 17.1 The five stages of the *community organization model* by Bracht (1990)

First stage	Analysis of the community to obtain information regarding the community and its needs, resources, social structure, and values Establish citizen leader and organizational involvement to create collaboration and broad community participation
Second stage	Development of the design of the community program and the initiation of the development of an organizational structure and the preparation of plans
Third stage	Implementing the plans into action
Fourth stage	Program maintenance and consolidation Community members and staff gain experience and success with the program, and the problems that arose at the beginning of the project, have now been dealt with
Fifth stage	Dissemination of the program and the reassessment of activities Community analysis is updated, the effectiveness of interventions is established, and future directions and modifications are discussed

The *RE-AIM* framework was originally developed as a framework for consistent reporting of research results (Glasgow, Vogt, & Boles, 1999) but was later also used to organize reviews of the existing literature on health promotion and disease management in different settings. The acronym stands for *reach, effectiveness, adoption, implementation, and maintenance* which together determine public health impact. RE-AIM has been used to translate research into practice and to help plan programs and improve their chances of working in "real-world" settings. The framework has also been used to understand the relative strengths and weaknesses of different approaches to health promotion and chronic disease self-management – such as in-person counseling, group education classes, telephone counseling, and Internet resources. The RE-AIM model aims to guide planning and evaluation of evidence-based interventions that address different levels of the socio-ecological model, such as those that target individual health behavioral change by increasing intrapersonal, organizational, and community resource support; see Table 17.2.

Table 17.2 The dimensions of the *RE-AIM* framework (Glasgow, Vogt, & Boles, 1999)

Reach	Percentage and characteristics of individuals receiving the intervention
Effectiveness	Impact of an intervention on outcomes, including anticipated as well as unanticipated effects, quality of life, and economic outcomes
Adoption	Absolute number, proportion, and representativeness of settings that adopt the intervention
Implementation	Fidelity of intervention use and intervention costs
Maintenance	Long-term sustainability at both the setting and individual levels and thus involves the assessment of the extent to which a program or policy becomes institutionalized or part of the routine organizational practices and policies

The model has been used to evaluate programmatic and policy interventions addressing a wide range of health conditions (e.g., diabetes, obesity, hypertension) and health behaviors (e.g., physical activity, dietary behaviors, and smoking) and the built environment (Gaglio, Shoup, & Glasgow, 2013).

Dunton and colleagues, for instance, applied the RE-AIM model in order to examine the reach, efficacy, adoption, implementation, and maintenance of a physical activity and nutrition curriculum for Californian middle-school students (Dunton, Lagloire, & Robertson, 2009). They found that this particular program reached approximately 50% of applicable students and was adopted by 42% of the teachers to whom it was offered. The program had a strong influence on physical activity and sedentary behaviors, whereas positive effects for dietary intake were observed for some but not all of the outcomes measured. The majority of teachers delivered all of the lessons and implemented individual lessons in the recommended order. The program used by teachers remained relatively constant during the prior five school years, with approximately 51% of students reached. Taken together, these findings indicate that this program had a moderate to high public health impact among middle-school students.

Intervention mapping (IM) by Bartholomew et al. (2001) is an approach which was also inspired by the PRECEDE–PROCEED model. IM provides a protocol for the development of theory- and evidence-based health promotion programs. The purpose of IM is to provide health education program planners with a framework for effective decision-making at each step during the intervention development process. It provides guidelines and tools for the selection of theoretical foundations and underpinnings of health promotion programs, for the application of theory, and for the translation of theory into actual program materials and activities (Kok et al., 2011). IM suggests specific steps that guide problem-driven development, application and integration of nutrition, and behavioral change theories. IM proposes a systematic way for program development that results in the development of intervention matrices. These matrices finally develop into an "intervention map" that turns the translation of objectives to change strategies into actual intervention activities explicitly. IM describes the process of health promotion program development in six steps. Following an intervention map, six core processes are addressed (see Table 17.3).

Table 17.3 The six core processes of *intervention mapping* (IM) (Bartholomew et al., 2001)

1. Process	Needs assessment
2. Process	Identification of objectives
3. Process	Methods and strategies
4. Process	Program development
5. Process	Adoption
6. Process	Implementation

An application of intervention mapping is described by Van Stralen and colleagues (2008) that occurred for the development of a program on physical activity (PA) for older adults of at least 50 years of age. The needs assessment revealed that older adults who do not reach the international PA guideline of at least 30 minutes per day on at least 5 days of the week should become aware of their insufficient PA level and increase and maintain a new PA level. A list of specific objectives were identified, such as older adults need to (1) monitor their recreational PA level, (2) indicate reasons to be physically active as recreation, (3) identify solutions to take away the barriers to being physically active for recreation, (4) make clear decisions to become more recreationally physically active, (5) make specific plans to become more recreationally physically active, (6) increase their recreational PA, (7) make specific plans to cope with difficult situations occurring while being recreationally physically active, and (8) maintain their recreational PA by enhancing their routine and preventing relapses.

Concerning the methods, it became clear that methods were needed that would aim at, for instance, personalization, tailoring, feedback, argumentation, persuasive communication, self-monitoring, consciousness raising, active learning, and social modeling. These methods should provide tailored feedback on a person's awareness level, attitude, social influence beliefs, self-efficacy, and action plans. Program development thus resulted in the development of tailored letters that were sent to program participants three times, thus providing them with highly personalized and tailored feedback on how to become aware of their physical activity levels, on how to become or remain motivated, and how to best cope with the specific barriers that were relevant for this particular person. The sixth step resulted in the implementation of this program and evaluation of the effects. The results showed that the program was significantly effective in increasing physical activity levels (van Stralen et al., 2008).

In conclusion, planning models help a person to identify the relevant steps in the planning process. Most planning models share similarities: all of them identify a phase, step, or stage in which the problem and factors related to the problem are analyzed, one that focuses on program development and evaluation and one that addresses steps related to program adoption and implementation. Core differences can also be observed, which are mostly the result of the articulation of issues that remain more implicit in other planning models. For instance, the I-Plan model clearly recognizes the need to include three types of target groups at the micro level (individuals), at the meso level (families, schools, worksites), and at the macro level (organizations responsible for the development of policies), as well as an access point analysis to identify where the target groups can be reached as steps that should precede program development. The RE-AIM model, although initially intended to evaluate program implementation and impact, is now also increasingly used as an overall planning framework to guide program development. Intervention mapping has elaborated the PRECEDE–PROCEED model and stimulates the user to develop very clear ideas concerning the objectives that are needed for the development of programs, using an array of matrixes that can be used to summarize important information of the various steps. It also stimulates the user to clearly reflect on theories and theoretical constructs, as well as practical methods that can be used to change behavior. We will discuss these theoretical constructs in more detail below.

Concepts and Variables

In order to be able to develop health education interventions, health educators have used a variety of theoretical models and concepts within these models to develop their intervention. We will first start by outlining the main concepts. Later we will discuss various models and will see how these concepts were included (or not) in these models by various scholars and also obtain an indication of the differences and similarities between these models.

Knowledge Many health education programs provide information and facts about a certain topic. The idea behind this approach is that the provision of knowledge will increase awareness concerning a particular topic, for instance, the importance of hygiene, facts about pregnancy, the importance of eating sufficient portions of fruits and vegetables, etc. A smoking prevention program, for example, can provide information and facts about smoking by pointing at the health dangers of nicotine, tar, and carbon monoxide and by indicating that smoking is related to premature morbidity and mortality. Knowledge differs from beliefs, in the sense that knowledge items can be justified as true or false, whereas beliefs can be accepted or not. For instance, "cigarettes contain tar" is an example of a knowledge item. One reason why knowledge information is provided, is that it will increase risk perceptions and change attitudes in the receiver and attitudes in turn affect behavior. This chain is also referred to as the knowledge–attitude–behavior (KAB) chain. Better educated people possess more general knowledge on a broader range of public affairs topics (Price, & Zaller, 1993), which may also lead to better recognition and acquisition of new information (Bonfadelli, 2002).

A related concept, more often used in the area of patient education, is the concept of *health literacy*. Health literacy is defined by the WHO as the "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (WHO, 2010). Health literacy includes the ability to understand instructions on prescription drug bottles, appointment slips, medical education brochures, doctor's directions and consent forms, and the ability to negotiate complex healthcare systems. Health literacy is not simply the ability to read and know.

It requires a complex group of reading, listening, analytical, and decision-making skills and the ability to apply these skills to health situations. But also general literacy is related to risk factors: low (health) literacy in a population is associated both directly and indirectly with a range of poor health outcomes (Parker & Jacobson, 2000). Persons with lower reading (health) literacy levels have a greater likelihood of hospitalization and higher expenses for healthcare than those with better reading skills (Baker et al., 1998), and higher health literacy is related to better health behavior, higher well-being, and lower risk of morbidity and premature mortality (WHO, 2013).

Knowledge about certain health topics may be distributed skewedly. For instance, studies in the previous century already demonstrated that people with more formal education learned and knew more about many issues than people with less formal education (Hyman & Sheatsley, 1947), findings referred to as the *knowledge gap hypothesis* (Tichenor, Donohue, & Olien, 1970). The authors also pointed at the risk that information programs may be more likely to help groups of higher socioeconomic status (SES) than those of lower SES groups. The knowledge gap hypothesis implies a relative association as high SES and better educated groups will access, use, and acquire information faster and more effectively and thus yield a relative advantage. Yet, knowledge gaps may also decrease when information on a given topic becomes easily available to everyone. The rise of Internet use led to similar concerns, since differences in Internet access may lead to an increase in digital divide, resulting into a widened gap between individuals with and without much information about health-related topics (Hoffman & Novak, 1998). Knowledge differences, however, may exist between several groups. For instance, a Dutch study found differences between men and women about early detection of cancer: women recognized significantly more symptoms that could imply cancer than men did. Additionally, higher educated respondents recognized more symptoms than lower educated respondents (de Nooijer, Lechner, & de Vries, 2002).

In sum, health education programs targeting knowledge can thus lead to changes in knowledge, for instance, about HIV/AIDS (James et al., 2006), but these programs do not necessarily alter attitudes and behavior. Hence, several reviews concerning the effects of knowledge on behavioral change suggest that knowledge acquisition may influence attitudes, but is mostly insufficient to lead to health behavioral change (Hansen, 1992; Green & Kreuter, 1999). Yet, health education programs addressing knowledge can set the stage for developing risk perceptions concerning a certain health problem.

Risk Perceptions Studies of risk perception examine the judgments people make when they are asked to characterize and evaluate hazardous activities and technologies (Slovic, 1987). Risk perception derives from *threat appraisal*, which is considered to be a major motivating factor in preventive and protective health behaviors. Perceptions of risk can be an important motivator of a number of health-related behaviors. It is therefore important to understand them and their role in changing health behaviors. Risk perceptions (i.e., beliefs about potential harm or threat) are included in many health behavior theories (see, e.g., Lippke & Ziegelmann, 2008; Weinstein, 1988; Vernon, 1999). Core constructs that determine the development of risk perceptions are the *perceived susceptibility* to a particular threat and its *perceived severity*. The greater the perceived risk, the greater the chance will be that a person develops the motivation to protect oneself from the threat.

Studies analyzing the impact of severity and susceptibility perceptions on health behavior show small to medium effect sizes (Brewer et al., 2004; Abraham & Sheeran, 2005; Milne et al., 2000). Yet, many studies used cross-sectional designs and often found inconsistent contributions of risk perceptions to behavior. This does not imply that risk perceptions are not important. One explanation is that risk perceptions should be regarded as a more *distal cognitive process* influencing communication acceptance, awareness, and attitude change (Leventhal & Cameron, 1987; Schwarzer 2008; de Vries et al., 2003).

Recent findings also suggest that when communicating risk perceptions, it is better to describe conditional risks which describe clearly the probability that a certain event will occur given that the adaptive behavior is, or is not, performed (van der Velde et al., 1996; Janssen et al., 2011). For instance, "How likely is it that you will get disease X (e.g., skin cancer), if you would not perform behavior Y (e.g., sunscreen use)?" Additionally, recent research also points at the importance of the role of affect on risk perceptions. Affect can be regarded as an experiential system with reliance on quick "gut" feelings or reactions to respond to risk. This system encompasses biological and survival responses relying on the fight or flight autonomic nervous system, and is thus a different system than the more analytical and rational system, which relies more on slower pathways and cognitive reasoning (Slovic & Peters, 2006). Several studies increasingly support the importance of differentiating between cognitive and affective components of risk perceptions. For instance, in an attempt to assess potential differences between the two types of risk assessments, affective and noncognitive risk perceptions were found to be the only factor related to smoking, fruit consumption, and sunbed use in a Dutch study (Janssen et al., 2012, 2013).

In conclusion, as for knowledge (and probably for most factors) one can conclude that risk perceptions constitute an important factor in the process of behavioral change. Its role, however, may be more important in the early awareness phase than in later phases of the behavioral change process. Hence, health education programs should certainly address risk perceptions in populations that are not fully aware of the potential health risks of a particular behavior, and should not neglect the importance of emotional reactions of persons to risks.

Attitude Early persuasion studies by Hovland and colleagues at Yale were controlled experiments testing various conditions under which opinion or attitude change would occur in the context of such variables as source credibility, fear, organization of arguments, the role of group membership in resisting or accepting communication, and personality differences (Hovland, Janis, & Kelley, 1953). Several definitions for attitude can be found. Thurstone (1931) provided a now well-known definition of attitude as affect for or against a psychological object. Fishbein and Ajzen define attitude as the result of beliefs about the consequences of performing a particular behavior multiplied by the evaluation of these consequences (Fishbein & Ajzen, 1975). An example of a *belief* is "smoking increases popularity"; an example of an *evaluation* is "being popular is good." The notion that an attitude is constituted by several beliefs concerning the outcomes of a particular behavior has gained wide acceptance. The consequence of this notion also implies that attitudes can be changed by changing the underlying beliefs, beliefs that may differ from person to person. Consequently, a careful inspection of the most salient beliefs that constitute a particular attitude in a group is therefore important (Ajzen & Fishbein, 1980).

Yet, the multiplication of these beliefs with evaluation has received quite some criticism (Gagne & Godin, 2000). Consequently, many researchers decide to only assess the beliefs to measure the attitude. Beliefs about the consequences are described as outcome expectations in *Bandura's social learning theory* (Bandura, 1986). Outcome expectations thus refer to a belief that a given behavior will or will not lead to a given outcome. These outcomes can refer to all sorts of outcomes, such as *social outcomes*, *emotional outcomes*, or *health outcomes*. Another related concept is *decisional balance* (Janis & Mann, 1977) that describes to the weighing of advantages (pros) of a particular behavior with the disadvantages (cons). Furthermore, recent studies also outline the importance of distinguishing emotional versus more rational beliefs (Conner et al., 2013). In general, the different concepts of attitudes, outcome expectations, pros and cons, etc., refer to quite similar variables, and many theoretical models include them into their key constructs (Lippke & Ziegelmann, 2008).

Multiple studies have investigated the role of attitudes for several health behaviors. Studies have also examined which variables or beliefs distinguish a healthy group from an unhealthy group (Godin & Kok, 1996). For instance, Holm and colleagues (Holm, Kremers, & de Vries, 2003) found that non-smoking and smoking adolescents differed concerning their perceived pros and cons of smoking. Panday and colleagues (2005) showed that attitudes may also differ by ethnic group and demonstrated that Black African students were less convinced of the pros of non-smoking than colored students (i.e., the reference to colored people is used in South Africa to refer people with heterogeneous ethnic background) and white students, whereas colored students were least convinced of the cons of non-smoking, followed by Black African and, in turn, white students.

As attitudes are generally formed by multiple beliefs, and belief structures may differ per subgroup, it is important to acknowledge these differences when designing studies and programs targeting attitudes toward a particular health behavior. For instance, when discussing the need for smoking cessation, the importance of pointing at the consequences of smoking for the unborn baby becomes relevant for pregnant smoking women (de Vries et al., 2006). Moreover, smokers may not be equally convinced of all consequences. For instance, person A may not be convinced of the risks for cancer and thus may need information about the consequences of smoking for developing cancer; person B may be convinced of this aspect, but is not convinced of the consequences of passive smoking; person C may not be aware of the negative consequences of her smoking as a role model for her child; etc.

In sum, the identification of attitude beliefs is important when developing effective health education programs. Health education approaches need to tailor information as much as possible in order to be able to optimally address the specific attitude beliefs of one particular person.

Social influence beliefs pertain to the perceptions of a person to what others are thinking or doing. Social influences play an important role in the development of behavior (Bandura, 1986; Turner, 1991). Social influences can be described as the processes whereby people directly or indirectly influence the thoughts, feelings, and actions of others. Interventions aiming to change behaviors often focus on changing the impact of social factors. Social influences are associated with both beneficial and detrimental effects on other person's thoughts and behavior.

Well-known studies were performed by three different authors: First, Milgram (1963) demonstrated how conformity can develop. Second, Sherif (1935) indicated how acceptance of new beliefs can develop. Third, Asch (1956) revealed how compliance can develop. The *social comparison theory* (Festinger, 1954) argues that humans have a drive to evaluate their opinions and abilities. Hence, it is not only the mere exertion of social influences that impact people's behavior; at least as important are the ideas, perceptions, and expectations that a person has concerning other persons' behaviors.

An important factor in this context is referred to as *social norms* (Fishbein & Ajzen, 1975). Social norms refer to perceptions of the opinion of important referent persons. Social norms have been found to predict various behaviors. For instance, several studies in the former century document the role of social norms for understanding deviant behavior in adolescents (Presson et al., 1984; Grube, Morgan, & McGree, 1986; Oostveen, Knibbe, & de Vries, 1996; Newman, Martin, & Ang, 1982). For health education programs, the importance of social norms implies that one can develop programs to change social norms, as well as programs focusing on resisting social norms to engage in healthy behavior.

Other social influence constructs can be identified as well. Richard Evans suggested the importance of direct pressures to understand the process of uptake of unhealthy behaviors, such as smoking by adolescents (Evans, 1976). The difference between social norms and social pressure may be subtle, but distinct: pressures are exerted much more openly and clearly felt. Social modeling is a core construct in Bandura's *social learning theory*. Social modeling of a behavior by a person (the actor) can result in the perception of positive outcomes in another person (the receiver). This process is also referred to as vicarious or observational learning. This factor is sometimes also labeled descriptive norms (Rivis & Sheeran, 2003). De Vries and colleagues demonstrated the importance of both social pressure and social modeling (the behavior of others) as well as direct pressures (de Vries et al., 1995).

Social network theories describe the importance of a person's position in a social network and how persons are tied to each other, also in order to better understand the role of social influences. An important recent finding was that the onset of smoking does not only occur because of social pressure from peers but also by the selection of youngsters that have a similar profile (Mercken et al., 2010). These results indicate that conformity to behavior can also result as a consequence to fit in a particular group and thus leading to acceptance of certain deviant health behaviors (de Vries et al., 2006; Mercken et al., 2009). This implies that the influence of groups may have bi-directional effects. One the one hand, other persons may influence a person directly. On the other hand, characteristics of a group may prompt a person to conform to behaviors of this group in order to fit in.

Social support refers to the perceived help that a person receives from others. This help can be expressed in various ways, such as comfort, care, listening, and encouragements. Various types of social support can be given to a person (Sarafino, 1994; Taylor et al., 1986; Cohen & Wills, 1985). *Emotional support* encompasses showing concern, caring, and empathy toward the person and gives a person a sense of reassurance, comfort, and being accepted as a person. *Informational support* refers to actions of others that provide the person with information, advice, suggestions, or feedback about how the person is doing and what he might do. *Material* or *instrumental support* entails actual goods and services that other people can provide to a person. Berkman and Syme published in 1979 classical findings linking *social relationship quality* to mortality (Berkman & Syme, 1979).

Subsequently various studies showed that low levels of social support were associated with higher mortality rates due to cardiovascular disease but also to higher cancer rates and infectious diseases. Social support encourages the performance of health-promoting behaviors such as non-smoking, moderate alcohol consumption, adherence to medical regimens, etc. Kamarck et al. demonstrated that the mere presence of a friend was related to lower blood pressure reactivity to an acute psychological stress (Kamarck, Manuck, & Jennings, 1990). This led to the formulation of a stress-buffering hypothesis function of social support (see, e.g., Cohen & Wills, 1985; Uchino, 2006, for an overview). In sum, there are two explanations for the effects of social support on health: the *buffering hypothesis* and the *direct effects hypothesis*. The direct effects hypothesis predicts that social support is beneficial all the time, while the buffering hypothesis predicts that social support is mostly beneficial during stressful times. For health education programs, the results on social support imply that health education programs need to outline the importance of obtaining social support to individuals as well as to organizations (e.g., schools, hospitals, worksites) to optimize chances that social support can be given by others.

Social influences can thus impact health behavior in several ways, and assessing its impact can be realized using different constructs. Some of them, such as social norms, are quite proximal to the behavior. Others, such as social network structures and parenting styles, may also impact behavior but more at a distal level and exert their influence by, for instance, influencing attitudes. Huver and colleagues found, for instance, that parenting influences impacted smoking behavior via influencing the attitudes of their offspring (Huver, Engels, & de Vries, 2006).

Hence, a critical analysis of relevant social structure processes that impact on a particular health problem is crucial when designing health education interventions. This analysis helps to make decisions on how to best build health education programs for a particular problem. Consequently, health education programs can then address the impact of social influences in different ways by, for instance, including lessons (a) about how to resist social pressures, (b) for parents on how to communicate better with their children, (c) about how to provide social support, and (d) including strategies on how to change social norms.

Self-Efficacy Self-efficacy is defined by Bandura as people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives in face of barriers (Bandura, 1977, 1986). In contrast to concepts such as self-confidence or self-esteem that refer to more general characteristics of a person, self-efficacy refers to a person's confidence to be able to perform one particular behavior. Self-efficacy expectations are thus different from self-esteem expectations in the sense that self-efficacy expectations are behavior specific: a person can have high self-efficacy not to smoke, whereas he may have low self-efficacy toward being physically active (de Vries et al., 1988). Self-efficacy expectations thus greatly depend on a particular behavior and the context in which it takes place. Self-efficacy influences all aspects of behavior, including the acquisition of new behaviors (e.g., a sexually active young adult learning how to use a particular contraceptive device), inhibition of existing behaviors (e.g., decreasing or stopping cigarette smoking), and disinhibition of behaviors (e.g., resuming physical activity after a myocardial infarction (Strecher et al., 1986)).

Furthermore, if a person has a high level of self-efficacy concerning a particular behavior or specific task, he or she will approach difficult tasks as challenges to be mastered rather than as threats to be avoided. High self-efficacy contributes to setting challenging goals, strong commitment to goals, and persistence toward reaching goals even if being confronted with temporary failures to attain these goals. People with high levels of self-efficacy attribute failure more rapidly to insufficient effort or deficient knowledge and skills than people with low senses of self-efficacy. Self-efficacy beliefs are cognitions that influence whether a certain health behavior will be planned and executed and how much effort will be expended to realize the behavior.

Self-efficacy is not only behavior specific but also context specific. A person can have a high level of self-efficacy toward being physically active, where he or she may have low levels of self-efficacy toward non-smoking. Yet and additionally, a person may also have different levels of self-efficacy depending on the context of the behavior. A person may have high self-efficacy to refuse from smoking after dinner, but may have low self-efficacy when being offered a cigarette by friends. Yet, this situation may be opposite for another person. Consequently, when aiming at increasing levels of self-efficacy, it is important to identify the specific situations that may put the realization of that behavior for that person at risk. In other words, the highest effects of health education programs toward increasing levels of self-efficacy will be attained when the assessment of the risk factors as well as the health educational feedback occurs as personalized and tailored as possible.

Consequently, within the construct of self-efficacy, different domains of self-efficacy have been identified defining specific types of self-efficacy related to different behavioral phases, such as action and coping self-efficacy and relapse self-efficacy, or to different types of self-efficacy for different challenging situations, such as social self-efficacy (for difficult social situations), skills self-efficacy (for difficult behaviors), or phase-specific self-efficacy (motivational self-efficacy imperative for adopting a behavior and volitional self-efficacy for maintaining a behavior and for coping with barriers) (see, e.g., Schwarzer et al., 2008; Dijkstra & De Vries, 2000; Pinto et al., 2008).

Self-efficacy expectations are influenced by the ability a person has to perform a behavior. Yet, ability is not a fixed attribute of a person, but the result of the interplay of cognitive, social, motivational, and behavioral skills (Bandura, 1993). This is also clearly illustrated by a classical experiment of Collins (1982) described by Bandura (1986) in which she selected children at three levels of mathematical ability – low, medium, and high. She found that at each level of ability, children who had higher levels of self-efficacy toward solving the math problems also solved the problems more quickly. These children also chose to rework more of the problems they failed and did so more accurately than did children of equal ability who were plagued by self-doubts. In sum, people who perform poorly may do so because of a lack of skills and/or because of a lack of self-efficacy. Skills are of course required to be able to perform a behavior, but high levels of self-efficacy to be able to execute the behavior facilitate learning new skills and coping with barriers that may hinder its execution.

The acknowledgment of the importance of self-efficacy led to adoption of specific self-efficacy-enhancing strategies in health education programs. These strategies often aim at increasing self-efficacy via *direct learning* of adequate healthy responses, *vicarious learning* (learning through observation), and *verbal persuasion* by which a person becomes stimulated by others to perform the adequate response. Via these strategies a person becomes aware of specific situations where efficacy may be low and how to react more effectively to these situations. Consequently, self-efficacy-enhancing strategies can be found in many health education programs for both healthy people and specific patient groups (see, e.g., Marks, Allegrante, & Lorig, 2005; Ashford, Edmunds, & French, 2010; Nichols et al., 2009).

Various studies demonstrate the importance of high self-efficacy levels for realizing various different health behaviors (O'Leary, 1985; Schwarzer, 1992), including smoking cessation (de Vries et al., 1995), reducing alcohol consumption (Oei & Burrow, 2000), smoking cessation and condom use (Hendriksen et al., 2007; Schaalma et al., 1993), fruit and vegetable consumption (Brug et al., 1995; Campbell et al., 1999), physical activity (Moritz et al., 2000), and skin cancer prevention (de Vries et al., 2005). Self-efficacy is quite similar to perceived behavior control and one of the two is included in most theories and models (Lippke & Ziegelmann, 2008). One older model, in which self-efficacy is not regarded, is the *theory of reasoned action* described in the following.

Intention and Stages of Change People may have positive or negative motivations to perform a particular behavior. The concept of motivation and motivational stage can be found in various theories. The concept of behavioral intention has become particularly popular since its introduction in Fishbein and Ajzens' *theory of reasoned action* (Fishbein & Ajzen, 1975). Behavioral intention is an indication of an individual's readiness to perform a given behavior. It is assumed to be an immediate antecedent of behavior. Intention scales assess the likelihood of whether people plan to engage in a particular behavior. Intention is considered to be the resultant of other motivational factors such as attitudes, social norms, and self-efficacy.

Some researchers categorize people into stages of readiness to change. Gollwitzer (1990) describes that the Rubicon model, for instance, posits four phases in the performance of behavior, the predisional action phase (characterized by wishing and deliberation), the decision-making phase (making new goal intentions), the preactional phase (characterized by action planning), and the action phase.

A related framework is described in the transtheoretical model of Prochaska and DiClemente. They developed a stage of change model with the following stages: *precontemplation* (people who are not intending to take action in the next 6 months), *contemplation* (people intending to change in the next 6 months but not within a month), *preparation* (intending to change within the next month), *action* (when people have already changed in the past 6 months), and *maintenance* (successfully maintained the change for at least 6 months) (Prochaska & DiClemente, 1983).

Weinstein and colleagues describe different stages: (1) *unaware of the health problem*, (2) *aware of the problem but not personally engaged*, (3) *engaged and deciding what to do*, (4) *planning to act but not yet having acted*, (5) *acting*, (6) *no action needed*, and (7) *maintenance* (Weinstein, 1988; Weinstein & Sandman, 1992). Several other strategies are possible as well. For instance, a Dutch model (de Vries et al., 2003) postulates three basic phases of change: *awareness* (determined by knowledge, cues to action, and risk perceptions), *motivation* (determined by attitudes, social influence beliefs, and self-efficacy), and *action* (determined by self-efficacy, action planning, and skills). Yet, other models have reduced the number of stages. For example, the health action process approach (HAPA) distinguishes three stages (unintentional, intentional, and action stage) without referring to a specific time frame (Schwarzer, Lippke, & Luszczynska, 2011).

Models using intentions as predictor of behavior without further recognition of stages are also referred to as *continuum models* (Weinstein & Sandman, 1992). In contrary, *stage models* imply that variables that are important for the transition from one stage to the next may be less or not important for the transition between other stages. Stage models can be subject to criticism and debate (see, e.g., Brug et al., 2005). For instance, concerning the definition of stages one may argue whether motivated persons should only include those who are willing to change within 1 month and not within 3 months. Furthermore, a person may misclassify his stage: for instance, a person who believes that he is sufficiently active may classify himself in maintenance, but actually may not be sufficiently active. Sutton (2000) questions why one needs to divide participants into stages of change, rather than their scores on the measure of behavioral intention (Sutton, 2000) and concluded that the stage of change algorithm underestimated motivation to quit smoking (Herzog & Blagg, 2007).

Yet, the application of the stage idea has found support as well. Studies have used experimental or longitudinal designs to assess whether social cognitive variables can predict transitions between the stages of change (de Vries et al., 1998; Plotnikoff et al., 2010a; Vries & Mudde, 1998). Authors like Weinstein and colleagues (1998) or De Vries and colleagues (2006) introduced the concept of match-mismatch studies. Match-mismatch experiments involve the development of interventions that are targeted at particular stages of change (for instance, a risk awareness intervention for those not being aware of a risk). The interventions are then matched, meaning that they are given to people in that particular stage of change (e.g., information about the pros of the health behavior for precontemplators), or mismatched meaning the interventions are given to people they were not designed for (e.g., information about action planning to precontemplators).

The hypothesis is that matched interventions should facilitate behavioral change, whereas mismatched interventions should not. In a study with the HAPA model by Lippke, Ziegelmann, and Schwarzer (2004) as theoretical backdrop, this matched-matched design was employed. The planning intervention was effective in terms of behavioral change only in intenders (matched) but not in non-intenders (mismatched; they would rather need a risk awareness intervention) and actors (mismatched they would require a maintenance intervention).

In one study 1540 smokers were randomized to one of the four conditions that provided information about the outcomes of smoking, self-efficacy, outcome beliefs, and self-efficacy or a no information control group. In comparison with the control group, contemplators benefited most from both sorts of information, whereas preparers benefited the most from self-efficacy-enhancing information only (Dijkstra et al., 1998), and results were repeated in another study (Dijkstra, Conijn, & De Vries, 2006). Yet, other studies using an experimental design did not find similar findings (Blissmer & McAuley, 2002; de Vet et al., 2008a; Quinlan & McCaul, 2000). In sum, the few experimental studies that have been conducted showed mixed findings, and much more experimental research is needed to be able to draw firm conclusions, as the studies also differed in how the matched feedback was given.

Practical advantages of a stage or phase approach are also described. For instance, health counselors can more effectively focus their attention when they identify the stage of their client, and health communication materials can be tailored toward the stage of the recipient. A similar conclusion can be drawn for brochures and leaflets. Instead of proving all the information at once, the reader may be guided to start reading segments that are most appropriate for this specific reader. Yet, further research is thus needed to determine whether the segmentation is most appropriate by using a stage of phase approach and how many stages or phases need to be distinguished.

In sum, the idea of stages has led to the development of stage-matched health education materials that sometimes show better results than nonmatched materials (Rakowski et al., 1998; Velicer, Prochaska, & Redding, 2006) although not all evidence is consistent (Aveyard et al., 2009;

de Vet et al., 2008b; Armitage, 2009). Yet, the idea of distinguishing different stages in the motivational process has been found helpful for researchers and in particular for medically trained specialists, that behavioral change cannot be summarized as a dichotomy (disease yes/no), but a complex process in which several steps are needed, each determined by different motivational factors.

Action Planning The significance of planning and execution of specific actions in order to realize a final outcome, such as a desired behavior, is an essential assumption in action planning notions that are derived from goal setting theories. Having a positive intention in itself does not necessarily guarantee actual realization of this behavior. Studies suggest that intention accounts for approximately 20–40% of the variance in behavior and behavioral change (Godin & Kok, 1996; Conner, & Armitage, 1998; Webb & Sheeran, 2006). People often fail to act on their intentions (Godin & Conner, 2008; Orbell & Sheeran, 1998) because the translation of intentions into behavior requires additional self-regulation strategies, strategies that we refer to as action planning (de Vries et al., 2003; Schwarzer, 1992; Bagozzi, 1992; Gollwitzer, 1999; Heckhausen, 1991).

Action planning implies the generation of a sequence of behaviors used to translate an individual's intention into actions aimed at goal achievement (Gollwitzer, 1999; Austin & Vancouver, 1996; Leventhal, Nerenz, & Steele, 1984; Handley et al., 2006; van Osch et al., 2008a, 2008b, 2010; Sniehotta, 2009; MacGregor et al., 2006). Action planning can be described as the process of planning and execution of several specific actions that may help to successfully adopt and maintain a new health behavior. Action planning is regarded as an effective way to overcome the so-called intention–behavior gap for both health and patient education. Effective action planning is more likely to occur when persons are motivated to change (Lippke, Ziegelmann, & Schwarzer, 2004; Gollwitzer, 1999; van Osch et al., 2010; Lippke et al., 2010; Sheeran, Webb, & Gollwitzer, 2005).

Action planning is related to goal setting. Both goal setting and action planning are directed toward realizing a specific goal. Goals can be regarded as internal representations of desired states (Austin & Vancouver, 1996). Goal setting thus refers to an end goal that one wishes to accomplish (Latham & Locke, 2006; Bandura, 1989) and may require considerable action planning (Abraham & Sheeran, 2003). Action plans thus pertain to the subset of actions needed to realize a final goal and can be regarded as setting proximal subgoals. Setting specific proximal goals further directs one's actions and enhances long-term motivation and performance (Stock & Cervone, 1990; Locke & Latham, 2002).

Action planning can entail at least two types of actions: preparatory actions and coping actions. Preparatory plans and actions pertain to the plans and actions that a person needs to undertake to prepare the behavioral change attempt (Bryan, Fisher, & Fisher, 2002; Goebbels et al., 2008; de Vet et al., 2011; Bagozzi & Dholakia, 1999). Coping plans refer to the types of plans and actions needed to maintain a behavioral change attempt and can contribute in a person's pursuit to cope and overcome obstacles and difficulties by anticipating how to address these obstacles and difficult situations (van Osch et al., 2010; Sniehotta et al., 2005; Lippke, Ziegelmann, & Schwarzer, 2005). Action planning may require much self-regulative effort since a person needs to identify which specific plans may be most effective for him or her.

Research by Gollwitzer led to renewed attention for a particular subset of action plans, *implementation intentions*. Implementation intentions are action plans that require little self-regulation, since they are linked to external cues that prompt the desired behavior (Gollwitzer, 1999). Implementation intentions are specific if-then plans that link a situational cue (e.g., a toothbrush) with a particular response (e.g., a health behavior, such as taking a vitamin pill). The idea is that a person acts according to the following schema: if situation Y is encountered, then I will initiate behavior Z in order to reach goal X. The assumption is that the linking of the behavior to a cue will increase the likelihood of an automatic reaction; this automatic reaction requires little self-management as its elicitation is then prompted by this external cue. Although implementation intentions are sometimes referred to as action plans, they thus imply a very specific type of action planning. An important precondition for implementation intentions is that the behavior will be under automatic control via a cue that prompts an individual to act. Not all action plans can be prompted automatically. For instance, planning to use nicotine replacement therapy (NRT) to quit smoking is an example of a preparatory action plan, but is difficult to be prompted automatically. Yet, after having made this action plan, a person can link regular NRT use to a specific cue (e.g., breakfast).

Action planning techniques can be effective for health education in the promotion of various health behaviors, such as physical activity (Milne, Orbell, & Sheeran, 2002; Sniehotta, Scholz, & Schwarzer, 2006; Ziegelmann, Lippke, & Schwarzer, 2006; Kwak et al., 2007), healthy dietary intake (Armitage, 2004; Verplanken & Faes, 1999), medical adherence (van Osch et al., 2010; Liu & Park, 2004; Sheeran & Orbell, 2000), cancer detection practices (Sheeran & Orbell, 2000), and several lifestyles (de Vries et al., 2008a). Implementation intentions and action plans can also lead to significant effects on behavior (Gollwitzer & Sheeran, 2006), although some studies did not find these effects (Jackson et al., 2005; Rutter, Steadman, & Quine, 2006; Skår et al., 2011). Perhaps this is because action planning and implementation intention formation outside the laboratory are realized by self-chosen plans instead of expert chosen plans (Sniehotta, 2009). Adding action plans to mass media campaigns is also possible: for example, the addition of action plans to the *Quit and Win campaign* led to more successful quitting. Van Osch found that addition of a coping planning intervention to the usual information about attitudes and self-efficacy increased conservative 7-month continuous abstinence rates from 10.5% to 13.4%, indicating that, if implemented correctly, coping planning can significantly reduce long-term smoking relapse (van Osch et al., 2010).

Health Behavior Models

As can be noted from the preceding section, many constructs can be identified as important in enhancing a person's motivation to adopt a healthy lifestyle. Research has demonstrated the importance of several motivational constructs of health behavior. These constructs include factors such as knowledge, risk perceptions, attitudes, social influence beliefs, self-efficacy, intention, and action planning. The identification of these factors is subject of research of many scholars. The mapping of these factors and how they operate together can be done in different ways, also depending on the type of health problem studied. Theories and models describe these mechanisms. Therefore, we focus on selected theories used for designing health promotion programs.

With regard to health behavior models, a distinction can be made between models that focus on *understanding behavior* versus models that (also) focus on *changing behavior*. The former type of models outlines the main factors that are related to health behavior, whereas the latter also provides strategies on how to change these factors. Since this distinction is not always clearly made, we will treat these models all as behavior (change) models in this chapter. Moreover, given the fact that many models are available, we need to be concise in giving this overview (see for other overviews other sources, such as Glanz, Rimer, & Viswanath, 2008; Conner & Norman, 2005).

Social Learning Theory Social Learning Theory (SLT) is a generic theory for both understanding and changing behaviors. It is one of the most frequently used and maybe the most influential theory for health education. Bandura outlines that a person's behavior influences personal factors and the social environment but is also influenced by personal factors and the social environment. Bandura (1986) outlines that these three factors (behavior, personal factors, and the social environment) operate interactively as determinants of each other. This interaction is known as reciprocal determinism. Reciprocal refers to the mutual action between these three causal factors. The environmental factors pertain to the factors that are physically external to a person. This factor is also called situation. A person's environment provides the social and physical context in which a person should function, as well as reinforcements or punishments for particular behaviors. Hence, important environmental factors are the level of reinforcement of behaviors by others and the extent to which others serve as a model (by modeling). The personal factors refer to the abilities of a person to learn from behavior through own experiences or observation of other's behavior ("vicarious learning"). The behavioral factor refers to the *capacities* a person has to be able to actually perform a behavior, for instance, specific skills, but also intellectual abilities or social support (Plotnikoff et al., 2008).

Learning can occur via several ways: enactive learning (learning by doing; observational learning, i.e., learning from others; and verbal instruction, i.e., learning via instructions). Social learning theory stresses the importance of learning from other persons. By observing others a person develops an idea of how new behaviors are performed and what the consequences of a particular behavior are. A person needs to have attention for a particular behavior and the model and remember the behavior and the consequences (retention), should be able to reproduce the observation, and should become motivated to perform this behavior him- or herself.

With respect to this motivational process, important constructs are self-efficacy, outcome expectations, and intentions. Self-efficacy beliefs play a pivotal role in a person's motivation to engage in a behavior. Self-efficacy expectations refer to a person's expectation whether he can perform the behavior and were described more extensively above. Bandura states that people are not motivated to act if they have low efficacy expectations. Hence efficacy expectations influence both behavior and the perception of outcome expectations (see also Strecher et al., 1986). Outcome expectations refer to a person's expectations regarding the positive and negative consequences of a particular behavior. Intentions or proximal goals refer to a person's determination to perform certain activities. Intentions are influenced by outcome expectations and self-efficacy expectations. Moreover, when a person has low efficacy beliefs, he/she is more likely to set relatively lower goals than when having high efficacy beliefs.

Social learning theory, or also referred to as *social cognitive theory* when referring to Bandura's elaboration of it, has influenced the development of many health education programs. As indicated earlier, one of its applications concerned the development of programs targeting self-efficacy. Another application of SCT concerned the utilization of modeling techniques (also referred to as peer modeling) to provide examples of healthy models. Additionally, SCT influenced the development of community health promotion programs in several countries (see, e.g., Farquhar et al., 1990; Puska et al., 2005; Perry, Kelder, & Klepp, 1994).

The Health Belief Model The Health Belief Model (HBM) was developed as one of the first social cognitive models in the 1960s in order to explain health behavior (Rosenstock, 1974; Janz & Becker, 1984). The HBM has been revised and expanded several times by adding other factors than those who were initially included in the model. Basic constructs in the HBM that determine health behavior are perceived threat, outcome expectations and barriers, cues to action, and demographical factors. The perceived threat is determined by a person's perception of the seriousness of the disease and his perceived susceptibility to this disease. The expected outcome expectations describe the perception of benefits of a particular action or health behavior and the barriers to taking that action (e.g., costs, danger, side effects). It is believed that the appraisal of threat and the perception of outcomes and barriers are dependent of other factors, such as cues to action (e.g., the perception of others who have a similar disease), but also demographic and psychological factors. At a later stage, the concept of self-efficacy was added to the theory by which the theory became more similar to the theory of reasoned action. The model has been applied to a variety of health behaviors and served as input for the development of several health education programs (see, e.g., Janz & Becker, 1984; King et al., 1994; Johnson et al., 2008; Brewer, Brewer,

& Fazekas, 2007; Vassallo et al., 2009; Skinner et al., 1998; Strecher & Rosenstock, 1997).

Theory of Reasoned Action (TRA) and Theory of Planned Behavior (TPB) TRA and its successor TPB are examples of a generic model which can be used to predict various behaviors over which an individual has (partial) volitional control (Fishbein & Ajzen, 1975; Ajzen & Fishbein, 1980; Fishbein & Ajzen, 2010). The theory states that behavior is predicted by the *behavioral intention*, although realization of the intention may not always be possible because of certain barriers. Intention is determined by the individual's *attitude* and the *perceived subjective norms* from other people. Attitude represents a person's general feeling of (un)favorableness toward a behavior (e.g., smoking is bad). Attitude is determined by (1) the beliefs ("b") about the behavior (e.g., smoking causes cancer) and (2) the corresponding evaluations ("e") of these beliefs (e.g., cancer is bad).

Attitude can be measured directly by asking how a person evaluates a particular behavior. Attitude can also be measured indirectly by measuring the specific beliefs and evaluations (Σ b*e). A person's subjective or social norm is his perception of whether the majority of important people thinks that the person should or should not perform a particular behavior. The subjective norm is determined by several normative beliefs ("nb"), which are perceived expectations of specific reference persons (e.g., my father does not want me to smoke) and by the person's motivation to comply ("mc") with these expectations (e.g., with regard to smoking, I do what my friends want me to do). The subjective norm can be measured directly by asking about the perceived opinion of other people about a behavior (e.g., most persons that are important to me think that I should (not) smoke). The subjective norm can also be assessed indirectly by measuring the combined impact of the normative beliefs with the corresponding motivation to comply: Σ nb*mc.

At a later stage, the concept of *perceived behavioral control* – very much similar to the concept of self-efficacy – was added to the theory by Ajzen (1988). Perceived behavioral control can be measured by asking direct questions about capability to perform a behavior or indirectly via a multiplicative function in which control beliefs are multiplied by frequency of occurrence of these control beliefs (Σ c*f).

The notions of Fishbein and Ajzen have been applied in multiple studies and served as input for many health education programs. Evidence for the importance of the constructs of their models is abundant (see, e.g., Godin & Kok, 1996; Montaño & Kasprzyk, 2008; Armitage & Conner, 2001; Plotnikoff et al., 2010b). Moreover, their constructs have been applied to a wide variety of topics, such as smoking, alcohol consumption, nutrition, physical activity, breastfeeding, sun protection, and health services utilization.

Protection Motivation Theory (PMT) was developed by Rogers (1975, 1983) who was inspired by the work of Lazarus (1966) and Leventhal (1970) who describe adaptive and maladaptive coping processes as a result to health threats. The PMT proposes that the protection motivation depends on four factors: (1) the *severity* of a certain threat (e.g., cancer); (2) a person's perception of his/her *vulnerability*; (3) *response efficacy*, referring to the perceived efficacy of the healthy action; and (4) *self-efficacy. Protection motivation* develops as the result of *threat appraisal* and *coping appraisal*. Threat appraisal occurs as a result of estimations of the severity of a threat and a person's vulnerability. Coping appraisal is how one responds to the situation. The coping appraisal consists of both response efficacy and self-efficacy. Threat appraisal develops as the result of vulnerability estimations of a certain estimation of the chance of contracting a disease (vulnerability) and estimates of the seriousness of a disease (severity). Coping appraisal consists of response efficacy and self-efficacy. Response efficacy is the individual's expectancy that carrying out recommendations can remove the threat. Self-efficacy is the belief in one's ability to execute the recommended courses of action successfully. Protection motivation is a mediating variable whose function is to arouse, sustain, and direct protective health behavior (Boer & Seydel, 1996; Smerecnik et al., 2011).

The protection motivation theory has been used to explain a wide array of health behaviors, such as smoking, alcohol consumption, nutrition, exercise, and health- and safety-related behaviors (see, e.g., Milne et al., 2000; Plotnikoff et al., 2010b; Norman, Boer, & Seydel, 2005; Floyd, Prentice-Dunn, & Rogers, 2000).

The Transtheoretical Model (TTM) Prochaska and colleagues suggest that the process of behavioral change can be divided into several stages (Prochaska & DiClemente, 1983; Prochaska et al., 1994). As described earlier according to the TTM people move from precontemplation, contemplation, preparation to action and then to maintenance or relapse. Movement through the stages involves a cycling and recycling process. Further distinctions within the precontemplation stage have also been proposed for other health behaviors such as smoking (Dijkstra, Bakker, & De Vries, 1997; Norman et al., 2000; Kremers et al., 2001).

The TTM also describes the importance of two other concepts: decisional balance and temptations. *Decisional balance* refers to a person's weighing of the advantages ("the pros") and disadvantages ("the cons") of a particular behavior. Research suggests that for a person who is not motivated to change (and is in precontemplation), the unhealthy behavior can be characterized by scoring high on the pros of the unhealthy behavior and low on the cons of the unhealthy behavior (or to state it differently: scoring low on the pros of the healthy behavior and high on the cons of the healthy behavior).

When a person is motivated to change (e.g., within a month when the person is in preparation), the person is much more convinced of the cons than of the pros of the unhealthy behavior. Moving, for instance, smokers from precontemplation to action thus implies convincing smokers of the advantages of quitting and of the disadvantages of smoking (Hall & Rossi, 2008), while also experiencing higher levels of self-efficacy. This pattern was also found in many different studies such as Dutch research (de Vries et al., 1998; de Vries & Backbier, 1994) and also other research groups (for a meta-analysis, see, for instance, Marshall & Biddle, 2001).

Temptations measure whether persons are tempted to fall back to their unhealthy behavior, and this construct is complemented with the *self-efficacy* scale; both scales refer to a person's level of self-efficacy. Both the self-efficacy and temptation measures have the same structure (Velicer et al., 1990). TTM research concerning smoking cessation often found three factors reflecting the most common types of tempting situations: negative affect or emotional distress, positive social situations, and craving. The temptation/self-efficacy measures are particularly sensitive to the changes that are involved in progress in the later stages and are also good predictors of relapse.

TTM furthermore postulates five cognitive and five behavioral processes that influence a person's motivation to change. The five *cognitive processes* (consciousness raising, social liberation, emotional arousal, self-reevaluation) are used mostly before behavioral actions occur. The five *behavioral processes* (commitment, countering, environmental control, rewards, helping relationships) are most used during the early phases of behavioral change (Prochaska & DiClemente, 1983). Yet, more research is needed to support the existence and importance of the TTM processes.

The TTM has been applied successfully to change and alter a variety of health behaviors, such as smoking, physical activity, alcohol consumption, and oral contraceptives (Adams & White, 2003; Horowitz, 2003; Dempsey, Johnson, & Westhoff, 2011; Noar et al., 2011; Prochaska et al., 2005; Babbin et al., 2011).

The Health Action Process Approach The Health Action Process Approach (HAPA; Schwarzer 2008) suggests a distinction between (a) preintentional motivation processes that lead to a behavioral intention and (b) postintentional volition processes that lead to the actual health behavior. Within the two phases, different patterns of social cognitive predictors may emerge. In the initial motivation phase (a), a person develops an intention to act. This intention is determined by risk perceptions, outcome expectations, and self-efficacy. After forming an intention, the volitional phase (b) is entered. The HAPA proposes five principles including a differentiation of the volitional phase into the preactional "intenders" and individuals already performing the behavior called "actors" (Schwarzer, Lippke, & Luszczynska, 2011).

The adoption and maintenance of a new behavior requires self-regulatory skills and strategies, such as action planning, social support, and recovery self-efficacy. Including planning and self-efficacy as volitional mediators and stages as moderators renders the HAPA into an implicit stage model because it implies the existence of at least a motivational and a volitional phase. Research using the HAPA model often employs path-analytic methods to assess and test these relations for several health behaviors (e.g., Lippke, Ziegelmann, & Schwarzer, 2005; Luszczynska & Schwarzer, 2003; Renner et al., 2008; Schwarzer et al., 2007; Ziegelmann et al., 2007). Not all of the five principles were tested so far (e.g., Lippke & Plotnikoff, in press) and much more research is needed.

The *I-Change model* (de Vries et al., 2003, 2008b) or the integrated model for explaining motivational and behavioral change is integrating ideas of Ajzen's theory of planned behavior (Ajzen, 1991), Bandura's social cognitive theory (Bandura, 1986), Prochaska's transtheoretical model (Prochaska & Velicer, 1997), the health belief model (Abraham & Sheeran, 2005), and goal setting theories (Locke & Latham, 2002). The I-Change model is a phase model rather than a stage model. The term phase is preferred as stages need to refer to qualitatively distinct stages (e.g., the transformation of a caterpillar into a butterfly, (Bandura, 1997)). Furthermore, the distinction between phases is not made on a time criterion but rather on the scores of the individual on several motivational factors. Together these scores are indicators of which phase a person is most likely to be. Three phases in the behavioral change process can be distinguished: (1) awareness, (2) motivation, and (3) action. For each phase particular determinants are specifically relevant.

Awareness of a particular problem in a person is the result of accurate knowledge and risk perceptions of the person about his own behavior. (Not all persons are aware of the level of their own behavior; for instance, many persons overestimate the amount of their physical activity.) Cues in their environment (e.g., a person with cancer) may also prompt a person to become more aware of a particular risk and the need to adopt a particular health behavior. Motivation to change a behavior is regarded to be dependent on a person's attitude (the results of perceived advantages and disadvantages of the behavior), social influence beliefs (norms of others, behavior of others, and support of others), and self-efficacy expectations (the perceived ability to perform a particular health behavior). The ultimate result in level of motivation to adopt a health behavior can be measured by intentions and related concepts such as the stage of change concept. Yet, intentions do not necessarily lead to behavior.

Factors determining action, besides a positive intention, are again self-efficacy, action planning and barriers. With regard to action planning, one can distinguish preparation planning (planning actions required to change), coping planning (planning the actions to cope with barriers and relapse in order to maintain the realized changes), and action enactment: the realization of the intended actions. Barriers are factors that may hinder the realization of the behavior and can be socially, economically, and environmentally determined. For instance, if a person wants to buy fruits, but has very little financial resources, this can be a barrier for realization of the desired behavior.

Finally, the I-Change model postulates that motivational processes are determined by various predisposing factors such as behavioral factors (e.g., lifestyles), psychological factors (e.g., personality), biological factors (e.g., gender, genetic predisposition), social and cultural factors (e.g., the price of cigarettes, policies), and information factors (the quality of messages, channels, and sources used). For instance, studies demonstrated that certain parenting styles and practices (a social factor) led to the development of attitudes in children concerning smoking (Huver et al., 2007; Harakeh et al., 2004) or that personality characteristics influenced the development of attitudes and behavior (Huver et al., 2006; de Bruijn et al., 2007).

The I-Change model has been used to explain and change several health behaviors, such as smoking, nutrition, physical activity, alcohol consumption, sunscreen use, participation in screening programs, breastfeeding, child abuse, oral health complaints, medication use, condom use, and adoption of interventions (see, e.g., de Vries et al., 2005, 2008b; Hoving, Mudde, & de Vries, 2006; Rosseel et al., 2010; Fransen et al., 2009; Dlamini et al., 2009; Segaar et al., 2007a, 2007b; Lotrean et al., 2010).

In sum, many models exist that explain health behavior and providing an overview of all models is impossible. Hence, we have not discussed models that explicitly focus on relapse processes (such as the *relapse prevention model* (Marlatt & George, 1984)) and models that explicitly focus on the importance of intrinsic and extrinsic motives (see, e.g., Hagger et al., 2011). Furthermore, several strategies can be used to change the determinants of behavior, which can be found in recent overviews (see, e.g., Bartholomew et al., 2011; Abraham & Michie, 2008; Webb et al., 2010).

When reading about these models, one other notion is important to consider. After reading the various models that outline how health behavior develops, one may get the impression that every person is carefully deliberating and comparing various behaviors. This may suggest that a person processes information very carefully and systematically when making decisions concerning executing a particular health behavior. However, the reality is more complex and suggests that health behaviors can be the result of such a deliberate process but may also be the result of less elaborate processing. The distinction between systematic and less systematic information processing is outlined in so-called dual process models. *Dual process models* outline that information processing can occur systematically but also peripherally (Fazio, 1990; Petty & Cacioppo, 1986). Well-known examples of dual process models are the *elaboration likelihood model* (ELM) by Petty and Cacioppo (1986) and Chaiken's *heuristic–systematic model of information processing* (Chaiken, Liberman, & Eagly, 1989). The latter describes two modes of processing of information, in which information processing can range from low to high. ELM refers to them as the central and the peripheral route whereas Chaiken refers to them as systematic and heuristic processing of information. In the *systematic mode*, a person processes information quite extensively and systematically and invests much cognitive effort into information processing and processes information quite extensively. In this mode people can spend a large amount of time, effort, and mental energy in systematically building beliefs and decisions. It is also believed that behavioral change is more likely to maintain when this mode is used. In the peripheral route, however, a person does not process the information elaborately, and decisions are based on, for instance, preexisting ideas and the persuasive qualities of the source that is providing the information. Behavior is then much more likely to be the result of direct automatic or unconscious responses to environmental cues (Bargh, 2005).

Habit strength is also one factor that may induce automaticity of environment–behavior processes. Repeated behaviors may be largely determined by habit rather than by reasoned action. When habits are formed, subsequent behavior can then be automatically triggered by specific environmental cues (Aarts et al., 1997; Kremers & Brug, 2008; Kremers et al., 2006).

The *dual mode perception of behavioral change process* implies that behavioral change can occur via both explicit and implicit processes (see, e.g., Epstein, 1994; Wiers et al., 2007; Hofmann, Friese, & Wiers, 2008; Strack, & Deutsch, 2004), chaotic versus cognitive processing (Resnicow & Vaughan, 2006), and automatic versus cognitively mediated environmental influences (see, e.g., Kremers, 2010). The existence of two different systems that influence behavior implies (1) a slow and reflective system which consciously regulates emotions and behavior-related processes and (2) a fast associative impulsive system which is responsible for automatic appraisal of stimuli and immediate behavioral action. There is increasing consensus arising that it may be unlikely that the fast associative impulsive system can be influenced by persuasive techniques.

Concerning the fast associative impulsive system, studies revealed that implicit approach tendencies and attentional biases determine behavior. Recent studies also demonstrated that retraining implicit associations can result in behavioral change (Schoenmakers, Wiers, & Field, 2008; Wiers et al., 2009). In other words, these findings imply that health education techniques for the future need to assess the conditions that determine the effectiveness of motivational reflective techniques on the one hand and implicit associative techniques on the other hand. Such an assessment is needed in order to be better able to best address a particular problem in a specific population and to determine which health education strategy may be more effective, an explicit and motivational strategy, an implicit associative technique, or maybe a combination of both.

Dissemination Theories

The previously outlined concepts and models typically relate to intervention development (i.e., the PRECEDE part of the PRECEDE–PROCEED model, cf. above). A systematically developed and evidence-based intervention, however, does not automatically lead to public health impact. In order to accomplish public health impact, the intervention needs to be disseminated successfully to the target group. In the next section, we describe several theoretical frameworks that describe how evidence-based practices are disseminated and how organizations realize changes such as the adoption of an evidence-based health education program. These theories are useful to understand the process of implementation and to guide the development of interventions to promote implementation.

Diffusion theory as described by Rogers describes that various stages within the process of the diffusion of an innovation can be distinguished (Rogers, 1983, 2003). The diffusion of a health promotion program can thus also be seen as an innovation. In most applications, five stages are proposed: (a) gaining knowledge about the innovation, (b) being persuaded to use the innovation, (c) deciding to try the innovation, (d) deciding to implement the innovation, and (e) confirming the decision, including integrating it into one's routine. When applied, these adoption stages are often referred to as *dissemination*, *adoption* (combining persuasion and decision), *implementation*, and *maintenance* or *sustained use* (Rohrbach et al., 2006).

A second tenet of diffusion theory that has been broadly applied is the concept that innovations have perceived attributes that affect their rates of adoption. These attributes include relative advantage, compatibility, complexity, trialability, and observability. Studies have shown that perceptions of these attributes are associated with adoption of evidence-based prevention programs (e.g., Hallfors & Godette, 2002).

Rogers defines an *innovation* as "an idea, practice or object that is perceived as new by an individual or other unit of adoption" (Rogers, 1983). Consequently, a critical component of an innovation (e.g., a health promotion program) is that the idea is perceived as new. *Diffusion* is defined as "the process by which an innovation is communicated through certain channels over time among the members of a social system" (Rogers, 1983). The *adoption* process differs, resulting in the discrimination of five different adopter categories: *innovators, early adopters, early majority, late majority*, and *laggards* with each group having different characteristics.

Diffusion theory has been useful in guiding research on methods to enhance or accelerate diffusion of prevention programs (Valente, 2002). For example, the theory suggests that multiple intervention strategies will be necessary, tailored to each stage in the diffusion process (e.g., Feifer et al., 2006; Parcel et al., 1989). The theory also suggests which features of a program could be marketed to speed its adoption (Rohrbach et al., 2006).

The model has been applied often to understand and explain why certain innovations occurred, for instance, individuals' or social networks' adoption of innovations (e.g., individuals and families adopting healthy dietary patterns) as well as organizations' adoption of health education programs. For instance, Rahimini used Rogers' diffusion theory to understand how the factors associated with the adoption of a computerized (Rahimi et al., 2009) provider order entry (CPOE) to reduce medication errors and increase safety in care settings and found, for instance, that (perceptions of) compatibility of such a system with existing methods may need to be improved in order to facilitate its adoption. Harting and colleagues (2009) assessed the determinants of guideline adherence for low back pain among physical therapists using Rogers' diffusion theory. They found, for instance, that physical therapists had rather unfavorable opinions about issues related to the dissemination of the guidelines, thus hindering the first phase of adoption. Segaar and colleagues (2007a, 2007b) integrated Rogers' diffusion theory with the I-Change model and found, for instance, that several nurses did not provide self-help guides on smoking cessations to cardiac patients that were smoking, thus hindering the adoption of these guidelines by patients.

Implementation Theories Implementation theories (Grol & Jones, 2000; Fleuren, Wiefferink, & Paulussen, 2004) build on Rogers' (2003) ideas, by putting additional emphasis on the user and the context that this user lives in. In general implementation theories define four broad groups of factors which determine the uptake and continued use of health education and health promotion interventions (Table 17.4).

Table 17.4 Features of implementation theories and what they include

(a)	*Features of the intervention*	Scientific basis (evidence) for the intervention and the source(s) of that evidence. The complexity of the change proposal is directly linked to its feasibility and its likelihood of uptake; presentation needs to be clear, logical, and attractive
(b)	*Features of the user (professionals)*	An understanding of and sensitivity to their knowledge, skills and attitudes, working practices, and personalities
(c)	*Features of the social context/ setting*	Expectations and working routines of professional colleagues and the culture operating within the target network, particularly the opinions of key individuals (opinion leaders)
(d)	*Features of organizational context*	Financial aspects of implementation (demand for resources, financial reimbursement), change in organization that implementation requires, structural aspects such as the availability of staff and equipment to implement the intervention, and legal and regulatory issues which might constrain the adoption of new, innovative practices

Organizational Change Theories Organizational change theories are in line with diffusion theory with respect to the assumption that change occurs in stages (Bartholomew et al., 2001). One example is the stage theory of organizational change, which describes multiple stages that organizations pass through as they accomplish an institution-wide change such as adoption of an innovation (Beyer & Trice, 1978). These stages range from *identifying the problem or need for change*, to *searching for solutions*, to *choosing a course of action and implementing it,* to *institutionalizing the change* so that it becomes part of the routine workings of the organization (Rohrbach et al., 2006).

Other theories suggest specific strategies for cultivating organizational change, such as forming a powerful guiding coalition within the organization, developing one vision and empowering members to act on the vision, planning for short-term wins, evaluating the change efforts, and providing feedback to members about their efforts (Senge, 1990). An important tenet of these theories is that in hierarchical organizations, innovations often require change by different levels of employees (e.g., managers, implementers, etc.) at different stages of the innovation adoption process (Bartholomew et al., 2001).

Health Education Methods and Settings

Various health education methods have been shown to have the potential to change behavior. Yet, health education can only have an impact at the public health level if it reaches the population. Hence, an access point analysis in the planning process is important (de Vries & van Dillen, 2007). Traditionally various settings are used for health education. When describing these settings for health education, we actually refer to channels that are used to reach our target groups. Below we will focus on different settings that address individual behavioral change, settings that have been traditionally used for health education such as schools, worksites, patients, and the general public. Other types of health promotion approaches that aim at communities will be discussed elsewhere in this book.

Schools

Children spend a large proportion of their waking life in schools (Kolbe, 1985). Schools can have a great impact on the health status of young people (WHO, 1985; Healthy people 2000: National health promotion and disease prevention objectives and healthy schools, 1991). Consequently, health education programs have existed in schools for many decades. Moreover, school infrastructure, school policies, curricula, and staff often yield an important potential to positively influence child health. The acknowledgment of school health education also illustrates the recognition that learning health-related attitudes and behavior is important at an early age.

School health education methods aim at the prevention of onset of unhealthy behavior and maintenance of healthy behaviors of individuals as well as stress management. Schools are often used for health education purposes since they are an important gateway to children but sometimes also to reach teachers and parents, which are important mediators between children and health educators. For instance, already in 1935 the *Health Education Section of the American Physical Association* described the school health program as consisting of three facets: (1) school health services, (2) school health education, and (3) healthful school environment. This example shows that an ecological approach, consisting of a health education program and the development of a healthy environment, has a long tradition.

Various methods have been used for developing school health education programs. Initially, many health education programs were based on the knowledge paradigm. After the Second World War, a gradual shift in focus emerged. Since the realization that other factors besides knowledge are also important, the focus of school health education programs shifted. In the 1980s, school health education became better grounded into health behavior theory. Consequently, many programs addressed attitudes, social influence perceptions, and self-efficacy and used a social inoculation approach (McGuire, 1985). Moreover, they taught children assertiveness techniques in order to cope with difficult (social) situations. In this aspect, the pivotal work of Evans and colleagues initiated a vast development of programs targeting social skills and resistance skills development (Evans, 1976). Other programs also addressed more generic lifestyle skills in order to address more factors, such as skills for enhancing self-esteem, learning creative problem-solving, reducing stress and anxiety, and managing anger, communication skills, and relationship-building skills (Botvin et al., 1980). Botvin's *LifeSkills Training* (LST) program has become a very frequently chosen drug abuse prevention program in the United States by elementary schools (Botvin et al., 2004).

Effective school health education programs have been developed for various health domains, such as the prevention of unhealthy habits as, e.g., alcohol, drugs, smoking, pestering, and gambling prevention on the one hand, and the promotion of healthy habits, such as physical activity, good nutrition habits, dental health, and sexual health on the other hand.

Although reviews of school health education program show inconsistent findings, an overall tendency for significant outcomes is often reported for various health behaviors (e.g., Hansen, 1992; Faggiano et al., 2008; Fletcher, Bonell, & Hargreaves, 2008; Evans-Whipp et al., 2004; Knai et al., 2006; Brown & Summerbell, 2009; Kirby, Laris, & Rolleri, 2007; Jurg et al., 2006). The results of various reviews provide a fairly consistent positive picture when short-term effects are concerned, but fail to show long-term effects after longer periods such as 5–10 years. For instance, many studies tried to realize long-term effects with regard to smoking prevention and – or but – were partly successful (Hansen, 1992; Bruvold, 1993; Peterson et al., 2000; Thomas, 2002; Elders, M.J. 1994). Yet, this does not necessarily imply that school health education is ineffective for delaying smoking onset. A pessimistic person could conclude that smoking prevention efforts are not effective at all in the long run. On the other hand, a more buoyant person would argue that it is unrealistically optimistic to expect huge effects from an approach with mostly a limited number of lessons for a problem that is reinforced by a multitude of smoking-promoting factors and that it may be naive to anticipate long-term effects of – for instance – only five lessons, since getting a driving license already requires many more lessons (de Vries et al., 2007). Although recommendations are available concerning a minimum amount of lessons needed (see, e.g., Glynn, 1989), no clear evidence exists concerning the minimal amount of lessons needed. Moreover, intensive school programs may not necessarily result in long-term effects. Lessons learned from the *Hutchinson trial* are that only school-based approaches – albeit very extensive – may not be sufficient in resulting in long-term effects (Peterson et al., 2000). On the other hand, other studies did realize long-term effects, for instance, with regard to smoking prevention (Bruvold, 1993). Hence, research is needed to identify which factors may foster long-term effectiveness, such as embedding them within a larger community perspective (Vartiainen et al., 1986), including addressing parents (e.g., parents do grocery and cook for their children and they are models) and environmental changes such as safe bike paths and sidewalks (Thomas & Perera, 2013).

One problem with school health education is that in many countries school staff may become overwhelmed by the supply of a great variety of school health education programs and time constraints. Low program fidelity has been found to be a serious problem (Dusenbury et al., 2003). Integrative programs addressing multiple risk behaviors may have the potential to overcome the burden on schools and teachers. Several authors have suggested that integrative programs can be efficient if the change processes or effective elements for different health behaviors are similar (de Vries et al., 2008a; Botvin, Eng, & Williams, 1980; Prochaska et al., 2008).

Several studies are also conducted to identify key factors of successful health education. For instance, a systematic review (Peters et al., 2009) identified five indicators of success for effective adolescent health education programs about substance abuse, sexual behavior, and nutrition: (1) grounded in social cognitive theory; (2) addressing social influences, especially social norms; (3) addressing cognitive-behavioral skills; (4) training of facilitators; and (5) using multiple components (e.g., school-wide elements, community involvement). Tentative evidence was found for the effects of (6) parent involvement and (7) a larger number of sessions.

In sum, what we can and should learn from our long history of school-based health education is that short-term effects can be realized. Yet, in the long period of childhood, adolescence, and early adulthood, several cues to act unhealthy will emerge to a child, an adolescent, and a young adult. Hence, school health education may and should serve as an essential ingredient to foster healthy conditions for a child. Yet, school health education is unlikely to be sufficient to guarantee a healthy continuation into adulthood.

Many reviews conclude that targeting social and environmental factors will be required as well. Hence, an integral approach including school, family, and the community as well as the environment may have the most optimal potential to foster healthy lifestyles in children (see, e.g., de Vries et al., 2003; Perry et al., 1996; De Meij et al., 2010), recommendations that are in line with basic principles of health promotion, as, for instance, outlined by Green and Kreuter (2005), Mc Leroy and colleagues (1988), and in Swinburn's Angelo model (Swinburn, Egger, & Raza, 1999).

Worksites

Worksites provide opportunities to reach many adults (e.g., more than 60% of adults in the United States; Nigg et al., 2010), including populations diverse in race, ethnicity, gender, age, occupation, income, and health status. A classic worksite intervention was conducted in 1974 in New York City which focused on screening employees for hypertension. Based on a screening of 180 employees, 94 were identified as hypertensive. Those were provided with a treatment lasting for 1 year which resulted in 81% achieving satisfactory blood pressure (Alderman & Schoenbaum, 1975). Over the past decades, the number of organizations and companies that offer a health promotion program for their employees at the worksite has increased (Aldana et al., 2005; Wilson, Holman, & Hammock, 1996). This is not only due to the fact that adults are spending increasingly larger portions of their waking hours at work but also because poor employee health comes at a cost to employers (Goetzel & Ozminkowski, 2008).

Worksite health education program can focus on primary, secondary, and tertiary prevention. *Primary prevention* efforts are directed at workers that are healthy and are aimed to maintain this level of health and to prevent diseases and disorders. Examples are programs encouraging smoking cessation, alcohol reduction, exercise and fitness, healthy eating, weight management, and stress management. Worksite health promotion can also entail *secondary prevention* aimed for individuals who are already at high risk because of their engagement in certain unhealthy behaviors (e.g., smoking, being sedentary, excessive alcohol consumption, high stress levels) and/or have abnormal biometric values such as high cholesterol, high blood glucose, overweight, and high blood pressure. Sometimes worksite health promotion includes elements of *tertiary prevention* which is also referred to as disease management. Then the programs are directed at workers with certain health problems, such as diabetes, cardiovascular disease, depression, etc. These programs can aim at improving lifestyles and/or optimal compliance recommendations (such as hand hygiene) and with medical treatment (Goetzel & Ozminkowski, 2008).

A review on the effectiveness of workplace health promotion (Harden et al., 1999) suggested that worksite health promotion interventions should include (a) visible and enthusiastic support for, and involvement in, the intervention from top management; (b) involvement of employees at all organizational levels in the planning, implementation, and activities of the intervention; (c) a focus on a definable and modifiable risk factor, which constitutes a priority for the specific worker group; and (d) interventions that should be tailor-made to the characteristics and needs of the recipients.

Various reviews have assessed the potential and effectiveness of worksite health education and health promotion programs (Harden et al., 1999; Ni Mhurchu, Aston, & Jebb, 2010; Groeneveld et al., 2010; Soler et al., 2010). Yet, these overviews report some methodological flaws in the designs used. Furthermore, they also do not demonstrate consistent findings for all interventions and all health behaviors. For instance, Groeneveld et al. found positive effects of workplace lifestyle-focused interventions on body fat, but not on other indicators for cardiovascular disease risk (Groeneveld et al., 2010). The effectiveness of a lifestyle intervention was shown to depend on whether the participants enrolled in the study had an elevated disease risk or not. One suggestion could be that studies aimed at high-risk populations may yield better results, have a larger health impact, and be more cost-effective than those targeting non-risk populations.

One other upcoming type of worksite health promotion programs is one that incorporates *health-risk assessment* or *biometric screening*. Assessments of health risks may be of interest to worksite health promotion planners, because they are easy to administer (computerized versions are available), convey a lot of information quickly, allow for access to a large number of people, provide workforce-wide estimates, and allow the potential for follow-up. A systematic review (Soler et al., 2010) showed strong or sufficient evidence for meaningful effects on the following outcomes: tobacco use, alcohol use, seatbelt nonuse, dietary fat intake, blood pressure, cholesterol, summary health-risk estimates, worker absenteeism, and healthcare service use. So far, there was insufficient evidence, however, to determine effectiveness for intake of fruits and vegetables, body composition, and physical fitness.

In conclusion, health education for worksites – as part of a more generic health promotion program – has the potential to reach many adults. It can reach both healthy workers, workers with elevated levels of risk, and workers who already have a particular disease. Additionally, it can be attractive for the worksite management to invest in worksite health education and promotion, not only to reduce costs (see, e.g., Goetzel & Ozminkowski, 2008) but also to increase the working climate in a company. Last but not least, worksite health education programs have the best potential in demonstrating effects when they are embedded in an ongoing, integrated program of health promotion and disease management that integrates specific components into a coherent, ongoing program (Pelletier, 2009).

HealthCare Settings

Patient education is a term typically used for educating, assisting, and empowering individuals in contexts of hospitals or clinical settings. Historically, educating patients has been considered a key feature of nursing (Henderson, 1966). Nurses, for instance, perceive patient education as an important part of their role today (Kruger, 1991). Patient education thus involves helping patients to become better informed about their condition, to inform them about the medical procedures that they may encounter during their process of treatment and choices they have regarding treatment.

Patient education entails the process by which health professionals and others pass on information to patients that will alter their health behaviors or improve their health status. When providing patient education, it is important to consider several important characteristics of the patient besides their specific disease and condition, such as a patient's literacy level, language skills, cognitive capabilities, social support, and economic situation, since the effects of patient education take place within a multifaceted context (Fox, 2009).

Patient education may imply helping to change a patient to adopt a healthier lifestyle. For instance, smoking cessation after the development of coronary heart disease (CHD) improves a patient's prognosis more than any other treatment (USDHHS, 1990). The hospital setting presents an excellent opportunity for cessation interventions. During hospitalization, cardiac patients are more aware of their personal vulnerability to the dangers of smoking, and their serious illness makes them more motivated to quit and more receptive to interventions. Consequently, the effects of providing patient education to smoking cardiac patients have been tested frequently and with some success. Rigotti and others conclude in their review that offering smoking cessation counseling to all hospitalized smokers is effective as long as supportive contacts continue for more than 1 month after discharge (Rigotti, Munafo, & Stead, 2008).

Another challenge for patient education is to foster *treatment adherence*. Several overviews describe the problem of non-adherent patients (see, e.g., Cramer, 2004; DiMatteo, 2004; Bolman, Arwert, & Vollink, 2011). For instance, daily use of prophylactic asthma medication (PAM, inhaled corticosteroids) is an effective medical treatment in preventing and reducing inflammatory reactions in asthma (Salpeter et al., 2006). Patient adherence to PAM is critical to successful asthma management because not taking the prescribed medication increases the risk of (severe) asthma attacks (Suissa & Ernst, 2001). Yet, often a minority of asthma patients take their PAM as prescribed, which can be caused by several factors that need attention in an intervention, such as breaking old habits, creating positive attitudes, and self-efficacy (Bolman, Arwert, & Vollink, 2011). Several studies have documented the effects of adherence-promoting interventions for patients, showing relatively positive results (McLean et al., 2010; Dean, Walters, & Hall, 2010; Cutrona et al., 2010) on the effectiveness of medication adherence intervention; the majority of all studies (88.9%) showed improved adherence. Studies show that improving patient's adherence can be hindered when they are confronted with comorbidities (e.g., depression, anxiety) and increased pain levels (McLean et al., 2010; Pomp et al., 2010).

When referring to the strategies used by patient education, a mix of strategies can be used for patient education, and several strategies are similar to those used by health education in general. These strategies can thus range from simply the provision of knowledge to counseling strategies, such as health counseling and motivational interviewing, and to more socio-ecological approaches that also address the larger environment of patients (Helmink et al., 2010). Besides the utilization of health education materials (such as brochures, self-help manuals, and more recently the Internet), patient education is often characterized by face-to-face interaction with a health counselor. Two health counseling strategies are often used in patient education: health counseling and motivational interviewing.

Health counseling refers to a strategy by which a health counselor aims to encourage patients to adopt healthy behavior, although such promotion of health behavior is not limited to this strategy. A well-known health counseling strategy for encouraging smoking cessation is the *5A's strategy* that stands for:

1. Ask: Identify and document tobacco use status for every patient at every visit.
2. Advise: Urge every tobacco user to quit in a clear, strong, and personalized manner.
3. Assess: Is the tobacco user willing to make a quit attempt at this time?
4. Assist: Use counseling and pharmacotherapy to help a patient willing to make a quit attempt plan specific strategies for quitting and resisting temptations for relapse.
5. Arrange: Schedule follow-up contacts.

Effects for smoking cessation are documented (Mays et al., 2012).

Motivational interviewing (MI) has also become popular and accepted as a method for patient education. It is a counseling technique, developed by Miller and Rollnick (2002), which is client-centered and based on the TTM. Accordingly, motivational interviewing acknowledges that persons may be in various levels of readiness to change their behavior. A key goal of MI is to assist individuals to work through their ambivalence about behavioral change. It appears to be particularly effective for individuals who are initially not ready to change (Resnicow et al., 2002). The approach attempts to increase the client's awareness of the potential problems caused, consequences experienced, and risks faced and to raise awareness what consequences of certain acts of a person may entail. At the same time, it entails unbiased discussion of the client's ambivalence about change and negative aspects of change. Through such balanced discussion of the client's own thoughts about the advantages and disadvantages of a particular behavior, the client is able to come to a greater awareness of the advantages and feasibility of a particular change.

Through this process, MI aims at mobilizing intrinsic motivation to change behavior. Effects of MI for patient education are, for instance, reported by Kemp et al. (1998) and van Keulen et al. (2011). There is evidence that MI patient-centered approaches to healthcare consultations may have better outcomes than traditional advice giving, especially when lifestyle change is involved (Britt, Hudson, & Blampied, 2004). Yet, MI is – as with most strategies – not a magic bullet, and reviews report mixed findings, most likely due to many variations in its implementation. Although often tempted to act otherwise, health counselors need to avoid a position in which they argue for change while the client argues against it (Hettema, Steele, & Miller, 2005). Yet, this may be a challenge that is not always easy to accomplish.

Adoption of recommendations by the patient requires actions from both the patient and the clinician. In the last decade, a trend can be observed showing that patient education and treatment decisions require indeed input from both patients and clinicians. An increasing emphasis on patient involvement in treatment decisions can be observed (Say & Thomson, 2003). Consequently, the patient-clinician relationship is moving more toward a *partnership* (Charles, Whelan, & Gafni, 1999).

Shared decision-making (SDM) is an approach in which the clinician and patient go through all phases of the decision-making process together and in which they share the preference for treatment and reach an agreement on treatment choice (Charles, Whelan, & Gafni, 1999). SDM involves clinician and patient, but often more since often the involvement of family members in treatment decision-making may be important as well. SDM requires that the patient and the clinician build a consensus about the preferred treatment. Therefore, the clinician needs to explain various treatment possibilities and their potential consequences for the patient. The patient and clinician together discuss and evaluate treatment options and together build a consensus on the treatment to implement. Joosten et al. report that SDM can be beneficial for improvements in patient satisfaction, treatment adherence, quality of life, and well-being. Also it may result in higher patient involvement and perceived control over their treatment. Results suggest that SDM may be particularly suitable for long-term decisions, especially in the context of a chronic illness, and when the intervention contains more than one session (Joosten et al., 2008).

The terms "patient education" and "self-management education" are closely related concepts (Coster & Norman, 2009). Self-management is the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a long-term disorder (Wilde & Garvin, 2007).

Bodenheimer and colleagues distinguish between patient education, which they suggest provides disease-specific information and technical skills, and self-management education which teaches problem-solving skills which allow patients to take appropriate actions to improve their health (Bodenheimer et al., 2002). They conclude that self-management education "complements, rather than substitutes for, traditional patient education."

Several reviews are available concerning the effectiveness of patient education. Coster and Norman studied several Cochrane Reviews of interventions designed to improve patients' knowledge and skills to manage chronic disease, with particular reference to nursing contribution and practice (Coster & Norman, 2009). Unfortunately, information on the professional delivering of the interventions was often not available, although 77% (23) of the reviews mentioned that nurses were involved in a proportion of studies. They concluded that educational programs resulted in benefits for several types of patients, such as patients suffering from asthma, diabetes mellitus, epilepsy, and mental health problems. However, they also outlined that it is still not clear what the active ingredients of many successful interventions were. This area thus definitely requires more systematic research.

Systematic reviews have shown that patient education intervention may be most effective when they (1) have motivational cognitive-behavioral approaches, (2) help patients practically to manage barriers, (3) improve factors related to healthcare providers and organizations, and (4) apply longer-term counseling strategies with regular reinforcement (McLean et al., 2010). Hence, the effectiveness of patient education is not only dependent on the quality of the health education materials used but also on the quality of the source providing the education. This implies that the behavior of the healthcare provider also plays an important role. Additionally, this conclusion also implies the importance of taking organizational and contextual factors into account. One important contextual factor concerns the level of social support that a patient encounters. DiMatteo found that practical social support had higher effects on adherence than emotional support (DiMatteo, 2004). When patients perceive their family as cohesive (e.g., warmth, closeness, acceptance climate), adherence was much higher than if the family was observed as conflicting. Thus, professionals working with patients should also try to involve the patient's social environment (such as family and friends) and improve the patient's ability to receive social support (Norris, Engelgau, & Narayan, 2001; Norris et al., 2002).

Although health education methods can be effective for patients, their public health impact is limited by lack of broad distribution and availability, implementation failure and/or underuse (Cranney et al., 2001; Glasgow et al., 2003), and reducing the intended health impact of these interventions. Segaar and colleagues investigated why cardiac nurses did or did not use an evidence-based protocol that was based on the 5A's. Ninety-four of 206 nurses did not fully apply the intervention in daily practice; they did not always provide patients with self-help guides, discuss smoking cessation aids, or provide follow-up care. Adherence was most likely if nurses consistently used an intervention card, perceived advantages of the intervention, had other nurses around them who used it, and had been involved in decision-making.

This example shows that effective patient education is not limited to the art of developing effective interventions but also to take into account a larger socio-ecological perspective. The use of effective patient programs may also be facilitated by linking patient education with *electronic patient files*. For instance, Bentz and colleagues found that *electronic health records* (EHRs) may be an effective tool to help clinicians address tobacco use more consistently (Bentz et al., 2007). They observed that during 12 months of follow-up, EHR-documented rates of advising, assessing, and assisting were significantly improved in the intervention clinics compared with the control clinics. A higher case mix index and the presence of a clinic champion were associated with higher rates of referral to a state-level quitline. EHR-generated provider feedback improved documentation of assistance with tobacco cessation.

In sum, patient education is an important area for health education. Significant effects can be found using various strategies. Yet, it is not clear what the active ingredients of many successful interventions are (Coster & Norman, 2009). It is therefore important to identify these ingredients in order to better be able to tailor the education to the needs of both the patient and others involved in the patient education process. Sometimes, this can imply very simple changes. For instance, nearly half of all American adults have difficulty understanding and using healthcare-related terminology and information, and there is a higher rate of hospitalization and emergency services utilization among patients with limited health literacy (Baker et al., 1998). Also, highly educated people may encounter trouble understanding instructions or other healthcare-related information. Hence, this illustrates an overall need for clear patient education strategies for all patients.

The communication challenges are also salient for our aging and growing portion of the population (Fox, 2009) as well as for certain at risk groups where health disparities are increasing, such as those with low levels of education. Additionally, since the process of patient education involves many stakeholders (such as the partner, families, healthcare providers, and hospitals), effective patient education has to acknowledge their needs and expertise as well. Given this, a socio-ecological approach for patient education, as for most if not all health education efforts, is important.

Mass Media Approaches

Mass media health education methods provide tools for providing health education to general and specific audiences. They are important tools in advancing public health goals. Communicating about health through mass media is complex, however, and challenges professionals in diverse disciplines. Yet, using the mass media to improve public health can be a very complex challenge if one does not specify specific objective and target groups (see, e.g., Winett & Wallack, 1996).

During the last decades, the types of mass media methods used for health education and health promotion have changed dramatically. In the late 1980s, mass media were thought of as "broadcast" media and aimed at reaching large segments of people. The old mass media concerns communication by, for instance, television, radio, newspapers, brochures, posters, billboards, etc. (Dictionary, 2010). Yet, the rise of the Internet resulted in the provision of a different type of new mass media communication, that also allows for interactive approaches that have the potential to also reach many people through personal computers, cellphones and smartphones, PDAs, tablets, etc. Health communication messages can now also be disseminated easily and rapidly via Web sites, blogs, discussion boards, RSS feeds, etc. (Abroms & Maibach, 2008). We will discuss this type of health education separately below.

Many examples of studies describing the effects of mass media programs can be found. For instance, mass media campaigns on health services utilization were regarded as effective, which is also concluded in the Cochrane Review by Grilli, Ramsay and Minozzi (2002). Mass media campaigns designed to raise awareness of HIV and AIDS have shown immediate significant but small effects in the promotion of voluntary counseling and testing for HIV (Snyder et al., 2004). Brinn et al. (2010) reviewed existing mass media interventions for preventing smoking in young people. They found seven studies, of which only three proved effective in terms of preventing the uptake of smoking in young people. Furthermore, studies also suggest that large-scale mass media interventions can be highly cost-effective as they target many people at relatively small costs compared to intensive one-to-one or group treatments (Morrison & Bennett, 2008).

The main advantage of both the traditional as the new mass media approaches is that many people can be reached, including through targeting those who are not initially motivated to participate in treatments. Health communication researchers tend to reach similar conclusions concerning the effectiveness of mass media interventions, namely, that they, by themselves or in combination with other programs, can significantly influence the health behaviors of populations, with different effects which are often rather modest. However, effective public health media campaigns have two important qualities: they feature well-designed messages, and those messages are delivered to their intended audience with sufficient reach and frequency to be seen or heard and remembered (Abroms & Maibach, 2008). In sum, mass media methods have the potential to promote public health by agenda setting, changing knowledge, attitudes, social norms, and behavior (Noar & Harrington, 2012). Moreover, they also can be used as powerful tool in broader health promotion strategies.

Internet and eHealth Methods

In general, *eHealth* refers to health services and information delivered or enhanced through the electronic devices, such as TV, telephone, and the Internet (Eysenbach, 2005). eHealth methods may concern any type of usage of health education and care via electronic and digital methods (Della Mea, 2001). Hence, eHealth may include the use of Internet, email, electronic patient systems, etc. In many national healthcare services, extensive eHealth infrastructures and systems are regarded as important for the provision of safe, efficient, high-quality, citizen-centered healthcare.

The advantages of eHealth programs are that they can reach much larger target groups than traditional approaches. With (mobile) telephone and the Internet, the distinction between mass media and individual health education has become less clear. For example, a web-based support network for those with diabetes may distribute material to thousands, may provide opportunities for dyads or small groups to exchange experiences and social support, and may provide information on obtaining individual health education and counseling from one's health provider system.

Another advantage of eHealth programs is that they provide options for *tailoring* intervention material to the needs of the recipients. In an early study, Kreuter and Strecher (1996) compared the effects of tailored HRA feedback with generic (non-tailored) feedback and found that individuals receiving the tailored feedback were 18% more likely to change at least one risk factor (usually cholesterol screening, dietary fat consumption, or physical activity).

People get questions and tasks, and on the basis of their responses a feedback report will be generated (Velicer et al., 1993; Strecher et al., 1994; de Vries & Brug, 1999; Kreuter et al., 2000). Hence, messages are based on the personal data that a person has given concerning his health behavior, the motivational beliefs related to this behavior, and other relevant personal characteristics (e.g., age, gender, disease profile). Most importantly, these characteristics are not only personal demographic characteristics, such as name, gender, and age, but rather motivational characteristics that determine whether a person does or does not adopt a particular health behavior (de Vries & Brug, 1999).

Computer tailoring can generate messages that are adapted to a person's beliefs about the advantages and disadvantages of a health behavior, how to cope with barriers and low self-efficacy, how to increase social support and/or cope with low levels of support, or how to develop specific action plans to translate intentions into actual behavior, all combining information and behavioral change strategies (Kreuter et al., 2000). Computer-tailored methods are more effective than generic health education messages due to the working mechanisms of computer tailoring. Because of the highly *personalized* nature of these messages, they are more likely to attract attention and to be read, appreciated, remembered, and regarded as personally relevant (Dijkstra & de Vries, 1999; Dijkstra, 2005; Ruiter et al., 2006; Hawkins et al., 2008) and thus are more likely to result in cognitive and behavioral effects. In fact, these outcomes provide support for one of the assumptions of the *elaboration likelihood model* (ELM) of Petty and Cacioppo (1986).

The ELM assumes that people may engage in two types of processing of messages, central and peripheral route processing, and suggests that the extent to which individuals are motivated to "elaborate" with regard to a message and engage in central processing is influenced by personal involvement with a message. Tailored messages clearly have the advantage of being personally relevant and thus increase the likelihood of central processing of these messages which will increase the chance for changing behavior.

Effects of computer-tailored messages have been demonstrated by several studies for various behaviors, such as smoking (Dijkstra & de Vries, 2000; Velicer, Prochaska, & Redding, 2006; Te Poel et al., 2009; Etter, 2009; Strecher, 1999; Strecher, Shiffman, & West, 2005; Borland et al., 2003), smoking prevention (Ausems et al., 2004; Dijk & de Vries, 2009), nutrition (Campbell et al., 1999; Brug et al., 1996, 1999; Kroeze, Werkman, & Brug, 2006; Oenema, Brug, & Lechner, 2001), physical activity (Kroeze, Werkman, & Brug, 2006; Smeets, Brug, & de Vries, 2008; de Vries et al., 2008), alcohol (Riper et al., 2008), screening (Strecher et al., 2008), and HIV prevention (Noar et al., 2009). Reviews and meta-analyses support the overall impression of positive outcomes of computer-tailored interventions (see, e.g., Noar et al., 2007). Additionally, eHealth programs offer substantial advantages in cost efficiency. A study by Lewis et al. (2010) compared an intervention delivered in a print format in comparison to be delivered as an Internet-delivered intervention. The Internet-delivered intervention appeared more cost-efficient relative to the print intervention but only if the total number of individuals receiving the intervention exceeded 352 (Lewis et al., 2010).

Internet-based health education has become very popular (Brouwer et al., 2010; Leung, 2008; Tu & Cohen, 2008) and can reach both large groups of recipients. For instance, the general public can receive via various Internet sites information concerning health-related topics. Additionally, Internet-based portals can help people make appointments, view laboratory results, refill medications, and communicate with their physician, pharmacist, or nurse online (Mulvaney et al., 2010; Armstrong & Powell, 2008; Grant et al., 2006).

Another advantage is that many people and especially adolescents spend much of their day using Web sites, social networking platforms, multimedia, and mobile media. Studies indicate positive aspects such as recruitment of teens who may not participate in other health education programs (Ito & Brown, 2010). However, despite these advantages, the actual potential of eHealth programs to attract people and to keep them interested in using eHealth programs can also fail (Eysenbach, 2005). It can be difficult to keep visitors engaged for a substantial time to participate in eHealth program and to become exposed to the most essential elements of a program (Eysenbach, 2005; Martinez, 2008; Tyler-Smith, 2006).

Future research should carefully assess the factors that determine its efficacy or inefficacy. Additionally, not everyone may profit equally from eHealth methods. Some researchers indicate that potential health inequalities may result from the differences in access and abilities to use the Internet and information technology, also referred to as the "digital divide" (Brodie et al., 2000; Wielm, 2004; Wagner et al., 2005). We speak of global digital divide when referring to differences in the Internet and information technology access between countries (Chinn & Fairlie, 2007). Studies suggest that the digital divide may particularly be affecting certain groups, such as the lower educated, the disabled, the elderly, and certain minority groups (Sarkar et al., 2011).

In conclusion, the rise of computer technology and the Internet has started a new type of health education methods that have the potential to reach healthy people and patients and to provide health education in a much more interactive way than traditional health education methods in the past. Yet, one of the disadvantages of Internet-based programs is that people may not remain highly motivated to use these programs. Research is thus needed to assess how to best use the potential of Internet and eHealth methods for health promotion.

Conclusions and Reflection

Health education and health promotion should be theory- and evidence-based. Therefore the knowledge of key predictors of behavioral change and how to address them is important. Key predictors are variables such as self-efficacy, intention/motivation, outcome expectancies, and action planning. Interventions can be tailored on these variables or matched toward the needs of the recipients. Such tailored and matched interventions are more effective than generic, non-individualized programs. New information technologies such as the Internet and mobile devices such as smartphones open avenues for designing interventions highly *personalized* to reach large groups of recipients.

However, in general too high expectations concerning its effects need to be tempered. This is not because health education might be ineffective. Rather, health education dosage is often minimal since programs do not last long. Moreover, health education programs are implemented in a broader context that may promote or impede on the intervention effects. Health education programs are therefore most effective when embedded in a broader health promotion approach that also targets the environment with the aim to make healthier choices easier. It is important to have a theory as backdrop when designing, implementing, and evaluating health education programs. Future research is needed for improving the reach and effectiveness of health education and health promotion programs.

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18

Promoting Early Detection and Screening for Disease

David P. French, Suzanne E. Scott,
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Introduction

The outcomes of many diseases, in terms of morbidity and mortality, are much more promising when those diseases are identified and treated at an early stage. For instance, when a woman has ovarian cancer identified and treated at stage 1 (i.e. small and localised), her probability of survival is 92%, compared to only 6% survival when it is identified at stage 4 (i.e. large and metastatic) (Cancer Research UK, 2011). It has been estimated that by encouraging early diagnosis of cancer, potentially 5000–10,000 deaths that occur within 5 years of diagnosis could be avoided every year in the UK alone (Richards, 2009). Similarly, early intervention for depression may prevent impaired psychosocial functioning and reduce the risk of suicide, and prompt treatment of air-borne diseases such as influenza and tuberculosis will prevent further spread within the community. Thus, for many diseases, the timeliness of diagnosis and treatment is important. Early diagnosis of disease may occur before people experience symptoms and feel subjectively ill or may be dependent on the presence of symptoms.

The aim of this chapter is to provide an overview of various approaches that have been used to encourage behaviours that bring about early detection and treatment of disease, including a consideration of the likely efficacy of these approaches in reducing morbidity and mortality. It is therefore concerned with secondary prevention, which has been defined as 'actions taken to identify and treat illness or injury early with the goal of curbing or reversing the problem' (Sarafino, 2004, p. 9). Thus, it does not include primary prevention efforts such as vaccination programmes, nor tertiary prevention to rehabilitate function and reduce complications where a health problem has progressed beyond the early stages. This chapter will consider three broad categories of behaviour that are included in this definition of secondary prevention: (a) increasing screening uptake, (b) self-testing, and (c) seeking medical care in response to symptoms.

Screening is concerned with identification of people at high risk of disease, in a population of ostensibly healthy people, in order to further investigate and diagnose those people, and thereby treat their disease at any early stage. Screening may be considered as the classical example of secondary prevention, in that existing disease has not yet caused overt signs, symptoms

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or dysfunction. Self-testing is a comparatively new phenomenon, whereby people attempt to identify the presence and nature of their own disease outside of organised healthcare systems. By contrast, when symptoms are experienced, promptly seeking medical care can result in disease being treated early, with good prognosis. Unfortunately, there is often considerable delay in seeking help from medical professionals in response to symptoms. Despite their common goal of early detection and treatment of disease, literatures on each of these categories of behaviours are fairly distinct: each does not seem to have been informed by insights derived from the other areas. In line with this, we will discuss each of these literatures in turn, before attempting to integrate common lessons from the three areas towards the end of the chapter.

Increasing Screening Uptake

What Is Screening?

The overall aim of screening is to maximise health benefits by identifying people with a diagnosable medical condition that would benefit from treatment. This is done by applying progressively more invasive tests, so that people who are judged by the earlier tests to be at low risk of the condition receive minimal testing, thereby minimising potential harms. By contrast, those who are judged to be at higher risk by the earlier tests then undergo more invasive testing, with the objective of diagnosing and consequently treating the condition. Screening is best conceptualised as a programme that identifies appropriate people to invite, offers screening, carries out screening tests, discusses the results of these tests, carries out diagnostic tests if required, discusses the results of these diagnostic tests and offers advice and treatment. Evaluations of screening should consider the whole programme, including likelihood of benefit from treatment, and not just the characteristics of the screening test.

Screening tests involve assessing or examining people without obvious symptoms to determine whether they are at high risk of having the disease for which they are being assessed. Those people who are identified as being at high risk by initial examinations or assessments, termed screening tests, are then invited to take a diagnostic test. This diagnostic test may then confirm a diagnosis of the disease, leading to treatment. However, many people identified as being at high risk by the screening test have no disease detected by the diagnostic test. These people are considered to be 'false-positives', in that they tested positive by the screening test, but were then found to produce negative test results on the more definitive diagnostic test; people who test positive on both screening and diagnostic tests are considered to be 'true positives'.

A key objective of screening programmes is to maximise the number of true positives, relative to the number of false positives (Morrison, 1998). The main benefits of screening programmes are accrued by people with true-positive results, as they receive early treatment of the disease detected, with the aim of preventing their disease progressing to cause morbidity and mortality. By contrast, the main harms of screening programmes are experienced by both people with true-positive results and those with false-positive results (Gray, 2004). People with positive screening test results undergo diagnostic tests, which may be invasive or painful, and may experience potential distress due to their screening test results, which would not have occurred had they not been screened (Shaw, Abrams, & Marteau, 1999; see also Collins, Lopez & Marteau, 2011). This distress may be at least partly due to uncertainty surrounding the meaning or implications of the screening result (see e.g. French, Maissi, & Marteau, 2004, 2006), although prolonged uncertainty does not necessarily lead to distress (e.g. Eborall, Griffin, et al., 2007). Many people with true-positive results will receive treatment that may be ineffective in preventing their disease progressing and, irrespective of this, may also have potentially severe side effects. They may also experience distress at an earlier time than would be the case if their disease had not been detected early due to screening.

Public Health Versus Informed Choice Agendas

The approach taken in this chapter is mainly concerned with a public health agenda which focuses on the nature and impact of interventions to promote screening to bring about early detection and treatment of disease, to improve prognosis. For example, a screening programme may attempt to detect people who have type 2 diabetes, but have not been diagnosed. The aim would be to alert such people by diagnosing their condition, so that changes in diet and physical activity, or in taking medication, may reduce the harms of this condition. An intervention may therefore focus on extending the reach of the programme, so that more people are diagnosed earlier with diabetes, receive treatment, and thereby public health is improved.

It should be noted, however, that other agendas exist. In particular, antenatal screening programmes tend to place considerable emphasis on informed choice, to ensure that women undergoing such screening understand that termination of pregnancy may be one possible outcome (Dormandy, 2007). This informed choice agenda is increasingly being endorsed for population screening programmes, not just antenatal screening. For example, in the UK the National Screening Committee (2011) trains health professionals with the explicit aim of 'ensuring individuals offered screening within the NHS are fully informed of their choices and receive the best possible care and experience along the screening pathway' (p. 15). For individuals to be considered fully informed they would need to be presented with information including the likelihood, meaning and implications of all possible test results, particularly the absolute probabilities of an individual benefitting or being harmed (Marteau & Kinmonth, 2002). Thus, to be considered informed, people invited to screening should be aware of the likelihood of receiving a negative result or a positive result, that both types of results could be in error (i.e. both 'false-positive' and 'false-negative' results are possible), and what procedures and future decisions might be involved in subsequent diagnostic tests were they to receive a positive test result.

Despite this drive for informed choice, invitations for population screening typically provide information about the prevalence and severity of the disease for which screening is being offered, and rarely provide information about the absolute chances of an individual benefitting or being harmed (Jørgensen & Gøtzsche, 2006). It therefore seems that despite the informed choice agenda many screening programmes explicitly endorse, the materials actually provided are implicitly based around a public health agenda. This may be due to a reluctance to highlight the potential harms of screening for fear of a reduced attendance rate. However, it is not clear that altering the materials used by screening programmes to provide a more balanced view of the likely benefits and harms of screening will have much effect on the attendance to such programmes (O'Connor, Bennett, et al., 2009). For instance, one recent trial found no difference in attendance for diabetes screening between a traditional screening invitation compared with a more balanced 'informed choice' invitation, even amongst more socially deprived groups (Marteau, Mann, et al., 2010).

Screening Programmes

The screening, diagnosis and treatment of people on a large scale is called mass screening or population screening, and is organised into screening programmes, which may be local, regional or national. Currently, throughout Britain there are several screening programmes which are offered to all people within populations defined by age and sex. These include programmes to detect and treat breast, cervical and bowel cancers and abdominal aortic aneurysm (UK National Screening Committee, 2013). In addition, there are antenatal and newborn screening programmes (e.g. to detect Down syndrome and cystic fibrosis), as well as a programme to detect retinopathy in all people with diagnosed diabetes. These programmes are free of charge to people offered them, publicly funded through taxation, and may achieve uptake rates of over 80% of the eligible population (National Screening Committee, 2011). Similar systems apply in many western European countries (e.g. the Netherlands). By contrast, in other countries, notably the USA, there is a charge for screening, usually paid for by health insurance, and access to screening is by self-referral or referral by a health professional (Miles, Cockburn, et al., 2004). Although bodies such as the American Cancer Society publish recommendations concerning screening, these do not constitute a national screening programme in the same sense as in the UK. In many low-income and middle-income countries, screening is even more patchy, and there are arguments that it may not be appropriate where the incidence of many conditions for which screening would be offered is lower than in wealthier countries, and attaining high levels of uptake of screening is challenging (Mittra, 2011).

The present section is concerned with evidence on promoting uptake of screening programmes, whether local, regional or national, rather than increasing informal screening by individual clinicians.

Contributions of Screening to Reduce Morbidity and Mortality

For any increase in screening attendance to translate into reduced population mortality, it is also necessary that screening programmes are effective at reducing mortality in those who attend. Although an evaluation of the effectiveness of screening is beyond the scope of this chapter (see Morrison, 1998), a brief overview of the evidence on this point is required.

Screening can be a controversial area (e.g. McPherson, 2010): although well-conducted screening programmes can prevent deaths, it is not clear that screening always does more good than harm (Gray, Patnick, & Blanks, 2008). An example of a well-conducted screening programme is the UK cervical cancer screening programme, which has been estimated to prevent 1300 deaths in England and Wales per year (Sasieni & Adams, 1999). However, it has also been estimated that about 1000 women would have to undergo cervical cancer screening for 35 years to prevent one death (Raffle, Alden, et al., 2003). It has been further estimated that less than 10% of cancer diagnosed is detected by screening (Hamilton, 2009a). So while this screening programme has saved many lives, it does not seem to have helped the majority of women who develop cancer, and also involves considerable resources.

In contrast to preventing mortality, screening is likely to be responsible for a considerable amount of harm. For instance, it has been estimated that for every death prevented by breast screening programmes, over 200 women will experience distress due to false-positive test results (Gøtzsche & Nielsen, 2011). Further, ten women will receive treatment who would not have been diagnosed without screening, and whose lives would not have been adversely affected, due to the cancer being slow-growing (Gøtzsche & Nielsen, 2011). This is at odds with the usual position in medicine: first, do no harm (Gray, 2004). Breast cancer screening is particularly controversial, at least partly because it has been proposed that the harms and costs associated with screening may outweigh the benefits (see McPherson, 2010). In addition, it has been argued that the likely individual benefit for any person invited for screening is often low, and crucially this information is not adequately communicated to the public (McCartney, 2010; Gøtzsche & Jørgensen, 2011).

Predictors of Screening Uptake

There have been a considerable number of studies which have investigated the correlates of screening attendance. Such correlates of screening attendance tend to be the targets for interventions to promote screening uptake. The pattern of results of these studies is somewhat mixed (Jepson, Clegg, et al., 2000), with many variables positively associated with screening uptake in some studies, and negatively associated in others, as well as not associated in yet further studies. Given the large number of studies, and often mixed results, the current section selectively reviews those variables which have been found to be correlated with screening attendance; the following section reviews the effects of interventions to increase screening uptake.

Demographic Factors and Health Inequalities

There is clear evidence that demographic factors are associated with screening uptake, although the precise pattern varies according to the condition for which a person is being screened and the country in which screening is taking place (Weller & Campbell, 2009; Allaby et al., 2009). For example, a national analysis in Britain showed that white British women were significantly more likely to have attended cervical screening than women from ethnic minorities (Moser, Patnick, & Beral, 2009). By contrast, women who lived in a household with a car and in owner-occupied housing were significantly more likely to have attended breast screening, but attendance was not linked to ethnicity (Moser, Patnick, & Beral, 2009). Generally, ethnic minority groups are less likely to attend screening; this difference remains even after statistically correcting for other sociodemographic variables (Szczepura, Price, & Gumber, 2008). Equally, socially deprived groups, e.g. as defined by education, are less likely to attend screening (Jepson, Clegg, et al., 2000).

Socioeconomic factors appear to be associated with screening uptake more strongly in countries without publicly funded national screening programmes, notably the USA (Breen, Wagener, et al., 2001). In the USA, lack of health insurance has a reliable association with lower uptake of screening (Jepson, Clegg, et al., 2000), even after controlling for other measures of deprivation, including education and income (Breen, Wagener, et al., 2001). Thus, not only is screening uptake higher where there are publicly funded screening programmes (Miles, Cockburn, et al., 2004), but publicly funded programmes appear to promote equality of access (Weller, Patnick, et al., 2009).

Social-Cognitive Predictors

It has been argued that demographic differences in screening uptake can be explained by social cognitive variables such as beliefs and attitudes (e.g. Weller & Campbell, 2009). Irrespective of whether this is true, it is certainly the case that social cognitive variables as assessed by the theory of reasoned action (Fishbein & Ajzen, 1975) and the theory of planned behaviour (Ajzen, 1988) are strongly predictive of attendance at screening programmes (Cooke & French, 2008). Across 33 studies identified in a systematic literature review, attitudes about the importance and benefits of the behaviour had a large association, and subjective norms (beliefs about others' expectations about engaging in the behaviour) and perceived behavioural control (beliefs about one's ability to engage in the behaviour) had medium associations, with intentions to attend screening (Cooke & French, 2008). Intention had a medium association, and perceived behavioural control had a small association, with actual attendance behaviour (Cooke & French, 2008).

The overall pattern of results for predictors of intentions to attend screening and of actual screening behaviour concealed substantial variation in these relationships according to the type of screening test (Cooke & French, 2008). For example, subjective norm was a strong predictor ($r = 0.69$) of intentions to attend prenatal screening, possibly due to the important ethical issues, such as potential termination of pregnancy, which are likely to affect people other than the woman attending screening (Michie, Dormandy, et al., 2004). By contrast, perceived behavioural control was a relatively weak predictor ($r = 0.17$) of intentions to attend prenatal screening, but there were strong associations between perceived behavioural control and intentions to attend screening for colorectal cancer and intentions to attend cervical screening ($r = 0.62$ and $r = 0.58$ respectively). Screening tests for both colorectal cancer and cervical cancer involve unpleasant and/or invasive procedures, which may act as a barrier to many people considering undergoing these tests.

How the Screening Programme Is Organised

There is clear evidence that how screening is organised can impact on screening uptake (Price, Zapka, et al., 2010). Screening programmes with centrally organised recruitment designed to ensure national coverage (as is the case in the UK) have higher rates of uptake than do programmes where recruitment is organised by individual providers or organisations (Weller, Patnick, et al., 2009). As noted above, national screening programmes also appear to promote equality of access and are likely to include more quality assurance measures to reduce harms of screening (Miles, Cockburn, et al., 2004).

Different methods of organising screening also appear to result in different social cognitive factors being associated with attendance. A systematic review showed that there is better prediction of intentions to attend screening within publicly funded programmes than when screening is paid for by the individual or their health insurance (Cooke & French, 2008). By contrast, the prediction of actual screening attendance is poorer where there are publicly funded programmes (Cooke & French, 2008). Thus, decisions about attending screening appear to be more 'reasoned' where it is free, but there is less of a 'gap' between decisions to attend or not to attend and behaviour where payment is required for screening.

Even within national screening programmes, organisational factors can affect uptake. For example, uptake of serum screening for Down syndrome was 73% in hospitals where screening was conducted as part of routine appointment, compared with 56% in hospitals where screening required a separate visit (Dormandy, Hooper, et al., 2002; see also Michie, Dormandy, et al., 2004).

Previous Attendance and Previous Test Results

Previous attendance at earlier waves of screening is a good predictor of attendance at subsequent waves of screening (Jepson, Clegg, et al., 2000). Further, social cognitive theories such as the theory of planned behaviour are much better at predicting attendance at the first wave of screening than at subsequent rounds, where previous attendance becomes the strongest predictor (Rutter, 2000; Drossaert, Boer, & Seydel, 2003). It has been proposed that the receipt of an invitation for subsequent waves of screening elicits a decision regarding screening attendance that has been previously made (Drossaert, Boer, & Seydel, 2003).

It is also clear that there is dropout over time, with higher rates of attendance at earlier waves of screening, compared with later waves (Steele, Kostourou, et al., 2010). One reason for this is that those who receive false-positive screening test results are less likely to attend for subsequent waves of screening. For example, 15% of women who were recalled for further examination after routine mammography did not attend their next routine breast screening appointment, compared with 8% who received a negative screening test result (Brett & Austoker, 2001). Further, amongst women who received a false-positive result, lower rates of reattendance were found for those who received more invasive diagnostic test procedures than for women who received less invasive diagnostic tests (Fitzpatrick, Fleming, et al., 2011). Receiving false-positive or ambiguous screening test results has been found to be associated with dissatisfaction with information provided (e.g. French, Maissi, & Marteau, 2004) and care provided (e.g. Hofvind, Wang, & Thoresen, 2003). Further, dissatisfaction with information provided is associated with anxiety and concern about test results for women who receive ambiguous cervical smear test results, even for those who subsequently received negative test results (French, Maissi, & Marteau, 2006).

Interventions to Promote Screening Uptake

There are several reviews of studies which have investigated the effects of interventions to promote screening uptake on screening attendance. These include a systematic review of all interventions (Jepson, Clegg, et al., 2000), interventions to promote equality of access to screening (Porter, 2008) as well as reviews of screening for cancers generally (Brouwers, De Vito, et al., 2011) and even particular cancers (e.g. Power, Miles, et al., 2009). The current section draws most upon the review of Jepson et al. (2000). Although now somewhat dated, this review is still the most comprehensive available of which we are aware, and used highly rigorous systematic review methodology, including examination of how study quality affected review conclusions. As with the literature on predictors of screening uptake, the results of interventions to promote screening uptake are often inconsistent, and somewhat mixed according to the type of screening programme being considered. Consequently, the following section is selective, and attempts to highlight where the evidence for the effects of interventions to promote uptake is most consistent, and considers likely explanations for these results.

Method of Invitation to Screening

It is generally found that where the usual route to attendance at screening is by physician recommendation, actively inviting people by letter, appointment card or telephone call to attend screening leads to higher attendance rates than usual care (Jepson, Clegg, et al., 2000). Such invitations may be where people are offered fixed appointment times, or where they are invited and asked to make an appointment time. The evidence is good that offering fixed appointment times leads to higher uptake (Jepson, Clegg, et al., 2000). For instance, a study of attendance at health checks in primary care found 70% attendance where invitation letters proposed a fixed appointment time, compared with 37% attendance where letters contained an open invitation to attend (Norman & Conner, 1993). This effect has been successfully replicated in subsequent studies (e.g. Hurley, Huggins, et al., 1994).

These studies highlight that even simple prompts to action may be effective in producing behaviour change. This may be explained by the phenomenon of 'inclined abstainers', which was demonstrated in the context of cervical screening (Orbell & Sheeran, 1998). Most women who intended not to attend for screening were successful in not doing so, but only 43% of women who were willing to attend managed to do so over the coming year. Thus, simple prompts may act as reminders to people who intend to attend screening, but would otherwise not get around to it. There may often be little need to persuade people to attend screening, by attempting to alter beliefs about disease and screening; instead, mere reminders may be sufficient where people are already positively inclined to attend. Further, the greater effectiveness of fixed appointments in achieving higher uptake may be due to this appointment system requiring little effortful decision-making over when to attend for screening.

The method of how people are invited to attend screening is a promising area of intervention, not least because the costs per person are likely to be much less than for other approaches to increasing uptake involving more in-depth contact.

Educational and Counselling Interventions

Another method of increasing uptake that has received considerable research attention is using educational materials to inform people of the potential benefits of screening. Generally, providing people with printed educational materials has been found to be ineffective at increasing attendance (Jepson, Clegg, et al., 2000). However, the results of educational interventions which were delivered during home visits, often to hard-to-reach groups, were more promising although still mixed (Jepson, Clegg, et al., 2000). One of the problems with interpreting studies that provided educational interventions delivered during home visits is that where such interventions are effective at increasing uptake, it is not clear whether the effects are due to the content of the educational intervention itself, or to simple prompts, or to the visits containing more than simple provision of information. The general lack of impact on attendance of 'pure' written educational interventions suggests that providing information is not sufficient to bring about changes in behaviour, although it is possible that these interventions may not change knowledge, due to literacy and numeracy issues in the target population.

There is reasonable evidence that interventions providing counselling produce increases in screening attendance, especially when such interventions are delivered via telephone, although there is heterogeneity (Jepson, Clegg, et al., 2000). In contrast to educational interventions, counselling interventions aim to change cognitions that social cognitive models propose act as barriers or facilitators to attend, rather than simply increasing knowledge (e.g. King, Rimer, et al., 1994). It is notable that in common with the broader literature on social cognitive models (e.g. Hardeman, Johnston, et al., 2000), the numbers of interventions based on social cognitive models lag behind the number of predictive studies using the same models.

Removing Economic Barriers and Health Inequalities

There is very good evidence that removing or reducing financial barriers to screening, e.g. by offering free screening, is effective at increasing screening uptake (Jepson, Clegg, et al., 2000). It should be noted that these results are most applicable in countries which do not provide publicly funded screening (e.g. the USA), and consequently where payment for screening is required from people attending screening or from their health insurance.

There is clear evidence of inequality of screening uptake across demographic groups in countries where there are publicly funded screening programmes as well as countries without such programmes (Allaby, Mulhall, & Lines, 2009). This suggests that these inequalities are not solely due to a lack of money, although transport and parking may still present a barrier. There have been comparatively few studies investigating interventions to reduce inequality in countries with publicly funded programmes (Porter, 2008). However, it appears that interventions which do not require literacy skills, such as face-to-face or telephone education and counselling, show more promise at encouraging people from lower socioeconomic status groups to attend screening than do interventions involving the distribution of letters (Porter, 2008). This finding contrasts with what has been found to be effective at promoting uptake for whole populations, suggesting that different interventions may be required to optimise screening uptake and reduce inequalities of screening uptake.

Interventions Aimed at Health Professionals and Organisational Change

A number of interventions have aimed to increase screening attendance by altering the behaviour of health professionals. For instance, reminding physicians to offer screening by tagging files or providing lists of people who are overdue for screening appears to be generally effective at promoting screening (Jepson, Clegg, et al., 2000). One study showed that computerised reminders to physicians increased the number of women attending cervical screening (from 13.7 to 16.1%), although not as much as when women were sent letters inviting for screening directly, where 25.7% attended (McDowell, Newell, & Rosser, 1989). This again suggests that providing patients with prompts to action is effective at increasing screening, although it is clearly not a complete solution on its own. Further, the effects may well be increased when such prompts are provided by physicians or health professionals.

It has been argued that interventions aimed at organisational change are more effective than interventions directly attempting to alter the behaviour of people to attend screening. One systematic review of interventions found that those interventions introducing organisational change were the most effective at increasing use of cancer screening services (Stone, Morton, et al., 2002). These interventions included setting up separate prevention clinics and designating specific staff as responsible for particular organisational tasks. These findings concerning the importance of organisational factors in producing high levels of screening uptake are supported by the observation that regions of France with organised programmes of colorectal screening have much higher screening uptake than do regions without such programmes (Eisinger, Cals, et al., 2008).

Future Directions in Developing Interventions

The section above has considered the effects of interventions delivered separately. However, it has been noted that multifactorial interventions employing more than one of these intervention approaches are most likely to be effective in promoting screening uptake (Jepson, Clegg, et al., 2000; Porter, 2008).

It is also essential when interpreting the literature on the effectiveness of interventions to promote screening uptake to bear in mind that the most consistent finding is the heterogeneity of the findings between studies. For example, a review of screening for breast, cervical and colorectal cancers found variation in apparent intervention effectiveness between the three cancers; it was not clear if this was due to genuine differences in effectiveness, or differences in the quality of evidence for the three cancers (Brouwers, De Vito, et al., 2011). The brief review above has attempted to identify the common results between studies. However, there are many conditions that can be screened for, with a variety of ways of organising programmes to carry out screening, with diverse and usually heterogeneous populations and varying and changing healthcare contexts. Consequently, it is not reasonable to expect that strategies that are effective for one screening programme will be effective in another programme for a different condition, in a different population, that is organised differently, and in a different healthcare system. In sum, although looking for commonalities of results across studies is a worthwhile endeavour, the bald fact of very high levels of heterogeneity of findings between studies makes it essential to consider how context moderates the effects of intervention.

Conclusion

In sum, there are a number of strategies for which there is good evidence that they are effective at increasing screening uptake. Further, increasing screening uptake to well-designed screening programmes results in fewer deaths in the people being screened. However, the likelihood of any one person benefitting is low, and less likely than experiencing a false-positive result or unnecessary treatment. Although a number of intervention strategies can improve screening uptake, there is increasing concern about merely increasing screening uptake, in line with a public health agenda, rather than promoting informed choices about screening. It is possible that when people make informed choices about screening, they will decide not to attend.

Self-Testing

Introduction

A range of devices are now commercially available with which members of the public can test themselves for illnesses without a doctor's recommendation and no or minimal contact with healthcare professionals. Ryan et al. (2006) identified 104 self-test kits available for purchase on the Internet to diagnose or screen for 24 health conditions without involving a health professional. Recent advances in genetics have also led to companies offering testing of genomes to detect individuals' hypothetical risks of a range of illnesses, from heart disease to melanoma.

There has been some debate about whether the development of self-test kits as a form of secondary prevention is a positive advance. On the one hand, self-testing could encourage people to test and identify illnesses for which they might not otherwise be tested, facilitating their access to healthcare in the event of positive results. On the other hand, questions have been raised as to whether receiving positive results in the absence of professional support would cause anxiety, and whether people would carry out and interpret tests accurately (Prasad, Wright, et al., 2008). It is particularly important that users are given adequate information to evaluate the accuracy of tests, including the likelihood of false-positive or false-negative results.

Important questions for secondary prevention are whether people find self-testing an acceptable and attractive method to screen or test for illness, what the impact of self-testing is on people and what factors may encourage or discourage people from using self-testing. If self-testing is acceptable, with minimal negative impact on users, then encouraging self-testing could be a useful strategy for screening programmes. Identifying factors predictive of self-test use would allow the effectiveness of such programmes to be maximised. On the other hand, if self-testing is acceptable only to a small proportion of the population and tends to cause unnecessary anxiety, then not only may it be of limited value to screening programmes but questions would be raised about the ethics of marketing such kits to the public.

Self-tests have been categorised into four groups (Ronda, Portegijs, et al., 2009): (1) tests where people conduct the test and obtain results themselves, with no outside support, which could be seen as true home-testing; (2) tests where people take their own sample but send this to a laboratory which returns results, for example, by Internet or post, which will be referred to here as self-sampling; (3) tests where people go to a laboratory for the sample to be taken with results returned by Internet or post; (4) tests available in public places such as supermarkets where a trained person takes a sample and delivers the results. It is tests within the first two of these categories which are addressed in this chapter (home-testing and self-sampling).

The use of self-test kits for sexually transmitted infections (STIs) is of particular interest for secondary prevention because these are illnesses where diagnosis is essential to allow people to access treatment and to limit transmission of the infection. Importantly, they are also highly stigmatised illnesses, so people may be deterred from accessing testing where contact with health professionals is required.

Three STIs that have received particular attention as potential targets for self-testing interventions to improve diagnosis and treatment are chlamydia, human immunodeficiency virus (HIV) and human papillomavirus (HPV). Issues surrounding acceptability, impact and determinants of self-testing vary between these three disease contexts. Self-testing in the context of these three diseases in turn is discussed to highlight the range of issues that have arisen in this emerging field.

Chlamydia

Genital chlamydia (caused by *Chlamydia trachomatis*) is the most commonly diagnosed STI in the UK but can be effectively treated with antibiotics (Cole, 2008; Horner, 2008). Chlamydia may be asymptomatic but, if untreated in women, can cause pelvic inflammatory disease, infertility, ectopic pregnancy or chronic pelvic pain (Horner, 2008). It has been estimated that for chlamydia transmission to fall, testing rates need to be maintained at above 35% (Hall, 2008); in 2009/2010, the testing rate in England under the National Chlamydia Screening Programme had reached just 22.1% (National Chlamydia Screening Programme, 2011).

Self-sampling kits for chlamydia are widely available to members of the public on the Internet and for purchase from pharmacies, allowing people who might be too embarrassed to go to a clinic to test and receive results without direct contact with a health professional. While many people who seek these tests are likely to do so diagnostically, and some online companies also provide treatment following a positive result, this technology has also been employed as a screening test by the National Chlamydia Screening Programme in England since 2003 (National Chlamydia Screening Programme, 2007). The programme has used strategies including distributing free self-sampling kits from general practitioner surgeries, pharmacies and non-medical settings such as university campuses to encourage 16–25-year-olds to test for chlamydia.

The kits provided by the National Chlamydia Screening Programme, and many commercial kits available to the public, require people to send urine samples or vulvovaginal swabs to a laboratory, and later being contacted with the result, for example, by text messaging. These are nucleic acid amplification tests (NAATs) and are currently considered the 'gold standard' measure because of their high sensitivity (extent to which the test identifies people who are infected as having the disease) and specificity (extent to which the test identifies people who are not infected as being disease-free) (Skidmore, Randall, & Mallinson, 2007). 'Point-of-care' tests have also been developed and can be accessed on the Internet, where test results can quickly be discovered without the need for posting samples away. However, there is not yet evidence of such tests meeting the standards of NAATs (Hislop, Quayyum, et al., 2010). In a systematic review, Hislop et al. (2010) found that while the point-of-care tests evaluated usually had good specificity, their sensitivity was generally lower than that of tests using NAATs, meaning that some people had infections that were not detected with the point-of-care tests and would have received false-negative results if they were tested with the point-of-care test alone. A false-negative result is particularly dangerous as the self-tester will not receive needed treatment and may infect other people. If members of the public are using these point-of-care tests it is vital that they are provided with good information about the risk of false-negative or false-positive results. In addition, in the studies reviewed, although participants may have self-sampled, the tests were professionally run, so the accuracy data does not take into account the risk of errors made by members of the public in conducting the test. It is crucial that the kits available to the public are accurate and reliable with sufficient information for people to both carry out the tests and understand the meanings of test results if self-testing is to form part of public health strategies.

Predictors of chlamydia screening behaviour in general (rather than screening specifically by self-testing) have been identified. Factors predictive of undergoing screening or of finding screening to be acceptable include perceiving chlamydia to be a serious condition (Chacko, Wiemann, et al., 2006; Pavlin, Gunn, et al., 2006), perceiving chlamydia to be common (Pavlin, Gunn, et al., 2006), having a new sexual partner (Pavlin, Gunn, et al., 2006) and wanting reassurance (Langille, Proudfoot, et al., 2008). Conversely, perceived barriers to screening include low perceived risk (Langille, Proudfoot, et al., 2008; Rose, Smith, & Lawton, 2008), being asymptomatic (Langille, Proudfoot, et al., 2008), fear, stigma and lack of knowledge (Rose, Smith, & Lawton, 2008).

There has been little research addressing self-testing for chlamydia outside of clinical settings. In these contexts, people take samples and receive test results without support from a healthcare professional but people who might not otherwise test may be more confident to do so. In randomised controlled trials, response rates to being posted home sampling kits were significantly higher than response rates to invitations to attend a medical clinic for testing (Cook, Ostergaard, et al., 2007; Østergaard, Andersen, et al., 1998; Xu, Stoner, et al., 2011). This suggests that, for this STI, a significant number of people prefer the privacy afforded by self-sampling to a face-to-face meeting.

One study examined the practice of inviting people aged 16–39 years to test for chlamydia using postal self-sampling kits (Low, McCarthy, et al., 2007). Invitations to take part were received by 14,382 people; 4731 people participated (39.5% women and 29.5% men). This level of uptake suggests that the process was considered to be reasonably acceptable given that, particularly within the wide age range, there were many people who were unlikely to consider themselves to be at risk. Qualitative interviews with a subsample of people invited to participate suggested that receiving the kit was acceptable to most. The privacy and convenience of the test were welcomed but the test method could cause concern; some worried that a urine sample might leak in the post and some (women) were put off by having to give a vulvovaginal swab. These findings are consistent with those of Ford et al. (2004): 120 black, Latino and white young adults aged 18–25 years were interviewed to elicit perceived advantages and disadvantages to using self-test urine STI kits. Privacy and convenience were seen as advantages, as were lower costs as it may be possible to avoid visiting a doctor. Perceived disadvantages included concerns about test accuracy and the potential for people with positive results to not receive treatment in the absence of immediate professional support.

There is a shortage of research incorporating psychological theory into the prediction of testing behaviour for chlamydia. Interviews with students about self-testing for chlamydia suggested that response efficacy (whether or not a test would give an accurate result) and self-efficacy (ability to correctly conduct the test) (protection motivation theory; Rogers, 1975, 1983) and subjective norm (the theory of planned behaviour; Ajzen, 1991) could be particularly relevant constructs in understanding the use of self-testing for chlamydia (Powell, Pattison & Marriott, 2016; see Powell, Pattison & Francis, 2016). The generalisability of these findings was tested in an online survey of individuals who were searching for, or reading about, chlamydia testing online (Powell, Pattison & Francis, 2016). Intention to self-test for chlamydia was predicted by perceptions of vulnerability and self-efficacy, with an almost significant effect for response efficacy ($p = 0.053$), supporting the use of protection motivation theory in this context. Further research is needed to examine factors that predict not only intention to test but also the actual testing behaviour carried out.

Low et al. (2007) also assessed the psychological impact of self-testing for chlamydia (Campbell, Mills, et al., 2006; Low, McCarthy, et al., 2007). Participants completed questionnaires at three time points: 1 month before kits were sent, when kits were received and after receiving a negative result. Screening did not seem to increase anxiety. A sample of participants with positive and negative test results were interviewed (Low, McCarthy, et al., 2007; Mills, Daker-White, et al., 2006). Some participants reported feeling anxious while waiting for test results and some were concerned about test accuracy, but severe anxiety was only experienced on receiving positive test results. Positive results were delivered by a nurse; people who learn of positive chlamydia status without such support may experience greater anxiety. Qualitative interviews with university students, some of whom had self-tested for chlamydia, suggested that a positive self-test result would lead to anxiety in the absence of professional support. Nevertheless, all 18 participants indicated that they would seek professional health advice under these circumstances (Powell, Pattison & Marriott, 2016). An online survey indicated that, of eight participants who reported receiving positive results after self-testing, all reported seeking treatment or help within a week (Powell, Pattison & Francis, 2016).

There is a need for further research to be conducted with people who choose to self-test for chlamydia outside of clinical settings to determine whether a positive result consistently leads to help-seeking. This is methodologically challenging when a key reason people would choose to self-test is privacy. Further research is needed to identify the factors predictive of self-test use so that programmes such as England's National Chlamydia Screening Programme can effectively devise interventions to increase uptake.

Human Immunodeficiency Virus

In the UK, 107,810 people had been diagnosed with human immunodeficiency virus (HIV) in 2009, including 5965 new cases within that year (Office for National Statistics, 2010). In the USA, at least 50,000 people are being detected with HIV each year, even though the availability of highly active antiretroviral therapy might have been expected to reduce transmission (see Moore, 2011). It is estimated that 21% of people with HIV infections in the USA are undiagnosed (Moore, 2011). Such individuals do not receive treatment and may unknowingly transmit the infection to others (Campbell & Klein, 2006). Increasing awareness of HIV status is therefore vital if HIV incidence is to be reduced.

The use of self-test kits for HIV could be one tool through which diagnosis rates could be increased, as some studies have suggested is the case for chlamydia. Self-sampling kits have been publicly available for some years, with the USA's Food and Drug Administration (FDA) granting approval to the first HIV self-sampling kit in 1996 (Nightingale, 1996). For this kit, an individual would send a blood sample to a laboratory for anonymous testing, receiving the result by telephoning the results centre with an identification number. In the UK, saliva self-sampling kits are available; again, the sample is sent to a laboratory and the results are received by telephone. With such self-sampling kits, professional support is available to individuals when they telephone for their results. Indeed, receiving results from a trained counsellor was a requirement of the FDA in granting approval (Food and Drug Administration, 1995).

Point-of-care tests have been developed for HIV and kits have been devised for home-test use, that is, where individuals not only take their own samples but also test those samples and gain results without professional support. However, home-testing for HIV infection has generated not only controversy and debate but also legislation governing its use; in the UK, it is illegal to sell point-of-care kits to the public ("The HIV Testing Kits and Services Regulations 1992" 1992 No. 460). With HIV being a particularly serious (and stigmatised) condition, concerns regarding testing errors and risks associated with absence of professional support seem more salient for HIV than with chlamydia self-testing.

An important specific concern for HIV testing is people testing within the 'window period' (FDA, 2005, 2006; Skidmore, Randall, & Mallinson, 2007). HIV tests detect antibodies to HIV; while these antibodies usually develop in two to eight weeks, it can take up to six months before they are detectable (FDA Consumer Health Information, 2008). It is therefore possible that people may test too soon after risky sexual behaviour for an infection to be detected, receive a false-negative result, and thus falsely conclude that they have no further need for concern. Nevertheless, not only may enabling people to use a wider range of tests increase accessibility to tests, but home tests can already be obtained over the Internet despite legislative restrictions.

The UK Government Response to the House of Lords Report of Session 2010–12 (2011) supported the recommendation that an alternative to the ban imposed in 1992 be developed such that home-test kits can be licenced where kits are of high quality and with appropriate advice being made available to individuals who use the kits. At the time of writing, the 1992 ban still stands in the UK, but in the USA, the FDA has recently for the first time approved an HIV home test (FDA, 2012).

One of the key arguments made by advocates of increasing self-testing availability is that by increasing access to testing they will allow people to be diagnosed with HIV who might not otherwise be tested. McQuitty, McFarland, Kellogg, White and Katz (1999) examined records of HIV antibody tests in San Francisco from August 1996 to December 1997. They found that the risk profile of people who tested at publicly funded sites was higher than those who self-sampled, that is, where people take their own sample but send this to a laboratory which returns results. However, a higher proportion of those who self-sampled had not tested in the past than those who tested at publicly funded sites (33.1% as opposed to 17.9%). Thus, while this study suggested that self-sampling had not made a large impact on populations with high-risk profiles, the procedure may have encouraged some people to test who would not otherwise have done so. Colfax et al. (2002) looked at reasons reported for not self-testing amongst 939 US adults who had heard of self-sampling kits but who had not used them. The most common reason for not testing was concern about the accuracy (56%). Other reasons included the lack of face-to-face counselling (47%), cost (34%) and perceived difficulty of use (30%). Although there is a lack of research directly applying theory to self-testing for HIV, the findings by Colfax and colleagues suggest that protection motivation theory (Rogers, 1975, 1983) may be relevant in this context, with concerns about accuracy (response efficacy) and perceived difficulty (self-efficacy) identified as barriers to testing.

Human Papillomavirus

Human papillomavirus (HPV) is a large group of viruses of which 30–40 types can infect the genital tract (Stanley, 2010). For majority of the people infected with HPV, up to 91% clear the infection without intervention within 2 years (see CDC, 2007). However, some HPVs cause genital warts, with which it is estimated that nearly one million people are diagnosed each year in the USA (Monk & Tewari, 2007). Other, 'high-risk' types of HPV are associated with cancers of the cervix (see Stanley, 2010). Unlike chlamydia and HIV, self-testing for HPV has received attention not as a method of reducing HPV itself, but because of its role in cervical cancer development.

Many countries in the developed world have effective cervical cancer screening programmes using Papanicolaou (Pap) smears, but allowing people to self-sample for HPV has the potential to increase access to screening for people who would not attend the clinic for a Pap smear. Findings suggest that screening for cervical cancer by HPV self-sampling may be less sensitive and specific than HPV screening by professional collection, but at least as sensitive as screening by Pap smears (if less specific) (De Alba, Anton-Culver, et al., 2008; Szarewski, Cadman, et al., 2007; Wright, Denny, et al., 2000).

While it may be unwise to market HPV self-sampling kits as diagnostic tests for cervical cancer, as a screening test they appear to be a valid alternative to Pap smears, especially in populations where women are reluctant to attend clinics for cervical screening.

A recent UK study randomised women who had not responded to invitations for cervical screening to either receiving a further invitation to attend for screening or to receiving a posted self-sampling kit (Szarewski, Cadman, et al., 2011). Significantly more women responded and screened in the self-sampling group than in the group receiving the invitation for screening (10.2 versus 4.5%). Two studies conducted in the Netherlands also found more positive responses in women invited to self-sample than those invited to attend a clinic for screening (Bais, van Kemenade, et al., 2007; Gök, Heideman, et al., 2010). These findings suggest that offering self-sampling to women who are reluctant to attend screening can increase screening uptake, although the large majority of women in this population still did not respond.

A systematic review examined 20 studies addressing acceptance, preferences and attitudes towards self-sampling for HPV (Huynh, Howard, & Lytwyn, 2010). Of the eight studies that addressed acceptability, self-sampling was considered acceptable by participants in seven. Thirteen studies considered preferences for test methods in women who had experienced both self-sampling and clinician-sampling; eight studies found women to prefer self-sampling. However, the authors note the important limitation that most studies only assessed the opinions of women who did self-sample. The one study that looked at responses from women who declined self-sampling found that women who declined were more likely to have concerns about self-sampling than those who did self-sample. Thus, while the studies, overall, suggest that many women find self-sampling acceptable for HPV testing, there is a high risk of bias in the data set.

Conclusions

There is clear potential for self-testing to increase the diagnosis rates of illnesses such as chlamydia, HIV and cervical cancer, with evidence suggesting self-testing may bring some people to test who would not otherwise do so. The studies that demonstrated higher levels of uptake where self-tests were offered suggest that this technology is acceptable, and indeed preferable to going to a clinic, for at least a proportion of the population. However, it is uncertain whether receiving positive results without the support of a healthcare professional would have a larger negative impact on people than if they received the results in a more formal setting. A particularly important group of people to study is those who have self-tested and received a positive result but these people are difficult to access, possibly because of the stigma associated with STIs, and those who test by self-testing may place a particularly high priority on privacy. It may be that more anonymous methods of recruitment, such as use of the Internet, could facilitate the participation of such individuals.

Test accuracy is a concern noted by both study participants and healthcare professionals. A false-positive result for an STI is likely to cause unnecessary distress, but a false-negative result is particularly dangerous, potentially resulting in people failing to receive treatment and unknowingly transmitting the infection to others. It is therefore concerning that some tests which may be available to the public have lower than optimal sensitivity. The technology for self-testing for a whole range of illnesses is developing rapidly and problems of test accuracy may reduce as a result. Nevertheless, it is vital that any publicly available test contains easily understandable information regarding test accuracy, in particular the risk of false-negative and false-positive results for that particular test.

The accumulating evidence suggests that there is a proportion of the population who would self-test as a preference to attending a clinic to be tested for an STI. There is therefore scope for self-testing to be exploited to a greater extent by public health bodies as part of secondary prevention strategies. It seems likely that different approaches will suit different people—for some, the desire for privacy may be of primary importance, making self-testing technologies more appealing. For others, knowing tests to be of high quality and the presence of professional support may be of higher value and testing at a clinic more appealing.

For chlamydia, health authorities in some countries already encourage people to self-test as part of screening programmes; in contrast, self-testing for HIV is legally restrained in countries, including the UK and USA. In order to support any such programmes, it is important to understand factors associated with self-test use, and to identify variables that could effectively be targeted with behavioural interventions. Evidence suggests that people welcome the privacy and convenience of self-test kits while concerns include test accuracy, perceived difficulty of testing and the lack of professional support on receipt of positive results. Remarkably little research has directly applied theoretical models to self-testing behaviour, but research has identified some factors (such as perceived test accuracy and difficulty of testing) which are highly relevant to psychological models such as protection motivation theory (as response efficacy and self-efficacy). An important avenue for future research is to directly incorporate theoretical models into research more to maximise the effectiveness of any interventions that are developed.

Seeking Medical Care in Response to Symptoms

Introduction

Despite the existence of screening programmes and the advent of self-testing, the majority of illnesses are diagnosed via people becoming aware of symptoms and subsequently seeking help from a healthcare professional. For example, Hamilton (2009a) estimated that in the UK over 90% of patients with colorectal, breast or cervical cancer enter the pathway to diagnosis via symptomatic presentation to healthcare professionals.

This section focuses on the processes that occur following the detection of symptoms and, in particular, symptom appraisal and the decision to seek healthcare. Throughout this section, the term 'symptom' is used to refer to any bodily changes or somatic information deemed to be abnormal (i.e. not the result of the environment or fluctuations of normal bodily processes) regardless of whether or not it can be observed by others, the meaning assigned to the bodily change or whether it turns out to be an indicator of disease. These bodily changes include both sensations (e.g. nausea, pain, thirst and fatigue) and visible alterations (e.g. rash, blushing, alteration of a mole). The detection of symptoms does not automatically mean a person will seek healthcare. In fact, upon noticing symptoms the majority of individuals will wait, do nothing or self-medicate (Patterson, Douglas, et al., 1992). This is usually an adaptive and beneficial response, as the majority of symptoms are indicative of minor illness or injury, or the result of fluctuations of normal bodily processes (e.g. indigestion after eating rich food). As such, most symptoms resolve naturally or with minimal intervention. The response of 'self-care' is also beneficial to the healthcare system: services would be overloaded should consultations occur for every symptom that arises. Stoller et al. (1994) found that the majority of respondents believed that their symptoms can be managed outside of the healthcare system (with the exception of certain symptoms such as chest pain and dizziness). Healthcare professionals therefore only encounter very few of the symptoms that occur. This phenomenon has been referred to as the 'symptom iceberg' (Hannay, 1979). A problem occurs when symptoms are due to an underlying pathology in need of medical treatment yet individuals continue to self-manage the symptoms rather than seek medical attention.

Understanding Help-Seeking Behaviour

Counter to what one might expect, the quantity and severity of symptoms are not strongly associated with the likelihood or timing of help-seeking behaviour. There does not appear to be a threshold of symptom severity that, once exceeded, will lead an individual to seek healthcare (Petrie & Weinman, 2003). Furthermore, some people will readily consult their doctor with what a healthcare professional would consider to be minor complaints. Different individuals with similar symptoms will also react in different ways. Yet this does not necessarily mean that people have a stable or dispositional pattern of help-seeking behaviour: individuals with similar symptoms at varying times often choose to seek help on one occasion, but not on another (Mechanic, 1982). This is supported by the finding that there is only weak evidence that sociodemographic factors (e.g. sex, age) are directly associated with different patterns of help-seeking behaviour (Leventhal, Easterling, et al., 1995). Instead, help-seeking behaviour is often reliant on the type of symptom, the context in which it occurs, and a number of cognitive, emotional and social processes (Macleod, Mitchell, et al., 2009; Petrie & Weinman, 2003). This is especially the case for symptoms that are vague or ambiguous (e.g. unexplained weight loss, fatigue, a change in bowel or bladder habits) as opposed to those that are striking (e.g. collapse, bleeding). As such, help-seeking behaviour has been defined as a process involving 'symptom perception, interpretation, appraisal and decision making in addition to having the ability and motivation to enforce the decision by visiting a healthcare professional' (Scott & Walter, 2010, p. 531). In turn, a biopsychosocial approach to help-seeking behaviour is required to understand the complex relationship between symptom experience and consultation with healthcare professionals.

Theoretical Models in the Understanding of Help-Seeking Behaviour

Research into help-seeking behaviour has been largely atheoretical [with the exception of a small number of applications of Leventhal's (1970) Self-Regulatory Model (see Cameron, Leventhal, & Leventhal, 1993, 1995)]. This has led to a disparate literature that often fails to build on existing knowledge. Rakowski et al. (1988) noted that it is difficult to establish the hierarchy of importance of the different variables that have been studied in relation to healthcare use, as different studies tend to investigate different predictors. Thus, more theory-based research in this area is vital.

Application of general models of (health) behaviour (see Compton & Esterberg, 2005; Hunter, Grunfeld, & Ramirez, 2003; Mulholland & Van Wersch, 2007) often fail to add to understanding of help-seeking behaviour. This may be because consulting a healthcare professional is not a frequent behaviour or a part of one's lifestyle such as exercise or smoking for which these models are normally used (Shaw, Brittain, et al., 2008). Instead, seeking help is an uncommon response to an event (detection of a symptom) that the individual may or may not have experienced before. A further explanation as to why these general models of behaviour have shown limited success in this field is that they tend to emphasise the rational side of decision-making and give little attention to emotional factors that may play a crucial role in help-seeking behaviour.

It may be useful to consider general models of health behaviour in combination with the specific models or frameworks for understanding help-seeking behaviour (Bish, Ramirez, et al., 2005). Building on the work of Safer et al. (1979), Andersen et al. (1995) developed a 'General Model of Total Patient Delay' which captured the decisional processes leading to healthcare utilisation. The model proposes a sequence of stages: 'appraisal delay' describes the time a person takes to evaluate a symptom as a sign of illness; 'illness delay' the time the person takes from the first sign of illness until deciding to seek professional medical care; 'behavioural delay' the time between deciding an illness requires medical care to acting on this decision by making an appointment; 'scheduling delay' the time between making an appointment and actually attending an appointment; and 'treatment delay' the time between the first appointment with a healthcare professional and the onset of treatment.

This model has been applied to a number of settings such as myocardial infarction (Hedges, Mann, et al., 1998), cancer (Walter, Humphrys, et al., 2010), paediatric services (Kaftarian & Safer, 1987) and sexually transmitted diseases (Pitts, Woolliscroft, et al., 2000). A systematic review of the application of the General Model of Total Patient Delay to the study of cancer diagnosis found that although there was evidence of identifiable stages, the differentiation between stages is not consistent (Walter, Webster, et al., 2012). Further, there is evidence that the process of help-seeking is more iterative and dynamic than this model suggests. For instance, 'individuals may go back and forth from symptom identification and monitoring to self-treatment to monitoring to consultation to self-treatment and monitoring again' (Burman, 1996). As such, a revised framework (the Model of Pathways to Treatment; Scott, Walter, et al., 2013; Walter, Webster, et al., 2012) has been developed which includes clear definitions and a dynamic representation of the pathway to treatment.

Process of Help-Seeking Behaviour

Two key aspects are involved in help-seeking behaviour. Firstly, the appraisal of the health threat or stressor (i.e. symptom perception and interpretation), and secondly the implementation of a response (i.e. seeking help) once the need to seek help has been recognised. These are each considered in turn with reference to research and theory that addresses the factors that influence these processes.

Symptom Perception and Interpretation

There is no close relationship between the presence of disease and awareness of symptoms. For vague bodily changes (such as fatigue, weight loss, stomach upset and muscle ache) people are relatively inaccurate at noticing their occurrence. Pennebaker and colleagues (see Pennebaker, 1982) have documented numerous laboratory studies that have found only low correlations between perceptions of physical symptoms and actual physiological states.

Awareness of and attention to bodily changes (symptom perception) are affected by expectations, emotions, beliefs, and biological, environmental, sociodemographic, and contextual factors (Broadbent & Petrie, 2007; Cioffi, 1991; Diefenbach & Leventhal, 1996; Geers, Wellman, et al., 2010; Kolk, Hanewald, et al., 2003). For instance, the quantity and quality of concurrent incoming information influence awareness of symptoms, with a competition of cues between internal (bodily) information and external information for our limited cognitive resource (Pennebaker, 1982).

Symptom interpretation (or appraisal) involves assigning meaning to a bodily change and this can include assessment of the need for healthcare. Symptom interpretation is different from (or beyond) perception as it does not just involve noticing a bodily change but also assessing whether the bodily change may be something wrong or abnormal (based on its expectedness and level of interference) and subsequently, whether it may require professional attention. Recognising the need for healthcare may not occur immediately as, for example, a person may attempt self-medication or ignore the symptom and only consider help-seeking following reinterpretation after the symptom has not resolved on its own or as a result of medication (Scott, McGurk, & Grunfeld, 2007).

Evidence of the importance of symptom interpretation is found across a wide range of conditions. For instance, the belief that symptoms experienced are those of a heart attack is a reliable predictor of early arrival in hospital (Clark, Bellam, et al., 1992; Horne, James, et al., 2000; Ruston, Clayton, J., & Calnan, 1998) and the predominant risk factor for patients' delaying seeking help following detection of cancer symptoms is 'lack of interpretation by patients of the serious nature of their symptoms' (Macleod, Mitchell, et al., 2009, p. S95).

The psychological processes involved in symptom interpretation have been explained using psychophysiological comparison theory (PCT; Cacioppo, Andersen, et al., 1989) and Self-Regulatory Model (SRM) (Leventhal, 1970). These theories stipulate that awareness of bodily changes will motivate an evaluation (a psychophysiological comparison) if they are not easily explained by the present context or expectations. Psychophysiological comparisons are made between the symptom experience and the concrete and abstract knowledge contained in an individual's illness schema. The result of the psychological comparison will generate hypotheses about the seriousness of their problem and the need for assistance. Previous symptom episodes and illness experience has a large bearing on symptom interpretation and help-seeking decisions (Leventhal, Weinman, et al., 2008). For instance, Smith et al. (2008) found men use previous bouts of ill health as a reference to monitor new symptoms. If new symptoms were similar to a previous episode then men decided not to seek help, whereas if they exceeded the duration of previous symptoms they caused concern and prompted help-seeking.

As an individual's explanatory models (illness schemas) reflect cultural beliefs and attitudes, experiences and responses, culture will play a role in symptom appraisal and responses to symptoms (Dein, 2004). Indeed, studies that addressed help-seeking behaviour of African and Afro-Caribbean women found lay beliefs that were particular to this population (Littlewood & Elias, 2000; Mathews, Lannin, & Mitchell, 1994). For example, Mathews et al. (1994) found that black women living in eastern North Carolina spoke about their advanced breast cancer as a disease arising from 'dirty' or 'bad' blood: blood that contained impurities which circulated through the system and tried to come out of the body through knots, lumps or boils called 'risens' or 'whiteheads'. These women often delayed seeking help as the idea of catching a lump early before it bothered them, and removing it before it started to grow did not make sense to them. In fact, surgery was considered risky as this would let air get to the disease, which in turn could increase the chances of it growing and spreading.

In both the SRM and PCT, the individual is seen as 'an active problem solver' (Diefenbach & Leventhal, 1996), with the appraisal of symptoms involving iterations of 'hypothesis generation, hypothesis testing and error correction' (Cacioppo, Andersen, et al., 1989). Indeed, in their qualitative investigation of how men self-monitor their health, Smith et al. (2008) reported that men talked about 'being a detective' in an endeavour to understand what was happening.

As the process of symptom appraisal is an idiosyncratic, psychological process, it is open to a number of biases. For instance, the nature and pattern of the symptom(s), the duration and familiarity will guide symptom interpretation (Jones, 1990; Pennebaker, 1982). Learnt heuristics also influence symptom interpretation and determine whether someone believes their symptoms are due to ageing, stress or illness (Cameron, Leventhal, & Leventhal, 1995; Prohaska, Funch, & Blesch, 1990). The process of symptom interpretation takes place within a social context and as such, significant others (e.g. friends and family) and heuristics involving social comparisons may contribute to symptom interpretation (Hay, 2008; Leventhal, Weinman, et al., 2008).

Seeking Help

Even though symptom interpretation plays a major role in a person's decision to seek help, it is not always sufficient for help-seeking to occur. Once a person considers seeking healthcare, a number of barriers exist that influence whether a person will actually seek help. These include cognitive, emotional, social, cultural and environmental factors.

Shaw et al. (2008) found that symptom appraisal and the need for treatment may be weighed against treatment appraisal. For instance, if treatments were thought to be too invasive or reliant on medication, then help-seeking was less unlikely to occur, especially if symptoms were appraised to be non-life-threatening and were having minimal impact on their quality of life. This observation concerning the importance of outcome expectancies is in keeping with many models of health behaviour, where it is a central construct.

Distress as a result of the symptoms or distress as a result of the perceived consequences can encourage or hinder help-seeking (Leventhal, 1970; Leventhal, Safer, & Panagis, 1983). A qualitative synthesis of help-seeking behaviour for cancer symptoms found a range of fears existed throughout the decision to seek help (Smith, Pope, & Botha, 2005). For instance, patients feared embarrassment through bothering the doctor with trivial symptoms, being seen as weak or unmasculine, or having symptoms in a sensitive or sexual area. Seeing cancer as a fatal incurable disease, having previous negative experiences of cancer, expectations of unpleasant treatment or the consequences of treatment (e.g. loss of sexuality) and shame were aspects of the fear of cancer. It is of note that fear occurred 'after patients had recognised symptoms'. As the appraisal of symptoms appears to be a key determinant of the time to seek help for symptoms of cancer, the impact of fear (although common) may be relatively small. However, the role of emotion is one area of research that still requires further investigation.

The decision and act of seeking help is also dependent on the perceived and real accessibility of the healthcare system. Penchansky and Thomas (1981) proposed a taxonomy to explain the varying dimensions of the concept of access. They suggested that access can be considered as the degree of fit between the patient and the healthcare system and comprises of several specific areas of fit: availability, accessibility, accommodation, affordability and acceptability. Availability refers to the volume and type of services/resources in relation to the requirements of patients. This can also refer to the availability of specialist equipment and healthcare professionals (e.g. surgeons, oncologists) necessary to treat disease. Accessibility refers to the location of services in relation to the location of patients. This is relevant to communities living in rural areas who may have to travel long distances to access healthcare. Accommodation is the organisation of the healthcare services (e.g. opening hours, walk-in facilities) in relation to the patients' needs. Inconvenience of making contact with a doctor can lead to substantial delays in seeking help (Paine & Wright, 1989). Affordability refers to the prices of healthcare services/insurance in relation to patients' income and ability to pay. Some research in the USA (Braun, Mokuau, et al., 2002; Underwood, Hoskins, et al., 1994) has found that time to seek help may be prolonged due to concerns about treatment costs whereas research in European countries (where healthcare is free at the point of delivery) rarely find this as a key influence on help-seeking behaviour (Smith, Pope, & Botha, 2005). Finally, acceptability refers to the individual's attitudes about the characteristics of the healthcare services/providers, the healthcare providers' attitudes about the characteristics of their patients and doctor–patient communication (Moore, Sickel, et al., 2004).

As with symptom interpretation, the decision to seek help occurs within the social and cultural context (Andersen, Paarup, et al., 2010). Cornford and Cornford (1999) found that patients spoke to up to 16 people prior to seeking help, with the average being 3–4 people. Further, 71% of patients reported that one or more conversations with others were important in their decision to consult a healthcare professional, with conversations with partners having the most influence. Relatedly, Smith et al. (2005) found that sanctioning of help-seeking by friends, family or wider social influences such as the media was important in legitimising use of healthcare when individuals were unsure as to the nature or importance of their symptoms. This played a key role in overcoming fear of being a 'time-waster'. Social approval was less necessary when individuals had appraised their symptoms as cancer or other serious illness, or when the symptoms interfered with one's ability to work. In these situations, it appeared that the appraisal itself or the impact of the symptoms sanctioned the need for consultation with a healthcare professional. Finally, for some cultures the norm may be to consult elders or traditional healers rather than formal healthcare providers and as such visiting a healthcare professional may be reserved for certain circumstances (Hay, 2008).

Delays Within the Health Care System

There are still challenges to early detection once a patient consults a healthcare professional: there is also a need for accurate and prompt diagnostic services. However, healthcare professionals may dismiss symptoms, fail to offer follow-up appointments to determine whether symptoms have resolved or may misdiagnose the condition. Misdiagnosis may result in inappropriate medication or management, referrals to an 'incorrect' specialist, or referral without the necessary urgency (Evans, Ziebland, & McPherson, 2007). This is particularly the case within healthcare systems in which healthcare professionals act as a gatekeeper to specialist services (i.e. systems in which patients do not have direct access to secondary care but instead require a referral from a primary care practitioner). There is also potential for delayed diagnosis and treatment if there are problems with access to services, for instance, due to administrative error, or lack of resources or long waiting times. Macleod et al. (2009) found that certain patient factors affected the speed at which referrals were made following presentation to a healthcare professional. Older patients with symptoms of breast cancer, upper gastrointestinal or colorectal cancer were referred more quickly than younger patients, yet older patients with symptoms of urological or lung cancer were referred more slowly than younger patients. The same systematic review found mixed evidence that a patients' socioeconomic status is related to practitioners' timely investigation and onward referral behaviour for cancer symptoms. Patients from lower socioeconomic groups may be referred more quickly than those from higher socioeconomic groups for gastrointestinal cancer symptoms but more slowly for colorectal cancer symptoms. Although patients from minority ethnic groups often wait longer before seeking help for some cancer symptoms, the systematic review found little evidence of the influence of patients' ethnicity on the time between first consultation with a healthcare professional and subsequent referral.

Due to the potential impact of the diagnostic interval (defined as the time between the first appointment with a healthcare professional and a formal diagnosis being made) on timely diagnosis and treatment, there is a growing body of research into healthcare professionals' responses to symptomatic patients, the diagnostic process (Baughan, O'Neill, & Fletcher, 2009) and symptom matrices that indicate potential pathology (Hamilton, 2009b). To facilitate appropriate design and targeting of interventions, detailed analyses of the pathways to diagnosis are required to establish which component is leading to late detection and what factors are behind delays in diagnosis.

Interventions to Promote Early Presentation and Diagnosis

Given the impact of delayed diagnosis, there is a strong rationale for developing ways to encourage early presentation of symptoms to healthcare professionals and prompt diagnosis. One challenge of such interventions is that the symptoms of serious disease are often not unique to that disease. For instance, dizziness can be a sign of acute myocardial infarction, but may also be a sign of anxiety, a drop in blood pressure, stroke or a common cold or influenza. Interventions aiming to encourage early presentation therefore face the challenge of avoiding an overload of healthcare services with those with benign or minor ailments and unwarranted anxiety amongst patients. A further challenge is the range of methodological issues that researchers face when evaluating interventions to encourage early presentation and detection of disease. The clinical impact of the intervention may take years to come into effect, and in the case of less prevalent disease, the required sample size to detect such changes may simply be unfeasibly large. As such, interventions often use proxy measures of impact such as knowledge/awareness of symptoms, risk perception and intention to seek help, resulting in a potential loss in external validity. Austoker et al. (2009) noted that standardised and validated measures of cancer awareness and duration of symptoms are needed to ensure reliable and valid outcome measures in the evaluation of interventions to promote early presentation, and some measures are now becoming available (see Stubbings, Robb, et al., 2009). Interventions also face problems in identifying a suitable control group, especially with mass-media campaigns. As a consequence, assessments of interventions are often not methodologically rigorous, and the effects are mainly only assessed in the short term (Burgess, Bish, et al., 2008; Caldwell & Miaskowski, 2002; Kainth, Hewitt, et al., 2004).

Interventions for Patients and the Public

Mass-media campaigns to encourage early detection of stroke and myocardial infarction have generally had a limited impact. For example, Becker et al. (2001) evaluated a community-based educational intervention in the USA involving public service announcements via television, newspaper advertisements and mail-outs. The intervention successfully improved knowledge of risk factors and symptom knowledge but not where in the body stroke occurs, or the intention to seek help (dial 911) in the event of a stroke. This demonstrates that an increase in knowledge and awareness alone may not be sufficient to result in earlier detection.

Austoker et al. (2009) systematically reviewed recent (2000–2008) individual-level interventions and community-level interventions that aimed to promote cancer awareness or early presentation. Both individual- and community-level interventions were found to increase cancer awareness at least in the short term, but the authors found no randomised controlled trials that assessed individual-level interventions promoting early presentation. The community-level interventions that promoted early presentation were found to have some promising effects for encouraging earlier detection of breast cancer, melanoma and retinoblastoma. These before-and-after studies have tested time-limited educational campaigns using a range of media such as community presentations, posters, leaflets and broadcasts. For example, a breast cancer educational program delivered by community health advocates in churches, workplaces and schools in Atlanta found the proportion of very early stage breast cancers increased from 12 to 26% and the proportion of very advanced stage breast cancers decreased from 17% to 9% (Gabram, Lund, et al., 2008). However, the review authors conclude that as the community-level interventions are often multifaceted, not theory-based and only evaluated in the short term, it is not yet clear what a campaign needs to make it work, make it work over the longer term or in different settings (Austoker, Bankhead, et al., 2009).

It is important that interventions reach those most in need (Bett, Tonkin, et al., 2005; Petti & Scully, 2007; Scott, Weinman, & Grunfeld, 2011; Waters, Nichols, et al., 1983). This may involve targeting interventions at those most at risk of developing the disease in question or those who currently delay seeking help. Interventions can also be tailored to those groups or individuals. For instance, de Nooijer et al. (2004) found tailored information to be more effective than general information in both knowledge of cancer symptoms, more positive expectations of the advantages of early detection behaviours, higher self-efficacy to paying attention to cancer symptoms and more positive intentions towards engaging in help-seeking for cancer symptoms. Importantly the intervention did not raise anxiety about cancer.

Interventions Involving Healthcare Professionals and the Healthcare System

In order to encourage early detection of disease there is also scope for developing interventions to change healthcare professionals' knowledge and behaviour, to alter aspects of the healthcare system or to involve healthcare professionals in the delivery of interventions to their patients. Surprisingly however, there has been minimal research into the impact of such interventions.

Where research has pointed to misdiagnosis or inappropriate management because of gaps in knowledge or proficiency (e.g. Greenwood & Lowry, 2001), then additional training and continued professional development may be warranted (e.g. Alberts, Perry, et al., 1992; Seoane-Lestón, Velo-Noya, et al., 2010). Kroenke et al. (2000) conducted a systematic review of interventions designed to improve diagnosis and treatment of mental disorders in primary care. The review concluded that educational strategies (e.g. lectures, seminars, self-study), interventions that target provider behaviour at the time of the visit (e.g. via memory aids for diagnosis and treatment, allowing longer clinic visits, supervision) or interventions that provide feedback on providers' actual performance can improve the process of care for mental disorders. However, this may not be the case for other diseases. For instance, Raasch et al. (2000) reported an educational intervention involving audit and feedback (e.g. a review of specific clinical performance highlighting specific deficiencies in physicians' performance) and found that the intervention did not improve practitioners' diagnostic performance of skin lesions.

Some attempts to encourage early diagnosis have focused on changing the pathways to diagnosis. For instance, in the UK, the National Cancer Plan (Department of Health, 2000) stipulated that no patient should wait longer than one month from an urgent referral for suspected cancer to beginning treatment. A 'fast track referral' (two-week wait) system was introduced, with referral guidelines for suspected cancer issued to primary care physicians by the National Institute for Health and Clinical Excellence (2005). The guidelines specify the symptoms for which an urgent diagnostic is warranted. However, there is continuing debate as to whether such initiatives are effective in improving patient outcomes (Hamilton, 2009a; Jiwa & Saunders, 2007). Other alterations to the healthcare system involve improving access to healthcare and diagnostic services, for instance, changing the opening hours of the healthcare centres or having diagnostic equipment available within primary care. Again, there is little research that has studied the effectiveness of these initiatives.

Finally, healthcare professionals can be involved in the delivery of interventions to promote early presentation. For instance, pharmacists and physicians are in a good position to provide education and counselling to reduce delay in seeking help for acute myocardial infarction in those patients with coronary heart disease and those who have previously experienced acute myocardial infarction (Dracup, Alonzo, et al., 1997; Holt & Hand, 1999). By explicitly encouraging early presentation, healthcare professionals may provide some sanctioning of seeking help and overcome patients' fear of wasting the doctors' time. Linsell et al. (2009) reported a randomised controlled trial of a psychoeducational intervention aimed to promote early presentation of breast cancer in older women. The intervention (a scripted one-to-one discussion and provision of a leaflet) was delivered by radiographers to women aged 67–70 years attending final routine appointment on the UK Breast Screening Programme. The training of radiographers was found to be feasible (Omar, Burgess, et al., 2010) and the intervention was found to increase breast cancer awareness, with the effect maintained after one year.

Conclusion

Many patients wait weeks or months prior to seeking medical care for symptoms of life-threatening diseases. This is not simply because patients do not want to seek help or have difficulty doing so, but more often because symptoms are dismissed or self-managed as the seriousness of symptoms is not recognised. The complex processes through which symptoms are detected and appraised and the subsequent decisions to seek help are influenced by psychological, social and cultural factors as well as the nature of the symptoms and the context in which they occur. Studying the pathways to diagnosis and the factors that influence the timeliness of diagnosis will help to identify targets for interventions to encourage early presentation and detection of disease. Such interventions could target healthy individuals who are at risk of developing disease, existing patients who are at risk of developing subsequent disease or healthcare professionals who may play a role in delays in diagnosis once patients have sought medical care. However, with some recent exceptions, existing interventions have shown limited success. This may be a result of the general lack of theory and techniques of behaviour change in the design and development of interventions, and/or a failure to reach or engage the target group. Furthermore, the evaluation of interventions requires better methodology, including use of valid and reliable measurement tools, assessment of the clinical impact of interventions and adequate control groups. These challenges are not insurmountable barriers, and thus there is huge potential for improving mortality and morbidity from a range of diseases through the development and implementation of interventions to encourage early diagnosis.

Summary and Future Directions

There is opportunity for improving the morbidity and mortality of a range of diseases by encouraging early detection and diagnosis, thorough screening, self-testing and timely healthcare use. Literatures concerning these three areas concerned with early diagnosis are often considered in isolation from one another, yet there are parallels amongst them. The main points regarding determinants, interventions and research required for each of these behaviours are provided in Table 18.1. There are a number of commonalities in each of these areas, but also notable differences.

Table 18.1 Summary of determinants, interventions to increase behaviours and research challenges and needs regarding key behaviours in promoting early detection and screening

	Screening	Self-testing (for STIs)	Timely response to symptoms		Diagnosis
			Symptom perception and interpretation	Seeking help	
Determinants of health behaviours	• Organisation of screening programme • Social-cognitive factors (differ by condition screened for) • Previous attendance (habit) • Previous (false-positive) test results • Demographic factors (especially income and ethnicity)	• Little current evidence addressing predictors, but social cognitive factors likely to be important, especially perceiving self to be at risk, self-efficacy, response efficacy) • Uptake also likely to be associated with wanting reassurance, knowledge about lack of symptoms • Not having to attend a medical clinic for testing	• Beliefs (e.g. expectations, individual's illness schema) • Context (e.g. environment, culture) • Nature of symptoms (e.g. pattern, duration, familiarity and interference) • Previous experience • Social input • Learnt heuristics	• (Mis)interpretation of symptoms (e.g. attribution to minor ailments) • Self-care • Emotions (e.g. fear, embarrassment) • Beliefs (e.g. outcome expectations regarding seeking care) • Context (e.g. environment, culture) • Previous experience • Social sanctioning • Accessibility of healthcare system	• Misdiagnosis by healthcare professional resulting in: dismissal of symptoms, inappropriate treatment, referral to incorrect specialty, failure to offer follow-up or lack of urgency in treatment/referral • Healthcare system barriers (e.g. lack of resources, administrative hurdles) • Demographic factors (e.g. age, ethnicity, socioeconomic status)
Interventions to increase health behaviours	• Organisational interventions (e.g. reminders for health professionals) • Methods of screening invitation • Counselling interventions, but not educational interventions • Removing economic barriers where payment for screening is required	• Currently lack of knowledge on how best to promote acceptability, impact and determinants of self-testing. • Different approaches suit different people, so self-testing useful additional option • Self-testing appears particularly important for stigmatising conditions such as STIs	• General lack of evidence and research on impact of interventions • Mass-media campaigns and community education programs may encourage earlier diagnosis and increase knowledge and awareness in the short term. • Provision of tailored information may be more effective than general information for increasing knowledge and awareness, self-efficacy and intention to seek help. • Promising results for interventions delivered by healthcare professionals		• Some evidence that educational interventions, memory aids lengthening duration of consultations, supervision and provision of feedback may improve diagnostic skills, but may differ between conditions
Research needed and challenges in research	• Need to assess impact of interventions at multiple levels, including population level interventions • Not clear what are the sources of variation between different screening programmes • Need to assess effects of interventions to promote informed choices, on both informed choices and screening uptake	• Little research has incorporated theoretical models into the study of self-testing behaviour; this is likely to maximise the effectiveness of interventions that are developed • Not clear if positive test results without health professional support have larger adverse impact; difficult group for research to access	• Interventions face a number of practical and methodological challenges (e.g. successfully reaching target group; incorporation of theoretical models; minimising potential for unwarranted anxiety or overuse of services; clinical impact may not be seen immediately; proxy outcome measures may lack validity; difficulty in identifying suitable control groups).		• Lacking research to determine impact of referral guidelines or other healthcare system factors on patient outcomes.

One notable commonality is that beliefs and other social cognitions appear to be related to all three behaviours of attending screening, self-testing and seeking medical help. However, the precise nature of the social cognitions examined appears to vary somewhat between the behaviours. There is good evidence that help-seeking in response to symptoms seems to rely heavily on expectations about symptoms and illness schemata, given that symptoms is the initial impetus for this behaviour, although outcome expectations play a key role in seeking help. For self-testing, appraisals can be important, but the evidence is stronger for the importance of constructs concerned with theories of risk, such as perceptions of susceptibility and self-efficacy and response efficacy. For screening attendance, more generic theories of behaviour such as the theory of planned behaviour have been successfully applied. This variation highlights that although each of these behaviours is concerned with secondary prevention through early detection of disease, the behaviours have different specific aims and will therefore have varying determinants. Thus, help-seeking is concerned with seeking an appropriate response to symptoms, self-testing is concerned with assessing health status where there is reason to suspect that one is at elevated risk, and screening is also concerned with assessing risk, but where there is typically no reason to expect elevated risk compared to the relevant screening populations.

It is notable that screening literature in particular has demonstrated the value of theory-based research. In contrast, theory has often been neglected in self-testing and help-seeking literatures and as such is an important avenue for future research (Rothman, 2004; Michie & Prestwich, 2010). As self-testing might be incorporated within a screening framework in some contexts (e.g. self-sampling for colorectal and cervical cancer screening programmes), the neglect of theory in self-testing literature is particularly unhelpful.

Another common theme is the association between behaviour and how services are organised. Where services are not free at the point of delivery and involve routinised appointment systems, interventions to facilitate invitations for screening appear effective at increasing coverage. Equally, features of medical systems appear to be important barriers to healthcare use and to appropriate diagnosis following patients seeking help. It is notable that even for self-testing, which is largely conducted outside of a healthcare setting, being able to avoid attending a medical clinic for testing is associated with uptake, where conditions are stigmatised.

Viewing the different literatures together could offer important insights for future research. For instance, screening literature has demonstrated the importance of demographic factors such as income and ethnicity in the uptake of screening, probably because the large numbers of people that can be identified prospectively at invitation facilitates examination of this area. Although the impact of these demographic factors has been explored in the context of diagnosis, there appears to be room for further examination of this in the areas of help-seeking and self-testing. This may indicate where there is a particular need for attention to identify and reduce health inequalities in certain groups.

The screening and help-seeking literatures indicate that a major concern is not providing people with full information due to concerns over causing anxiety. For instance, there is reluctance to describe potential harms in invitations for screening or outlining signs of symptoms of diseases for fear that this may cause anxiety and in turn delay help-seeking rather than encourage it. In contrast, the research evidence in both fields indicates that ensuring patients are fully informed does not raise anxiety, reduce screening uptake or hinder help-seeking. That is, although the steps one might take to increase screening uptake are different from those that one might take to promote informed choice (French & Marteau, 2007), it seems that these two aims are not necessarily antagonistic. Given the increasing promotion of informed choice, this is likely to become more of a research issue.

There are a number of methodological issues facing these areas, especially self-testing and help-seeking research, which is mostly retrospective, focusing on those who have undergone self-testing and used healthcare services. A focus on those who choose not to be screened or self-test or are unaware of self-testing opportunities or who choose not to seek help is rare, although it potentially offers considerable insight into the cognitive and emotional processes involved. However, researchers face the methodological challenge of finding ways of identifying and recruiting these samples, especially when studying stigmatised conditions.

A theme common to all three areas is the importance of context, where some constructs are predictive of behaviour and useful targets of interventions in one setting, but less useful in other settings. It is important that future work adequately theorises the different processes that are important in different contexts, based on evidence, to allow future interventions to benefit more from existing work.

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19

Adherence

Lora E. Burke, Yaguang Zheng, and Jing Wang

Introduction

Adherence has been described as a multilevel phenomenon, one that involves the individual, the provider, and the healthcare system (Hill & Houston-Miller, 1996). However, the provider and the healthcare system are only two components in the larger picture when adherence is viewed from the broader perspective of the social-ecological model (SEM) framework (Addison, 1992; Sallis, Owen, & Fisher, 2008). Adherence is the adoption and maintenance of recommended behaviors so that they are aligned or consistent with public health or clinical recommendations; to achieve long-term benefits to health, there is an emphasis on maintenance of those behaviors, e.g., following the recommended dietary or physical activity guidelines or taking prescribed medications (Burke, Dunbar-Jacob, & Hill, 1997). As suggested in the definition of adherence, we will focus on the alignment of medication, diet, and physical activity habits with guidelines to prevent as well as manage chronic diseases. Multiple interdependent factors influence these behaviors including the social context, the person, and the environment (Banks-Wallace, 2000; Streuber, Knoblich, et al., 2011). The SEM permits a conceptualization of the interdependence of these factors and how they influence the adoption and maintenance of new behaviors. Moreover, the underlying theory suggests that sustaining the behavior requires the support of programs that include numerous levels of influence (Emmons, 2000).

In this chapter, we will address adherence – its assessment within the SEM framework, particularly the individual, the social and contextual factors that influence the individual's adherence within the greater community, and the resources that can be called upon to improve or support adherence. Evidence-based strategies that have been demonstrated to improve adherence to chronic disease regimens (e.g., diet, physical activity [PA], medication taking, appointment keeping) will be discussed.

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Assessment of Adherence

Using the SEM framework, we need to consider and assess the multiple levels of influencing factors. The exact terms used to describe the components or levels of the SEM vary, for example, the Centers for Disease Control and Prevention use *individual*, *relationship*, *community*, and *society* (Dahlberg & Krug, 2002). We will use the terms described in an earlier study (McLeroy, Bibeau, et al., 1988), which was recommended by the Institute of Medicine, as useful to examine levels of influence related to adoption of health-promoting behaviors (Smedley & Syme, 2000). Thus, assessment would involve four levels: *intrapersonal*, *interpersonal*, *community and environment*, and *organizational*.

Nonadherence is ubiquitous and is influenced by an array of factors that range from within the individual to a multitude of factors that interact with the different levels of the SEM framework, e.g., dietary adherence can be influenced by individual food preferences, family eating patterns, and access to healthy foods within the residential, work, and social environments (Gidding, Lichtenstein, et al., 2009). For other behaviors, such as taking medication or engaging in PA, the influence of intrapersonal factors and how these interact with the interpersonal, community and environment, and larger organizations, such as the healthcare delivery organization, can vary widely. Thus, adherence needs to be assessed in all settings with an emphasis on the different layers of factors represented in the SEM, depending on the behavior being assessed.

In assessing adherence, it is important to distinguish between adherence and therapeutic or clinical outcome, which can be affected by an array of other factors. For example, inadequate control of serum cholesterol may be due to inadequate drug dosage or individual variation in the drug's pharmacokinetic factors or personal factors. Inversely, the achievement of the clinical target or resolution of symptoms does not confirm adherence. Clinical outcomes are indirect measures of adherence, whereas patient behaviors (e.g., taking the medication or exercising) are direct measures. It remains difficult to measure behavior directly, and thus we rely on self-reported behavior in many situations.

In conducting an assessment of adherence, one could include the self-efficacy construct, which has been demonstrated as a predictor of adherence across multiple behavioral domains (Burke, Dunbar-Jacob, et al., 2005; Mielenz, Kubiak-Rizzone, et al., 2013; Warziski, Sereika, et al., 2008). One might view Bandura's distinction between efficacy expectation and outcome expectation as being similar. Efficacy expectation predicts if the individual will perform the adherence behavior, based on the individual's perceived self-efficacy to do so. Outcome expectation is the person's confidence in the treatment having a positive effect (Bandura, 1997). Thus, if the person has low outcome expectancy, he or she may choose not to adhere or engage in the treatment even if he or she has a high self-efficacy for performing the behavior.

A bias toward overestimation of adherence is a common flaw in adherence measurement (Miller, Alpert, & Cross, 2008). This can be partially explained by the period being measured, which often is not representative of the person's usual behavior, e.g., in a clinic appointment, the patient is asked to recall how he/she is following a recommended diet or a medication regimen. The person recalls the behavior close to the assessment encounter, which is apt to be better than usual, and consequently reports a better than usual behavior pattern. Research has shown that patients' adherence varies in relation to the clinical appointment, with adherence increasing immediately prior to and after the visit (Cramer, Scheyer, & Mattson, 1990). An array of methods are available to measure adherence to medication taking, appointment keeping, and therapeutic diet or physical activity, which include self-report, biologic and electronic monitoring devices or electronic diaries, accelerometers and pedometers, pill counts, and records such as pharmacy refills (Table 19.1).

Self-Report Measures of Adherence

Self-report measures consist of interviews, structured questionnaires, and diaries, which can be either paper and pencil or electronic. *Questionnaire*s or paper-and-pencil adherence

Table 19.1 Methods of adherence measurement, strengths, and weaknesses

Method		Behaviors	Strengths	Weaknesses
Self-report	Questionnaire	All behaviors	Extensively used; inexpensive; quick turnaround	Requires literacy; usually must be kept short; response rate may be low for mail and email questionnaires; measures need validation
	Diary	All behaviors	Provide detail of circumstances of behavior, no recall bias; the problem of day-to-day variation is reduced when multiple days are recorded	Time consuming; under- or overreport adherence; may have recall bias; may influence behavior; can be burdensome
	Interview	All behaviors	Inexpensive; provide details; quick turnaround	Interviewees may not recall important information; overestimate actual adherence
Objective	Biologic assays	Medication adherence, diet	Direct measure of adherence; may provide a validation of behavior	Expensive; limited assays available; other factors may influence the measure indirectly
	Technology supported, e.g., medication event monitoring system, accelerometers, pedometer, scales, smart cards for CPAP adherence, or continuous blood glucose monitoring	Medication taking, physical activity, weight, sleep disorder treatment, diabetes management	Provide real-time measures of adherence; easy storage of large amounts of information; ease of updating information	Loss of data if device is damaged or lost, can be quite expensive
	Pill count	Medication taking	Inexpensive; easy to conduct	Clients are able to manipulate the number of pills remaining prior to the visit
	Refill audit	Medication taking	Easy to conduct	Requires a closed or centralized pharmacy system; can be manipulated by patients

assessment is used most frequently, most likely due to the low cost and ease of administration. However, increasingly more, electronic diaries and monitoring devices are available for individuals to track their behaviors, e.g., downloadable apps to self-monitor diet or food intake. Although this is self-report, the use of the electronic diary may ease the burden of daily tracking and permit the patient to share a log with the provider for a review of recent behavior (Burke, Wang, & Sevick, 2011). *Interviews* are used frequently in clinical encounters and also in the research setting to assess adherence behavior at each contact or at specified intervals. Adherence to therapeutic regimens can also be ascertained through a 7-day recall interview by asking the patient to report the number of pills and the times at which these were taken for each day or the episodes of exercise and eating behavior for the past week. However, these tend to provide an overestimation of adherence

(Daniels, Goodacre, et al., 2011; Ross-Degnan, Pierre-Jacques, et al., 2010) and are biased to recall (Stone, Turkkan, et al., 2000).

Medication-Taking Adherence *Self-report* of medication adherence is assessed by questionnaire or by interview. The Morisky Medication Adherence Scale (MMAS), a four-item questionnaire about medication taking (Morisky, Green, & Levine, 1986), is the most often used instrument in medication adherence research (Morisky, Ang, et al., 2008). The MMAS-8 is an eight-item modified version of the MMAS (ter Bogt, Bemelmans, et al., 2011). Other self-report measures used to assess medication adherence include the Hill-Bone Compliance to High Blood Pressure Therapy Scale (Van Horn, 2011) and the Osteoporosis-Specific Morisky Scale (Urban, McCrory, et al., 2011). A systematic review of 58 studies focused on self-reported medication adherence for routine clinical practice recommended the development of a measure that can be completed by caregivers and also be used to differentiate between intentional and unintentional nonadherence (Garfield, Clifford, et al., 2011). Additionally, persistence in taking medication is considered as another indicator of adherence, measuring the duration from initiation to discontinuation of therapy (Caetano, Lam, & Morgan, 2006), e.g., proportion of days that the medication was taken during the specified period has been used to measure medication-taking persistence (Benner, Glynn, et al., 2002).

Dietary Adherence Assessing dietary adherence requires a determination of what the person eats and the degree to which the food intake approximates the recommended diet (Dixon, Subar, et al., 2007). The unannounced 24-h dietary recall is considered the gold standard for assessing dietary intake. In this *interview* approach, the individual is asked to recall food and beverage intake for the previous 24 h (Tucker, 2007). The unannounced assessment prevents individuals from changing their food intake in anticipation of the recall. The five-pass method permits a more exact description of foods (e.g., brands, degree of fat modification) but also requires interviewer skill for prompting recall and eliciting detail. Benefits of the 24-h recall are increased accuracy because of the shortened recall period. There may be reduced patient burden compared to recording in a food diary, but the 30–45 min interviews can also be burdensome. To reduce bias, it is important to collect the data for days on which the eating pattern is typical (Tucker, 2007).

Several techniques have been used to enhance accuracy of individuals' estimate of their food intake, e.g., the US Department of Agriculture (USDA) Automated Multiple-Pass Method (AMPM), a 5-step multiple-pass 24-h dietary recall method (Blanton, Moshfegh, et al., 2006). This is a computer-assisted 24-h dietary recall interview guide that provides cues to stimulate respondents' recall processes and has been shown to provide valid measures of total energy and nutrient intake among healthy normal-weight women (Blanton, Moshfegh, et al., 2006) and obese women (Conway, Ingwersen, et al., 2003), normal-weight men (Rumpler, Kramer, et al., 2008), and overweight/obese adults (Stote, Radecki, et al., 2011). Based on the AMPM approach, the well-established Nutrition Data System for Research (NDSR) is a comprehensive software program that is based on the AMPM approach and is available for assessment of dietary intake through 24-h dietary recalls, food records, menus, and recipes. The NDSR program, which contains over 18,000 foods, was developed by the Nutrition Coordinating Center at the University of Minnesota and is updated annually to reflect marketplace changes and new analytic data (NDSR, 2010, University of Minnesota, Minneapolis). It has been used in numerous large and small clinical trials (Burke, Hudson, et al., 2007; Kroenke, Caan, et al., 2012; Lin, Chen, et al., 2012). Additional software programs are available to collect dietary data, e.g., the USDA Nutrient Database for Standard Reference (Washington, DC), ProNESSy (Princeton, New Jersey), Food Processor (Salem, Oregon), and the more recently developed program in which the individual completes the recall online (Zimmerman, Hull, et al., 2009). Innovative approaches that are new include the eButton, which is a wearable computer that takes still photos of food being consumed and then uses computerized camera calibration to measure food portion size (Chen, Jia, et al., 2013; Yue, Jia, & Sun, 2012), the development of a mobile telephone food record in which image analysis and volume estimation are used, and another more objective approach being introduced (Six, Schap, et al., 2011). Each of these programs provides a comprehensive summary of dietary data with extensive detail of macronutrients and micronutrient intake.

Dietary adherence can be measured by several established *questionnaire*s. The Food Frequency Questionnaire (FFQ) is the most widely used measure to provide estimates of usual dietary intake over time (typically 6 months to a year) in large epidemiological studies (Boeing, 2013; Parr, Hjartaker, et al., 2013). FFQs include an extensive list of foods with a response requiring a report of frequency and amount of foods consumed. The commonly used ones include the Harvard/Willett FFQ (Weaver & Grunstein, 2008), National Cancer Institute's Diet History Questionnaire (DHQ) (Schmidt, Absalah, et al., 2008), and the Fred Hutchinson FFQ (Kong, Beresford, et al., 2012). The major limitation of FFQ is the number and types of items listed, which can limit its utility among ethnic groups (Tucker, 2007). FFQs have been adapted and validated to assess the diet of diverse populations (Matt, Rock, & Johnson-Kozlow, 2006), e.g., US-Chinese women (Tseng & Hernandez, 2005), elderly populations of low socioeconomic status (Quandt, Vitolins, et al., 2007), pregnant women (Vioque, Navarrete-Munoz, et al., 2013), and free-living elderly people (Pfrimer, Saes Sartorelli, et al., 2013). A regionally specific FFQ has been developed for white and black adults residing in the southern region of the USA (Tucker, Maras, et al., 2005).

Physical activity adherence measures include questionnaires, interview, and diary records. Each offers a simple and inexpensive estimate of habitual PA (Shephard & Aoyagi, 2012). Due to cost and convenience, the *questionnaire is* the most common measurement of PA. It assesses overall activity as well as intensity, frequency, duration, and type. The long version of the International Physical Activity Questionnaire (IPAQ-L) collects data on PA of the past week within leisure, transportation, occupation, and domestic domains (Cleland, Ball, et al., 2010). Godin Leisure-Time Exercise Questionnaire (LSI) is a four-item query of usual leisure-time exercise habits and average duration and frequency of light, moderate, and vigorous activity (von Gruenigen, Frasure, et al., 2012). The 7-day Physical Activity Recall and the Paffenbarger PA Questionnaire are widely used in various settings, e.g., African-American churches (Shuval, DeVahl, et al., 2011), the workplace (Gazmararian, Elon, et al., 2013), and with adolescents (Banks, Manlhiot, et al., 2012) and adults (Umstattd Meyer, Baller, et al., 2012). *Interviews* are often used in the research setting to assess adherence behavior at set intervals and can be conducted by telephone or in person (Hayden-Wade, Coleman, et al., 2003), usually guided by established questionnaires, e.g., Paffenbarger Activity Questionnaire (Burke, Choo, et al., 2006), Modified Activity Questionnaire (Conroy, Yang, et al., 2011), and 7-day Physical Activity Recall (Gazmararian, Elon, et al., 2013; Schoenborn & Stommel, 2011). *Diary records* may be used alone or with an accelerometer and include assessment of type of daily exercise and duration; these can be a paper-and-pencil or an electronic diary (e.g., downloadable program on a desktop or mobile computer platform) (Anton, LeBlanc, et al., 2012; Burke, Styn, et al., 2012; Shay, Seibert, et al., 2009).

Questionnaires, whether administered by interview or paper and pencil, are less susceptible to recall bias when the interval covered is brief. However, since lifestyle behaviors may change with the season, the shorter period decreases the likelihood of capturing representative eating and exercise behaviors. It is important to be aware that the individual's ability to store and retrieve information also affects the data's reliability and validity (Stone, Turkkan, et al., 2000). Additional concerns include the clinician's approach and how the question of adherence is posed. The individual needs to be given permission to be nonadherent, and the provider needs to be nonjudgmental in querying the person.

Diaries Daily diaries for food intake or exercise circumvent the bias of recall but require training and cooperation of the individual, which limits its use to motivated, literate individuals. Although diaries are also considered a centerpiece of interventions targeting behavior change, they may be used for assessment of adherence. Food and exercise diaries may cover a 3- or 7-day period, including one nonwork or leisure day. Recording for 3 or more days may reduce accuracy, and the recording may begin to influence the recorder's behavior. Several investigators have used diaries to measure adherence to the exercise and diet protocol (Acharya, Elci, et al., 2009; Burke, Choo, et al., 2006; Conroy, Yang, et al., 2011).

While self-report measures continue to be used most frequently, several measurement issues remain a concern, e.g., response biases due to social desirability and deliberate and nondeliberate errors in reporting, e.g., underreporting amount or types of foods consumed (Johnson, Friedman, et al., 2005; Yon, Johnson, et al., 2006) and overreporting physical activity (Colley, Hills, et al., 2008; Walsh, Hunter, et al., 2004); the latter two being common among overweight and obese individuals. Additional concerns related to eating behaviors include the difficulty individuals have in accurately estimating portion size; for medication taking, it is difficult to recall each individual episode. When using diaries to assess adherence, the individual needs to be assured that a full range of behaviors is expected to prevent less than truthful reports and also that it is important to record the behavior immediately after it occurs to avoid forgetting. Despite their limitations, self-report measures are common, easy to use, inexpensive, and provide information on the circumstances surrounding the good or poor adherence.

Objective Measures

Several objective measures are used to assess medication adherence that do not apply to eating or exercise behaviors, e.g., pill counts, pharmacy refills, electronic event monitoring, drug levels, and biological and physiological markers (Ho, Bryson, & Rumsfeld, 2009; Osterberg & Blaschke, 2005). *Refill audit* is defined as the percentage of doses refilled and is often used in a closed pharmacy or centralized system (Hudson, 2004; Olson, Gaffney, et al., 2008). *Pill count* can be easily conducted, through using telephone-based unannounced pill count (Kalichman, Amaral, et al., 2008) or counting pills during pharmacy refill visits. More recently, medication orders from electronic health records have been used as a measure of medication adherence (Conklin, 2006).

Biologic Measures These measures are at best indirect indicators of adherence; however, as stated previously, there are numerous factors that may be reflected in plasma levels of a pharmacological agent that do not reflect adherence behaviors. Biologic markers are often used as indicators of medication adherence, e.g., viral load as a measure of adherence to antiretroviral therapy (Kalichman, Amaral, et al., 2008). Medication adherence can be defined as a continuous level or by a cut point, e.g., of 80–100% (Benner, Glynn, et al., 2002; Ho, Bryson, & Rumsfeld, 2009). Clinicians often use glycosylated hemoglobin level as an indicator of patient's self-management of diabetes behaviors (Krapek, King, et al., 2004) which is interpreted as adherence to the overall regimen. Smoking cessation behaviors are often measured by assays that include saliva thiocyanate or cotinine level (Fuentes, Munoz, et al., 2010) or urine sodium for dietary sodium intake (Leiba, Vald, et al., 2005; Pärna, Rahu, et al., 2005). However, there are several limitations to measuring adherence through this approach, e.g., cost, daily variability in adherence cannot be detected, biological measures are not available for most dietary factors and drugs, and, finally, several other factors may influence biological assays (Charlton, Steyn, et al., 2005).

Electronic Monitoring The gold standard for electronic monitoring of medication taking is the use of the medication event monitoring system

(MEMS), a method that uses electronic microcircuitry embedded in the medication package, which generates a time and date stamp of the removal and replacement of the medication bottle cap (Jacqueline Dunbar-Jacob, 1996; Dunbar-Jacob, Sereika, et al., 2012). Another application of the electronic monitor for medication use includes the IDAS II (Intelligent Drug Administration System, Bang and Olufsen Medicom, Denmark) that accommodates blister pill packs (Santschi, Wuerzner, et al., 2007). This device uses visual and audible reminders to the patient to enhance adherence. Similar to the MEMS, the IDAS II has demonstrated acceptability and improved adherence with its use (Santschi, Wuerzner, et al., 2007).

Mobile devices that can collect data on food intake are undergoing development and testing, but none are available for use in clinical practice today. For example, a wearable computer referred to as the eButton captures digital pictures of food and permits portion-size estimation by the computer (Chen, Jia, et al., 2015; Yue, Jia, & Sun, 2012); others are using mobile phone-captured food images to identify food and volume that can be calculated to estimate portion size, energy, and nutrients consumed in real time (Aizawa, Maeda, et al., 2014; Six, Schap, et al., 2011). There are also several technology-based methods to assess physical activity, e.g., pedometers and accelerometers. Pedometers are used to measure steps during ambulatory activity and are the most inexpensive objective monitoring device for physical activity (von Gruenigen, Frasure, et al., 2012). Some limitations are that pedometer accuracy is influenced by walking speed, and it will not detect activities such as bicycling (Storti, Pettee, et al., 2008).The more recent models will store data up to 42 days permitting the individual to bring in the device to have the data uploaded and the memory cleared. Accelerometers are motion sensors that register body accelerations and decelerations and thus provide a direct and objective measure of movement intensity and frequency during physical activity (Pellegrini, Duncan, et al., 2012; Rogers, McAuley, et al., 2012). Sazonova and colleagues developed a footwear-based device with an embedded accelerometer, and insole pressure sensors showed this device can accurately estimate the energy expenditure associated with common daily postures and activities (Dannecker, Sazonova, et al., 2013; Sazonova, Browning, & Sazonov, 2011). The Actigraph accelerometer (Manufacturing Technologies Inc., Fort Walton Beach, Florida) and the Caltrac accelerometer (Muscle Dynamics Corp., Torrance, CA) have been used to assess physical activity levels among adults with congenital heart disease (e.g., corrected atrial septal defect) (Dua, Cooper, et al., 2007) and among individuals of all ages in the 2003–2004 National Health and Nutritional Examination Survey (Evenson & Wen, 2015). Typically, the person is asked to record their activities in a log to capture the activities not detected by accelerometer (e.g., swimming) (Rogers, McAuley, et al., 2012). The SenseWear® Armband (BodyMedia, Inc., Pittsburgh, PA) is a device worn on the upper right arm that contains an accelerometer and temperature sensors and monitors PA and energy expenditure. Data can be uploaded to a computer for analysis using the SenseWear® Software. This device has been shown to reliably determine energy expenditure in the active and resting state (Almeida, Wasko, et al., 2011; Villarini, Pasanisi, et al., 2012) and during resistance training (Reeve, Pumpa, & Ball, 2014).

Electronic Diaries Electronic handheld diaries are available to record eating and physical activity behaviors (Burke, Styn, et al., 2012; Burke, Wang, Sevick, 2011; Spring, Schneider, et al., 2012). Unlike the earlier version of diaries that were referred to as personal digital assistants that had to be brought into the clinic to have the data uploaded, the data on the currently available electronic diaries may be sent in real time to a server or have the data accessed through a portal on the Internet as these functionalities have been incorporated into mobile phones and tablets (Hutchesson, Rollo, et al., 2015). Mobile electronic diaries include software programs that facilitate recording, e.g., nutrient database for diet self-monitoring programs and databases of numerous forms of physical activity and exercise (Azar, Lesser, et al., 2013; Breton, Fuemmeler, &

Abroms, 2011). Recalling foods eaten and other events or symptoms is plagued by recall inaccuracies. Mobile devices facilitate immediate access and thus avoid this barrier by permitting individuals to record experiences close to the time of their occurrence. While these data are self-reported, they provide an excellent window into what the person is reporting in real time. Some of these devices include a date and time stamp so the provider can also measure adherence to the self-monitoring protocol, e.g., the Wi-Fi-enabled smart card for measurement of adherence to continuous positive airway pressure (CPAP) (Weaver & Grunstein, 2008). Previously, adherence to self-weighing was assessed by a digital scale that provided date- and time-stamp data and stored the weight data in the scale, which could be uploaded later at the center (Gokee-Larose, Gorin, & Wing, 2009). More recently, digital, Wi-Fi-enabled scales are available that can transmit the weight data in real time to a server (Music, Styn, et al., 2013).

Appointment Keeping Unlike adherence to the behaviors described above, there is a standard approach to monitoring appointment keeping, e.g., the attendance at PA sessions documented by research staff (Smith, Lanesskog, et al., 2012). It has been clearly demonstrated that in the context of research, attendance at intervention sessions decreases over time (Acharya, Elci, et al., 2009) and also that in longitudinal studies, it is increasingly more difficult to retain participants for completing assessments (Akl, Briel, et al., 2012; Page & Persch, 2013). Cancelation of appointments or not showing for a treatment session or assessment is a strong indicator of nonadherence.

Regardless of how adherence is measured, it is important to note that patient adherence to complex treatment regimens may vary across the treatment components (Atienza, King, et al., 2008), e.g., medication adherence may improve, while adherence to the dietary regimen could decrease. Acharya et al. reported varying levels of adherence to the five components of an intervention in a randomized clinical trial of behavioral treatment for weight loss (Acharya, Elci, et al., 2009). For example, while the highest level of adherence was to attendance of treatment sessions, adherence to the other components (self-monitoring of diet and exercise, daily calorie and fat gram intake goals, and weekly exercise goals) varied from 85% to 27% with varying patterns of adherence over 12 months. The largest decrease was in self-monitoring of diet and exercise, which was 85% initially and decreased to 26% at 1 year, which was performed with a paper diary.

In summary, adherence varies over time and often declines. Thus, ongoing and repeated assessments are essential. Moreover, repeated assessments convey to the individual that adherence is important. Furthermore, adherence should not be assumed, and when possible, the context of the behavior and its surrounding circumstances should be assessed, such as the components included in the SEM that go beyond the individual.

Determinants of Adherence

There are factors that are consistently identified as related to adherence, and, most importantly, they can be addressed through interventions. For this discussion, we have categorized them according to the SEM: intrapersonal, interpersonal, community and environment, and organization. There may be overlap across categories. Some of the determinants of adherence viewed in these categories may not be amenable to change, but one needs to be sensitive to their presence and develop interventions to improve adherence where feasible.

Pertinent to the SEM is an emerging topic, *social determinants* of health, a concept and term that was added to the Healthy People 2020 document. The 2020 plan emphasizes the need to consider all the aspects of social structure that not only influence the population's health but also the ability of many to achieve health equity (Koh, Nelson, & Cook, 2011; U.S. Department of Health & Human Services. Office of Disease prevention and Health Promotion, 2013). Additionally, it notes that the health of the individual is almost inseparable from the health of the larger community. Thus, this perspective emphasizes the ecological approach to health promotion and disease prevention and reinforces the need to assess and intervene to improve adherence across the different levels of the SEM.

Intrapersonal Individual characteristics are important factors that influence medication adherence and other adherence behaviors. Low health literacy is a major impairment to medication-taking and dietary adherence (Ownby, Waldrop-Valverde, et al., 2012; World Health Organization, 2003). Sociodemographic factors such as being older, having higher education, and a history of previous engagement in exercise have been shown to have a positive association with PA adherence (Courneya, Segal, et al., 2008; Courneya, Stevinson, et al., 2010; Tobi, Estacio, et al., 2012), while being a female and having a lower income, higher percent body fat, and reduced functional health status (e.g., osteoarthritis) are negatively associated with PA adherence (Courneya, Segal, et al., 2008; Trombini-Souza, Fuller, et al., 2012). Self-management, self-efficacy, and adherence can be notably affected by several factors, including the individual's perception of the severity of the disorder (DiMatteo, Haskard, & Williams, 2007), self-concept and the person's perception of the effect of medications (Thomas, 2007; Vlachopoulos & Neikou, 2007), or the benefits of exercising regularly (Cleland, Ball, et al., 2010; Gyurcsik, Brawley, et al., 2013; Seghers, Van Hoecke, et al., 2014). Other intrapersonal factors include prior adherence behavior, e.g., history of canceling appointments, the presence of supportive others, and satisfactory rapport with the health provider (Fuertes, Mislowack, et al., 2007). Skills for implementing the regimen are crucial, e.g., learning how to make dietary changes or follow a complex medication regimen demands that the individual receives training and a chance to practice and receive feedback.

Interpersonal Resources The absence of family or a social support network may negatively affect medication adherence. Culturally relevant social support (Stepnowsky, Marler, et al., 2006), family support (Mayberry & Osborn, 2012), and parental support for children (Conn, Halterman, et al., 2007) have been reported to impact medication adherence. The adoption of new behaviors, such as exercise, can be enhanced by supportive networks or even a partner (Aggarwal, Liao, & Mosca, 2010; Gorin, Wing, et al., 2008; Norton, Norton, et al., 2011). A study testing the role of types of support in diabetes management showed that nondirective support was associated with better metabolic control among those less than 30 years old, while directive support appeared counterproductive among those 30 or older (Fisher, La Greca, et al., 1997). A recent weight loss study using e-coach support showed that a directive support condition had more engagement than the nondirective support condition (Gabriele, Carpenter, et al., 2011). Both companionship and encouragement are important components to increasing PA adoption (Springer, Kelder, & Hoelscher, 2006). Reducing family conflict and improving communication are family-based behavior strategies that can enhance adherence (Koenigsberg, Bartlett, & Cramer, 2004).

Community and Environmental Resources The impact of the surrounding community or neighborhood is the center of extensive study that is rapidly growing (Cummins & Macintyre, 2006; Gordon-Larsen, Guilkey, & Popkin, 2011; Gordon-Larsen, Hou, et al., 2009b). The resources to which a person has access can greatly impact adherence to diet and prescription refill. Environmental influences on diet are partly considered to involve two pathways: access to foods from supermarkets and grocery stores for home consumption and access to ready-made food for home and out-of-home consumption (e.g., takeaways, restaurants) (Boone-Heinonen, Popkin, et al., 2010; Cummins & Macintyre, 2006; Gordon-Larsen, Boone-Heinonen, et al., 2009a). Living closer to fast-food restaurants led to more fast-food consumption, particularly among low-income men (Boone-Heinonen, Gordon-Larsen, Kiefe, et al., 2011), while increases in community-level prices of fast food and soda were associated with reductions in individual-level fast-food consumption (Gordon-Larsen, Guilkey, & Popkin, 2011). Supportive community and environmental resources are also associated with higher adherence to exercise (Boone-Heinonen, Gordon-Larsen, Guilkey, et al., 2011). Some examples of the supportive physical environments are availability, accessibility, and convenience of destinations; good urban design, e.g., good lighting of streets, presence of sidewalks and bike paths, and green spaces in community development; as well as safe streets, e.g., unattended dogs and safety from crime (Boone-Heinonen, Gordon-Larsen, Guilkey, et al., 2011; Gordon-Larsen, Nelson, et al., 2006; Pan, Cameron, et al., 2009).

Within the context of the SEM, the clinic setting is part of community resources. There is extensive evidence demonstrating that treatment-related factors can significantly impact adherence behavior (Ho, Bryson, & Rumsfeld, 2009; Natarajan, Santa Ana, et al., 2009). Several factors have been identified as having a negative impact on medication adherence; among these are the complexity of the regimen and the number of concurrent medications and the steps involved in mastering the treatment regimen, e.g., learning how to check blood glucose and administer insulin, make major dietary changes, or begin a walking program. Regimen-specific issues, such as the absence of immediate benefit, actual or perceived unpleasant side effects, and interference with one's lifestyle, have been identified as having a negative impact. The provider can control some factors that negatively impact adherence, e.g., reducing the number of medications taken per day.

Organizational Resources At this level, there are numerous factors related to system policies or management that can impact adherence, e.g., restricted formularies, high drug costs, long wait times, or inconvenient hours. Adherence can be influenced by the frequency of needing to refill a prescription, which may work in either direction, e.g., a 60-day prescription may result in better adherence than with a 30-day prescription (Batal, Krantz, et al., 2007); however, the cost of a 60- or 90-day refill may be prohibitive for some (Gellad, Haas, & Safran, 2007). Furthermore, availability of reimbursement after exceeding the cap amount among Medicare beneficiaries may lead to poor adherence (Hsu, Price, et al., 2006). There is evidence that high patient co-payments, inconvenience in accessing medications, and choice of initial therapy influence medication adherence (Budd, Mariotti, et al., 2011; Burke, Tuite, & Turk, 2009; White, Whisenhunt, et al., 2002). Lack of healthcare insurance, inability or difficulty accessing healthcare (Lafay, Thomas, et al., 2001), provider communication skills, disparity in health beliefs between providers and patients, lack of positive reinforcement, and lack of follow-up or continuity of care were all factors contributing to medication nonadherence (Krueger, Berger, & Felkey, 2005). Support from nonphysician health professionals can exert a strong positive influence on motivation for adopting a diabetes meal plan (Rosland, Kieffer, et al., 2008), while suggestions and information from professionals have been shown to have a positive influence on PA adherence (Schmidt, Absalah, et al., 2008). Health-oriented organizations can provide support and guidance for adopting healthy habits through online programs, e.g., the American Heart Association's My Heart. My Life.™ Another program is Heart360 that can facilitate sharing of data with one's primary provider (American Heart Association, 2013). Similarly, other nonprofit and government agencies provide programs that support adoption of a healthy lifestyle.

Models of Behavior Change for Adherence Enhancement

Various models of behavior change have guided interventions to improve treatment adherence. Earlier models included the theory of reasoned action, the theory of planned behavior, the health decision model, and the model of illness behavior, to name a few (Glanz, Rimer, & Viswanath, 2008). Currently, researchers are examining adherence from the perspective of cognitive-motivational models that focus on beliefs, intentions, self-efficacy, self-regulation, and readiness to change. Although these models focus on the individual's cognition and behavior and how they affect and are affected by the environment, they do not view the environment in the detail that the social-ecological model does. The SEM envisions the interdependence of the individual, those making up the person's social network, and the numerous components of the micro- and macroenvironment and how these factors influence the adoption and maintenance of new behaviors. The existing US environment has been termed obesogenic. As we learn increasingly more about the influence of the environment and the barriers it poses to health-related behaviors, e.g., limited access to healthy foods and safe places to engage in physical activity, interventions to support adherence need to incorporate the consumers and stakeholders at multiple levels in the greater community, e.g., drawing from the community and the organizational resources (Mozaffarian, Afshin, et al., 2012).

There is overwhelming evidence that poor lifestyle behaviors, e.g., suboptimal diet, physical inactivity, and tobacco use, are the leading causes of preventable diseases in nearly all countries (Mozaffarian, Afshin, et al., 2012), contributing 40% of preventable morbidity (Vogeli, Shields, et al., 2007). Further, potentiating these health risks, many of these behaviors often co-occur (Johnston, Buscemi, & Coons, 2013). Moreover, the presence of these poor health habits may also impact medication adherence. Thus, improving health behaviors, i.e., adherence to public health guidelines and prescribed treatment is a major component of chronic disease management. The following section describes the intervention strategies that have been demonstrated to be most robust in improving adherence across a wide range of settings that are consistent with the social-ecological model perspective.

Adherence-Enhancing Intervention Strategies

Multiple strategies have demonstrated efficacy to improve treatment adherence; however, greater improvement is observed using a combination of these strategies. Some may overlap, e.g., goal setting is intrinsic to many behavior change interventions, as well as self-monitoring and the provision of feedback. Thus, approaches that combine strategies targeting different components of behavior result in improved outcomes (Table 19.2).

Self-Monitoring The purpose of self-monitoring is to increase awareness of one's behaviors and the context in which the behaviors occur and to identify the barriers to changing a behavior. Self-monitoring also enables recognition of progress made toward a goal (e.g., taking a medication every day or reducing fat intake); thus, it provides feedback and supports self-evaluation, components of Kanfer's self-regulation model (Kanfer, 1990, 1991, 1996). This strategy has been described as the cornerstone of behavioral treatment for weight loss (Burke, Wang, Sevick, 2011) and an important therapy for diabetes patients' blood glucose control (Meetoo, McAllister, & West, 2011). Self-monitoring interventions can be simple, such as pencil-and-paper logs of foods eaten, medications taken, daily weights, steps taken, or distance walked (Burke, Wang, Sevick, 2011; Vasbinder, Janssens, et al., 2013). Self-monitoring is usually accompanied by feedback on the content recorded or when using mobile devices; an algorithm can read the data and deliver a tailored feedback message in real time (Ambeba, Ye, et al., 2015; Burke, Styn, et al., 2012).

Both observational data and evidence from clinical trials demonstrate the importance of self-monitoring in achieving behavior change. As part of an intervention, the frequency, consistency, and fidelity of self-monitoring can impact its effectiveness. In the Women's Health Initiative Dietary Modification Trial (Tinker, Rosal, et al., 2007), independent predictors of dietary change at 1 year included younger age, more education, being optimistic, greater treatment session attendance, and submitting more self-monitoring diaries. Notably, at 3 years, predictors of dietary maintenance were better attendance and submitting more self-monitoring records (Tinker, Rosal, et al., 2007). There is evidence that self-monitoring appears to be an

Table 19.2 Adherence enhancement strategies according to the social-ecological model framework

SEM level	Adherence enhancement strategies	
Intrapersonal	Self-monitoring	Self-monitoring consists of systematically observing and recording one's behavior and is positively related to successful weight control
	Goal setting	Teach participants the importance of setting goals for behavior change, which can lead to enhancement of motivation. They are instructed to set daily and weekly goals for calorie and fat consumption, exercise time, and behavior change, e.g., to eat breakfast daily and alter the content of snacks
	Psychological and motivational interventions	Self-efficacy enhancement strategies are based on the four sources of self-efficacy (mastery, modeling by a credible source, verbal persuasion, and physiological cues) and consist of providing opportunities for goal attainment or mastery, which is based on realistic goal setting
		Motivational interviewing is a directive, patient-centered counseling style for helping individuals examine and resolve ambivalence about changing a behavior. It is through reflective listening that the interviewer helps the patient identify and resolve uncertainty and ambivalence and thus increases self-motivation to change
	Relapse prevention	Teach participants to recognize situations that place them at risk for lapses from their dietary behavior change program. They learn how to use behavioral and cognitive strategies for handling these situations in the future
	Reinforcement	Providing positive feedback on progress made toward the goal of behavior change supports self-motivation by acknowledging accomplishments and instilling confidence in the individual's capability of attaining a goal
	Stimulus control	This strategy recognizes that multiple cues exist in the immediate and distant environment that can trigger behaviors, both healthy and unhealthy. The patient can be counseled to remove those stimuli and to restructure the environment to minimize the willpower needed to overcome strong stimuli
Interpersonal	Social support	Enlisting the support of others in one's environment includes work, social and home settings; sharing goals with those who can support one's efforts in behavior change
	Assertiveness training	The skill of being assertive in social situations that threaten desirable eating and physical activity behaviors is essential to behavior change in weight loss. Participants are taught three communication styles (aggressive, passive, and assertive) and how to use assertive skills in situations that may threaten their ability to meet their eating and physical activity goals
	Modeling	Modeling consists of having an individual observe another person performing the recommended behaviors, e.g., preparing healthy food or exercising
	Cueing	Develop a system of reminders or cues to perform activities that support one's goals, e.g., set out exercise shoes to remind one to walk and fresh vegetables prepared to eat in front of refrigerator
	Ongoing contact	Ongoing contact is through postal or electronic mail, telephone, or Internet to follow up the patients
	Habit building	The basic assumption is that often behavior is automatic and responsive to stimuli, but establishing a relationship between the triggers or stimulus and the target behavior can modify behavior
	Contracting	This strategy involves the person in the plan and specifies the details in writing, e.g., expectations of person, what will be accomplished, the steps that should be taken to reach the goal, and the time frame
	Tailoring the regimen	This approach entails being flexible to accommodate the needs of diverse patients and also being sensitive to cultural issues in recommending dietary change or other behaviors and being sensitive to literacy and financial constraints
	Teamlet model of primary care	An approach involving the clinician and health coach assistants and spending time with the patient before and after the clinical visit and also providing follow-up in the interval between clinic visits
Community	Safe walking areas	Including the community as the intervention setting. The community is primarily defined geographically and is the location in which interventions are implemented. Such interventions may be citywide, using mass media or other approaches, or may take place within community institutions, such as neighborhoods, schools, churches, work sites, voluntary agencies, or other organizations. Various levels of intervention may be employed, including educational or other strategies that involve individuals, families, social networks, organizations, and public policy
	Access to healthy foods	
Organizational	Medical home	Using patient-centered approach, establish partnerships among individual patients, families, and physicians through registries and health information exchange to facilitate patient-centered care
	mHealth interventions	Using mobile devices to collect information, facilitate communication between healthcare professionals and patients, or deliver an intervention, e.g., smartphone, tablets, accelerometers, SenseWear armband, CGMS

effective complement to behavioral intervention strategies in both white and minority populations (Burke, Wang, Sevick, 2011).

Technology Use With the growth of technology, behavior interventions are increasingly delivered through mobile devices, e.g., smartphones (Hutchesson, Rollo, et al., 2015; Turner-McGrievy, Beets, et al., 2013). For example, wearing the SenseWear armband demonstrated significant improvement in PA adherence (Almeida, Wasko, et al., 2011). More recent versions of the SenseWear armband can synchronize the energy expenditure data with an online dietary self-monitoring program that requires recording energy consumption (Chowdhury, Kulcsar, et al., 2012); this program then provides energy balance and feedback to the user. Recently, the armband was used to augment standard behavioral treatment for weight loss with improved outcomes compared to standard behavior treatment alone (Pellegrini, Verba, et al., 2012; Shuger, Barry, et al., 2011). Continuous glucose monitoring system graphs (CGMS) can also be used to teach individuals with diabetes about interactions between diet, PA, medications, and glucose levels; this feedback improved PA adherence in one study (Allen, Fain, et al., 2008). There are numerous advantages including the use of technology, e.g., ability to reach a larger number of people, easy storage of large amounts of information, ease of updating information, ability to provide personalized feedback, convenience for users, ability to reach people who are isolated or feel embarrassed or stigmatized, timeliness of access, and ease of adapting information for specific populations' intervention (Fanning, Mullen, & McAuley, 2012; Katon, Lin, et al., 2010; Reid, Coleman, et al., 2010). Other important features are that technology use can augment care delivered in the clinical setting (Blackburn, 2012) and that individuals can become reengaged with the programs when they are ready (Rao, Burke, et al., 2011).

Nonface-to-Face Approaches Considering the barriers to face-to-face intervention (work schedules, travel, childcare), recent studies have examined the effectiveness of interventions without in-person contact, such as telephone and the use of the Internet (Svetkey, Stevens, et al., 2008; Wing, Tate, et al., 2006). Advantages of Internet-based interventions are that they are available at any time, may provide tailored information and messages, and provide privacy and anonymity (Butryn, Webb, & Wadden, 2011; Kodama, Saito, et al., 2012). However, literacy, language, culture, and limited skills may preclude individuals from utilizing Internet-based interventions (Kaphingst, Zanfini, & Emmons, 2006). The use of the Internet can allow healthcare providers to reach a greater number of individual who could benefit from interventions targeting a healthy diet or regular PA in a cost-effective manner; however, several important questions remain unanswered, e.g., effectiveness of this approach in low-income and minority samples, utility for improving adherence to healthy lifestyle habits, and long-term sustainability (Almeida, Wasko, et al., 2011).

Goal Setting Evidence indicates that setting goals at the initiation of a program is important to achieve the desired behavior change (Pearson, 2012). In most situations, setting specific goals leads to better performance than having no goals or vague goals (Broekhuizen, van Poppel, et al., 2012). Goals may vary by degree of difficulty and specificity; for example, being adherent to once daily medication may be less complex than initiating an exercise program. Setting goals that are specific in outcome, proximal in terms of achievement, and realistic for the person's capability will lead to more successful outcomes (Donaldson & Normand, 2009). It is better to have the goals targeting a behavior the person can observe rather than a physiological outcome and also to have the level of challenge appropriate for the person (Broekhuizen, van Poppel, et al., 2012), e.g., setting a specific, attainable goal such as walking 15 min three times a week and then increase the duration as the person reaches the 15-min goal (Pearson, 2012). Goals that are too simple may be ignored, or overambitious goals are less likely to be attempted than a moderate, achievable goal (Strecher, Seijits, et al., 1995). To reinforce mastery, it is essential to provide regular reinforcement on goal attainment (Pettman, Misan, et al., 2008). Finally, goals need to be set in a collaborative manner with patient and provider. The more the provider engages in collaborative goal setting with the patient, the more likely it increases the patient's trust in the provider, which has been shown to improve patient adherence (Tate, Jackvony, & Wing, 2006). Monitoring progress toward goal attainment can be done through self-monitoring, a tool that can also be used to provide feedback and reinforcement on progress attained toward the goal (Burke, Styn, et al., 2012).

Reinforcement Providing positive feedback on progress made toward the goal of behavior change supports self-motivation by acknowledging accomplishments and instilling confidence in the individual's capability of attaining a goal (Lafata, Morris, et al., 2013). The feedback can highlight consequences of a dietary change such as energy reduction and weight loss, which may motivate individuals to persevere or provide direction for modifying the behavior to achieve the goal (Shuger, Barry, et al., 2011). There is extensive evidence supporting the role of feedback in successful behavior change interventions. Examples include provision of feedback about baseline status which highlights where the need for change is and subsequent assessments provide current information on progress and need for additional change (Bodenheimer & Handley, 2009).

Stimulus Control This strategy recognizes that multiple cues exist in the immediate and distant environment that can trigger behaviors, both healthy and unhealthy. Self-monitoring can help identify the triggers that lead to undesirable behaviors. Using this information, the patient can be counseled to remove those stimuli and to restructure the environment to minimize the willpower needed to overcome strong stimuli, e.g., place unhealthy foods where they are not readily visible (Foreyt & Goodrick, 1993), place exercise equipment in a place that is easy to access, lay out exercise clothes and shoes before going to bed (Epstein, Paluch, et al., 2004), and have morning medications near the coffee maker or bedtime medications near the alarm clock (Reeder, Franklin, & Bramley, 2007).

Social Support Counseling the individual to enlist the support of others in their efforts at behavior change can help ensure successful outcomes. This may include family and friends but also coworkers and the community, individuals who can be supportive allies at times of setbacks and success (Tamers, Beresford, et al., 2011). Parental support is positively associated with PA among children (Heitzler, Martin, et al., 2006) and adolescents (Peterson, Lawman, et al., 2012). Social support has been shown to be important in most types of behavior change and also can be instrumental in medication adherence (Kripalani, Yao, & Haynes, 2007).

Ongoing Contact The evidence supporting the decline in adherence as provider contact is decreased or withdrawn is voluminous (Acharya, Elci, et al., 2009; Artinian, Fletcher, et al., 2010; Forsman, Nordmyr, & Wahlbeck, 2011; Kottke, Battista, et al., 1988; Norris, Lau, et al., 2002; Wadden, West, et al., 2009; Wing & Hill, 2001; Wing, Tate, et al., 2006). Ongoing contact through postal or electronic mail, telephone, or the Internet has consistently demonstrated improved adherence (Marcus, Napolitano, et al., 2007; Wing, Tate, et al., 2006). Advancements in technology are moving this strategy forward in many important ways, particularly in terms of ease of use, access, cost, and convenience. Mobile devices support ongoing communication in real time, which can provide feedback and reinforcement to the individual on progress made or direction for change, e.g., several studies have implemented text messaging as a means to provide reminders to take medications, exercise, or follow a healthy eating plan (Patrick, Raab, et al., 2009; Shapiro, Koro, et al., 2012). Ongoing contact through community physicians and pharmacists or the use of handheld technology leads to improved adherence to medication taking (Heron & Smyth, 2010), adoption of healthy lifestyle habits (Wing, 2010), and weight loss maintenance (Perri, Limacher, et al., 2008; Svetkey, Stevens, et al., 2008). Accountability plays a role in the ongoing contact, a factor that patients identify as important for sustained adherence. Another approach to ongoing contact is the provision of healthy foods and access to PA facilities in the immediate neighborhood, resources that reinforce the healthful message.

Habit Building The stimulus control model is the underlying basis for this strategy. The basic assumption is that often behavior is automatic and responsive to stimuli and behavior can be modified by establishing a relationship between the trigger or stimulus and the target behavior. This strategy can be effective when a person is in a new environment, e.g., traveling. In this situation, it would be helpful to pair the behavior (taking a medication) with an established habit (brushing teeth) and place the medication bottle with the toothpaste.

Contracting This strategy involves the person in the plan and specifies the details in writing, e.g., expectations of person, what will be accomplished, the steps that should be taken to reach the goal, and the time frame. The contract needs to specify a behavior rather than the health outcome. If a contingency reward is included, it should be reinforcing to the healthier behavior.

Problem-Solving The standard approach to problem-solving entails five steps: identification or acknowledgment of a problem, defining the problem, generating potential solutions, and selecting one solution to resolve the problem, which is completed by evaluating the success of the problem-solving attempt (D’Zurilla & Goldfried, 1971). Use of this strategy is central to sustaining behavior change as the individual will encounter numerous barriers to sustaining healthy behavior changes (Allen, Whittemore, & Melkus, 2011; Chisholm, Atkinson, et al., 2011). Anticipating high-risk situations and problem-solving in advance can help a person prepare for an upcoming event, such as a holiday gathering. Having the person practice by actively engaging in role-playing can enhance successful outcomes.

Relapse Prevention Lapses or slips will occur during the course of any behavior change program. The work of Marlatt and Gordon (1980) demonstrated that slips or lapses are natural occurrences in the process of behavior change. The relapse prevention strategy makes a person aware that it is normal to deviate episodically from the program (Wells & Wells, 2007). It is helpful to teach individuals to recognize past situations that have placed them at risk for lapse and how to use behavioral and cognitive strategies for handling these situations (Burke, Dunbar-Jacob, et al., 2005). Because of the high rate of recidivism following intentional weight loss, this strategy is an important component of standard behavioral treatment for weight loss. Studies have demonstrated that individuals begin to lapse and regain weight after 6 months of treatment (Burke, Ewing, et al., 2011; Burke, Styn, et al., 2012; Wing, Tate, et al., 2006), which is similar to the lapse rates for exercise programs (Conroy, Simkin-Silverman, et al., 2007).

Tailoring the Regimen This strategy recognizes that not all individuals can meet the same goal or follow the same program to achieve their goals; it acknowledges what is realistic for the patient to achieve behavior change taking into consideration cultural diversity, socioeconomic status, preferences, support systems, and resources (Hawkins, Kreuter, et al., 2008). This approach entails being flexible to accommodate the needs of diverse patients and also being sensitive to cultural issues in recommending dietary change or other behaviors and being sensitive to literacy and financial constraints (Radhakrishnan, 2012). This strategy calls upon the social-ecological model and its implications. Numerous papers have addressed the diverse needs of the patient population in promoting behavior change and treatment adherence and the need for tailored approaches

(Almeida, Wasko, et al., 2011; Fleury & Lee, 2006; Stuart-Shor, Berra, et al., 2012). Current technology facilitates the development of sophisticated tailored algorithms that can collect personalized information and provide individualized feedback to individuals (Burke, Styn, et al., 2009; Lustria, Cortese, et al., 2009).

Use of External Cognitive Aids External aids include an array of reminders to enhance appointment adherence. Today, more of these reminders use technology, such as emails and text messages to remind individuals of appointments; however, the use of phone calls continues to be a primary form of appointment reminders (Forjuoh, Reis, et al., 2007). In clinical trials, a letter is often sent if a person has missed more than one treatment session (Burke, Choo, et al., 2006).

Other Strategies Unique for Medication Adherence Other strategies that have been shown to positively influence medication adherence included drug education, written instructions, special medication packaging, medication side effect monitoring, and dose modification (Conn, Hafdahl, et al., 2009). Intervention strategies targeting the healthcare system level for medication adherence have included reducing medication costs, providing free medications, and a multifaceted intervention incorporating collaborative care between pharmacists and primary care physicians (Ho, Lambert-Kerzner, et al., 2014). A study by Chisholm et al. revealed that 1 year of free medications did not improve medication adherence, as patients became nonadherent after 10 months, even when there was no charge for the medications (Chisholm, Vollenweider, et al., 2000). However, Gibson (Gibson, Wang, et al., 2011) found that a value-based insurance design program showed promise for cost savings for the insurance company by reducing patient cost sharing for asthma, hypertension, and diabetes drugs. The delivery setting of the medication adherence interventions also matters. While a meta-analysis (Conn, Hafdahl, et al., 2009) did not find the intervention delivery setting (home or clinic) to be a significant predictor of medication adherence, a pharmacist-led Web-based home monitoring program resulted in higher medication adherence (Martin, O'Neil, & Pawlow, 2006).

Psychological and Motivational Interventions *Self-efficacy enhancement* and *motivational interviewing* are covered in this section, strategies that have a strong theoretical basis. Strategies for enhancing self-efficacy are based on the four sources of self-efficacy (mastery, modeling by a credible source, verbal persuasion, and physiological cues) and consist of providing opportunities for goal attainment or mastery, which is based on realistic goal setting (Bandura, 1997). Providing feedback and reinforcement for progress can be conducted through a review of the self-monitoring record (Kanfer, 1970), conveying to the person that he or she is capable of performing the behavior through verbal persuasion and interpreting symptoms of physiologic response, such as reduced fatigue and diminished symptoms from exercising following weight loss and regular exercise (Bandura, 1997). Research has provided evidence across multiple behavior domains that increased self-efficacy is associated with improved adherence to healthy food choices, self-management in type 2 diabetes, and sustaining weight loss maintenance strategies (Bandura, 1998; Chapman-Novakofski & Karduck, 2005; Di Noia, Contento, & Prochaska, 2008; Di Noia & Prochaska, 2010; Warziski, Sereika, et al., 2008). Modeling, one of the four sources of self-efficacy enhancement, consists of having an individual observe another person performing the recommended behaviors, e.g., preparing healthy food or exercising. This strategy can be easily implemented by the use of in-person or video cooking demonstrations and personal PA training. The key is having credible individuals demonstrate the behavior; having the individual practice immediately afterward is an excellent way to reinforce the learning (Yanek, Becker, et al., 2001).

Motivational interviewing (MI) is a patient-centered counseling style for helping individuals examine and resolve ambivalence about changing a behavior (Rollnick, Miller, & Bulter, 2008). This strategy cannot always be used in its fullest extent in settings where time and possibly clinician expertise are limited; however, it is possible to follow the patient-centered focus and employ the four core principles: express empathy, develop a discrepancy, roll with resistance, and support self-efficacy. It is through reflective listening that the interviewer helps the patient identify and resolve uncertainty and ambivalence and thus increases self-motivation to change (Rubak, Sandbaek, et al., 2005). Behaviors that characterize the delivery of MI include seeking understanding of the person's perspective through reflective listening, expressing acceptance; eliciting and selectively reinforcing the person's own self-motivational statements, expressing recognition of stated problems, concerns, wishes, intention, and ability to change; observing the person's degree of readiness to change; ensuring that resistance is not generated by moving ahead of the person; and confirming the person's freedom to choose and self- direct the behavior. Motivational interviewing has been demonstrated to be effective across an array of health conditions and population groups, including treatment adherence and study retention (Smith West, DiLillo, et al., 2007), increasing physical activity (Hardcastle, Taylor, et al., 2008), improving medication adherence among hypertensive blacks (Ogedegbe, Schoenthaler, et al., 2007), and insuring minorities postcoronary stent placement (Palacio, Uribe, et al., 2014). A systematic review found that phone-based motivational interviewing shows promising evidence in promoting medication adherence (Teeter & Kavookjian, 2014). An integrative review also found that combing motivational interviewing with cognitive behavioral interventions led to improved medication adherence (Spoelstra, Schueller, et al., 2014). Training in the application of motivational interviewing strategy is essential.

Future Directions for Enhancement of Long-Term Adherence

Patient-Centered Medical Home (PCMH) PCMH is an emerging model for improving healthcare quality in the USA (Chowdhury, Kulcsar, et al., 2012). This model may provide an ideal way to integrate behavioral health and primary care services, particularly for persons with chronic conditions such as diabetes (Bojadzievski & Gabbay, 2011) and psychiatric disorders (Amiel & Pincus, 2011). At the organizational level, the PCMH includes several resources, e.g., evidence-based algorithms and care plans, electronic medical records, and referral to other community-based resources for patients (Marrero, Ard, et al., 2013). The central characteristic of the PCMH is the interdisciplinary, collaborative team, a key component of the PCMH. Reflecting an ecological perspective, the interdisciplinary team functions as an organizational-level intervention that influences the paired interactions of clinicians and patients (Marrero, Ard, et al., 2013). Evidence has demonstrated that patients in the medical home reported better care experiences, e.g., patient activation and involvement (Reid, Coleman, et al., 2010), were more likely to have one or more adjustments of insulin and antihypertensive medications (Katon, Lin, et al., 2010), and demonstrated increased adherence to antidepressant medication (Gilbody, Bower, et al., 2006).

New Models of Self-Management The Chronic Care Model (CCM) transforms the daily care for patients with chronic illnesses from acute and reactive to proactive, planned, and population based (Wagner, Austin, et al., 2001). The premise of the model is that quality chronic care is delivered by an integrated system involving six essential elements: health system leadership and support, community resources, self-management support, delivery system design, decision support, and clinical information systems (Coleman, Austin, et al., 2009). Bodenheimer et al. reported improved adherence resulting from their Chronic Care Model, an approach to self-management of chronic disorders (Bodenheimer & Laing, 2007; Bodenheimer, Lorig, et al., 2002). The model of care delivery involves the clinician along with health coach assistants who work with the patient prior to and after the clinical visit and also provide follow-up between clinic visits. The health coach engages the patient in collaborative goal setting and develops an action plan for the regimen that needs to be addressed (Chen, Thom, et al., 2010). Using a patient-centered approach, Calvert and colleagues found that a combination of enhanced inhospital counseling sessions, addressing adherence barriers, communication with community pharmacists and physicians, and continued adherence assessment by community pharmacists resulted in improved medication adherence after hospital discharge (Calvert, Kramer, et al., 2012).

Delivery of Multicomponent Interventions In contrast to single strategies, the majority of the clinical trials evaluate multicomponent interventions, e.g., the use of self-monitoring and self-efficacy enhancement. Today, multicomponent programs may include combinations of technology support or use of media (Burke, Styn, et al., 2012), group- and/or individual-based delivery strategies, telephone-delivered intervention sessions, or delivery of text messages (Patrick, Raab, et al., 2009). In most intervention studies, there are several components to the intervention, e.g., various behavioral strategies are implemented and may include goal setting, , feedback, social support, and problem-solving. The evidence suggests that the use of more than one strategy for all behaviors results in improved adherence outcomes (Almeida, Wasko, et al., 2011; Haynes, McDonald, & Garg, 2002; Hedegaard, Kjeldsen, et al., 2014). For medication adherence, the interventions with the strongest evidence include education combined with behavioral interventions (Dean, Walters, & Hall, 2010; Olson, Gaffney, et al., 2009; Osterberg & Blaschke, 2005; Stewart, George, et al., 2014). Nevertheless, a recent Cochrane review on medication adherence interventions revealed that multicomponent intervention studies generated the lowest level of bias, and while being effective and complex, these studies did not generate a large improvement in adherence or clinical outcomes. A suggestion for future interventions included targeting long-term feasibility and examining patient-centered clinical outcomes (Nieuwlaat, Wilczynski, et al., 2014).

Summary and Recommendations

Several factors may influence a person's ability to adopt and sustain new behaviors. When considering adopting a new behavior, the person needs to evaluate the anticipated benefits, which need to compare favorably to their current situation, and they need to have positive expectations regarding future outcomes. The decision to maintain a behavior is dependent, at least partially, on whether the outcomes achieved with the new behavior are sufficiently desirable to sustain the behavior. Most individuals have clear expectations about what a new lifestyle will provide; if their experiences do not meet those expectations, they will be dissatisfied and less motivated to maintain it, particularly in environments that often are not supportive of a healthy lifestyle.

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20

Patient-Provider Interactions: Promoting Effective Behavior and Providing Optimal Care

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Patient-Provider Interactions: Meeting Patients Where They Are to Provide Optimal Care

Over the last several decades, there have been dramatic changes in patient-provider relationships, with a movement toward more patient-centered care and increased expectations for healthcare providers to play a central role in promoting patients' effective health behavior change. The overarching change has been a movement along a spectrum from paternalistic (or doctor-centered) to patient-centered care (see Fig. 20.1). With these changes, there has been increasing interest in the relationship between patient-centered care and healthcare outcomes. The present chapter reviews the evolution of the patient-provider relationship; the methods used to assess, understand, and modify the relationship; and the various ways patient-provider encounters may impact patient-oriented outcome variables such as satisfaction with care, adherence to treatment recommendations, and clinical outcomes.

Evolution of the Patient-Provider Relationship

Paternalistic Model of Healthcare

Rooted in the Hippocratic tradition, the patient-physician relationship, or more broadly patient-provider relationship, has historically been a paternalistic one. The paternalistic patient-provider relationship was based on the "expert role" of the provider and assumed that the provider was responsible for making healthcare decisions in the patient's best interest (Parsons, 1951; Pellegrino & Thomasma, 1988). The patient was expected to be passive in decision-making and trust in their provider to make appropriate healthcare decisions, even if these decisions were occasionally in contrast to the preferences of the patient. While this type of patient-provider relationship was clearly an autocratic one, it was not necessarily problematic. The paternalistic patient-provider relationship allowed the patient to assume a "sick role" and relived the patient of the "burden" of making healthcare decisions (Childress, 1982). While there is no standard

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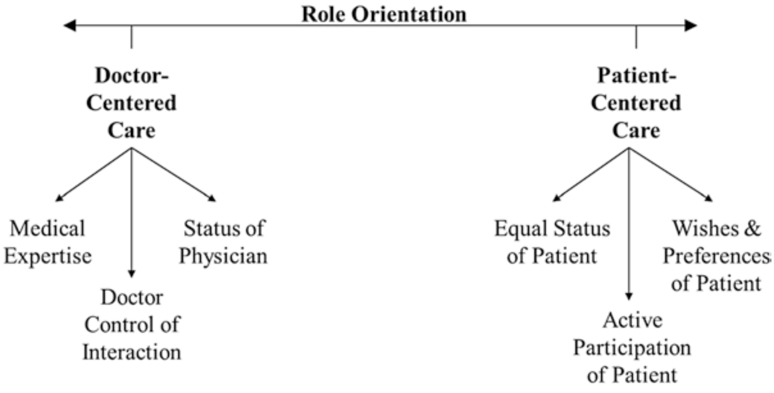

Fig. 20.1 Spectrum of patient-provider relationships

definition of the paternalistic patient-provider relationship, it is traditionally characterized by two factors: asymmetrical decision-making and a biomedical model of illness.

First, the paternalistic patient-provider relationship is characterized by decision-making that is directed by the provider (i.e., doctor-centered). The provider is entrusted to make decisions regarding diagnostic testing and treatment planning based on his or her professional expertise. For example, in the case of a patient with breast cancer, the decision to pursue surgical intervention, chemotherapy, radiation therapy, or a combination treatment would be at the discretion of the physician, based on his or her assessment of the patient's illness. In the doctor-centered model of decision-making, information regarding the various treatment options (e.g., side effects of each treatment, risks for treatment complications, and chances of remission) would not necessarily need to be presented to the patient in order for the patient to choose a treatment plan. Instead, the provider may present only the necessary amount of information about treatments to reassure the patient that the treatment plan is in the patient's best interest. One presumed benefit of doctor-centered decision-making is that patients are not overwhelmed by healthcare information and are not required to make decisions based on their limited medical knowledge and perhaps in times of emotional distress, such as immediately after receiving a diagnosis of cancer (Childress, 1982).

Second, the paternalistic model of healthcare is also associated with a biomedical model of illness. The reductionistic, biomedical model of illness assumes that illness is caused by a biological factor (e.g., virus, bacteria, genetic mutation) that can be treated using a medical intervention (e.g., medications, surgical interventions, radiation). The biomedical model generally ignores other factors that may contribute to illness, such as social and emotional factors. In the paternalistic model, healthcare decisions are often driven by a focus on ridding the body of an identified illness, without full appreciation of the patient as a "whole person" and consideration of the familial, social, behavioral, and emotional factors that may impact disease development, disease management, and treatment outcomes.

Patient-Centered Care: An Alternative to Paternalism

Over the last several decades, the standard model of healthcare has moved away from paternalism, or doctor-centered care, in favor of an alternative patient-centered model (see Fig. 20.1). A review of videotaped patient-physician interactions from 1986 to 2002 found that physicians engaged in significantly more information sharing behavior in 2002 compared to 1986 (Bensing, Tromp, et al., 2006). It is notable that in this study, while information sharing increased, process-oriented talk decreased. Specifically, physicians engaged in less talk about concern for their patients and less partnership building, which suggests that the movement from doctor-centered to patient-centered care has not occurred in a standard or uniform way. In 2005, the National Healthcare

Quality report found that patient-centered care was "always" or "usually" present in 89% of healthcare encounters (Agency for Healthcare Research and Quality, 2005). Patient-centered care has also come to represent a measure of quality care—in 2001, an Institute of Medicine report identified patient-centered care as one of the six aims of healthcare (National Institute of Medicine, 2001).

This rise in patient-centered care is likely due to several factors. First, with the ratification of the Patient Self-Determination Act (1991) and the Doctrine of Informed Consent, the ability for providers to make autonomous decisions has been reduced. Providers are now required to give patients sufficient information regarding treatment options and risks and benefits of treatments in order for patients to give informed consent for diagnostic and treatment procedures (Briss, Rimer, et al., 2004). Second, it has also been proposed that the rise in patient-centered care has been influenced by the development of direct-to-consumer advertising by pharmaceutical companies. In a recent survey, 35% of patients reported that they had asked their provider for more information about a drug because of an advertisement, and 19% had specifically asked for a prescription for an advertised drug (Wilkes, Bell, & Kravitz, 2000). Furthermore, when asked what they would do if their provider refused to prescribed the requested drug, 46% said they would be disappointed, 25% stated they would try to change their provider's mind, and 15% said they might switch providers (Wilkes, Bell, & Kravitz, 2000). Finally, it has been suggested that the changing demographics in the United States have contributed to the increased interest in patient-centered care. As more adults are living with chronic illnesses that require frequent patient-provider encounters and increased self-management, paternalistic or doctor-centered models of illness have become less applicable, in favor of patient-centered models of illness (Lambert, Street, et al., 1997).

Although there has been increasing interest in the provision of patient-centered care, a standard definition of this concept has not been established. Early work described patient-centered care as understanding an individual patient's perception of his or her work and illness (Balint, 1957; Roter & Stewart, 1989). Others have described patient-centered care as the opposite of doctor-centered (or paternalistic) care (Bensing, Tromp, et al., 2006). Lambert et al. (1997) posited that patient-centered care differs from paternalistic care in two key ways: a focus on information sharing and a focus on the socioemotional aspects of healthcare.

A review by Mead and Bower (2000) proposed perhaps the most comprehensive definition of patient-centered care and identified five key dimensions that distinguish patient-centered care from biomedical or doctor-centered care. Patient-centered care uses a biopsychosocial model of illness, focuses on the "patient as a whole person," emphasizes shared decision-making, and highlights the therapeutic alliance between patient and provider. Though sometimes overlooked, it also considers the "doctor as a whole person." Each of these aspects is explained in further detail below.

Biopsychosocial Model of Illness Patient-centered care utilizes a biopsychosocial model of illness. Engel (1977) proposed that illness develops as interaction of biological (e.g., a bacteria, virus), psychological (e.g., coping skills, stress), social (e.g., marital status, social support), and cultural (e.g., socioeconomic status, educational level) causes. In the biopsychosocial model of illness, these multiple causes of illness are identified and addressed as targets of treatment (Engel, 1977). For example, when treating a patient with hypertension, a provider utilizing the biopsychosocial model of illness would consider the way that the patient's current depressed mood, increased marital stress, and limited literacy may impact his ability to manage his hypertension. It has been suggested that the utilization of this biopsychosocial model of illness is the fundamental component of patient-centered care.

Patient as a Whole Person Patient-centered care focuses on the patient as a whole person (Balint, 1957), meaning that consideration is paid to the personal meaning or impact of an illness. The impact of a particular diagnosis may vary significantly between patients based on their personal and family histories, daily activities, and understanding of the illness. For example, one 35-year-old woman newly diagnosed with stage 1 breast cancer may feel very hopeful about her prognosis and treatment options if she had a sister with a history of cancer who completed treatment with few side effects and has been in remission for 5 years. However, another patient with a similar breast cancer may be devastated by her diagnosis if her mother died of cancer after a prolonged and difficult treatment process. Seeing the "patient as a person" also includes consideration of how a diagnosis and treatment may impact a patient's self-concept. For example, patients may experience feelings of embarrassment when diagnosed with a psychological disorder like depression and experience decreased self-esteem regarding decreased sexual function, a common symptom of depression and side effect of antidepressant medications.

Shared Decision-Making A third aspect of patient-centered care is shared decision-making and shared power between patient and provider. This dimension of patient-centered care represents a significant difference from the traditional paternalistic relationship, which was characterized by a power differential between the "expert" provider and the "uninformed" patient (Parsons, 1951). Several definitions of shared decision-making have been proposed, but perhaps the most comprehensive is the definition offered by the United States Preventive Services Task Force (USPSTF). According to the USPSTF, a shared decision-making process is one in which a patient (1) understands the diagnosis and the seriousness of the diagnosed condition, (2) understands the treatment options and the risks and benefits of the various options, (3) evaluates the options with regard to their personal values and preferences, and (4) participates in decision-making at the level at which he or she is comfortable. Shared decision-making requires input from both patient and provider during all stages of care throughout assessment, diagnosis, treatment, disease management, and relapse prevention. It also requires that the physician provides patients with information about the diagnosis and treatment options and requires that patients take an active role in eliciting necessary information (e.g., asking the questions they need answered in order to make treatment decisions) and making their provider aware of their preferences and values that impact their treatment planning.

Therapeutic Alliance Patient-centered care is characterized by an interest in the therapeutic alliance between patient and provider. Borrowing from psychotherapy literature, Rogers (1961) posited that providers need to express (1) empathy or understanding of a patient's personal emotional experience of illness, (2) congruence or genuine expression of their experience of the interaction, and (3) unconditional positive regard, that is, a positive evaluation of the patient as a person, despite the possibility of negative evaluation of a patient's actions, such as poor adherence to treatment. Rogers argued that these conditions lead to development of a positive therapeutic alliance, which is considered *necessary* and *sufficient* to elicit change in psychotherapy. With respect to eliciting healthcare changes, however, a positive patient-provider therapeutic alliance may encourage patients to take a more active role in their healthcare and increase adherence to treatment recommendations. It is notable that many interventions to improve patient-centered care are aimed at increasing provider communication skills consistent with Rogers' theory (e.g., active listening, empathic reflection of emotions, eliciting patient experience), in an effort to improve therapeutic alliance.

Doctor as a Whole Person The final aspect of patient-centered care includes consideration of the "doctor as a whole person." Just as a patient's participation in healthcare is influenced by his or her psychological and social state, a provider's participation is likewise influenced by his or her psychological and social state. Providers are subject to the same biases, subjectivity, and emotional reactions as patients. For example, a provider may be more likely to engage in shared decision-making with a patient whom they perceive as being collaborative, displaying more positive emotions, and having good communication skills (Street, Gordon, & Haidet, 2007). However, that same provider may be less likely to engage in shared decision-making with a patient whom they perceive as having poorer communication skills, displaying more negative emotions, or being more contentious (Street, Gordon, & Haidet, 2007).

Assessing Patient-Provider Relationships

Patient-provider relationships have generally been assessed using questionnaires (i.e., patients' reports on the type of interaction between patient and provider) or observation (i.e., coding of videotaped encounters). Although direct observation is likely to provide the most accurate categorization of the patient-provider relationship, it is often impractical given cost, equipment, and time constraints. However, questionnaire methods are also likely to yield important information about patient *perception* of and *satisfaction* with patient-provider interactions in a more cost-effective and time-efficient manner. As there is no standardized definition of patient-centered care, there also appear to be no standardized measures of patient-centered care. The following section will briefly review a few of the questionnaires and observational coding schemes used to assess patient-provider relationships.

Interpersonal Process of Care (IPC) Questionnaire (Stewart, Napoles-Springer, & Perez-Stable, 1999) The original IPC scale is a 41-item scale that assesses three domains consistent with patient-centered care: general communication, decision-making, and interpersonal style. Scoring allows for computation of 13 subscale scores across these three domains. General communication subscales include general clarity, explanation of condition, explanation of processes, explanation of self-care, explanation of medications, elicitation of patient concerns and responses, and empowerment. Decision-making subscales include responsiveness to patient preferences and consideration of patient's ability to comply. Interpersonal style subscales include friendliness and courteousness, respectfulness, discrimination, and emotional support. The original form of the IPC was developed and validated with an ethnically and racially diverse low socioeconomic status sample; however, a revised 29-item form and an 18-item short form have been developed for use across ethnic, racial, and socioeconomic status groups (Stewart, Napoles-Springer, et al., 2007).

Health Care Climate Questionnaire (HCCQ) (Williams, Grow et al., 1996) Rooted in self-determination theory, the HCCQ assesses patient perceptions of autonomy support from their healthcare provider. According to self-determination theory, autonomy is one of the fundamental needs that underlie motivation. In the case of healthcare, meeting the need for autonomy is necessary to promote patient motivation to participate in healthcare and engage in self-management of illness, consistent with the information sharing and shared decision-making aspects of patient-centered care. The long form of the HCCQ is 15 items and the short form is 6 items. Sample items include "I feel that my physician has provided me with choices and options" and "My physician listens to how I would like to do things." The HCCQ has been used to assess perceived autonomy support (and patient-centered care) in a variety of patient populations, including patients in weight management treatment, patients in smoking cessation treatment, and patients with diabetes (Williams & Deci, 2001; Williams, Freedman, & Deci, 1998; Williams, Rodin, et al., 1998; Williams et al., 1996).

Patient Assessment of Chronic Illness Care (PACIC) Scale (Glasgow, Wagner, et al., 2005) The PACIC was designed as a brief measure to determine if patients with chronic illnesses were receiving care that was consistent with the Chronic Care Model of illness (Wagner, Austin, & Von Korff, 1996). It was designed as a patient version to complement the Assessment of Chronic Illness Care questionnaire, a tool used by clinicians to evaluate their practices and improve quality of care. Specifically, the 20-item PACIC assesses patient perceptions of care in five domains: patient activation/involvement, delivery system/decision support, goal setting/tailoring, problem-solving, and follow-up/coordination. The PACIC was validated in several chronic illness populations, including patients with hypertension, diabetes, arthritis, pain, asthma, and depression, and was found to have adequate validity and reliability (Gensichen, Serras, et al., 2010; Glasgow, Whitesides, et al., 2005; Schmittdiel, Mosen, et al., 2008).

Bales Process Analysis System (Bales, 1950) Growing out of research on social interaction and small groups, the Bales method has been adapted to measure verbal interactions between patients and providers. Complex verbal interactions are divided into individual "units" of interaction, which are roughly equivalent to a simple sentence. Each of these units is then coded into one of 12 mutually exclusive categories. These 12 categories have been grouped into six affectively neutral categories and six affectively charged (either positive or negative) categories (Roter & Hall, 1989). Affectively neutral categories include task-related behaviors such as giving information and giving suggestions, whereas affectively charged categories reflect socioemotional behaviors such as agreeing or disagreeing with the patient or showing tension in the interaction. The Bales system has been widely used to assess and categorize provider behavior and to examine the relationship between provider behavior and outcomes, such as patient adherence with medications and patient satisfaction (Davis, 1968; Stewart, 1984).

Roter Interaction Analysis System (RIAS) (Roter & Larson, 2002) The RIAS is currently the most widely used system for coding provider behavior in medical encounters and includes assessment of 28 discrete categories of behavior. The various behaviors have been conceptually divided into two domains: a socioemotional domain and a task-oriented domain. The socioemotional domain is broadly defined as "affective" behavior and includes specific behaviors such as engaging in social conversation, making statements of concern, providing reassurance, and demonstration of empathy. The task-oriented domain is broadly defined as "behaviors that define the role of the physician" and "comprise the 'expertness' for which a physician is consulted" (Roter & Hall, 1989). This domain includes behaviors such as giving instructions, asking closed- and open-ended questions, and providing counsel. The RIAS system has been used to code interactions across countries, medical settings (e.g., pediatric medicine, emergency medicine, primary care), and patient diagnoses (e.g., asthma, hypertension, diabetes) (Hampson, McKay, & Glasgow, 1996; Roter & Ewart, 1992; Roter & Larson, 2002; van Dulmen, Verhaak, & Bilo, 1997; Wissow, Roter, et al., 1998; Wissow, Roter, & Wilson, 1994).

Four Habits Coding Scheme (4HCS) (Krupat, Frankel, et al., 2006) The 4HCS is a tool for assessing physician behavior in accordance with the Four Habits Model utilized to teach communication skills. The Four Habits Model encourages physicians to invest in the beginning of the encounter (e.g., show familiarity with patient medical history, greet patient, elicit patient agenda), elicit the patient's perspective (e.g., patient's understanding of the problem, goals for visit), demonstrate empathy (e.g., encourage patient emotions, accept patient feelings), and invest in the end of the encounter (e.g., offer rationale for tests, involve patient in decisions, encourage questions). The 4HCS includes 23 items that assess these core skills and includes instructions for coding both verbal and nonverbal physician behaviors. The 4HCS differs from other coding schemes in that the coder distinguishes between levels of performance in each of the domains, rather than simply providing frequency counts of observed behaviors. The 4HCS has been found to have adequate reliability and good convergent validity with other scales, such as the RAIS (Krupat, Frankel, et al., 2006).

Provider Behavior Questionnaire (PBQ) (Cvengros, Christensen, et al., 2009) The PBQ was developed to assess patient perceptions of provider behavior in three domains: information sharing and shared decision-making, patient self-management of illness, and provision of socio-emotional support. These domains were chosen to correspond to patient preferences for healthcare, as measured by the "Behavioral Involvement" subscale of the Krantz Health Opinion Survey (Krantz, Baum, Wideman, 1980) and the "Sharing" and "Caring" subscales of the Patient-Practitioner Orientation Scale (Krupat, Rosenkranz, et al., 2000) (these scales are discussed in detail later). Patients answer the nine PBQ items (three items per domain) using a true/false format, rather than a Likert format, to achieve provider behavior ratings that are as objective as possible. The PBQ was developed as a proxy for direct observation of the patient-provider interaction when this method is impractical or not feasible. The PBQ has been shown to have acceptable reliability and validity (Cvengros, Christensen, et al., 2009).

Factors Associated with Patient-Centered Care

Physician Correlates of Patient-Centered Care

Using various measurement methods, researchers have tried to identify which providers are more likely to utilize patient-centered care. Unfortunately, the data are limited and have yielded inconsistent findings. In a study of communication patterns between patients and physicians, physicians who tended to use a more biomedical model of communication (i.e., more physician-directed and focused on physical symptoms) were younger than those who tended to use a more psychosocial model of communication (Roter, Stewart, et al., 1997). In contrast, another study found that younger physicians were more likely to engage in shared decision-making, a behavior consistent with a more patient-centered approach to communication (Young, Bell et al., 2008). Roter et al. (1997) also found that male physicians were more likely to use a more biomedical model of communication, and female physicians tended to use a more psychosocial model of communication. A meta-analysis of almost 30 studies confirmed this gender effect on physician communication—female physicians were more likely to engage in partnership building, psychosocial question asking, and psychosocial counseling than male physicians (Roter, Hall, & Aoki, 2002).

Physician communication style is also influenced by observed or perceived patient characteristics. Johnson, Roter, Powe, and Cooper (2004) found that providers engaged in less patient-centered care with black patients compared to white patients. Cené, Roter, Carson, Miller, and Cooper (2009) found that this racial effect may be compounded by poor adherence with treatment, such that black patients who also had poorly controlled hypertension received particularly less rapport building and less psychosocial communication from their physicians. Finally, Street and colleagues (2007) found that providers were more likely to engage in patient-centered communication with patients they perceived to be "good historians," patients they perceived to be active participants in care, and patients they believed would be more adherent with treatment. These authors suggested that there may be a reciprocal effect between patient-provider communication and outcomes, such that good patient-provider communication may lead to positive outcomes, which may in turn lead to improved patient-provider communication.

Providers' engagement in patient-centered care may also depend on their perception of individual patients' interest in this type of care. As such, a systems or interactional approach may be a helpful framework for studying and promoting patient-centered care. For example, patients could be trained to initiate a more active role and draw out more patient-centered care from their providers. Patients with type 2 diabetes who received a brief, personalized training session to assist with formulating a strategy for shared decision-making immediately preceding a clinic visit were twice as effective in obtaining information from their physician during the visit than patients who received educational materials (Greenfield, Kaplan, et al., 1988). Moreover, these patients had better diabetes adherence (lower hemoglobin A1c levels) and fewer functional limitations. Interventions that change patients' behavior in clinical encounters can accordingly change providers' behavior in response.

Impact of Patient-Centered Care on Outcomes

Patient Satisfaction With the growing interest in patient-centered care, researchers have also begun to examine the impact of patient-centered care on outcomes. One of the most common outcomes studied is patient satisfaction with care. While this outcome may be considered a subjective or "soft" outcome, patient satisfaction continues to be an important patient-centered outcome. Indeed, patient satisfaction has been identified as a marker of quality care by both the Joint Commission on Accreditation of Healthcare Organization (JCAHO) and the United States National Center for Health Research and Development. Also, health systems are very concerned about patient satisfaction, as it is related to their overall position and market share in their communities.

Roter et al. (1997) audiotaped 537 interactions between patients and physicians and coded them into five communication patterns using the RAIS coding scheme. Interactions were categorized along the dimension of doctor-centered to patient-centered care. Patient satisfaction was highest among patients whose interactions were characterized as "psychosocial," where the physician spent equal time on psychosocial and biomedical talk and was positive and accepting of patient input, which reflects a more patient-centered approach to care. Similar results were found when assessing patient-centered care using survey methods. In a study of over 4000 patients receiving care for a chronic condition (e.g., diabetes, chronic pain, coronary artery disease), those who perceived their care to be patient-centered using the PACIC (described earlier) were twice as likely to rate their satisfaction with healthcare as "very high" to "best healthcare possible" (Schmittdiel, Mosen, et al., 2008). In pediatric medicine, parents' perceptions of greater patient-centered care have also been associated with greater satisfaction with their child's healthcare (Wanzer, Booth-Butterfield, & Gruber, 2004).

Despite the positive results using observational methods, intervention studies with the goal of promoting a more patient-centered patient-provider interaction have yielded equivocal results in terms of patient satisfaction. Kinmonth, Woodcock, Griffin, Spiegal, and Campbell (1998) conducted a randomized trial comparing patient-centered care to treatment as usual among patients with type 2 diabetes. Patients in the intervention group received care from nurses and physicians who had received up to a day and a half of specialized training in providing patient-centered care. Specific skills included education and practice of active listening and facilitating behavioral change (Kinmonth, Woodcock, et al., 1998). At one-year follow-up, patients in the intervention condition were more likely to report excellent communication with their physicians and greater satisfaction with care. Martin, DiMatteo, and Lepper (2001) compared outcomes for patients in an experimental inpatient unit that emphasized patient-centered care to patients in other traditional units in the same hospital. Patients in the patient-centered care unit reported significantly greater satisfaction with care than patients receiving treatment as usual (Martin, DiMatteo, and Lepper, 2001). On the contrary, in a study of general practitioners, subspecialists, and nurse practitioners (Brown, Boles, et al., 1999) and in a study of physicians only (Joos, Hickam, et al., 1996), training in patient-centered care led to observable changes in provider behavior, but these changes in behavior were not associated with patient satisfaction.

Patient Adherence In addition to satisfaction, research has examined the impact of patient-centered care on adherence to treatment. As discussed in the chapter by Burke, *infra*, adherence to treatment is suboptimal across many disorders, with only approximately half of patients demonstrating adequate adherence with treatment (DiMatteo, Giordani, et al., 2002). Rates of nonadherence are highest among preventive and chronic regimens, where patient-centered care may be of most importance (DiMatteo, Giordani, et al., 2002). Nonadherence is a costly problem for both the individual patient and larger society. Poor adherence with treatment is associated with increased disease burden, disease relapse, hospitalization, and treatment failure (Christensen, 2004). For example, poor control of diabetes is associated with neuropathy, retinopathy, and cardiovascular disease. Nonadherence to antiretroviral medications for HIV is associated with increased viral load and development of AIDS (Katzenstein, Lyons, et al., 1997). From a societal perspective, nonadherence to medication has been implicated in the development of drug-resistant strains of bacteria and viruses (Katzenstein, Lyons, et al., 1997). Annual costs of nonadherence are estimated at $100 billion, including increased healthcare costs and lost productivity costs (Berg, Dischler, et al., 1993).

In their seminal work on the Health Belief Model, Becker and Maiman (1975) found that aspects of the patient-provider relationship could impact patient adherence. Specifically, their review of early work suggested that "impersonality" of the physician and "less reciprocal interaction" between patient and physician were associated with poorer treatment adherence (Becker & Maiman, 1975). More recent studies using contemporary models of patient-centered care have supported these results. Piette, Schillinger, Potter, and Heisler (2003) examined the relationship between patient-provider communication and completion of self-care behaviors (e.g., foot care, medication adherence, activity) by patients with diabetes. Using an adaptation of the IPC as a measure of patient-centered care and general communication style, they found that the probabilities of daily foot checks and adherence to daily diet, daily exercise, and diabetes medication regimens were significantly higher among patients receiving communication reflective of more patient-centered care (Piette, Schillinger, et al., 2003). Using the PACIC measure, Schmittdiel et al. (2008) found that patients who felt they had received patient-centered care were significantly more likely to engage in five self-care behaviors: utilizing self-management services, eating five or more servings of fruits and vegetables daily, performing self-management tasks, exercising regularly, and participating in stress management. Unfortunately, PACIC scores were not significantly related to measures of medication adherence (Schmittdiel et al. 2008).

Intervention studies have shown that although providers can be successfully trained to increase patient-centered care, this increase is not robustly linked to improved outcomes. Kinmonth et al. (1998) compared patients with type 2 diabetes receiving care from providers with additional training in patient-centered care to patients receiving treatment as usual. The primary marker of diabetes regimen adherence, hemoglobin A1c, was not statistically different between groups. In the study by Joos et al. (1996), increased patient-centered care was not associated with medication adherence or compliance with follow-up visits.

Disease Outcomes Researchers have also studied the impact of patient-centered care on health outcomes such as self-reported health, objective markers of disease progression, and healthcare utilization. Patient report of greater patient-centered care was associated with decreased pain among patients with chronic fibromyalgia (Alamo, Moral, & Perula de Torres, 2002) and decreased symptom discomfort among patients in general medical practice (Stewart, Brown, et al., 2000). Ratings of greater patient-centered care following a heart attack were also associated with lower chest pain at one-year follow-up (Fremont, Cleary, et al., 2001). In an observational study, 315 patient-physician interactions were coded for patient-centered care on three domains: exploring the illness experience, understanding the whole person, and finding common ground (Stewart, Brown, et al., 2000). Patients also completed a questionnaire assessing perceptions of patient-centered care. Although patient-centered care coded from audiotapes was not associated with health outcomes, perceptions of patient-centered care were associated with patient-rated symptom improvement and overall health. In the Kinmonth et al. (1998) study, although the differences were small and of questionable clinical significance, body mass index (BMI) and triglyceride concentrations were significantly lower in the patient-centered care intervention group compared to the control group. Notably, blood pressure, cholesterol, and prescription of hypoglycemic medications did not differ between groups. A more recent study of primarily oncology patients utilized a patient-centered intervention that included up to 10 h per month of patient contact from members of the healthcare team (Sweeney, Halpert, & Waranoff, 2007). Patients in the patient-centered condition received significant education, frequent phone calls (average of 24 per month), home visits, and goal setting. Compared to patients who received treatment as usual, patients in the patient-centered condition had significantly fewer hospital admissions, fewer emergency room visits, and greater hospice and homecare days. Survival rates were not statistically different across treatment conditions (Sweeney, Halpert, & Waranoff, 2007).

Healthcare Costs If patient-centered care improves patient outcomes, such as patient adherence to treatment and disease outcomes, healthcare utilization costs may be decreased. However, only a few of the intervention studies reviewed in this chapter have directly examined the cost-effectiveness of the patient-centered intervention. In the Stewart et al. (2000) observational study of primary care patients, perceptions of patient-centered care were associated with fewer diagnostic tests and referrals. In the Sweeney et al. (2007) study of patients with life-limited disease receiving intensive patient-centered care versus treatment as usual, overall cost was reduced in the patient-centered care condition by 26%.

Summary A number of studies have developed protocols designed to promote providers taking a more patient-centered approach that emphasizes shared control and a highly active patient role in clinical encounters (Lewin, Skea, et. al. 2001). However, the literature on the impact of patient-centered care on outcomes such as patient satisfaction, adherence to treatment, and disease outcomes has failed to demonstrate a robust connection between patient-centered care and improved outcomes. Perceptions of patient-centered care appear to be associated with greater satisfaction with care, improvement in some health behaviors, and lower subjective disease burden. Interventions designed to improve patient-centered care through training of providers and utilization of a team approach to care have not consistently led to improved patient outcomes. This inconsistency in findings has led researchers to consider the role of patient preferences regarding patient-centered care. It has been hypothesized that the relationship between patient-centered care and positive outcomes may be moderated by patient preferences: patient-centered care may only improve outcomes for those patients that want or value it (Christensen, Howren, et al., 2010)!

Patient Preferences Regarding Healthcare

Variability in Patient Preferences

A study of nearly 3000 adults in the United States assessed patient preferences in three aspects of patient-centered care: seeking information, discussing options, and making treatment decisions (Levinson, Kao, et al., 2005). For each aspect of care, patient preferences fell at a different point along a dimension from patient-centered to physician-centered. For example, while 96% of respondents reported a preference to be asked about their opinions regarding healthcare, 52% of respondents reported that they preferred to leave the final decision to the physician (Levinson, Kao, et al., 2005). Swenson et al. (2004) found similar results by asking participants to view videotapes of simulated patient-physician interactions that varied from very doctor-centered to very patient-centered. Although the majority of respondents preferred the patient-centered interaction, a sizable minority (over 30%) preferred the very doctor-centered interaction (Swenson, Buell, et al., 2004). Two studies of actual patients yielded conflicting results. In a study of patients with asthma, roughly 25% preferred an active role, 35% preferred a collaborative role, and 40% preferred a passive role (Caress, Beaver, et al., 2005). However, in a study of primary care patients, nearly all patients showed high preference for a collaborative patient-centered approach (Little, Everitt, et al., 2001). Taken together, these studies highlight the wide variability in United States patients' preferred roles in their own healthcare and in the clinical encounter.

Within the United States, patient demographic factors have been associated with particular preferences for patient-centered care. A higher preference for patient-centered care has been found among patients who are younger (Caress, Beaver, et al., 2005; Coulter & Jenkinson, 2005; Levinson, Kao, et al., 2005; Swenson, Buell, et al., 2004), are female (Levinson, Kao, et al., 2005; Swenson, Buell, et al., 2004), have higher educational attainment (Caress, Beaver, et al., 2005; Swenson, Buell, et al., 2004), have better self-reported health (Levinson, Lesser, & Epstein, 2010), and have higher socioeconomic status (Caress, Beaver, et al., 2005). In terms of racial, ethnic, and cultural group status, African-American and Hispanic patients were more likely than Caucasian patients to prefer a more provider-centered approach to care (Levinson, Kao, et al., 2005), and Pacific Islander/Asian-American patients in Hawaii were less assertive and participated less in their healthcare encounters than patients who identified culturally as mainland Americans (Young & Klingle, 1996).

Though limited, international research in this area suggests that geographic and cultural factors also affect variability in patient preferences. In a multi-country European survey, patients reported a general desire for a more autonomous role in their healthcare and a higher degree of involvement in decision-making than they had been experiencing (Coulter & Jenkinson, 2005). Interestingly, preferences differed significantly across countries. Polish and Spanish patients proportionately preferred more paternalistic interactions, with the provider as primary decision-maker, whereas Swiss and German patients endorsed high preferences for patient involvement and Swedish, Slavonic, Italian, and British patients formed a middle group. Across all countries, however, younger patients (under age 35) expressed a desire for more patient-centered care and active patient involvement. This age-related effect mirrors that observed in the United States.

In a comparison of patients from Hong Kong, the Hawaiian Islands, and the mainland United States, cultural factors were associated with varying preferences for patient-provider communication (Kim, Klingle, et al., 2000). More individualistic/independent cultural characteristics were associated with positive beliefs about patient participation, including patient assertiveness and positive response efficacy. On the other hand, more collectivist/interdependent cultural characteristics were associated with more negative perceptions of patient participation and greater avoidance of communication with providers. As such, patients from Hong Kong were less willing to be assertive during a medical interview than patients from the Hawaiian Islands or the mainland United States. In addition to evaluating such broad cultural characteristics as individualism and collectivism, it is relevant to consider factors that are directly applicable to the healthcare interaction, such as cultural differences in communication processes. For example, Japanese, Korean, and Chinese cultures have more high-context communication, tending to value indirect communication and avoid self-disclosing, demanding, asserting, or openly criticizing others (Gudykunst & Kim, 1992). On the other hand, the United States culture has predominantly low-context communication, valuing more direct communication and self-disclosure (Gudykunst & Kim, 1992).

Notably, global variability in providers' behavior toward patients and in general cultural beliefs about illness also impact the patient-provider interaction. A recent qualitative analysis of Ghanaian medical students' experiences on a medical rotation in the United States described cultural differences in these domains. Regarding provider behavior, one student stated that "'in Ghana … the patient entrusts their life with you. Therefore you are God, you decide whatever—everything—for them'" (quoted in Abedini, Danso-Bamfo, et al., 2015, p. 164). In comparison, this student found that a patient in the United States is more like a "'customer'" and that the doctor's role is to "'listen to the patient, give options, let the patient make choices—which I think is very good medicine to practice'" (quoted in Abedini, Danso-Bamfo, et al., 2015, p. 164). In terms of patient attitudes toward illness, these students considered Ghanaian cultural taboos associated with illness (e.g., "The gods are angry") and Ghanaians' generally more limited access to medical information to be barriers to active patient engagement and illness self-management. Ultimately, these African students reflected that these cultural differences in both patient and provider behavior affect patients' degree of autonomy and shared decision-making in clinical encounters.

Notably, interindividual, intraindividual, intercultural, and intracultural variability in preferences exists. As reviewed, patients vary in their preferred interactions with providers. Moreover, an individual patient's preferences are not unifactorial or permanent. Rather, a patient's preferences may vary across one's stage of life or illness course or based on contextual factors such as the unique healthcare setting and presenting healthcare circumstance. For example, a patient may feel more comfortable having a primary role in making a decision about his or her diabetes regimen in a routine primary care appointment than they do deciding between treatments following a cancer diagnosis or making end-of-life decisions. Consideration of between- and within-patient variability in preferences may be critical in improving satisfaction with care and treatment recommendations, as will be reviewed later.

Matching Patient-Provider Relationships with Patient Preferences

Studies that examine the concordance, or match, between patient preferences for their role in healthcare and provider attitudes and behavior have found that greater concordance is associated with more positive outcomes. Early work in this area was conducted by Krupat and colleagues, who developed the Patient-Practitioner Orientation Scale (PPOS) to assess patient preferences regarding patient-provider interactions. The PPOS is a 33-item scale with two subscales: a sharing subscale (17 items) and a caring subscale (15 items). Items on the sharing subscale assess the degree to which patients believe "physicians should share power with the patient in terms of agenda setting and decision making, and the extent to which information should be shared with the patient" (Krupat, Yeager, & Putnam, 2000, p. 710). Items on the caring subscale assess the degree to which patients prefer that "physicians care about providing warmth and support to patients and the extent to which physicians should go beyond the patient's symptoms and care about the patient as a whole person" (Krupat, Yeager, et al., 2000, p. 710).

In the original measure validation study, college students completed the PPOS and were then presented with two simulated patient-doctor scenarios: one with a provider that demonstrated high levels of "sharing" and "caring" and one with a provider that demonstrated low levels of "sharing" and "caring." Students rated their satisfaction as if they were the patient in the scenario. Satisfaction was higher for interactions with the provider who demonstrated high levels of sharing and caring, but this relationship was moderated by students' PPOS scores. Those with preferences for greater sharing and caring were more satisfied when the provider demonstrated more, compared to less, sharing and caring (Krupat, Yeager, et al., 2000).

A follow-up study examined the role of congruence in actual practice (Krupat, Rosenkranz, et al., 2000). In the first phase of the study, physicians completed the PPOS and were categorized as having high, neutral, or low scores on the sharing subscale. Twenty physicians with high, low, and neutral information sharing scores, respectively, were chosen for the second phase of the study, during which patients of these physicians also completed the PPOS. Patients were divided into the same three categories based on PPOS scores. Overall, satisfaction was higher among patients whose physicians were categorized as high on information sharing. However, the match between patient and physicians was also associated with satisfaction. Satisfaction was significantly lower among patients who endorsed higher information sharing scores than their physicians. These data support the hypothesis that information sharing is associated with greater patient satisfaction; however, they also provide support for the congruence hypothesis. Satisfaction is significantly lower when there is a poor match between patient and physician, specifically when patients endorse a higher preference for information sharing than their doctors (Krupat, Rosenkranz, et al., 2000).

In their 2001 study, Krupat, Bell, Kravitz, Thom, and Azari examined the impact of PPOS congruence on visit satisfaction and trust in the physician. Prior to a specific outpatient visit, physicians and patients completed the sharing subscale of the PPOS. Patients also completed a measure of trust in their physician. Following the outpatient visit, patients completed measures of satisfaction with care and "endorsement of the physician" (e.g., I would recommend this physician to a friend). Rather than grouping patients based on tertiles (e.g., high, neutral, low), as in previous studies, PPOS congruence was computed using the difference between patient and physician raw PPOS scores. Analyses also controlled for clustering of patients within physicians. It is notable that the correlation between a given patient's PPOS score and their physician's score was extremely small and nonsignificant, suggesting that patients do not systematically self-select providers with similar attitudes. A greater absolute value of the difference in PPOS scores (discordance in either direction) was not predictive of patient satisfaction with the visit. However, larger differences in PPOS scores between patient and physician were predictive of lower trust in the physician and lower endorsement of the physician. Conversely, patients whose PPOS scores were congruent with their physician's scores were more likely to recommend their physician to others, more likely to follow their physician's advice, and more likely to make a special effort to see that physician (Krupat, Bell, et al., 2001).

Given the previous findings that congruence in beliefs as measured by the PPOS are associated with positive patient satisfaction outcomes, Krupat, Hsu, Irish, Schmittdiel, and Selby (2004) conducted an intervention that matched patients with primary care providers. Patients were randomized to an informed choice, guided choice, or usual care control condition. In the informed choice condition, patients were given information on provider demographics, training, personal interests, and openness to complementary and alternative medicine. In the guided choice condition, patients were also given a list of two to five providers whose PPOS scores were closely matched to the patient's scores. Patients in the usual care condition were assigned to providers using whatever method was usually used at that clinic (e.g., first available appointment). All patients were then surveyed after 1 year to measure satisfaction with care, trust in physicians, and attitudes toward the healthcare system. Contrary to the study hypotheses, there was not a significant difference in PPOS discrepancy across intervention groups. In other words, initially giving new patients additional information about providers did not result in patient-provider dyads with more congruent beliefs. However, results regarding congruence in PPOS were consistent with previous studies, such that PPOS congruence was a significant predictor of all outcomes (Krupat, Hsu, et al., 2004).

Effect of Congruence on Patient Outcomes

Christensen and colleagues have extended work on attitudinal congruence between patients and providers in a number of ways, including measurement of additional aspects of patient beliefs and healthcare preferences and conducting this work within a chronic illness model with a focus on patients with renal disease, diabetes, and hypertension (Christensen, Howren, et al., 2010; Cvengros, Christensen, et al., 2009). Finally, their work has examined patient outcomes, such as adherence to treatment, using both self-report measures and objective markers of clinical outcomes. A conceptual model for this work is presented in Fig. 20.2.

In a study of 16 primary care physicians and 146 of their patients, Cvengros, Christensen, Hillis, and Rosenthal (2007) examined the impact of attitudinal congruence between

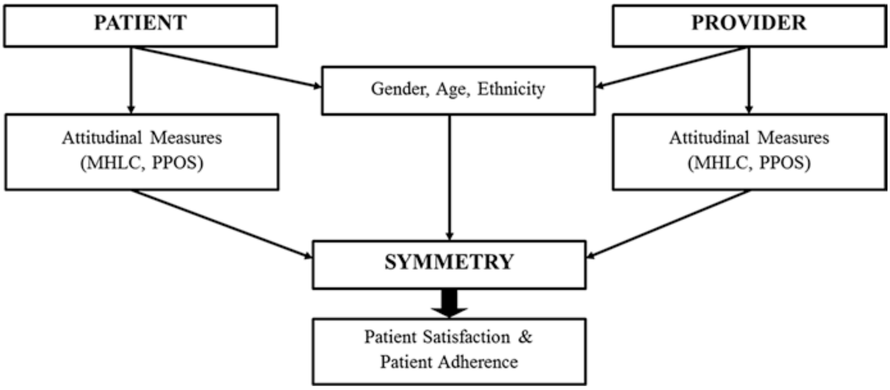

Fig. 20.2 Conceptual model of patient-provider congruence

patients and physicians on patient-reported satisfaction with care and self-reported adherence to treatment. Patients and physicians completed the PPOS as well as the Multidimensional Health Locus of Control Scale (Wallston, Wallston, & DeVellis, 1978). While the PPOS is designed to be administered to patients or physicians, the MHLC is designed for patients only. The authors developed a modified version that could be administered to physicians to assess their beliefs about patient locus of control over health. For example, a patient item from the MHLC is "I am in control of my health," representing a patient's internal control expectancies, and the corresponding physician item is "Patients are in control of their health," representing a physician's belief that patient outcomes are contingent on patient actions. Patient-physician dyads were categorized into three groups based on their congruence on each measure. One group represented patients with lower control expectations than their physician, one group represented patients with similar preferences as their physician, and one group represented patients with higher control expectations than their physician. Although congruence on the PPOS was not predictive of patient satisfaction or adherence, contrary to previous findings, congruence on the MHLC was predictive of both satisfaction and adherence. Specifically, patients whose beliefs about internal locus of control were congruent with their physician's beliefs reported significantly higher satisfaction with care and reported better adherence with treatment recommendations (Cvengros, Christensen, et al., 2007).

A follow-up study of patients with comorbid hypertension and diabetes found similar results using an objective marker of medication refill adherence (Christensen, Howren, et al., 2010). In this study, 18 primary care physicians and 246 of their patients completed the physician-modified MHLC and original patient-oriented MHLC, respectively. Adherence to treatment was derived from medication refill data for approximately 1 year prior to enrollment and defined as percentage of time patients had an undersupply of the medication (were not adherent in refilling and using medication) during that year. Values of hemoglobin A1c and blood pressure were also retrieved from the patient medical record. Using the same categorization of patient-physician dyads as in the previous study, Christensen et al. (2010) found that congruence in beliefs was predictive of medication refill adherence and blood pressure control. Specifically, patients in patient-physician dyads with similar beliefs about patient control over health outcomes (i.e., internal locus of control) demonstrated better adherence to medications and demonstrated lower diastolic blood pressure. Patient-physician congruence was not significantly associated with systolic blood pressure or hemoglobin A1c values.

The preceding studies examined congruence between patients' attitudes or beliefs regarding healthcare and physicians' parallel attitudes or beliefs. Another important dimension is congruence between what patients say they want and what they feel they have received from their healthcare. Cvengros et al. (2009) examined this congruence between patient preferences for patient-centered care and patient perceptions of received patient-centered care. In this study, 218 patients with diabetes completed measures of preferences for patient-centered care (e.g., information sharing and self-management of illness) prior to a target visit with their primary care provider. Within 2 days after the target visit, patients rated the degree of patient-centeredness of their received care and their self-reported diabetes medication adherence. Additionally, the hemoglobin A1c laboratory value closest to each patient's target visit was collected from the medical record as an objective marker of glucose control. This study was unique in that data were not collected from the providers; rather, the study focused on congruence between what patients *wanted* and what they *felt they received* with respect to the dimensions of information sharing and self-care. Consistent with previous work, congruence in preferences and perceptions of patient-centered care was associated with both subjective and objective adherence. Patients who had a high preference for behavioral involvement and self-management of their diabetes but felt that they had received a lower level of this behavior from their provider reported lower adherence to their diabetes regimen, compared to patients whose preference for and perception of this behavior were congruent. Similarly, patients who had a high preference for information sharing regarding their diabetes but felt they had received a low level of this behavior from their provider had higher A1c values (reflecting poorer glycemic control) than patients whose preference for and perception of information sharing were congruent (Cvengros, Christensen, et al., 2009).

Congruence in Patient Expectations for Care

The Cvengros et al. (2009) study raises the suggestion that patients may have specific expectations regarding the role they take in regard to their own healthcare when they present for a visit at their provider's office. Furthermore, when these expectations are met, patients are likely more satisfied and adherent with care. There is a growing body of literature that examines the role of patient expectations for other aspects of the patient-provider encounter. In a study using direct observation of over 500 patient-provider interactions, Kravitz et al. (2003) found that nearly 25% of patients made at least one request for a diagnostic test, specialty referral, or new medication. Nearly 15% of those patients who made requests had at least one request declined (Kravitz, Bell, et al., 2003).

This line of research is consistent with research on patient-provider congruence, in that failure to meet patient expectations for diagnostic tests, specialty referrals, and medications may also lead to lower satisfaction with care and poorer adherence with treatment. Bell, Kravitz, Thom, Krupat, & Azari (2002) used a checklist questionnaire to measure unmet patient expectations regarding collection of clinical data (e.g., questions the provider should have asked, parts of the physical exam that should have been completed), allocation of clinical resources (e.g., diagnostic tests that should have been ordered, medications that should have been prescribed), and information and counseling (e.g., information that should have been shared). The presence of one or more unmet expectations was associated with lower satisfaction with care, less improvement in symptoms, and lower intention to adhere to treatment recommendations (Bell, Kravitz, et al., 2002). In a similar study of over 900 patients, Kravitz et al. (2002) found that 84% of patients reported making explicit requests during their visits (e.g., requests for medical information, diagnostic tests, medications, or specialty referrals) and, of those making a request, 80% reported complete fulfillment of their request. Incomplete fulfillment or denial of requests were associated with lower satisfaction with care, higher health concerns at follow-up, and smaller improvement in symptoms at follow-up. Interestingly, those patients who made no requests had similar outcomes to those patients who reported complete fulfillment of requests (Kravitz, Bell, et al., 2002).

Promoting Patient Behavior Change

An increasing number of clinical treatment plans involve patient self-management and behavioral change efforts to improve health outcomes. Meeting patient expectations for the patient-provider interaction is just one way that healthcare providers play a potentially pivotal role in promoting and maintaining patients' effective health behavior. Understanding exactly how physicians can influence what patients do outside of the clinic, however, is less clear and can represent a formidable challenge to healthcare providers. Research from psychology and communication can help providers better utilize their central role in supporting patients' health behaviors. One psychological approach that has been adapted for use in healthcare settings is motivational interviewing. This approach involves a collaborative relationship between the patient and provider that addresses the patient's ambivalence toward change as a step toward increasing their motivation. Promotion of lifestyle changes and adherence has also been influenced by research in information processing and communication, which has been applied to health behavior change through the use of tailored healthcare communication. These customized, personally relevant health messages offer ways to inform patients, provide individualized feedback, encourage preventive health measures, and monitor progress. Motivational interviewing and tailored health communication each represent tools to help providers promote patient behavior change and will be reviewed in detail.

Motivational Interviewing

Making and adhering to health-conscious lifestyle changes remain challenging for patients (Stewart, 1995). A potential explanation for this is that providers' approaches to guiding behavioral interventions may fail to reflect their patients' readiness to change. For example, the typical approach to promote health behavior change (such as to decrease substance use or increase exercise) is for a health professional to provide action-oriented advice to the patient (Rollnick, Kinnersley, & Stott, 1993). When faced with a health issue and provided with medical rationale for behavioral changes, however, most patients are not immediately ready to transform their lifestyles (Rollnick & Heather, 1992). Rather, patients often experience ambivalence when called upon to make lifestyle changes. If this ambivalence is not addressed, individuals may become resistant to the behavioral change efforts (Britt, Hudson, & Blampied, 2004). Accordingly, such advice-giving encounters can be ineffective and frustrating for providers and patients alike, since action-oriented advice is premature without corresponding patient motivation, and resistance is counter-effective to change (Rollnick, Kinnersley, & Stott, 1993).

In contrast, the approach of motivational interviewing (MI) works explicitly with patients' ambivalence toward change and represents "something close to the polar opposite of advice-giving" (Rollnick & Heather, 1992). The interpersonal relationship functions in a reciprocal manner, in which practitioners provide facts related to objective health measures and patients provide personal interpretations of those facts (Emmons & Rollnick, 2001). This collaborative approach facilitates behavior change by helping patients explore and resolve their ambivalence toward the change. As such, these strategies affirm individuals' autonomy and self-determination while increasing their self-efficacy regarding behavior change. Instead of prescribing a set of techniques or a distinct treatment for providers to apply, MI entails overlapping collaborative processes and an underlying spirit with which to approach clinical work. The "collaborative, goal-oriented style of communication" at the heart of MI is approached through the processes of therapeutic engagement, focusing on a direction, evoking discussion of change, and planning change (Miller & Rollnick, 2013, p. 29). The underlying spirit of MI entails active partnership with the patient, acceptance of the patient, acting compassionately toward the patient, and evoking the patient's own strengths and motivation (Miller & Rollnick, 2013).

Rather than conceptualizing patient motivation as a stable personality trait, proponents of the motivational interviewing approach consider motivation to be a fluctuating state of readiness to change (Britt, Hudson, & Blampied, 2004). Importantly, motivation is evoked *in* the patient, rather than imposed *by* external influences (Rollnick & Miller, 1995). Motivation surfaces through a collaborative discussion of evidence for and against making a behavior change, with the practitioner helping to elicit and strengthen the patient's motivation (Miller & Rollnick, 2009). For example, a practitioner and patient may discuss how current health behaviors conflict with one's values and long-term goals, leading to an evaluation of the risks and rewards of making lifestyle changes. By applying the health information to one's own life, the patient discovers their own motivation to change, and their commitment is strengthened. As providers use an MI approach, over time the proportion of patient statements promoting change ("change talk") to those promoting maintenance of the status quo ("sustain talk") increases (Miller & Rollnick, 2013).

Although initially developed for working with patients with alcohol use problems, MI appears to be a highly face valid and generalizable approach that is now used internationally to address various lifestyle changes (Knight, McGowan, et al., 2006; see Rollnick, Miller, & Butler, 2007, for an in-depth discussion of the application of MI in healthcare settings). The integration of motivational interviewing into routine medical care is rapidly increasing, as patient behavior change is an essential aspect of disease prevention and adherence to medical regimens (Emmons & Rollnick, 2001). MI-informed approaches have been incorporated into many health behavior change efforts, including smoking cessation, diabetes self-management, medication compliance, HIV/AIDS risk reduction, increased fruit and vegetable intake, increased exercise, cancer screening, hypertension, asthma, and medical treatment retention (Emmons & Rollnick, 2001; Hettema, Steele, & Miller, 2005; Knight, McGowan, et al., 2006; Resnicow, DiIorio, et al., 2002).

The outcome research documenting the application of motivational interviewing to physical health issues has yielded promising, yet inconsistent, results (Burke, Arkowitz, & Menchola, 2003; Hettema, Steele, & Miller, 2005; Knight, McGowan, et al., 2006; Resnicow, DiIorio, et al., 2002; Rubak, Sandbaek, et al., 2005). A meta-analysis found that MI-informed treatments for alcohol, drugs, diet, and exercise were as effective as other active treatments and more effective than placebo or no-treatment controls for these health issues and had sustained long-term effects (Burke, Arkowitz, & Menchola, 2003). For decreasing alcohol and drug use, a motivational interviewing approach yielded the same 50% improvement rate in two sessions as psychotherapy attained in eight sessions, suggesting that MI could be a more cost-effective and time-efficient approach (Burke, Arkowitz, & Menchola, 2003). For smoking cessation, HIV-risk behavior reduction, and diabetes care, however, there is a lack of empirical support for the efficacy of motivational interviewing (Burke, Arkowitz, & Menchola, 2003; Heinrich, Candel, et al., 2010). One study found that adding MI techniques to existing diabetes self-management education was less effective than the diabetes education alone, as evidenced by a significantly lower mean change in hemoglobin A1c levels for patients who received motivational interviewing (Welch, Zagarins, et al., 2011). In another study, MI failed to offer advantages over usual nursing care for diabetes, and fat intake and HDL cholesterol were actually adversely affected in patients who received MI in addition to usual care (Heinrich, Candel, et al., 2010).

The variability in results of empirical analyses of MI in healthcare settings mirrors the overall MI research literature (Miller & Rollnick, 2013). The motivational interviewing approach is inherently difficult to evaluate empirically because its delivery is variable and reflects contextual factors in the provider-patient relationship (Miller & Rollnick, 2013). Perhaps it is not surprising that manualized MI interventions have been less effective than nonmanualized MI treatments, since MI is built upon meeting each patient at their own individual readiness level, and a manual purportedly provides each patient the same treatment (Hettema, Steele, & Miller, 2005). The highest effect sizes for MI have come from nonmanualized treatments in samples of ethnic minorities and samples of clients who are more angry, resistant, and less motivated to change (Heather, Rollnick, et al., 1996; Hettema & Hendricks, 2010; Hettema, Steele, & Miller, 2005). In a meta-analysis of clinical trials in the United States, MI studies with patients from minority populations (largely African-American and Hispanic) had effect sizes double those of MI studies with predominantly Caucasian non-Hispanic patients (Hettema, Steele, & Miller, 2005). These effects warrant further investigation, as motivational interviewing could represent a particularly effective approach for working with ethnic minorities and individuals whom more conventional approaches fail to engage.

Motivational interviewing is an attractive approach to integrate into healthcare settings because it can be employed by a variety of practitioners, such as doctors, nurses, and dieticians. While it remains unclear how much training is necessary for practitioner competence in motivational interviewing, 12–15 h of training, plus ongoing coaching and feedback, has been cited as the ideal training model (Britt, Hudson, & Blampied, 2004; Rollnick & Heather, 1992). The developers of motivational interviewing describe it as "simple but not easy" and insist that competency in its implementation necessitates disciplined practice and coaching (Miller & Rollnick, 2009). While in theory MI can be conducted by a variety of practitioners, doing so likely yields differential effectiveness. A meta-analysis reported that MI practiced by doctors and psychologists was effective in approximately 80% of studies, whereas MI done by other healthcare providers was effective in only 46% of studies (Rubak, Sandbaek, et al., 2005). Further research is required to support the claim that motivational interviewing can be integrated into the daily activities of primary care settings.

For patients, there is no empirical standard for the amount, frequency, and duration of motivational interviewing (Hettema, Steele, & Miller 2005). Importantly, practitioners can incorporate motivational interviewing strategies into regular clinical care or employ it as a brief stand-alone intervention (Miller, 2004; Rollnick & Heather, 1992). Although 64% of studies using an MI intervention of less than 20 min and 40% of studies with only one MI session were effective, effectiveness increases both with the amount of time spent on MI and the number of sessions of the intervention (Rubak, Sandbaek, et al., 2005).

Motivational interviewing aligns with patient-centered medical care efforts and offers a promising avenue for effective health behavior change. In approximately 80% of studies, motivational interviewing outperformed traditional practitioner advice-giving (Rubak, Sandbaek, et al., 2005). Because the approach is flexible and responsive to each patient's readiness to change, trained practitioners are prepared to work with a range of patients. MI also has the potential to effectively address multiple health behaviors that an individual is simultaneously facing (Prochaska, Butterworth, et al., 2008). Although clinical results yield preliminary support for implementing this approach in medical settings, further research on motivational interviewing is necessary to identify the active ingredients of change, type and amount of training required, and best ways to translate the techniques into medical settings.

Tailored and Targeted Health Communication

Other interactive and innovative approaches to the challenge of promoting effective health behaviors include providers' use of targeted and tailored health communication. Targeted health communication messages use a common approach to deliver health information to a segment of a population or members of a group (Kreuter, Lukwago, et al., 2003; Noar, Benac, & Harris, 2007). Examples include delivering smoking cessation information to pregnant women that emphasizes risks to the fetus and newborn child or providing cancer prevention materials to African-American males that emphasize underdiagnosis or delayed diagnosis of prostate and colorectal cancer in their group. Targeted health communications emphasize shared characteristics or concerns within a group and, therefore, implicitly assume a high degree of homogeneity among targeted group members. This may limit their effectiveness (Kreuter, Lukwago, et al., 2003).

Tailored health communication, on the other hand, improves customization by acknowledging known differences between individuals and addressing factors that are important to each recipient (Kreuter, Lukwago, et al., 2003; Kreuter, Strecher, & Glassman, 1999). Tailored health materials acknowledge that group or cultural membership does not necessitate uniformity of experience or belief (Kreuter, Strecher, & Glassman, 1999). Rather, it promotes individualizing tailored materials to focus on the most appropriate health information and strategies for an individual, based on his or her unique characteristics and preferences, as assessed by relevant psychological measures (Kreuter, Strecher, & Glassman, 1999; Rimer & Kreuter, 2006). The specific goals of these communications are diverse but generally aim to accomplish one or more of the following: enhance patient understanding of health information, facilitate informed clinical decision-making, increase motivation for health behavior change, provide strategies for behavior change, and provide evaluative or normative health feedback (Abrams, Mills, & Bulger, 1999; Rimer & Kreuter, 2006; Skinner, Campbell, et al., 1999). Among the health issues and lifestyle changes frequently addressed by tailored messages are smoking cessation, cancer screening, alcohol use, dietary change, exercise, and condom use (Kreuter, Oswald, et al., 2000; Sanderson, 2004). Targeted and tailored messages may address the same health behaviors, but targeted messages do so based on broader group membership and tailored messages do so on the basis of more fine-tuned individualized assessments.

The most influential theoretical underpinnings of tailored health communication are Cacioppo and Petty's (1984) elaboration likelihood model and Prochaska and DiClemente's (1983) transtheoretical (stages of change) model. According to the elaboration likelihood model, the perception of personal relevance of incoming information affects an individual's motivation to elaborate on it, with more personally relevant information leading to enhanced elaboration and processing (Cacioppo & Petty, 1984; Rimer & Kreuter, 2006). Since materials are tailored based on information from individual assessments, this customization increases "the chances that the message will be viewed as personally relevant, central processing will take place, and an individual will be persuaded" (Noar, Benac, & Harris, 2007, p. 684).

The transtheoretical model (TTM), which assesses an individual's readiness for health behavior change, is frequently used as a basis for tailored health communication (Rimer & Kreuter, 2006). Proponents of the TTM believe that patients cycle through five stages of change: precontemplation, contemplation, preparation, action, and maintenance (Norcross, Krebs, & Prochaska, 2011). Health communication can be tailored to reflect a patient's level of readiness for change, thus providing individuals with information consistent with the experiences at their stage. Using the example of stage-based tailoring for increasing physical activity, an individual in the contemplation stage may receive information regarding the health benefits of exercise, whereas someone in the preparation stage may receive information regarding exercise classes and gym memberships.

Tailoring based upon an individual's stage of change has been an effective approach for addressing various health behaviors, including smoking, stress, medication adherence, diet, exercise, and sun exposure (Prochaska, Butterworth, et al., 2008). In one smoking cessation study, abstinence rates were significantly greater at a six-month follow-up point for participants who received stage-matched tailored information compared to participants who did not (Prochaska, Velicer, et al., 2001). Furthermore, the difference between the two groups increased at each follow-up, eventually yielding a 24-month 25% abstinence rate for the stage-matched tailoring group, which was 30% higher than the abstinence rate for individuals in the control group

(Prochaska, Velicer, et al., 2001). Additionally, stage-based tailoring has been effective for simultaneously addressing multiple health behaviors in various populations, such as stress, inactivity, smoking, and BMI in a worksite sample and smoking, diet, and sun exposure in a parent sample (Prochaska, Butterworth, et al., 2008; Prochaska, Velicer, et al., 2004).

No universally accepted model or medium of tailoring exists. Rather, health messages have been tailored on an assortment of personal variables and delivered through multiple modes of communication. The choice of which variables to base tailoring on is still evolving, and an individual's stage of change is just one example. Criteria used to customize content include basic characteristics such as gender, age, education level, and culture (Sanderson, 2004). An individual's psychosocial characteristics, such as locus of control, coping strategy, need for information, self-efficacy, motivation, health practices, and risk factors, are also used to customize content yet require more in-depth individualized assessments of influential mediators (Abrams, Mills, & Bulger, 1999; Lustria, Cortese, et al., 2009; Sanderson, 2004). Modes of message delivery are constantly changing but include home mailings, phone calls, video, audio, pamphlets, and various computer programs (Kreuter, Strecher, & Glassman, 1999; Skinner, Campbell, et al., 1999).

A body of research has shown that tailored print materials are more effective in creating health behavior change than non-tailored materials (Kreuter, Oswald, et al., 2000; Noar, Benac, & Harris, 2007; Skinner, Campbell, et al., 1999). In a study comparing the effects of a non-tailored nutrition letter to a nutrition letter tailored on psychosocial variables, the tailored letters elicited significantly higher readership, discussion with close others, and relevance ratings (Brug, Glanz, et al., 1998). Furthermore, individuals who received the tailored letters consumed significantly less fat and more fruits and vegetables than individuals who received generic nutrition information (Brug, Glanz, et al., 1998). In another study comparing tailored and non-tailored mammography information, individuals who received the tailored information were significantly more likely to remember the content of the message than those who received non-tailored information (Skinner, Strecher, & Hospers, 1994). A recent meta-analysis found that tailored interventions have been 36% more effective than control conditions and that they have had a clinically significant impact on behavioral risk factors such as smoking (Krebs, Prochaska, & Rossi, 2010). No significant differences between communicating via print, telephone, or computer messages were found (Krebs, Prochaska, & Rossi, 2010). While the effects of tailoring declined after the intervention regardless of tailoring method, dynamic tailoring with iterative assessment and feedback was more effective over time (Krebs, Prochaska, & Rossi, 2010).

Current research seeks to optimize the effects of tailored health communication by assessing how and under what conditions tailoring works (Rimer & Kreuter, 2006). Effectiveness is difficult to empirically evaluate, as study outcome measures and specific methods of tailoring range across studies and health behaviors (Skinner, Campbell, et al., 1999). Some key features of successful tailoring, however, have emerged. Skillful customization is essential, since tailored materials will not be effective if patients fail to read them or to find them personally applicable (Kreuter, Oswald, et al., 2000). Additionally, design and layout are important, with more visual and brief print communication, such as pamphlets and magazines, more effective than letters and manuals (Noar, Benac, & Harris, 2007). Tailored messages regarding preventive and screening behaviors appear to be the most effective, yet particular participant variables being tailored to (e.g., age, culture, or psychosocial factors) do not influence the effectiveness of the message delivered (Noar, Benac, & Harris, 2007).

Currently, there is significant interest in electronic and Internet-based tailored health communication. Electronic tailoring expands the realm of tailored communication by providing instant adaptation and feedback in an interactive and iterative format (Lustria, Cortese, et al., 2009). The modalities for electronic and Internet-based tailored communication change as technology progresses but include electronic mailings, discussion rooms, electronic diaries, online quizzes and games, risk assessments, calorie counting programs, virtual reality experiences to view the consequences of health decisions, instant messaging with health professionals, and email reminders of appointments and self-examinations (Abrams, Mills, & Bulger, 1999; Lustria, Cortese, et al., 2009; Noar, Benac, & Harris, 2007).

An important dimension is the frequency of monitoring and messaging. Emerging developments include advanced interactive applications for cellular phones to enable instant and mobile interaction that monitor, say, eating, physical activity, and blood sugar levels among those with diabetes and deliver individualized messages responsive to changes during the day. Studies indicate their effectiveness on behavioral and clinical measures (Piette, Mendoza-Avelares, et al., 2011; Quinn, Shardell, et al., 2011; Williams, Bird, et al., 2012) and the potential for linking them with sources of live support (Aikens, Trivedi, et al., 2015).

Electronic tailoring appears to offer advantages over traditional tailored print materials. Of primary note are increased patient engagement in self-care, self-regulation, and self-monitoring (Lustria, Cortese, et al., 2009). Additionally, electronic tailored health communication holds the potential to efficiently reach a wider audience, such as those in rural areas, thus effectively eliminating geographic boundaries. Lack of access to technology is a potential barrier to the success of electronic communication. Efforts have been made to place computer kiosks in community locations, such as shopping malls and libraries, to address this issue (Lustria, Cortese, et al., 2009). Patients not only need exposure to the electronic material, however, but must also find it relevant in order for effective results.

While researchers suggest that tailored materials are cost-effective in the long run, there is an acknowledged lack of data to support this, making it a necessary subject for future research (Krebs, Prochaska, & Rossi, 2010; Kreuter, Oswald, et al., 2000; Kreuter, Strecher, & Glassman, 1999; Skinner, Campbell, et al., 1999). Initial development of tailoring programs represents a significant investment. Once developed, however, the continuing costs are minimal (Lairson, Newmark, et al., 2004). For example, the estimated total cost of developing a computer-generated tailored intervention used for mammography promotion was $264,390, 65% of which was spent on personnel costs (Lairson, Newmark, et al., 2004). If this intervention were used over 7 years with 10,000 participants, the average cost of developing the tailoring system would be $4.24 per person (Lairson, Newmark, et al., 2004). When considering both cost and adherence rates, another mammography promotion study found that a tailored letter was the most cost-effective strategy, when compared to a tailored phone call or a combination of a tailored letter and phone call (Saywell, Champion, et al., 2004). In 2008, the University of Michigan released a free, open source software package for individuals to use in creating and circulating their own tailored materials (available at http://chcr.umich.edu/mts/). The Michigan Tailoring System is an affordable way for researchers and health agencies to use tailored health communications for their noncommercial purposes.

Tailored health communication represents a versatile approach to health promotion. With implementation at the population level and tailoring at the individual level, such communication efforts are capable of having a great impact. Important considerations in tailored health communication include the timing of message delivery, comparative effectiveness for different behavioral topics and populations, and intricacies of various modalities of message delivery (Abrams, Mills, & Bulger, 1999; Skinner, Campbell, et al., 1999). As researchers seek a more precise understanding of tailored health communication, it will become an even more multifaceted and widely used tool in the future.

Summary and Implications for Clinical Practice

In summary, patient-centered care can be used as an umbrella term to represent several aspects of patient-provider interactions and patient and provider attitudes toward care. Three dimensions of patient-centered care that have received considerable attention are attitudes toward information sharing between patient and provider, preferences for self-management of illness by the patient, and preferences for provision of socioemotional support by the provider. The data to support the hypothesis that greater patient-centered care is associated with better outcomes is limited. However, recent studies conducted by the present authors and others have supported the congruence hypothesis. Specifically, greater *congruence in patient and provider attitudes regarding the healthcare encounter* is associated with more positive patient outcomes, such as greater satisfaction with care, higher trust in the physician, and greater adherence with treatment. This pattern is consistent with broader theory and research suggesting that patient individual differences and characteristics of the treatment delivery context interact to determine patient outcomes (Christensen, 2000).

Attitudinal congruence between patient and provider appears to be important and can be achieved in several ways. First, patients may “shop around” to find a provider with similar attitudes and preferences toward care. Second, patients may seek out providers that have been recommended by family or friends who endorse similar preferences as the patient. Third, providers may adapt their practice style toward a particular patient in response to that patient’s expressed preferences. Not to be overlooked is providers’ sensitivity in the moment to how circumstance (e.g., a new diagnosis) and personality may combine to make one or another interaction style appropriate. Finally, a match between patient and provider may arise through a combination of these methods. Future work in the area of patient-provider interactions should focus on identifying methods to improve congruence in patient and provider attitudes toward healthcare. This will include studies to determine effective algorithms for matching patients to providers, perhaps through the use of brief screening tools. This may also include studies of providers’ ability to adapt, or tailor, their care in response to patient preferences, perhaps through the use of “cheat sheets” which provide information on patient preferences for care.

As healthcare continues to evolve, providers will be increasingly called upon to play a central role in the promotion of positive patient health behaviors for disease prevention and management. Over the coming decades, the development of more treatment alternatives and more detailed algorithms guiding their use will continue to make patient-provider interactions more complex. With this evolution, providers will be called upon to play increasingly varied roles in guiding, serving, and collaborating with their patients. Further refinement of models, technologies, and other tools that facilitate patient-provider interaction and collaboration will play a pivotal role in this process (Howren, Van Liew, & Christensen, 2013). Recognition of the heterogeneity of target populations and the added value of customizing interventions to patients’ characteristics or readiness to change, such as through tailored health communication and motivational interviewing, allow healthcare providers and delivery systems to maximize the reach and effectiveness of their impact on patient outcomes. By meeting patients where they are with regard to readiness to change and preferences for information sharing, illness self-management, and socioemotional support, healthcare providers can impact patient adherence and satisfaction with care.

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Child and Family Interventions

21

Persis Commissariat and Alan M. Delamater

This chapter considers intervention studies that are specific to children and families living with a chronic health condition. It is important to note that given the dozens of chronic diseases that can affect children and, by extension, their families, each is distinct in its own way. This chapter will cover trends for three chronic health conditions – obesity, asthma, and diabetes – along with evidence-based interventions targeting themes that are consistent in the treatment of these different conditions. The review is not exhaustive but focuses on well-regarded intervention studies that aim to improve regimen adherence and physical and mental health in medically compromised children and adolescents. The majority of intervention studies reviewed were conducted in the USA, although many techniques addressing family relationships, behavior change, coping skills, and social issues may be applicable to children and families worldwide. Child and family intervention approaches addressing these three common childhood chronic health conditions are reviewed, as well as their global prevalence, physiological complications, and related psychosocial issues. We review a number of evidence-based interventions that address educational, behavioral and psychosocial, psychological, peer, and digital technology approaches for managing these conditions, as well as psychosocial issues associated with them. The concluding section discusses and summarizes the findings and briefly considers future research needs.

Background

Chronic illnesses are conditions with a long duration and slow progression encompassing four main types: cardiovascular diseases, cancers, chronic respiratory diseases, and diabetes (World Health Organization, 2015). In 2012, about half of all adults in the USA – 117 million people – had one or more chronic health conditions (Ward, Schiller, & Goodman, 2014). Children are equally affected by chronic conditions: a recent study estimated that anywhere from 43% to 54% of children in the USA suffer from a chronic health condition (Bethell, Kogan, & Strickland, 2011). Such conditions increase the likelihood of comorbid physical and mental health conditions, complications from mismanagement, increased health-care costs, and reduced quality of life. For example, obesity in childhood has a high risk of persisting into adulthood and increases the risks for diabetes, cardiovascular disease, and cancer (Torpy, Campbell, & Glass, 2010).

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Regimen adherence is essential for good management of these conditions. However, inadequate regimen adherence is a major problem among youth with chronic health conditions, with 50% average adherence across conditions (Drotar, 2000; La Greca & Mackey, 2009; Rapoff, 2010). Also among adults nonadherence rates for chronic illness regimens and lifestyle changes are about 50% (Haynes, Taylor, & Sackett, 1979).

To better understand regimen adherence difficulties in children and adolescents with chronic health conditions, it is helpful to use an ecological model: adherence may be determined by multiple levels of influence, including child characteristics (e.g., age, gender, temperament, psychological functioning), psychosocial factors (e.g., parental psychological functioning, family structure and socioeconomic status, parental monitoring and support of the regimen, family conflict, peer relationships), medical system factors (e.g., relationships with doctors, frequency of contact with health-care team), as well as cultural factors (e.g., culture-specific health beliefs) (Delamater, 2012; Marrero, Ard, et al., 2013).

With about one-half of children with chronic health conditions struggling with regimen adherence, researchers have focused considerable attention on the development and implementation of adherence-promoting interventions (Drotar, 2000; Graves, Roberts, et al., 2010; Kahana, Drotar, & Frazier, 2008; La Greca & Mackey, 2009). Interventions that improve regimen adherence among youth cover a wide variety of conditions; diabetes and asthma have been particularly well-studied (Kahana, Drotar, & Frazier, 2008).

Most interventions have been developed based on social cognitive theory (SCT) (Bandura, 1986). According to SCT, behavior is determined by environmental factors (such as modeling, family and peer influences, social reinforcement and support, social norms) and cognitive factors (such as self-efficacy, self-concept, beliefs). Individuals are more likely to engage in behaviors that they see others modeling or being rewarded for, as well as those they are directly reinforced for engaging in. Thus, a key component of intervention for youth is to involve parents in modeling health-promoting behaviors and providing social reinforcement for their children when they also engage in them. Self-efficacy for engaging in particular behavior is also integral to this theoretical model. This model additionally acknowledges the role of affective factors (such as depression and stress) as they may influence behavior. SCT-based behavioral and psychosocial interventions are reviewed below. These particular approaches have been integrated with family systems theory and therapy resulting in new interventions for youth in which behavioral interventions are employed within a family systems context (Robin & Foster, 2002).

Self-determination theory (SDT) is another approach that has been useful in the development of interventions. According to SDT, motivation is a key mechanism for understanding the drivers of human behavior (Ryan & Deci, 2000). In SDT, there is a distinction made between intrinsic and extrinsic motivation. Intrinsic motivation refers to incentives that are intrinsic to an activity such as better health and personal satisfaction, while, in extrinsic motivation, behavior is motivated by external incentives or pressures such as reduced insurance premiums for not smoking (Deci, Koestner, & Ryan, 1999). Individuals may be motivated both intrinsically and extrinsically, but SDT focuses on intrinsic motivation in order for individuals to achieve their best quality performance in various aspects of life. Development of intervention approaches based on SDT involves motivational interviewing, which has been applied to health promotion interventions (Resnicow, Dilorio, et al., 2002) by addressing intrinsic motivation for self-care.

Obesity

The global prevalence of obesity in children has been steadily increasing in recent years. A 2010 study found that 43 million preschool-aged children worldwide were estimated to be overweight or obese (de Onis, Blossner, & Borghi, 2010), and an expected 9.1% of preschool-aged children will be overweight or obese by the year 2020 (de Onis, Blossner, & Borghi, 2010). Throughout developed countries of the world, 23.8% of male children and adolescents and 22.6% of female children and adolescents were overweight or obese in 2013. However, recent epidemiological data indicate that in the USA, almost one-third of children are overweight or obese (Ogden, Carroll, et al., 2014). In developing countries, 12.9% of male children and adolescents and 13.4% of female children and adolescents were found to be overweight or obese in 2013 (Ng, Fleming, et al., 2014). Socioeconomic status and ethnicity have also been found to affect the prevalence of obesity. In middle-income countries such as China and Russia, members of higher SES households are more at risk for obesity due to a more sedentary lifestyle. However, in more developed, higher-income countries such as the USA, children in the lowest SES group have the greatest risk of obesity (Wang, 2001).

As with many chronic health conditions, obesity at an early age places the child at risk for comorbid physical conditions as well as psychological problems. Obese children and adolescents are at elevated risk for hypertension, high cholesterol, type 2 diabetes, and obstructive sleep apnea (Daniels, Arnett, et al., 2005), as well as obesity and obesity-related complications in adulthood (Freedman, Khan, et al., 2005). Furthermore, as obesity is a highly visible condition, children may also feel stigmatized by the fact that they do not look like their nonobese peers. Studies have found that obese children are consistently more stigmatized by other children than thin and normal weight children; when children have been shown drawings of other children with various forms of disability and asked to rank who they liked most, obese children were most often the least liked (Richardson, Goodman, et al., 1961; Latner & Stunkard, 2003). Early stigmatization may lead to low self-esteem and poor coping strategies later in life. For example, obese adolescents are more likely to suffer from low self-esteem and feelings of sadness and loneliness and more likely to cope through the use of substances such as cigarettes or alcohol (Strauss, 2000). These health- and mental health-related complications require early intervention and maintenance to improve child health during the current obesity epidemic.

Asthma

After obesity, asthma is one of the most common chronic health conditions of childhood. An asthmatic episode is characterized by lung sensitivity to various environmental stimuli, resulting in airway inflammation and constriction, causing the child to wheeze in an attempt to breathe normally (American Lung Association, 2014). Asthma can be life-threatening if not properly managed with both preventive measures to resist an attack and rescue measures to counter an attack. One of the most current global studies of asthma, conducted by the International Study of Asthma and Allergies in Childhood, found that the global prevalence for current asthma in the 13–14-year-old age group was 14.1%, while prevalence in the 6–7-year-old age group was 11.7%. Notably, asthma prevalence was widely variable even within regions of the same city; this suggests the importance of specific environmental factors that affect asthma attacks and diagnoses (Mallol, Crane, et al., 2013).

Given the traumatizing situation of being unable to breathe, it is not surprising that asthma is related to psychological issues in children and their caregivers. Poor asthma control has been found to be significantly associated with increased symptoms of depression, anxiety, and risky behaviors in children and adolescents in studies conducted in the Netherlands and the USA (Letitre, de Groot, et al., 2014; Peters & Fritz, 2010). Depression and anxiety symptoms have also been found to be higher in mothers of children with asthma than mothers of healthy children without asthma in Turkey (Ozkaya, Cetin, et al., 2010). Furthermore, from a social perspective, children in Norway with asthma have endorsed fear of a loss of control, exacerbation of their symptoms, and worry of how asthma affected their body, as well as fear of being ostracized by peers (Trollvik, Nordbach, et al., 2011).

Diabetes

The incidence of both type 1 (T1D) and type 2 diabetes mellitus (T2D) in children has also been increasing worldwide, leading to increased health-care costs and requiring complex treatments performed daily by the child and family. T2D, while much more common in adults, is caused by a combination of genetic and environmental risk factors. In T2D, the pancreas either produces an insufficient amount of insulin to counter glucose in the body, or the body becomes insulin resistant despite insulin production. Insulin resistance is often associated with excess adiposity (Lebovitz, 1999). The recent increase in childhood T2D is likely driven by the current obesity epidemic and decreased physical activity and increased sedentary behavior of children. A recent review conducted in the Netherlands of global trends for T2D in youth suggests incidence and prevalence rates of 0–330/100,000 person years and 0–5300 per 100,000 person years, respectively, depending on the population studied. T2D is far less prevalent in European countries, while Pima Indians in the USA have the highest incidence in children and adolescents. Overall, ethnic minorities have the highest incidence of T2D in the majority of countries studied (Fazeli Farsani, et al., 2013). However, relatively little behavioral intervention research has been conducted with youth with T2D (Pulgaron & Delamater, 2014).

T1D, the most common endocrine disorder diagnosed in childhood or adolescence, is an autoimmune-mediated chronic illness in which the pancreas becomes unable to produce insulin. In those with T1D, the body destroys its own beta cells in the pancreas, causing the body to become unable to produce insulin (American Diabetes Association, 2009). Without the production of insulin, children with T1D must manually replace insulin in their bodies through the use of insulin injections or a subcutaneous insulin pump. Without proper management, glucose levels rise in the blood and can cause severe complications, including acute symptoms of hyperglycemia or hypoglycemia, and with more chronic poor glycemic control, increased risks for nephropathy, neuropathy, retinopathy, and cardiovascular disease.

An initial report from the Diabetes Mondiale (DIAMOND) project described the incidence of T1D in children from 1990 to 1994 as approximately 4.5% of a population of over 75 million under the age of 15, through review of registries at 100 diabetes centers in 50 countries worldwide (Karvonen, Viik-Kajander, et al., 2000). An updated report from the DIAMOND Group (2006) reported that from 1995 to 1999, there was a 3.4% increase of T1D incidence in a population of 84 million children under the age of 15 in 57 countries. At present, data suggest that there are approximately 500,000 children under the age of 15 with T1D worldwide, with the majority from Europe and North America (Patterson, Guariguata, et al. 2014). This data demonstrates a marked increase in children with T1D worldwide compared to earlier reports from the DIAMOND group. Data on pediatric T1D incidence and prevalence are lacking in many countries in Africa and other developing countries worldwide, due to the lack of medical research, resources, and care and consequent early death of children with T1D.

Beyond the physiological complications, adolescents with T1D are twice as likely as their healthy peers to develop depression or anxiety (Grey, Whittemore, & Tamborlane, 2002; Hood, Huestis, et al., 2006). Depression has also been found to be more likely to contribute to regimen nonadherence (Hood, Huestis, et al., 2006), as well as poorer metabolic control and more hospitalizations (Lawrence, Standiford, et al., 2006).

Intervention Research

Each of the three chronic conditions described above has both psychological and behavioral issues that must be addressed in order to improve health outcomes and avoid health complications and reduced quality of life. Across conditions, interventions have aimed to improve disease management skills, regimen adherence, and psychological and family functioning through various approaches to treatment. While some interventions with older adolescents target personal motivation and self-management, others utilize support from parents, peers, and changes in the school environment or other community settings. Such interventions are markedly different from adult-focused work, as family functioning and peer interactions have significant influences on children's behaviors. Furthermore, interventions may vary based on the chronic condition being addressed. Several overarching themes emerge across health conditions including educational, behavioral, psychological, family and peer involvement, and digital technology intervention approaches.

Educational Interventions

Educational interventions rely on the assumption that patients and their parents lack important disease-specific knowledge and skills, and therefore increasing their knowledge of the illness will help to improve health outcomes (Delamater, Marchante, & Daigre, 2014). This section will focus primarily on asthma-focused education with which a number of studies have shown significant effects on asthma in the UK (Murphy, Rayman, & Skinner, 2006; Van Sluijs, McMinn, & Griffin, 2007).

A meta-analysis by Guevara, Wolf, Grum, and Clark (2003) found that educational programs for children with asthma were associated with improved lung function and self-efficacy, and with reduced number of missed school days, days requiring restricted activity, and visits to the emergency room. Given the technological sophistication of today's youth, interactive, computer-based programs to improve knowledge of asthma and its management have also been found to be helpful. For example, children who received routine patient education combined with the use of Interactive Multimedia Program for Asthma Control and Tracking (IMPACT) showed increased asthma knowledge, decreased symptoms and emergency room visits, lower daily medication doses, and less frequent urgent care (Krishna, Francisco, et al., 2003). The additional program provided interactive, online education of asthma pathophysiology, triggers, medication, and control strategies through the use of asthma-specific vignettes.

A preventive asthma intervention program targeted parents of inner-city children with asthma in making physical changes to the home environment (e.g., exposure to dust, pets, mold, etc.) in order to reduce asthma triggers in their children. Parents received six in-home modules with feedback from an environmental counselor who provided knowledge, skills, motivation, equipment, and supplies necessary to make environmental changes in the home. Results showed that this type of individualized, comprehensive evaluation and intervention significantly reduced asthma symptoms in children (Morgan, Crain, et al., 2004). Similarly, comprehensive education on triggers, symptoms and warning signs, and medication usage provided by a clinic nurse during initial allergy visits, as well as monthly follow-ups, resulted in significantly better health outcomes: children and caregivers who were provided with the educational intervention had a reduced number of emergency room visits, hospitalizations, and asthma-related health-care costs per year (Kelly, Morrow, et al., 2000).

Although increasing disease-related knowledge and skills is important and necessary, education alone does not always lead to behavior change. Research has determined that while education is effective in improving certain chronic conditions, provision of education-only interventions – without additional behavioral intervention – does not appear to significantly improve disease-specific management across conditions (Kahana, Drotar, & Frazier, 2008). It is important to note that many educational interventions focusing on self-management typically include some behavioral components (e.g., goal-setting and self-monitoring), which may have stronger effects on regimen adherence than education alone. This has been shown in the research literature on pediatric obesity, in which nutrition education (without behavioral intervention) has been utilized as a control condition in family-based behavioral intervention studies, and has consistently been shown not to be effective for behavior change leading to weight control (Epstein, Valoski, et al., 1994).

Behavioral Interventions

Chronic illnesses in childhood require long-term, sometimes lifelong care and treatment. As many chronic conditions involve disruptive, time-intensive treatment, regimen adherence is understandably difficult for many children and adolescents. As noted above, poor regimen adherence is a major concern among youth with chronic illnesses (Drotar, 2000; La Greca & Mackey, 2009; Rapoff, 2010). Diabetes provides an excellent example of how behavioral interventions can be used effectively to improve regimen adherence. Studies suggest that glycemic control is particularly difficult during adolescence, as adolescence marks a time of deteriorating metabolic control, poorer adherence, and heightened emotional distress (Helgeson, Snyder, et al., 2007; Korbel, Wiebe, et al., 2007). As adolescents mature, many diabetes-related tasks (such as proper insulin replacement and blood glucose monitoring) can interfere with the adolescent's ability to feel independent and fit in with peers and may result in poor adherence to treatment and lead to poorer health outcomes.

Behavioral interventions are problem-focused and address specific maladaptive behaviors and barriers to optimal regimen adherence. Systematic reviews indicate that behavioral interventions are effective in improving adherence in children and adolescents with T1D (Delamater, 2012; Delamater, Marchante, & Daigre, 2014; Hood, Rohan, et al., 2010). Typically, these interventions target families, as youth, particularly younger ones, depend greatly on parents or other adult caretakers for support and guidance with their diabetes management, and with older youth, there is often conflict regarding diabetes management tasks.

In attempting to improve children's health behaviors, it is essential to address the role of parent behaviors and family functioning. For example, parental involvement in diabetes care has been shown to be a very important factor in children's glycemic control (Delamater, 2012; Delamater, Marchante, & Daigre, 2014). Research has shown that supportive parental involvement was significantly associated with blood glucose monitoring adherence, which in turn was associated with better glycemic control (Anderson, Ho, et al., 1997). An early study by Satin, La Greca, Zigo, and Skyler (1989) demonstrated the necessity of involving parents in the treatment of T1D. Using a randomized control design, families were provided with either standard diabetes care, a multifamily intervention group that targeted improving communication and problem-solving, or a multifamily intervention plus parent simulation group in which parents engaged in the child's medical regimen (checking blood glucose and using saline injections). Adolescents in the group whose parents simulated diabetes care showed significant improvement in glycemic control and more positive attitudes toward diabetes, effects which were maintained at 6-month follow-up (Satin, La Greca, et al., 1989).

Behavioral family systems therapy (BFST) has also shown promise as an intervention to improve diabetes treatment adherence as well as family functioning. Designed by Robin and Foster (2002), BFST utilizes four major therapeutic skills: problem-solving training, communication skills, cognitive restructuring, and functional and structural family therapy. Though initially this intervention was not designed specifically for families dealing with diabetes, it addresses family functioning related to core issues of diabetes management in childhood and adolescence – conflict resolution, group decision making, effective communication of concerns and solutions, identifying and changing exaggerated beliefs, and cross-generational discordance. Wysocki, Harris et al. (2000) modified the BFST approach specifically for diabetes: behavioral family systems therapy for diabetes (BFST-D). In a randomized controlled trial, BFST-D was not only associated with improved family relationships, it also demonstrated significant improvements in glycemic control, mediated by improvement in regimen adherence (Wysocki, Harris, et al., 2007).

This theme of improving child health outcomes by improving family functioning has been demonstrated in many other studies. Notably, increased parental involvement in diabetes can sometimes undermine the child's personal self-care behaviors and increase conflict in the parent-child relationship, particularly if parental involvement and advice are construed as blaming or shaming the child's efforts (Anderson, Brackett, et al., 1999). However, Laffel et al. (2003) used a family-focused teamwork intervention to improve

T1D management in youths. Results indicated that teaching the family how to share responsibilities and avoid conflict by working as a team had a significant effect in improving glycemic control. Family involvement in diabetes management also increased and was maintained over time and was not associated with increases in family conflict (Laffel, Vangsness, et al., 2003).

Educational and psychoeducational interventions that help families to employ supportive behavioral strategies with their children with T1D have been successfully used to prevent later difficulties with disease management. For example, a psychoeducational program with children and their parents that promoted problem-solving skills and increased parental support and praise for child self-care behaviors resulted in improved long-term glycemic control of children when applied in the months after diagnosis of T1D (Delamater, Bubb, et al., 1990).

When integrated with routine clinic appointments, family-centered programs in the UK have improved parental involvement and glycemic control, particularly when families participated in such sessions more frequently (Murphy, et al., 2007). Similarly, American studies utilizing "Care Ambassadors" demonstrated improved frequency of outpatient visits and reduced adverse outcomes such as hypoglycemia and emergency room visits (Laffel, Brackett, et al., 1999; Svoren, Butler, et al., 2003). Care Ambassadors reached out to families to assist in scheduling appointments and encourage timely disclosure of concerns to medical providers between outpatient appointments (Laffel, Brackett, et al., 1999; Svoren, Butler, et al., 2003). In a more recent large multisite randomized controlled trial, a brief family teamwork intervention delivered during routine outpatient visits was associated with improved glycemic control for young adolescents; however, effects were not as strong for older children (Nansel, Ianotti, & Liu, 2012). Similarly, when the Care Ambassador role was combined with the delivery of a manualized intervention – focused on improving family teamwork in diabetes management through the use of problem-solving exercises and role-playing of realistic expectations for teamwork – results indicated that more youth in the psychoeducation group maintained or improved their glycemic control and increased parent involvement, without a negative effect on quality of life or increased family conflict (Katz, Volkening, et al., 2014).

However, while these intervention approaches may be helpful with many children and families who do not present with significant psychological or psychosocial issues, they may not be sufficient to improve outcomes in those youth who do have significant psychosocial difficulties. Many youth with T1D are at risk for poor glycemic control due to a variety of stressors that are more common in lower-income and single-parent families and among ethnic minorities (Delamater, de Wit, et al., 2014). Often these youth do not keep in close contact with the health-care team, and research has shown that youth with inconsistent health-care contacts have worse glycemic control (Kaufman, Halvorsen, & Carpenter, 1999). Therefore, additional intervention approaches are needed to reach them and intervene with them in effective ways.

Multisystemic therapy (MST) was developed particularly for high-risk youth and in recent years been applied with youth with T1D. MST utilizes strategies from cognitive-behavioral therapy, parent training, and behavioral family systems therapy to target adherence problems related to the family, peer network, and community (e.g., health-care system and extracurricular activities). This type of intervention offers a timeline-flexible intervention strategy, addressing issues within each of the youth's environments to individualize treatment for each child and family's specific needs and environmental factors. In contrast to BFST-D, MST is unique in its use of multiple behavior-focused interventions that are delivered in patients' natural environments (home, school, community) to improve diabetes management and glycemic control. By targeting every system in which the adolescent could encounter diabetes-related issues, controlled research with MST has demonstrated efficacy in improving self-management of T1D. Studies have shown that adolescents receiving MST increased the frequency of blood glucose monitoring, improved glycemic control, and reduced the number of hospitalizations for poorly controlled diabetes, resulting in reduced medical costs (Ellis, Frey, et al., 2005; Ellis, Naar-King, et al., 2008). Specific intervention strategies used in MST for T1D (Ellis, Frey, et al., 2005) are shown in Table 21.1. This is an excellent example of the application of an ecological approach for understanding the factors related to poor glycemic control and working with a high-risk group of adolescent patients (Marrero, Ard, et al., 2013).

Family-based behavioral interventions have also been successfully applied with overweight children in the USA and Israel, with significant weight loss maintained even 10 years after treatment in the US sample (Nemet, Barkan, et al., 2005; Epstein, Valoski, et al., 1994). Family-based interventions for weight loss include nutrition and physical activity education, daily self-monitoring of physical activity and dietary intake, goal-setting, stimulus control, and training parents in behavior modification for children's reduced caloric intake, increased physical activity, and reduced sedentary behavior (Delamater, Pulgaron, & Daigre, 2013). Multiple family members attend intervention sessions as the unit of change is the family, not just the child. Research indicates that parental weight loss is a robust predictor of child weight loss in family-based behavioral intervention programs (Wrotniak, Epstein, et al., 2004), attesting to the importance of parental role modeling and the adoption of healthy eating practices by all members of the family, not just by the overweight child.

A recent study compared the effects of a multicomponent family-based behavioral outpatient program to a brief family intervention in overweight children and adolescents (Steele, Aylward, et al., 2012). Significant improvement in body mass index and quality of life was observed for both treatment groups at posttreatment and maintained at 1-year follow-up for the children but not for the adolescents in the study. Similarly, both prescribed and self-directed approaches to

Table 21.1 Select multisystemic therapy techniques used to improve T1D adherence

	Individual	Family	Peer	School	Community
Cognitive-behavioral therapy	CBT for self-reported depressive symptoms		Have peers be actively involved in treatment (e.g., reminders)		Promoting self-care during extracurricular activities
Parent training		Monitoring of self-care, providing rewards and discipline to increase parent engagement		Working with school to monitor and provide more opportunities to engage in self-care (e.g., finding a private place to inject and test glucose)	
Behavioral family systems therapy		Creating scheduled meal times together, improving communication between caregivers and between parent and adolescent		Improving communication between family and school about adolescent's needs and adherence behaviors	
MST therapist addition		Attending medical appointments with families, resolving barriers to attending appointments			

Based on Ellis, Frey, et al. (2005)

family-based behavioral intervention for child obesity have resulted in significant weight loss up to 2 years after treatment (Saelens, Lozano, & Scholz, 2013).

Psychological Interventions

Psychological and psychosocial interventions addressing mental health issues are particularly useful in chronic illness as many conditions can affect mental health, which in turn may adversely affect disease management. As described above, health conditions such as diabetes, asthma, and obesity can affect self-esteem, mood, social skills, coping abilities, and treatment adherence. Interventions that target the emotional components of living with a chronic condition may be beneficial in improving mental health and long-term adjustment, as well as disease management. For example, a number of psychological intervention strategies have been shown to improve the quality of life, regimen adherence, and glycemic control of adolescents with T1D, including coping skills training (CST), communication skills training, social problem-solving, and stress management (Delamater, de Wit, et al., 2014; Grey, 2011). Thus, broader intervention approaches targeting stress management and coping skills may generalize to other aspects on life besides managing health conditions.

Cognitive-behavioral therapy (CBT), which includes strategies used in CST and stress management, has been used to improve a variety of psychological disorders in pediatric populations, including anxiety disorders (Heimberg, 2002), depression, eating disorders, and issues related to self-esteem and social competence. This would suggest that the application of such interventions would be helpful for youth with T1D among whom depression (McGrady & Hood, 2010) and anxiety (Herzer & Hood, 2010) have been shown to be associated with decreased regimen adherence. Similarly, given the high rate of eating disorders among youth with diabetes and the relationship of eating disorders to poor disease management (Neumark-Sztainer, Patterson, et al., 2002; Rydall, Rodin, et al., 1997), it would be worthwhile to examine the effects on regimen adherence of CBT interventions addressing disordered eating in youth. Nevertheless, CBT intervention studies to reduce depression, anxiety, or eating disorders among youth with T1D and evaluate the effects on regimen adherence have not yet been reported.

In applications to T1D, cognitive-behaviorally based interventions such as CST focus on general life issues as well as improving the behaviors and skills necessary to manage T1D and achieve better glycemic control and psychosocial outcomes (Grey, 2011). Controlled research with adolescents receiving intensive insulin therapy has shown that CST led to better glycemic control and improved self-efficacy, coping, and quality of life following the intervention (Grey, Boland, et al., 1998), and these improvements were maintained 1 year after completion of the intervention (Grey, Boland, et al., 2000). CST was used to increase adolescents' sense of competence and mastery by retraining them in more positive and effective coping styles and patterns of behavior. Thus, programs such as this may help many adolescents adapt to living with T1D as well as provide them with a generalizable strategy to cope with other life experiences, thereby improving self-efficacy and quality of life and reducing depression.

Psychological interventions have been shown to be effective in both asthma and obesity. Castés et al. (1999) created an intervention for Venezuelan children that included relaxation/guided imagery, cognitive stress management therapy, and a workshop to improve self-esteem. During the intervention, children showed a significant improvement in their asthma with a reduced number of asthmatic episodes, reduced use of bronchodilator medication, and an improvement in pulmonary function (Castés, Hagel, et al., 1999). Research also suggests that inpatient psychosocial interventions for Canadian children with asthma had a greater effect on asthma improvement than outpatient interventions, with better management of asthma symptoms and feeling better about having asthma (Brazil, McLean, et al., 1997).

In a recent review of interventions for adolescent obesity, it was shown that the majority of prevention programs with a mental health component took place in schools and resulted in mixed findings as to whether or not obesity prevention programs had any effect on mood, self-perception, and quality of life (Hoare, Fuller-Tyszkiewicz, et al., 2015). However, overweight and obese adolescents who participated in a group-based weight control intervention had significant improvements of social adjustment and self-concept (Jelalian, Sato, & Hart, 2011).

As adolescence is a time when teens strive to be independent from their parents, it may be important to develop interventions that provide guidance and structure without excessive importance placed on the role of parents. By targeting the developing adolescent alone, interventions can focus on encouraging and empowering adolescents to take control of their diabetes. One study paired youth ages 11–16 with a "diabetes personal trainer." Trainers worked with the adolescents to improve self-monitoring, goal-setting, and problem-solving related to their diabetes care. Results indicated that the personal trainer intervention had a significant effect on glycemic control among older adolescents in the study (Nansel, Ianotti, et al., 2007), an effect that was maintained at 2-year follow-up (Nansel, Ianotti, et al., 2009). This suggests that middle adolescence (typically defined as ages 14–16) is a particularly difficult time in the struggle for independence, and adolescents in this age group are more willing and receptive to help with diabetes that makes them feel empowered and supported while still in control. The use of an outsider acting as a "diabetes personal trainer" seems to provide the necessary structure and support for adolescents without the dual role of a parent, which may hinder the perception of independence and individual self-efficacy.

Similarly, motivational interviewing has been found to be an efficacious method for improving diabetes management in adolescents with T1D. The results of a randomized multicenter trial conducted in the UK indicated that adolescents receiving motivational interviewing improved their long-term glycemic control and quality of life (Channon, Huws-Thomas, et al., 2007). The use of motivational interviewing has also been efficacious with youth who have asthma. Research provides preliminary support for the use of motivational interviewing to improve regimen adherence in urban, African-American youth with asthma (Riekert, Borrelli, et al., 2011).

Peer Support Interventions

Peer relationships play a significant role during childhood and adolescence. Thus, developmental stage is especially important to take into account when designing interventions for youth that involve social support. For many young children, their closest relationship is with a parent or guardian. For adolescents, parental involvement may become less desired as they struggle to be more independent while achieving peer group identity. Along with these essentially normal challenges of adolescent development, living with a chronic health condition can make independence and fitting in with peers much more difficult. Some research has addressed the role of peers for youth with chronic health conditions. In a study assessing friend support for T1D, La Greca et al. (1995) found that friends provided useful emotional support by helping the adolescent feel accepted and companionship support by engaging in healthy eating or exercising behaviors together. Thus, interventions that involve peers would do well to allow active participation in education and treatment of the chronic condition.

A review of peer support interventions by Funnell (2010) demonstrated the concentration of peer-based interventions in adult populations rather than child and adolescent populations. This is a relatively underresearched area in pediatric health behavior research. Greco et al. (2001) found that when peers were included in a five-session, multisystemic, home-based intervention for children and adolescents with T1D, better glycemic control resulted. It is important to tailor peer support interventions to the individual child or adolescent, as perceptions of what constitutes "support" may differ between the parent and child (Pendley, Kasmen, et al., 2002).

In order to build more school and peer support for children with asthma, Clark et al. (2004) found that education for US students as well as school personnel resulted in significant symptom reduction in children with asthma, better grades, and less absenteeism. Peer involvement in asthma management has also been seen to positively affect quality of life. A peer education program in Australia in which older students taught younger students about asthma control resulted in less absenteeism and improved quality of life (Shah, Peat, et al., 2001). Similarly, when peers were trained as "peer leaders" in asthma management for their schools in the USA, the quality of life significantly improved in students with asthma within those schools (Rhee, Belyea, et al., 2011).

In diabetes research, peer-focused interventions generally include psychoeducation to deal with social situations that may impede optimal self-care. One study found that educating adolescents with diabetes and their best friends together resulted in increased knowledge of diabetes, increased social support, and decreased family conflict related to diabetes (Greco, Pendley, et al., 2001). Another study utilized a group format using only children with diabetes in group problem-solving sessions to counter the typical decline in glycemic control during adolescence (Anderson, Wolf, et al., 1989). Besides CST (Grey, 2011), there are a number of other examples of intervention studies for youth with T1D that used peer groups to deliver interventions. These studies indicate that stress management, problem-solving, and CST delivered in small groups of youths reduced diabetes-related stress in American children (Boardway, Delamater, et al., 1993; Hains, Davies, et al., 2000), improved social interaction in children in Spain (Mendez & Belendez, 1997), and increased glucose monitoring and glycemic control in American children (Cook, Herold, et al., 2002). It is important to note that, as discussed by Pendley et al. (2002), perceptions of support are subjective and relative. Adolescents in poor control of their diabetes may be more concerned with peer perceptions of their care and feel supported by friends who ignore their diabetes status. Interventions should be sure to properly educate both participants and peers in order to have a positive effect on health. Nevertheless, it is clear that intervention approaches that utilize peer groups may be beneficial for diabetes management in youth.

Obesity research has also done well to involve peers in treatment. One study compared "peer-enhanced adventure therapy" combined with traditional CBT for weight loss with the combination of aerobic exercise and CBT. Significantly more adolescents in the "peer-enhanced adventure therapy" group maintained at least 10 pounds of weight loss at 10-month follow-up. The peer-enhanced activity involved working together in a group to complete physical challenges (such as climbing and mazes) with mental exercises aimed at developing social skills and self-confidence. This proved to be an effective supplement to CBT for weight loss, particularly in older adolescents, who valued their peer support far more than exercise (Jelalian, Mehlenbeck, et al., 2006).

Another study implemented a school-wide, peer-led program to prevent obesity in Canadian children attending elementary schools. Older students were trained in nutrition, physical activity, and realistic body images before being paired with younger students. Results of this program indicated that those who participated in the intervention showed an increase in knowledge, healthy behaviors and attitudes, as well as a benefit in bringing children closer to recommended weight guidelines (Stock, Miranda, et al., 2007). Student-led programs may be especially useful as they may benefit both the leader and paired student.

Electronically-Based Health Interventions

Interventions delivered electronically to improve health behaviors and health outcomes are important to discuss given the growing number of children and adolescents who have access to the internet. Such interventions are referred to as eHealth or mHealth (mobile health) interventions. According to a review conducted in the UK, more than two-thirds of the world's population has a mobile phone (Free, Phillips, et al., 2013). Children are now given greater access to technological devices for games, online learning, and communication at a younger age than ever before. Mobile technology allows the user the opportunity to research, take breaks, respond at convenient times, and receive support from a huge network of users. This medium has great potential for delivering health information to youth.

For example, an Internet-based self-management intervention program for adolescents with T1D addressed barriers to effective self-management by targeting problem-solving skills. Adolescents who participated in the intervention showed significant improvements in self-management of their diabetes (Mulvaney, Rothman, et al., 2010). In another eHealth study, the effects of CST for adolescents delivered over the Internet were examined in comparison with an internet-delivered educational intervention. Results from this randomized controlled multisite trial showed clinical improvements for youth in both groups, supporting the idea that behavioral interventions can be effectively provided to youth with T1D using the Internet (Grey, Whittemore, et al., 2013).

Mobile health interventions have also recently been examined. One study in Canada developed a mobile app to improve diabetes management in adolescents with T1D, with input from youth in the design of the app. The app was able to transfer blood glucose meter readings, communicate with a community of other users, and reward routine diabetes management behaviors with tangible prizes such as iTunes music and apps. Results showed increased blood glucose monitoring in adolescents (Cafazzo, Casselman, et al., 2012).

The use of mobile technology to deliver evidence-based interventions has also proven effective. A recent study delivered BFST-D to two groups of youth with T1D through either live videoconferencing on Skype or in person at the clinic. Although there were no differences between groups, the Skype intervention had statistically significant improvements in self-management behaviors and glycemic control. This suggests mHealth technology is an effective medium for delivering therapeutic interventions that were previously only done in person. Youth may be more amenable to participating in treatment if given the option to participate in programs on their own schedules in a flexible way. Another study conducted in the UK demonstrated mHealth to be an efficacious medium to provide support to youth with T1D. "Sweet Talk" sent scheduled text messages to engage young people with diabetes in between clinic visits and allowed them to respond with questions and information for their health-care providers. Participants were also able to share their own tips and life lessons with the greater community, establishing the system as an effective way to provide support to youth with diabetes (Franklin, Greene, et al., 2008).

eHealth technology has also been beneficial in improving self-management of asthma in youth. The Health Buddy, an interactive device, was designed for children to monitor their asthma symptoms and report their quality of life securely to their health-care providers. After 90 days, children using the Health Buddy were less likely to report any limitation in activity or make urgent calls to the hospital and had improved their self-management behaviors for asthma symptoms (Guendelman, Meade, et al., 2002). Another computer-based program called Watch, Discover, Think, and Act provided education on asthma and its necessary management. Children and preteens who used the program scored significantly higher on questions assessing asthma prevention, regulation, and treatment. They also reported greater self-efficacy and importance of engaging in self-management behaviors (Shegog, Bartholomew, et al., 2001).

In obesity treatment, mobile technology and text messaging seem to be well-received by youth and their families. Parents of obese children have been enthusiastic about receiving text messages to offer suggestions for improving their child's health (Sharifi, Dryden, et al., 2013), and teens have reported that mobile technology that supports and reinforces healthy behaviors is useful to them (Arteaga, Kudeki, & Woodworth, 2009). A web-based family program for overweight children was demonstrated to be feasible and resulted in short-term weight loss (Delamater, Pulgaron, et al., 2013).

A recently created iPhone platform was used to motivate teenagers to engage in physical activity through the use of well-known iPhone games that require movement through GPS tracking or arm movement. Each user completed a brief, 10-question version of the Big Five personality test to help personalize the platform to each person. Based on their self-reported personality characteristics, users were offered specific games and motivational phrases through an "agent": a kind, supporting female or a stern, commanding male. Motivational statements were provided during the activities, encouraging the user to keep going or invite friends to join the game. Teens using the program were very responsive to the agents, thus utilizing the program as an effective tool to be more physically active (Arteaga, Kudeki, & Woodworth, 2009). Another study used tailored text messages in conjunction with a weight management program for obese adolescents. A large number of messages were created about weight-related behaviors and sent to individuals based on their difficulties with weight loss. Participants found the messages to be very personally relevant and useful, citing meal suggestions as most helpful. Thus, text messaging as a supplement to a weight-loss program was reported to be an enjoyable way to improve healthy behaviors (Woolford, Clark, et al., 2010).

Summary and Conclusions

Chronic health conditions in childhood can make physical and psychosocial development very challenging for the child, resulting in distress, poor mental health, and maladaptive coping strategies that adversely affect physical health outcomes. These conditions may also adversely impact family functioning and parental quality of life. In an effort to ease the burden on the child and family, a number of interventions have been developed for a variety of chronic conditions. This chapter summarized intervention approaches typically used with three common chronic health issues in childhood: obesity, asthma, and diabetes. The results of this research, conducted primarily in the USA and Europe, have shown that interventions typically have involved five approaches: (1) education for the child and family, (2) facilitating behavior change via psychosocial processes, (3) addressing personal and social psychological issues, (4) employing peers as part of the intervention to increase social support, and (5) utilizing digital, web-based, or mobile technology to deliver evidence-based interventions.

Using three health conditions as examples, research indicates that education is most useful when used in conjunction with other approaches. Behavioral interventions implemented through modeling, social reinforcement, cognitive-behavioral strategies, and modification of family functioning directed toward key health behaviors have shown to be a very well-developed and efficacious method for addressing chronic health conditions as they involve the family in addition to the child. Because they target changing family behaviors related to effective management of health conditions, this is essentially a psychosocial intervention approach. Psychological interventions often focus on personal adjustment and stress related to management of chronic illness and typically involve a behavioral component in an attempt to make care seem normal, routine, and less burdensome. Interventions to increase intrinsic motivation have also been employed to manage the complex regimens associated with these conditions. Technology-based interventions have shown great promise for interventions with youth, as many of today's youth are comfortable and familiar using digital technology, and reach to the population of youth can be significantly enhanced. Future research would do well to incorporate multiple approaches, using the child and family together, to address the management of chronic health conditions in a social context.

Despite the commonalities found in interventions across obesity, asthma, and diabetes, it should be noted that these conditions are distinct and unique in their physiological, emotional, and social effects on the child and family. Obesity poses long-term threats to health and organ function; however, in childhood and adolescence, concerns regarding body image and the possibility of social rejection are far more salient to youth. Intensive diet and exercise as treatment for obesity is difficult, and weight-loss progress can be slow, which may lead to a lack of motivation and decreased optimism regarding change.

T1D poses both immediate physiological and social difficulties in daily life. Youth with T1D often sacrifice their self-management routine for a variety of reasons: "burnout" from time-consuming self-care behaviors, fitting in with friends, or determining that other tasks may assume higher priority than diabetes care. Many youth with T1D may view self-management as a burden: as the body adjusts to chronic hyperglycemia, self-management no longer seems necessary to "feel better" and instead acts as a social hindrance and/or a trigger for family conflict. Many teens with T1D seem less affected by their providers' warnings of complications when complications are not immediately felt. Rather, the feeling of isolation and burden is immediate when treatment is so time intensive, and blood glucose is affected by physical activity, dietary intake, hormonal change, and emotions.

For children and adolescents with asthma, rescue bronchodilator treatment may be viewed as very valued given the fact that uncontrolled asthma can have life-threatening consequences. The inability to breathe causes panic in both the child and family members, as asthma attacks can be acute and without warning. It would then be understandable that a fear of asthma attacks may affect the child's self-confidence and increase anxiety.

Cultural factors are also important to consider when determining an intervention approach for families. For example, low-income families may find it difficult to manage obesity when their financial means only allow for high-calorie fast foods. Those who live in neighborhoods with high crime rates may not have the option of engaging in physical activity without a safe space nearby. Thus, ecological contextual factors are important to consider in treatment planning.

This review of child and family interventions for children with chronic health conditions revealed several themes applicable to the various conditions. Given the long-term duration of a chronic condition, most require time-intensive and often burdensome treatments that may affect a child's mental health, social status, and typical development. Education was noted to be an important aspect of many intervention programs, although in most cases is best thought of as a necessary but not sufficient condition to ensure optimal health behaviors for good health outcomes; often this approach has been used to supplement behavioral interventions.

Most intervention studies utilized a primarily family-based behavioral approach focused on the necessary health behaviors required by the child and family to manage the condition and ensure good health. Behavioral interventions usually involve parents and family members to facilitate encouragement and support of key health behaviors. Based on social cognitive theory, behavioral interventions use social reinforcement of key target behaviors, with clear expectations of what is required for success. Modeling is another key component of behavioral interventions based on SCT and has been particularly helpful in guiding intervention development. This approach has also been informed by family systems theory, and applications to diabetes management have been shown to be efficacious. Thus, these interventions typically focus on a key mediator of regimen-related behaviors – family functioning. These behavioral interventions appear to work by changing family behaviors such as clear communication about goals and responsibilities, modeling of effective self-care behaviors, and social reinforcement of behaviors key to ensuring good health.

Psychological interventions informed by SCT are important and necessary, since many chronic health conditions affect psychological functioning and quality of life. Psychological variables such as depression, anxiety, self-efficacy, and self-esteem are often assessed as outcomes rather than the focus of intervention. Research using cognitive-behavioral interventions to address stress and coping has shown promise in improving health outcomes and quality of life in youth with diabetes. More work is needed to address depression, anxiety, and eating disorders in youth with chronic health conditions, as studies have shown these psychological disorders may undermine effective self-care.

Another psychological intervention approach based on self-determination theory utilizes motivational interviewing, focusing on increasing intrinsic motivation for self-care. Although preliminary results are promising in applications to T1D and asthma, more research is needed using this approach to manage other chronic health conditions.

Interventions utilizing peers are another common approach to address chronic health conditions in youth. Researchers have employed peers in several ways for intervention: led by healthy peers, alongside peers with the same condition, or alongside healthy friends. Overall, the use of a paired or group format seems to provide the support necessary for children and teens to learn from each other in a way that feels less stigmatizing and less like a lecture than adult-led programs.

Technology-based, eHealth and mHealth interventions hold great promise for increasing reach to the populations of children living with chronic health conditions in order to effectively deliver interventions to improve health. It can be especially convenient for older adolescents and parents who may have busy schedules or other priorities, as it still allows them to engage and utilize services on their own schedules. Studies have already demonstrated the feasibility and efficacy of this approach in management of obesity, diabetes, and asthma in youth, but more work is needed to demonstrate effectiveness in larger scale trials.

Based on the benefits derived from each type of intervention, long-term programs to help youth and their families deal effectively with chronic health conditions may combine aspects of each type of intervention approach (i.e., education of the disease and associated psychological complications, behavioral and psychosocial, psychological, peer, and technology). After careful assessment, these approaches can skillfully address relevant issues at each level of the ecological model, including potential knowledge and skills deficits, problem-solving, coping and stress management skills, motivation for self-care, psychological disorders, peer and family support, as well as contacts and relationships with the healthcare team in order to provide effective follow-up support over time.

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22

Peer Support in Prevention, Chronic Disease Management, and Well-Being

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Social support and the social bonds on which it is based are fundamental among primates (Harlow & Harlow, 1966; Harlow & Zimmerman, 1959) and extend to a variety of mammals including, e.g., elephants (Archie, Moss, & Alberts, 2006). Thus, peer support provided by "community health workers," "lay health advisors," "*promotores de salud*," and individuals with a number of other titles is built upon a fundamental and powerful dimension of human behavior. Reflecting this, peer support has been shown to play influential roles in health and the health-care delivery system (Gibbons & Tyus, 2007; Perry, Zulliger, & Rogers, 2014; Swider, 2002; Viswanathan, Kraschnewski, et al., 2010). Table 22.1 describes some of the benefits noted for peer support including encouraging appropriate regular care, providing practical and emotional support for complex behaviors that are critical to staying healthy, and helping individuals cope with the stressors chronic diseases and conditions so often entail (Brownson & Heisler, 2009; Cherrington, Ayala, et al., 2008; Colella & King, 2004; Dunn, Steginga, et al., 2003; Fisher, Brownson, et al., 2005; Fisher, Strunk, et al., 2009; Heisler, 2010; Parry & Watt-Watson, 2010; Rosenthal, Brownstein, et al., 2010; Solomon, 2004; Whitley, Everhart, & Wright, 2006). Accordingly calls to action and formal policy recommendations call for the implementation of peer support approaches (Bhutta, Lassi, et al., 2010; Bielaszka-DuVernay, 2011; CDC, 2015; Goodwin & Tobler, 2008), including in a joint position statement of the Society of Behavioral Medicine, the National Council of La Raza, the Harvard Law School Center for Health Law & Policy Innovation, and Peers for Progress (Sharp, Fisher, & Gerber, 2015) and in a strong emphasis on community health workers in the World Health Organization's Global Health Workforce Alliance (Global Health Workforce Alliance, 2010).

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Table 22.1 Specific ways in which peer support contributes to health (e.g., Heisler, 2010; Rosenthal, Brownstein, et al., 2010)

- Link people to share knowledge and experience
- Provide health education at the individual as well as community level
- Provide practical assistance for how to achieve and sustain complex health behaviors that are needed in chronic disease management and prevention
- Provide emotional and social support
- Help people cope with the stressors that so often accompany health problems
- Help people get the clinical care and other services that they need; assist in navigating the system
- Build individual and community capacity for understanding health problems and promoting ways of addressing them
- Advocate for patients and their communities
- Build relationships based on trust rather than expertise
- Build cultural competence through peer supporters that often come from the communities they serve
- Above from the National Community Health Advisor Study (Rosenthal, Wiggins, & Brownstein, 1998)

Community health workers benefit from

- Shared experience with the people and communities they serve
- Shared life experiences, shared health condition or diseases
- Shared cultural, community ties, and social-economic status

As a result, the community health worker brings a special combination of expertise in the areas they address and deep experience with the perspectives of the individuals and communities they seek to serve

Ubiquity of Peer Support

Clearly, peer support contributes to or is part of broader approaches of self-management, self-management support, patient education, or patient engagement. The ubiquity of peer support, however, attests to its importance as a frequent component of each of these. A search of PubMed for papers with a variety of terms related to peer support (e.g., "community health worker," "*promotora*," "lay health advisor," "health coach") in their titles or abstracts yielded 431 hits for CY 2005, 936 in 2010, 1836 in 2014, and 2082 in 2015. Figure 22.1 presents the complete data for all years. There was a 483% increase for all papers with terms related to peer support between 2005 and 2015.

Evidence for Benefits of Peer Support

A review by Perry and his colleagues in the 2014 *Annual Review of Public Health* (Perry, Zulliger, & Rogers, 2014) identified contributions of community health workers to basic health needs (e.g., reducing childhood undernutrition), to primary care and health promotion, and to disease management.

Another review (Fisher, Boothroyd, et al., 2017) included peer support interventions from around the world that addressed a wide variety

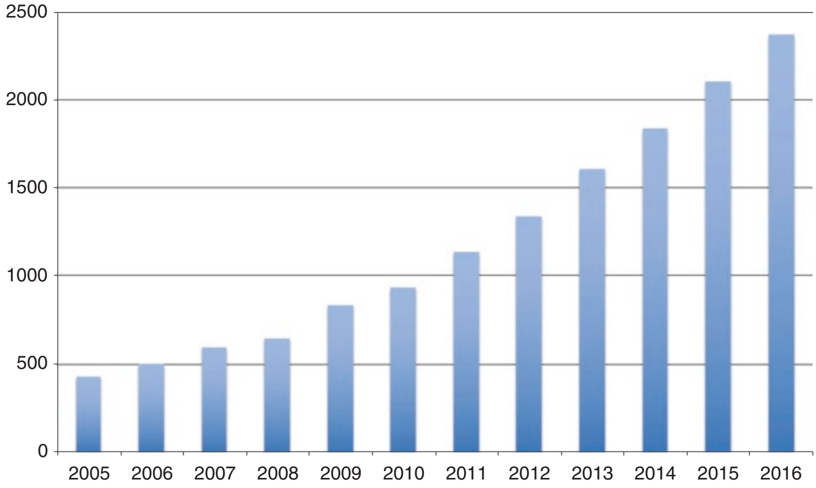

Fig. 22.1 Publications in PubMed with peer support and related terms in titles or abstracts, 2005 through 2016

of prevention and health objectives entailing sustained behavior change (in contrast to relatively isolated acts such as cancer screening) and using a broad definition of peer support entailing assistance and encouragement for those behaviors as well as linkage to appropriate care. It identified papers from the USA (34 papers), Canada (7), the Bangladesh, England, Pakistan, and Scotland (4 each), and Australia, Brazil, Denmark, Ireland, Mozambique, New Zealand, South Africa, and Uganda (1 each). The health issues papers addressed included pre- and postnatal care (17 papers), cardiovascular disease (10), diabetes (9), asthma (6), HIV (6), mental health (8), cancer (4), substance use (3), and chronic fatigue syndrome and chronic obstructive pulmonary disease (1 each). Across all 65 papers, 54 (83%) reported significant between-group or pre-post changes showing benefits of peer support. Among the 48 papers reporting RCTs, 39 (81%) reported significant between-group or pre-post changes.

The review by Fisher et al. also included summary of 24 reviews of peer support interventions (Andrews, Felton, et al., 2004; Ayala, Vaz, et al., 2010; Brownstein, Chowdhury, et al., 2007; Campbell, Phaneuf, & Deane, 2004; Chapman, Morel, et al., 2010; Dale, Caramlau, et al., 2008; Eysenbach, Powell, et al., 2004; Gibbons & Tyus, 2007; Giugliani, Harzheim, et al., 2011; Hoey, Ieropoli, et al., 2008; Hunt, Grant, & Appel, 2011; Ingram, MacArthur, et al., 2010; Kenya, Chida, et al., 2011; Lewin, Munabi-Babigumira, et al., 2010; Nemcek & Sabatier, 2003; Norris, Chowdhury, et al., 2006; Parry & Watt-Watson, 2010; Pfeiffer, Heisler, et al., 2011; Repper & Carter, 2011; Swider, 2002; van Dam, van der Horst, et al., 2005; Viswanathan, Kraschnewski, et al., 2010). Across these 19 reviews, a median of 64.5% of papers reviewed reported significant effects of peer support.

An ambitious 2015 review by the UK-based Nesta Health Lab and National Voices examined 1023 studies of peer support provided by a wide range of individuals, paid and volunteer; trained and not extensively trained; group and individual; phone, face-to-face, social media based; ranging from "one off" to over 1 year (Nesta Health Lab & National Voices, 2015). Recipients included:

- People at risk (e.g., smoking, alcohol, poor diet)
- People with long-term physical conditions
- People with mental health conditions
- Carers of people with physical or mental health conditions
- Parents, including breastfeeding mothers
- Children and young people
- Students
- Older people
- Employees
- Groups with specific experiences (e.g., veterans, sex workers)
- Healthcare professionals

Across this wide range of peer support and recipients, many reports found benefits in "experience and emotions," "behavior and health outcomes," and "health costs and service use." The report concludes cautiously that "the evidence available suggests that peer support is worth investing in, including commissioning more robust evaluations of the impacts and the reasons why peer support works better in some contexts and for some groups." Table 22.2 (Table 14, p. 23 from the report) summarizes recommendations for investment in peer support.

In addition to broad evidence of effectiveness, there is emerging growing evidence of cost-effectiveness of peer support, as summarized in Table 22.3.

Chapter Overview

Given the evidence for peer support in disease prevention and management, this chapter focuses on key considerations in developing scalable, disseminable models of peer support. The following section examines individual studies extending beyond efficacy to address the feasibility, reach, and sustainability of peer support. After that, the subsequent section reviews more fundamental psychological research related to social support and its implications for peer support. This chapter then turns to models of dissemination and, following that, key features of peer support pertinent to its success and its contributions to improving population health, including its ability to engage those too often "hardly reached" in

Table 22.2 Summary of expected benefits from various types of peer support

Type of peer support	Expected return on investment
One-to-one telephone support delivered by unpaid peers	• Inexpensive to set up and manage • May have variation in quality • Difficult to reach large numbers • Likely to reduce anxiety and isolation
One-to-one telephone support delivered by paid peers	• Potentially more costly • Difficult to reach large numbers • Likely to reduce anxiety and isolation • Moderate uptake rates
One-to-one in-person support delivered by unpaid peers	• Inexpensive to set up • Some management may be needed • High uptake rates • Likely to reduce anxiety and isolation • May improve health outcomes and behaviors
One-to-one in-person support delivered by paid peers	• Some costs for set up and management • High uptake rates • Difficult to reach large numbers • Likely to reduce anxiety and isolation • May improve health outcomes and behaviors
Support groups led by trained but unpaid peers	• Some investment in organization required • Likely to reduce anxiety and isolation • Easier to reach larger numbers
Educational groups co-led by paid peers and professionals	• Investment in organization required • Likely to reduce anxiety and isolation • Easier to reach larger numbers • May improve health outcomes and behaviors
Online support groups/forums	• Inexpensive to set up and manage • May have lower uptake rates and high drop out • Likely to improve knowledge and reduce anxiety by helping people feel less alone

Adapted from *Peer Support: What is it and Does it Work?* (Nesta Health Lab & National Voices, 2015)

Table 22.3 Examples of cost-effectiveness of peer support

In a community health center for low-income individuals in Denver, Colorado (Whitley, Everhart, & Wright, 2006)
• Shifted costs from urgent care, inpatient care, and outpatient behavioral health care
• Increase utilization of primary and specialty care visits
• ROI = 2.28:1.00
Diabetes initiative of Robert Wood Johnson Foundation (Brownson, Hoerger, et al., 2009)
• 3 of 4 projects in cost analysis emphasized peer supporters
• Cost per quality-adjusted life year (QALY) = $39,563 (well below $50,000 criterion for good value)
Asthma CHW project with Medicaid-covered children in Chicago (Margellos-Anast, Gutierrez, & Whitman, 2012)
• Three to four CHW home visits over 6 months and liaison with care team
• ROI: $5.58 saved per dollar spent
Lifestyle modification for low-income Latino adults with diabetes (Brown, Wilson, et al., 2012)
• CHWs and nurse educator: home visits, self-management education, individual counseling
• $10,995–$33,319 per QALY
• Especially cost-effective among those with HbA1c > 9%
Preventing rehospitalization in schizophrenia, depression, bipolar disorder (Sledge, Lawless, et al., 2011)
• Recovery mentors provided individualized frequency, mode, content of support
• Over 9 months: 0.89 vs. 1.53 hospitalizations, 10.08 vs. 19.08 days in hospital ($p < 0.05$)
Reducing depression/anxiety disorders in India (Patel, Weiss, et al., 2011)
• Education about psychological problems, ways of coping, and interpersonal therapy delivered by lay health counselors with primary care and psychiatric backup
• 30% decrease in prevalence, 36% in suicide attempts, 4.43 fewer days no work/reduced work in previous 30 days
• Lowered time costs resulted in intervention being cost-effective and cost saving

health care, integration of behavioral health, reaching populations and its role in primary care, integration with digital support, and organizational factors in implementing peer support. Given the wide range of programs, approaches, and models peer support entails, this chapter closes with discussion of peer support as a continuum cutting across many areas of health promotion and care.

Evidence from Individual Studies

Central to scalability is whether a program is feasible, reaches its intended audience, and is sustainable and adoptable (Glasgow & Emmons, 2007; Glasgow, Nelson, et al., 2006). Here and in much of the rest of this chapter, we include examples from the reports of investigators funded by and collaborators of *Peers for Progress*, a program dedicated to promoting peer support in health care and prevention (peersforprogress.org). Greater detail of these and similar studies is available through a supplement of the *Annals of Family Medicine* (Acheson & Fisher, 2015; Fisher, Ayala, et al., 2015).

Figure 22.2 portrays a general approach to thinking about program evaluation, from whether a program is feasible to whether it is adopted. This borrows from popular approaches to planning and evaluation such as Green and Kreuter's Precede-Proceed model (Green & Kreuter, 1999) and Glasgow's RE-AIM model (Glasgow, 2006; Glasgow & Emmons, 2007; Glasgow, Nelson, et al., 2006; Glasgow, Vogt, & Boles, 1999). In the following, we review evidence addressing these aspects of programmatic evaluation of peer support, drawn from Peers for Progress investigators and collaborators as well as select citations from the broader literature.

Feasibility

A global perspective provides an important frame for concerns about feasibility. In Thailand, Village Health Workers have been a part of the national health system since 1978, a system that spends the equivalent of $264 (US) per capita on health care (in 2013), relative to the US $9146 per capita (Global Health Observatory Data Repository). In Pakistan, an estimated 96,000 "Lady Health Workers" support maternal and child services through the primary care system that reaches an estimated 80% of Pakistan's rural population (Rahman, 2007; Rahman, Malik, et al., 2008).

- Across 14 projects funded by Peers for Progress in 9 countries on 6 continents, many in under-resourced settings, all were able to implement planned peer support programs. This speaks to the broad feasibility of these approaches in varied settings and populations.
- Among nine recipients of start-up grants from the Taiwanese Association of Diabetes Educators, all were able to develop and implement peer-led, ongoing support programs.
- Among African-American adults with diabetes in rural Alabama, intervention mapping was used to engage the community at multiple stages of program development. This iterative process led to the adoption of a flexible, client-tailored approach to providing ongoing support and the creation of a network for peer supporters to enhance teamwork, retention, and morale, minimize burnout, and permit case reassignment (Cherrington, Martin, et al., 2012).
- At the conclusion of a 2-month pilot in the UK, participants and peer supporters wanted to continue meeting, demonstrating that the

Fig. 22.2 General evaluation plan

peer support intervention was deliverable and acceptable to people with diabetes (Simmons, Cohn, et al., 2013).

- Training is central to peer support. Tang and her colleagues (Tang, Funnell, et al., 2011; Tang, Nwankwo, et al., 2014) have published several reports on training of peer supporters. In one program, 8 African-American adults with type 2 diabetes completed a 46-hour group training program. Attendance was 100%, and all 8 demonstrated competency objectives for diabetes knowledge, empowerment-based facilitation, active listening, and promoting self-efficacy. They also indicated willingness to facilitate subsequent peer support programs (Tang, Funnell, et al., 2011).
- In another project with African-American churches, Tang and her colleagues detailed the feasibility of training nonprofessionals to provide peer support for both diabetes prevention and ongoing diabetes self-management support (Tang, Nwankwo, et al., 2014).
- In prevention, a weight management program for immigrant Latino women in the USA was led by *Promotores*. It was well received and led to 2.1 kg losses (Cherrington, Willig, et al., 2015).
- A program for overweight African-American youth and families led by lay health leaders led to BMI reductions from 2.46 to 2.38 (Burnet, Plaut, et al., 2011).
- Mentors from the "Parents As Teachers" program improved weight management among postpartum adolescents through home visits and classroom and website activities (Haire-Joshu, Schwarz, et al., 2015).

Reach/Engagement

The 14 projects funded by Peers for Progress showed strong ability to reach and retain individuals for whom improved diabetes management was a priority. Across the projects, the number of participants in the peer support condition ranged from 46 to 810, and the average retention of these for follow-up evaluations was 78.6% (range from 45.7% to 99.4%). The average initial hemoglobin A1c (HbA1c) measure of blood sugar control for each site ranged from 7.1% to a high of 11.1% at one site. Overall, the average across sites was 8.41%, indicating these projects were reaching those for whom improved diabetes management was important. (For otherwise healthy adults, desired HbA1c is <7%. Goals of 7–8% are considered appropriate for those with limited life expectancy, long-standing diabetes, a history of severe hypoglycemia, or complications such as chronic kidney disease, nerve problems, or cardiovascular disease. National Diabetes Information Clearinghouse, 2014) Similarly, average systolic blood pressure across sites was 137.3 mmHg, and average BMI was 31.8.

- Among 102 entering a 6-month program in Vietnam, 86 completed it (Thanh, Deoisres, et al., 2013).
- In a 6-month program in Cameroon, only 1 of 100 participants dropped out.
- Emphasizing community partnerships, the peer support program for low-income African-Americans in underserved, rural Alabama communities exceeded its recruitment goals of 400 participants.
- In Cambridgeshire, UK, 1299 adults with diabetes enrolled for a peer support program, and 167 of these trained as peer support facilitators (Simmons, Prevost, et al., 2015).
- In Argentina, weekly phone calls were regularly maintained throughout a 12-month follow-up period (Gagliardino, Arrechea, et al., 2013).
- In China, the Beijing Diabetes Prevention and Treatment Association set objectives of enrolling peer supporters through each of 50 cooperating hospitals and community health centers to reach a goal of 5000. It succeeded in enrolling almost 5500 participants.

Efficacy/Effectiveness

- Among the 14 projects funded by Peers for Progress and using the sites as the unit of calculation, HbA1c declined from an average of 8.49% to 7.74%, systolic blood pressure from

137.0 to 133.6 mmHg, and BMI from 31.96 to 30.85 (Fisher, Ayala, et al., 2015).

- A "coach" intervention implemented as an extension of clinical teams caring for low-income and ethnic minority patients with diabetes in a large health center in San Francisco showed significant reductions in HbA1c measures of glucose control relative to controls (Thom, Ghorob, et al., 2013).
- A program for Latino adults with diabetes showed that volunteer peer leaders (PLs) could be as effective as staff community health workers (CHWs) in sustaining improvements in HbA1c over 12 months after a 6-month diabetes self-management education program (Tang, Funnell, et al., 2014).
- In *Clínicas de Salud del Pueblo* in southern California, the *Puentes* ("Bridges") program trained 34 volunteer peer leaders, each to provide support to 5–8 patients through telephone contact, in-person, individual, and group support. Among those randomized to the Puentes peer support condition, HbA1c decreased from 8.7% to 8.4%. This was significantly greater than among controls ($p = 0.05$) among whom HbA1c was unchanged (Ayala, Ibarra, et al., 2015).
- In Cameroon, peer support included group meetings and activities, such as group meals to demonstrate the possibility of healthy and tasty traditional meals, and frequent individual contacts – five times a month. Benefits included reductions in BMI (28.6–25.9 kg/m^2), systolic and diastolic blood pressure (142.0–124.4, 84.4–77.7 mmHg), and HbA1c (9.6–6.7%) (Assah, Atanga, et al., 2015).
- In Thailand, Village Health Volunteers were trained to include diabetes management in their work with individuals and communities. Baseline and post-intervention for 53 adults with type 2 diabetes showed declines in HbA1c from 8.64% to 7.91% ($p = 0.027$) and BMI from 26.66 to 25.17 ($p = 0.07$). Survey data included increases in measures of healthy diet, exercise, and self-efficacy and increases on the WHOQOL-BREF measure of quality of life (Fisher, Boothroyd, et al., 2012; Sanguanprasit, Leelaphan, et al., 2011; WHO Programme on Mental Health, 1996).
- In Uganda, individuals were paired in dyads and then linked by a telephone/text message network with each other and a clinic nurse who coordinated the program. Average diastolic blood pressure dropped from 85.39 to 76.27 mmHg, and average HbA1c declined from 11.1% to 8.3%. The number of participants with HbA1c values less than 7% nearly doubled, from 17% to 32%. Final evaluation feedback from participants also reflected perceptions of improved care from clinic staff, an important finding for enhancing linkages to care (Baumann, Frederick, et al., 2015).
- Among the first 110 participants entering the program of the Beijing Diabetes Prevention and Treatment Association, the percentage with HbA1C less than 7% has increased from 48% to 64% during initial 8 months of intervention.
- Three months' diabetes self-management education plus 12 months of ongoing peer support showed benefits in cardiovascular risk among African-American adults with diabetes. At 15-month follow up and in comparison to controls who received only the 3 months' education, the group that also received 12 months' peer support had significantly better measures of low-density lipoprotein cholesterol (−15 mg/dL, $p = 0.03$), systolic blood pressure (−10 mm Hg, $p = 0.01$), diastolic blood pressure (−8.3 mm Hg, $p = 0.001$), and body mass index (−0.8 kg/m2, $p = 0.032$) (Tang, Funnell, et al., 2015).
- Also identifying benefits for cardiovascular risk and extending previous findings of benefits of group support for blood pressure (Schulz, Pischke, et al., 2008), Simmons and his colleagues found reductions in systolic blood pressure through group peer support among middle-class, mostly retired adults with diabetes recruited through primary care in Cambridgeshire in the UK (Simmons, Prevost, et al., 2015).

Program Sustainability

Note on Terminology

Sustainability, dissemination, scalability, and adoption are overlapping and often confused. Here we have included sustainability of *individuals*' changes and benefits under efficacy/effectiveness because the provision of support for ongoing behavior change, e.g., diabetes self-management support (Powers, Bardsley, et al., 2015), is one of the primary rationales for peer support (Fisher, Earp, et al., 2010). We have then distinguished sustainability of individual programs *within their initial settings or organizations* from spread/adoption of programs to or by other settings or organizations. Thus, the ability of the program in Capetown, South Africa, to secure local funding to continue its activities is included under sustainability, while the adoption of the program of 15 sites of WellMed by all 23 of its sites in *other settings* is included under spread/adoption. Under spread/adoption, we have also included extension of programs from one problem, e.g., diabetes, to other problems such as childhood obesity.

- Four years after the end of funding from Peers for Progress, Village Health Volunteers in Thailand were still implementing diabetes activities, education, and support for which they had been trained. Local administrative offices in the provinces in which the program was developed committed to provide support to the project, both in cash and in-kind support, in order to ensure its sustainability. This is because the local administrative offices recognized the value of the project not only in terms of health but also in building unity and sense of belonging among people. In one community, Supan Buri, a member of the local administration who is also a Village Health Volunteer participating in the project, volunteered to work with other VHVs and local health staff to continue the activities and expand the coverage of the project.
- In light of successes with diabetes described later in this chapter, the Anhui Provincial Health Bureau in China has extended a peer support program to additional communities and to cardiovascular disease prevention and management (Zhong, Wang, et al., 2015).
- In Cambridgeshire, over 100 peer leaders and participants met in October, 2013, at the end of the formal study (Simmons, Prevost, et al., 2015) to discuss ongoing organizational structure for the program. This led to further funding from the UK government and collaboration with Diabetes UK to extend the program to six areas in the eastern region and West Midlands.
- Also in the UK, after a successful pilot funded by Nesta Health Lab and the Cabinet Office, the Royal National Institute for the Blind (RNIB) has embedded a new peer support service for people affected by sight loss into their core service offering. The service – called Time to Talk – is a series of four weekly telephone support sessions that give people affected by sight loss a safe space to (a) discuss their sight loss with others, (b) identify their needs, and (c) give and receive information around living with sight loss. Each session is led by a trained volunteer facilitator who helps the group to discuss a particular topic and exchange information and experiences. The pilot involved 1027 older people with sight loss as participants and included 4108 h of peer support contact. In the evaluation of the pilot, it was found that participants felt an increase in their knowledge of services and subsequent take-up of those services, increase in well-being measures including confidence, positivity and feelings of self-worth, and reduced isolation.

Experience in Uganda has led to an important perspective on sustainability. There, the nurse who had coordinated the program reported that the program as a whole had *not* been continued but that important elements of it had been incorporated into routine activities. For example, the nurse reported that she schedules patients who had been linked in peer support dyads for attendance at clinic on the same day, sustaining their relationship and utilizing it to support their care. It may be helpful to broaden our ideas about sustainability, not only to focus on maintaining whole programs but also to emphasize their *incorporation* into existing practices and procedures.

Spread/Adoption

- In Texas, WellMed originally agreed to implement a peer support diabetes program in 15 sites but, based on its own initial appraisal, extended it to all 23 of the clinical sites in its network (Knox, Huff, et al., 2015).
- In *Clínicas de Salud del Pueblo* in southern California, the *Puentes* program for adults with diabetes was used as a model for health initiatives among children and helped guide changes to the clinics system of care, including provider training and electronic health record changes to ensure documentation of peer support (Ayala, Ibarra, et al., 2015).
- In the USA, the Department of Veterans Affairs (VA) sets an example for spreading peer support at the national level. Since 2007, the peer workforce in the VA has increased more than 2.5 times and continues to grow; in 2013, the VA hired 800 mental health peer specialists in addition to the number originally planned for the year. In one national survey across the VA mental health system, 70% of sites reported hiring a peer specialist, 51% reported that implementation is "going well," and 96% stated that peer specialists are having a positive impact on veterans' care (Chinman, Salzer, & O'Brien-Mazza, 2012).
- In healthcare reform in the USA, the *Affordable Care Act* or "Obamacare" includes a number of provisions for support of community health worker interventions in prevention as well as chronic disease management and reducing avoidable hospital care such as among those recently hospitalized for problems like pneumonia, myocardial infarction, or heart failure (Peers for Progress, 2014b). The emphasis on team-based, patient-centered care has encouraged medical practices to begin employing community health workers as part of a strategy to improve patient-provider communication, reduce costs, and improve quality of care.
- In Kerala, India, Oldenburg and his colleague have extended peer support interventions for adults with diabetes and combined them with community approaches to health promotion to develop a community-based, peer support program for diabetes prevention (Sathish, Williams, et al., 2013). After the formal, 12-month intervention, a number of the peer supporters and community groups with which they have worked have taken the initiative to develop "extension activities" in their own neighborhoods and communities.

Fundamental Features of Social and Peer Support

The previous sections have described the broad evidence that peer support is feasible, beneficial, adaptable, sustainable, and cost-effective. The 550% growth from 2005 to 2016 in number of publications addressing peer support depicted in Fig. 22.1 (from 431 to 2369) also points to it being ubiquitous! There is a reason peer support is effective and gaining increased attention in health care and public health. As shown through a rich and varied base of research, social support and our connections with others are fundamental and important components of human biology, psychology, and community. The following sections review some of this research and its implications for peer support interventions.

Fundamental Value of Connection

As noted earlier, social support and the social bonds on which it is based are fundamental among many mammals (Archie, Moss, & Alberts, 2006) and primates (Harlow & Harlow, 1966; Harlow & Zimmerman, 1959). Reviews show the importance of this in that social isolation, the lack of social support, is as lethal as smoking cigarettes (Holt-Lunstad, Smith, & Layton, 2010; House, Landis, & Umberson, 1988). Evidence indicates that, in addition to a variety of benefits through health behaviors and psychological status (See Uchino et al., *infra*), social support "gets under the skin" as in the demonstration that the range of social relationships is associated with cold and flu symptom response to rhinovirus exposure (Cohen, Doyle, et al., 1997).

The implications of this for peer support are substantial. If those who have someone they can talk to about personal matters and call on for a favor (a simple indicator of connection) are better able to address a variety of life's challenges (e.g., Lowenthal & Haven, 1968), then peer support may provide benefit through its most fundamental features.

The value of simply "being there" is illustrated in a program of telephone-based peer support for those with diabetes in Hong Kong (Chan, Sui, et al., 2014). Developed to focus on diabetes self-management and implemented by telephone, participants had a median of 20 telephone calls with peer supporters, although the protocol anticipated only 12 over one year. Clearly, they saw value in talking with peers. Moreover, as will be detailed later in this chapter, those in the peer support condition with initially elevated measures of depression, anxiety, and/or stress (Szabo, 2010) showed substantial reductions in these, even though the intervention was designed to focus on diabetes management. Thus, it appears the simple provision of peer support is valued by those receiving it (the average of 20 calls instead of the 12 called for in the protocol) and is beneficial to emotional well-being.

The implications of this fundamental value of connection are important. Although knowledge about disease and its prevention or management and skills for caring for oneself are frequent and enduring themes of peer support programs, program managers and peer supporters themselves should recognize that their first task is simply to be someone who is interested in and has time to spend with those they would help. Even if they fail to convey helpful knowledge and assistance in prevention or disease management, simply "being there" for people may convey substantial benefit. Recent research by the Nuffield Trust on the Stroke Association's peer support model in the UK suggested that stroke survivors attending peer support groups appreciate the social aspect of these groups, this being often a motivation for attending. In the words of stroke survivors themselves, peer support groups gave them "an opportunity to spend time with others and offered a route back to having a social life" (Compiled by the Nesta Health Lab; http://www.nesta.org.uk/health-lab).

Secure Base

The Attachment Theory of Sir John Bowlby (1988), Mary Ainsworth (Ainsworth, Blehar, et al., 1978), and others provides an important framework for understanding peer support. Infants and those who parent them show remarkably reproducible patterns of interaction in which, optimally, the child uses his caregiver as a "secure base" from which to explore surroundings and to which to turn for comfort when stressed. In contrast to this securely attached pattern, an anxious and ambivalent pattern entails heightened arousal when stressed and both clinging to but inability to gain comfort from the parent. In an avoidant pattern, the child is aloof from the parent in both stressed and more routine circumstances. Research shows the securely attached pattern to be related to greater psychological and general well-being relative to the other types both in childhood and in adulthood (Mikulincer & Shaver, 2007).

These naturally occurring patterns of attachment may provide a template for peer support. Ideally, the peer supporter becomes something of a secure base from which the individual can explore ways to live in a healthier manner but also provides a source to which to turn when stress or unfamiliar issues arise. Some will interact with the peer supporter in an anxious-ambivalent manner. This may include appreciable emotionality expressed more quickly than might be expected, but also reactions of suspicion and annoyance over actions or words that the recipient feels indicate distancing or negativity. These reactions are thought to emerge from a history of inconsistent parenting or of relationships in which emotional support was directed more by the mood of the parent or significant other than the needs of the individual (Bowlby, 1988). For these individuals, the peer supporter's consistency, patience, and clear communication of interest and valuing of the person are paramount.

Those who have been frustrated in their attachments may develop an aloof, avoidant style in which they communicate little interest in emotional support and, perhaps, skepticism about peer support or social support in general. They may say things like "I don't want this to become a crutch" or "I only want information and answers to my questions." For such individuals, efforts by the peer supporter to encourage emotional sharing too early may discourage the relationship. Rather, interactions should stay within the range of topics with which the individual appears comfortable. At the same time, consistency is just as important as with anxious-ambivalent individuals who are often more colorful or exaggerated in their self-presentation. With consistent interactions that do not go too far beyond what the avoidant individual finds comfortable, the individual is likely to turn to the peer supporter when stressed, providing then the opportunity for broadening the relationship.

Consistency → Trust

As just discussed, consistency is a key feature in getting past individuals' difficulties in developing an effective and strong relationship with a peer supporter. In a program for low-income, unmarried mothers of children who had been hospitalized for their asthma, asthma coaches succeeded in reaching and engaging 89% of mothers (Fisher, Strunk, et al., 2009). For many, it took 3 months and several telephone calls before the mothers became engaged with the coaches. The coaches' strategy was flexible, nondemanding, but persistent effort to develop a relationship. If a mother indicated little interest in the coach's help, the coach would say something like, "That's fine. I'll just call back in a few weeks and check in with you." The coaches and study team felt the choice of words was important. "Check in with" suggests interest without intrusion or demand, in contrast to "Check up on" which, at least in US English, suggests surveillance.

Anecdotal reports of the mothers indicated this approach was noticed. They explained that, in their usual experience, those who call back usually have bad news or bothersome matters to discuss. The coaches, in contrast, called back without making demands or threats, just renewing an offer of help. Consistent, reliable, predictable, and persistent contacts were noticed by the mothers and, apparently, important in engaging them.

Nondirective and Directive Support

Social support can be conceptualized in different ways, including type (e.g., emotional, instrumental, informational, appraisal) (Cohen & Hoberman, 1983), role (e.g., functional vs. structural), and measurement perspective (e.g., perceived, received, provided) (See Uchino et al., *infra*). In addition to these, authors have considered how support may sometimes not be helpful. Problematic or unwanted support, for example, is support that is unsolicited or imposed upon the recipient (Boutin-Foster, 2005). In a study investigating the effects of social support among 197 patients with rheumatoid arthritis, problematic support was associated with greater depressive symptoms. Further, among patients receiving low levels of positive support, the relationship between problematic support and depressive symptoms was especially pronounced (Riemsma, Taal, et al., 2000). These findings regarding the detrimental effects of problematic support on health outcomes have been confirmed for other conditions, including HIV (Ingram, Jones, et al., 1999), cancer (Figueiredo, Fries, & Ingram, 2004), and acute coronary syndrome (Boutin-Foster, 2005).

Other research has developed a distinction between nondirective support (i.e., support that is accepting of the recipient's feelings and choices and cooperative with their plans) and directive support (i.e., support that prescribes "correct" choices and feelings). Nondirective support has been associated with reports of improved health behaviors, better disease management, and positive coping, whereas directive support has generally been found to have no effect or a detrimental effect on these outcomes (Fisher, Jr., Bickle, et al., 1997; Gabriele, Carpenter, et al., 2011; Harber, Schneider, et al., 2005; Stewart, Gabriele, & Fisher, 2012). For instance, in a community sample, nondirective support was associated with reports of greater physical activity, greater fruit and vegetable intake, and lower alcohol use after controlling for demographic variables (Stewart, Gabriele, & Fisher, 2012). In another study, nondirective support was associated with adaptive coping among those with non-small cell lung cancer (Walker, Zona, & Fisher, 2006).

All of the research on problematic as well as directive and nondirective support has examined associations among reports of support and various outcomes. This leaves how these distinctions might be pertinent to peer support interventions unanswered. Among five projects supported by Peers for Progress that administered a measure of nondirective and directive support that participants perceived from their peer supporters, nondirective support was significantly associated with reports of lower depression, while directive support was significantly associated with higher depression (Kowitt, Ayala, et al., 2017). This still leaves unanswered, however, how these types of support might be manipulated.

Jeanne Gabriele led an ambitious study to examine what happens when people systematically receive nondirective or directive support (Gabriele, Carpenter, et al., 2011). First was the challenge of how to manipulate them. Given the nuanced distinction between nondirective and directive support, it would be hard for an individual to be totally consistent in providing one or the other in live interactions. Instead, Gabriele and her colleagues utilized email messages that could be written and checked against protocols for nondirective and directive support before they were sent. She recruited university employees interested in an email weight loss program and then provided them 12 weeks of feedback and suggestions in response to their reports of eating patterns, physical activity, and weight.

Distinctions between nondirective and directive support included choices in the order of topics covered, for nondirective, and a fixed order for directive. Nondirective weekly messages provided choices among several observations as to what others or the research literature report as helpful, e.g., “Some people who have gained a pound or two find it helpful to….” Directive messages gave, instead, one specific suggestion for what the individual should do.

An important question was whether participants would even notice the fairly subtle distinctions between the nondirective and directive interventions. In ratings of the support provided by the e-coach, the two conditions differed in the pattern of nondirective versus directive support reported ($p < 0.01$). Those in the nondirective condition reported more nondirective support and a greater ratio of nondirective to directive support than those in the directive condition. So, nondirective and directive support could be manipulated through emails in a way that participants would notice. What about outcomes?

Women in the nondirective support condition lost, on average, 2.5 kg over the 12-week program in contrast to those in the directive condition who lost, on average, 4.5 kg ($p = 0.01$). (Men showed an opposite pattern, 6.57 kg loss in nondirective versus 3.35 kg in directive, but their numbers were too small to allow separate analysis or analysis of the interaction between sex and intervention.)

So, at least for women, a directive approach to weight management may be more effective than a nondirective approach. Note that participants signed up for a weight management program to be conducted by email. Presumably, they were looking for something to guide their weight loss, not to help them decide if they really wanted to lose weight. In terms of Prochaska’s *transtheoretical model* (Prochaska & Velicer, 1997; Velicer, Brick, et al., 2013), they were probably in preparation or action stages of change. It may be that directive support is more appropriate for those seeking help in enacting a change, while nondirective might be more helpful for those in precontemplation or contemplation, thinking about change, as well as for those in maintenance who may have learned what it is they must do, but whose challenge is to maintain motivation and performance. Other studies reviewed by Gabriele and her colleagues (Gabriele, Carpenter, et al., 2011) have indicated directive support may be more appropriate in dealing with acute or serious problems or those for which the individual is ill prepared.

The implications for peer support are important. Some data indicate that peer support is perceived as nondirective by those receiving it. Among low-income, unmarried mothers of children hospitalized for asthma, 66 of 80 chose "Help you to do what you think is right for your child's asthma" rather than "Push you to do what she thinks is right… " when asked to choose which best described their asthma coach. Additionally, 78 of 80 chose "Help you to 'take charge' of your child's asthma care" rather than "'Take charge' of your child's asthma care" (Fisher, Strunk, et al., 2009). In rural Alabama, on the other hand, 44% of participants reported that their peer advisor was most similar to a video portraying a nondirective style of counseling, but 56% thought their advisor most similar to a video portraying a directive counseling style (Lewis, Cherrington, et al., 2014). It seems clear that the relationships among nondirective and directive support, health and health behaviors, and peer support are not simple.

There may be occasions when people benefit from being given clear directions for how to do something. These may be when they are in the action stage of behavior change, when they are faced with stressful challenges, and/or when they are faced with challenges for which they do not know the skills required. At such times, peer supporters may provide direct assistance to those they would help, e.g., "I can make that appointment for you" or "I'll arrange for someone to watch your children, you just worry about keeping that appointment." At other times, perhaps most often, when challenges are more familiar or routine or when they are more a matter of motivation than learning skills, nondirective support may be the best approach for peer support.

Implicit Support

Many countries have expressions for talking about valued emotional support similar to "It wasn't anything she said or did, it was just knowing she was there."

- In Dutch this may be expressed as, "*Het was niet zozeer wat zij zei of deed, het was het besef dat zij er was*."
- In German, "*Es war nichts was sie gesagt oder getan hat, nur zu wissen, dass sie da war, reichte aus*."
- In Mandarin, "她怎么说或怎么做都不重要，重要的是知道有她在那里" (literally, "It did not really matter what she said or did. What mattered was to know that she was there").
- In Portuguese, "*Nao e' tao importante o que ela disse ou fez, o que importa foi saber que ela estava presente*."
- In Spanish, "*No importaba lo que ella dijera o hiciera, lo importante era saber que ella estaba allí*" (It didn't matter what she said or did, what mattered was that she was there).
- In Thai, "มันไม่ใช่คำพูด หรือ การกระทำ แต่มันคือการทีฉันรู้สึก ว่า เขาจะคอยอยู่ดูแลช่วยเหลือฉันเสมอ."

(Thanks to Associate Editors Ulrike Ehlert, Yan Guo, and Frank Snoek and to colleagues Silvana Barros, John Piette, and Chanuantong Tanasugarn, for translation assistance.) This suggests two things. First, emotional support can be very subtle and hard to describe. Second, emotional support can be conveyed without talking about emotions. Research indicates that in Asian cultures, for example, implicit support is more acceptable than explicit emotional support. This is linked to cultural emphases on the family and harmony and, consequently, individuals being reluctant to burden family or groups of which they are a part with their own, individual problems or concerns. Instead, the support of the family or group is conveyed and assumed without explicit discussion (Kim, Sherman, & Taylor, 2008), and, indeed, explicit support in such cultures may be ineffective or even counterproductive.

Representing programs in three distinct cultures (rural African-American women and urban Latinos in the USA, middle-class retirees in the UK) peer supporters described how emotional support emerges in their work with individuals. Peer supporters represented programs for low-income Latinos through an FQHC in Chicago, low-income, African-American women in rural North Carolina (Cummings, Lutes, et al., 2013) and retired, middle-class adults in Cambridgeshire, England (Simmons, Prevost, et al., 2015). They also identified implicit support as important (Kowitt, Urlaub, et al., 2015). Examples included showing interest and concern through attending a support recipient's art exhibit, "giving hugs," praying for/with people, group walks, talking about family, and playing cribbage with one another.

Implications for peer support include the sensitivity of the peer supporter to reluctance of some to engage in explicit discussion of emotions, but also the recognition that emotional support can be provided in numerous ways other than verbal discussion of emotions. Shared activities and sensitivity to instrumental or informational needs ("I thought you might find this interesting") can convey interest, concern, and liking that encourage the recipient and improve mood.

Emotional Support and Categories or Types of Support

Categories of social support often identified in research are emotional, informational, appraisal, and instrumental or tangible support (Cohen & Hoberman, 1983). Anecdotally, individuals frequently indicate interest only in information and answers to their questions from a peer support program, not emotional support. The structured interviews with peer supporters in the previous section explored how emotional support may emerge in the course of peer support interventions. In addition to the importance of implicit support, two important themes emerged (Kowitt, Urlaub, et al., 2015). First was the gradual evolution of emotional support out of informational support and after trust had been developed. Second was the interweaving of emotional and informational support. Rather than informational, instrumental, or emotional support being distinct categories, they appeared often to be different dimensions of the same actions and exchanges. These findings have important practical import. Where program planning to take at face value reports that individuals are only interested in information and answers to their questions, important dimensions of actual peer support interventions might be overlooked.

The importance of emotional support was reflected also in a program in Anhui province in China, described later in this chapter (Zhong, Wang, et al., 2015). A number of participants reported valuing the opportunity to share feelings with their peer supporters. The fundamental commitment of the family to its members in Chinese culture can engender a reluctance to obligate or place a burden on one's family with one's own concerns. Peer leaders however are not obligated to participants in the same way as family members and, so, provided an outlet for emotional expression free of concerns about "burdening" others.

In our penchant for categories, researchers have emphasized types of social support, including the categories of nondirective and directive of several of the current authors. It may be closer to reality to think of dimensions of support – instrumental, informational, appraisal, emotional, and, perhaps, nondirective and directive – with most all acts of support being some combination of these dimensions. For example, in a 2-year demonstration project in a community health center in Chicago (Alivio Medical Center, discussed in detail later), 8 *promotores* provided peer support contact to 3347 (90.8%) of the total of 3687 patients with diabetes Alvio served. This included 19,188 separate contacts. Of these, at least one dimension of instrumental, informational, appraisal, and emotional support was provided in 92% of contacts. Approximately 87% of contacts involved more than one dimension and 46% involved more than two dimensions of support.

Peer support programs should be planned, and peer supporters trained to be sensitive to the varied needs of participants and to recognize that, even when talking about some very concrete topic in prevention or disease management, the peer supporter's care and interest in the conversation will also convey important emotional messages. Conversely, emotional reassurance may have a central role in motivating and encouraging concrete disease management behaviors as well as lifting mood and enhancing quality of life.

Diversity of Social Networks and Total Institutions

In their provocative 1997 study showing that social ties were protective against infection with the "common cold" (rhinoviruses), Cohen and his colleagues examined what aspects of social connections were most strongly related to resistance (Cohen, Doyle, et al., 1997). Participants reported in which of 12 types of relationships (e.g., with family members as well as workmates, or members of religious organizations) they had contact with at least one person face-to-face or by telephone over the preceding 2 weeks. Diversity was assessed as the number of different types of relationships reported, 0–12. Also assessed was the total number of individuals with whom the participant spoke in the 2 week period. Results indicated that diversity strongly predicted greater resistance to infection, but number of contacts did not predict resistance at all. As Cohen and colleagues concluded, "The association between network diversity and susceptibility held even after controlling for the number of people in the social network indicating that it is diversity of the network (having multiple types of relationships) that matters not the sheer number of network members" (Cohen, Doyle, et al., 1997, p. 1944).

The importance of diverse networks and social roles was articulated by the anthropologist Erving Goffman in his writing on what he called "total institutions" such as prisons and mental hospitals and other *asylums* (Goffman, 1961). Goffman defined total institutions as limiting those within them to a single social role such as prisoner, patient, or inmate. All behaviors are interpreted in the context of that role so that, for example, a patient's complaint about mistreatment is construed as the complaint *of a patient* and as the manifestation of their pathology, not as a valid report of a staff member's behavior. In contrast, having several roles allow us to comment in one on the problems in others. With our family members, a complaint about our job supervisor is taken not as the predictable dissatisfaction of a marginal employee, but as a report about unfair or harsh treatment that should not occur. Discussions with our family about our friends and vice versa provide the opportunity to think about important relationships without challenging those relationships directly.

An important part of peer support may be the opportunity to talk about relationships that are challenging to us without fear of reprisal or immediate dismissal of our thoughts. This may include concerns about one's healthcare providers. In this regard, there may be advantages to peer supporters being closely linked with but not part of the clinical team, so that individuals may feel they can share concerns with their peer supporter without those immediately being conveyed to doctors or nurses. That peer supporters and those they serve may have much in common demographically or in the communities in which they live will tend to place the recipient of support not in the role of patient but rather in other roles as parent or university graduate or resident of a particular neighborhood. This may help the individual make sense of their health and health care in a way that is not easy within the clinical setting.

Context: "It Always Depends"

Across a number of the topics discussed above, the importance of context emerges. One might assert that there are no absolutes in social or peer support. Whether nondirective or directive support is more beneficial may depend on the seriousness or threat posed by a problem, on the skills of the individual for coping with it, and, no doubt, on the provider of support (e.g., La Greca, Auslander, et al., 1995). Consider again the email delivered support for weight loss of Gabriele (Gabriele, Carpenter, et al., 2011). How might the context of email have been important in the effectiveness of directive support? Although we may think of it as impersonal, email may be an essentially nondirective medium. We control its access to us. If someone is predictably annoying or harsh in their emails, we can leave them unopened or erect a filter to send their messages to a separate folder or even delete them unopened. We can delay responding until a time we choose. In contrast, directive support provided in a live encounter is hard to avoid and will tend to demand response. So, the directive email support in the weight loss intervention of Gabriele may be seen as directive messages delivered through a nondirective medium.

This contingency on context extends beyond nondirective and directive support. Whether emotional or more instrumental support is called for will depend on the situation of the recipient and the ability or position of the provider. In his writing on attachment, Bowlby described key features in the development of secure, health attachments, emphasizing that “the ordinary sensitive mother is quickly attuned to her infant’s natural rhythms and, by attending to the details of his behavior, discovers what suits him and behaves accordingly… Ainsworth and her colleagues have noted that infants whose mothers have responded sensitively to their signals during the first year of life … cry less during the second half of that year … (Ainsworth, Blehar, et al., 1978)” (Bowlby, 1988, p. 9). Emphasizing the sensitivity of the parent to the child’s changing needs and circumstances in the earliest of relationships reflects the importance of sensitivity and responsiveness to differing contexts across relationships and individuals’ activities throughout the lifespan. Context matters!

Contextual differences are apparent also among the varying approaches to delivering peer support. Heisler and colleagues showed impressive benefits among adults with diabetes exchanging support in dyads (Heisler, Vijan, et al., 2010). A similar intervention was not effective among those with heart failure who appeared not to have the energy to engage in dyadic support (Heisler, Halasyamani, et al., 2013). Another study with heart failure examined factors associated with engaging in group or dyadic support. Older European American women with better health status, functioning, social support, and confidence in their ability to manage their disease and less difficulty with the physical and emotional aspects of living with heart failure were most likely to engage in support (Mase, Halasyamani, et al., 2015).

Peer support does not occur in a vacuum but rather within the context of other sources of support. Spousal support, for example, moderated dietary outcomes with pregnant Latino women (Shah, Kieffer, et al., 2015). Regarding a common question of the advisability of delivering peer support to groups or individuals, Latino adults recruited through churches preferred group to individual telephone coaching, although they saw individual coaching as a possible supplement to the group (Baig, Locklin, et al., 2012).

Dissemination Models

The importance of contexts poses challenges for dissemination. On the one hand, adaptability to varying contexts and populations is very important. On the other hand, adoption is also advanced by identification and standardization of important features of peer support. Such identification of important features of support should still allow flexibility to accommodate contextual and population differences (Fisher, Earp, et al., 2010). Given these challenges, Peers for Progress initiated a consultation organized through the WHO in 2007 (World Health Organization, 2008). Representatives from over 20 countries encouraged a view that, although programs would have to be tailored to individual health systems, cultures, and patient populations, nevertheless, key aspects of peer support could be generalizable across those differences in settings.

Accordingly, Peers for Progress has pursued a strategy of defining peer support not by specific implementation protocols or details but according to four “key functions of support” (Fisher, Earp, et al., 2010). This follows a strategy of “standardization by function, not content” (Aro, Smith, & Dekker, 2008; Hawe, Shiell, & Riley, 2004). The four key functions are (i) assistance in daily management, (ii) social and emotional support to encourage management behaviors and coping with negative emotions, (iii) linkage to clinical care and community resources, and (iv) ongoing availability of support because chronic disease is for the rest of one’s life (Boothroyd & Fisher, 2010). Pursuing standardization in this way also has the advantage of defining peer support in terms of what it does, not who is doing it.

With tailoring according to needs and strengths of a specific setting or health challenge, the four key functions become a template for planning and evaluating peer support programs (Fisher, Boothroyd, et al., 2012). The hardiness of this approach was documented through programs in Cameroon, South Africa, Thailand, and Uganda and benefits they achieved across clinical, self-management, and quality of life indicators (Fisher, Boothroyd, et al., 2012). These documented both the feasibility and early impacts of peer support as well as how each program tailored the template of key functions to its own population, healthcare system, and organizational setting.

The Four Key Functions in China

Dissemination in China needs to respect preferences that programs include Chinese contributions to planning, development, and implementation. The four key functions have provided a strategy for dissemination in China, in which great value is placed on things being "made in China." Emphasizing the four key functions rather than a concrete product has created a base for a number of collaborations. In conjunction with leaders of the Chinese Diabetes Society and in healthcare settings in several cities, over 600 program managers, clinicians, and diabetes educators have been trained to develop and implement programs. Training includes large workshops in conjunction with national meetings but then, very important, ongoing consultation by conference call and online forum to facilitate coping with problems in developing and implementing peer support programs.

Interestingly, when promoting the four key functions, two of them, "social and emotional support," and "ongoing availability of support," seem to resonate the most among Chinese healthcare professionals. Individual programs have reported intentionally utilizing peer support groups to strengthen social support among participants. They have also taken advantage of online chat utilities (QQ and WeChat) and naturalistic settings such as grouping participants from the same communities to facilitate ongoing support in their communities.

Outcomes have included over 35 programs being developed, the expansion of the section on patient education and management of the Chinese Diabetes Society, and the demonstration project of the Beijing Diabetes Prevention and Treatment Association, described above, engaging 50 hospitals and community health centers and over 5000 individuals with diabetes.

Setting a model for adaptation of peer support to China was a demonstration project in community health centers in Anhui province. The program trained mostly retired adults with diabetes to co-lead monthly informational and educational meetings with staff of community health centers. The peer leaders also led discussion groups that provided greater opportunity for participants to talk about self-management plans, obstacles encountered, and successes. The peer leaders also promoted informal groups within housing complexes such as for tai chi, morning walking, shopping, and even fishing. Reported advantages included peer support as a "bridge" between community health centers and their patients. In two sites in which it was implemented, a "peer leader" program achieved significant benefits relative to controls for knowledge, self-efficacy, BMI, SBP, DBP, and both fasting and 2-hour postprandial blood glucose (Zhong, Wang, et al., 2015). In light of these results, the Anhui Provincial Health Bureau has extended the peer leader program to other communities and to cardiovascular disease prevention and management (Zhong, Wang, et al., 2015).

Success Factors

In addition to key functions of peer support, there are a variety of important characteristics of how peer support is delivered (Funnell, 2010). These include an emphasis on empowerment and the encouragement of self-efficacy. In most cases, peer support should also take a person-centered approach, addressing not only clinical issues or prevention but also reflecting the values, interests, and other problems of the individual, e.g., problems with an adolescent child that may take precedence over personal health. This reflects the wide variety of social, economic, and community stressors that influence chronic disease management. In the intervention that reduced hospitalizations among children with asthma, described earlier (Fisher, Strunk, et al., 2009), asthma coaches' contact records indicated discussion of a variety of issues including stress around moving residence (39.6% of parents), social service resources (34.4%), housing (11.5%), illness or other problems of the parent (24.0%), and new jobs (6.3%), with only 9.4% of parents discussing no such topics.

Articulating these and other success factors was a landmark survey of community health workers, the National Community Health Advisor Study (Rosenthal, Wiggins, & Brownstein, 1998). Table 22.1 contains important features of peer support as identified through it and others. Shared experience with the people and communities they serve is an important base for the benefits of community health workers. That shared experience includes life experiences, health conditions or diseases, as well as culture, community ties, or socio-economic status. With training, then, the community health worker brings a special combination of expertise in the areas they address and deep experience with the perspectives of the individuals and communities they seek to serve. The central role of the community health worker in linking communities, individuals, and organizations like health centers is widely recognized in the USA (Reinschmidt, Hunter, et al., 2006). It was also noted by a community health center director in a program in Anhui province, China, who commented that peer leaders serve as "the bridge to link our [clinic] with patients in their served neighborhood."

Proactive Contact

Papers reporting failure of community-based peer support often have failed to engage individuals in peer support, e.g., an average of 5 of 9 meetings attended and 18% attending none at all (Smith, Paul, et al., 2011a, 2011b) or 50% with one or fewer contacts and 32.3% with none (Hunkeler, Meresman, et al., 2000). There is little evidence however about the types of engagement strategies utilized by peer supporters and the impact of these engagement strategies on intervention outcomes.

A systematic review of 47 peer support interventions for breastfeeding identified proactive engagement strategies: face-to-face interaction (89% of papers), active initiation of peer support (81%), both prenatal and postnatal contact (62%), and contact initiated within 72 h of birth (52%). The odds of reporting significant differences in breastfeeding outcome between groups, those who received peer support and those who did not, significantly increased with each additional engagement strategy utilized (OR = 4.5, *p*-value = 0.002). No unique combination or "magic bullet" of engagement strategies emerged – it was the *number* of *different* strategies that mattered. This reflects other findings in behavioral medicine (e.g., Kottke, Battista, & DeFriese, 1988) that it is the number and variety of intervention strategies, not any particular critical ingredient that is most related to success.

Reaching the Hardly Reached

Varied "high-risk" groups account for disproportionate avoidable and expensive care but are often not reached by clinical and preventive services. In addition to the 83% of "high-need" patients at Alivio Medical Center, discussed later, published papers show peer support to be effective in reaching and engaging "hardly reached" populations. For example, in the project described earlier, asthma coaches pursuing a nondirective, flexible, stage-based approach were able to engage 89.7% of mothers of Medicaid-covered children hospitalized for asthma. The coaches sustained that engagement, averaging 21.1 contacts per parent over a 2-year intervention and reducing rehospitalization by 52% (Fisher, Strunk, et al., 2009). Similarly, home visits from community health workers led to clinically significant increases in symptom-free days among children with asthma in low-income neighborhoods of Seattle (Krieger, Takaro, et al., 2009).

Remarkably, studies have shown peer support to be most successful among “hardly reached” groups among whom one might expect least success. In a peer support intervention for diabetes management among ethnic minority patients of safety net clinics in San Francisco (Thom, Ghorob, et al., 2013), participants were categorized at baseline as low, medium, or high on medication adherence and on self-management. The relative impact of peer support versus usual care was *greatest* among those initially in the low-adherence and low-self-management groups (Moskowitz, Thom, et al., 2013). In support exchanged between pairs of veterans with diabetes (Heisler, Vijan, et al., 2010), improvements in blood glucose measures were greatest among those with initially low levels of diabetes support or health literacy (Piette, Resnicow, et al., 2013).

In parts of Bangladesh with low care utilization and high infant mortality, pre- and postnatal home visit by community health workers reduced neonatal mortality by 34% (Baqui, El-Arifeen, et al., 2008). In a novel approach among HIV+ individuals who also were active drug users, each individual took separate roles of both receiving and providing peer support, receiving support from one participant and providing it to a different participant (Broadhead, Heckathorn, et al., 2002). Of 15 participants in this pilot study, 14 engaged in the reciprocal support, keeping 80% of the appointments with each other. Positive outcomes included clinic appointment keeping and reduced needle sharing.

Another way to think about disparities is to analyze their socioeconomic determinants. If a program reduces the effect of low-income status on some important outcomes, for example, then it would be reducing disparity related to low income. Preliminary studies for an intervention for postpartum depression in Pakistan, discussed in detail later, showed that household debt and lack of financial empowerment (managing daily expenditures) were associated with greater depression. An intervention delivered by Lady Health Worker subsequently reduced the extent to which these variables were associated with depression (Rahman, Sikander, et al., 2012). That is, the intervention offset factors that, otherwise, would have inclined individuals to worse outcomes.

Two systematic reviews have examined how those hardly reached are identified and how peer support may reach and benefit them. In a first review, Sokol and her colleagues evaluated whether cultural/environmental, demographic, or individual characteristics were used to distinguish those hardly reached. Of 334 papers identified, 74.9% used characteristics from at least two of these domains, and only 25.2% used characteristics from only one domain to identify hardly reached individuals (Sokol, Fisher, & Hill, 2015). Thus, being hardly reached is not a reflection of one or a few troublesome individual characteristics but is rather associated with a range of social, organizational, and demographic as well as individual characteristics. A subsequent review then identified 47 papers reporting peer support interventions with hardly reached groups. Of these, 44 (94%) showed significant benefits. Additionally, papers that reported the use of strategies to promote trust and respect within peer support interactions reported greater retention, 82.8% than those that did not, 48.1% ($p = 0.0027$) (Sokol & Fisher, 2016). Across these studies emerges a very important feature of peer support, its apparent value in reaching and benefitting those whom healthcare and promotion initiatives too often fail to reach.

Integration of Behavioral Health and Peer Support

As indicated in the review of characteristics associated with being hardly reached, psychological distress plays a prominent role. Among all characteristics used to identify hardly reached groups, “psychological and/or cognitive factors” was the most common, included by 38.92% of papers reviewed (Sokol, Fisher, & Hill, 2015). Additionally, attention is focusing increasingly on psychological characteristics associated with chronic diseases and complicating their management and associated quality of life (Fisher, Chan, et al., 2012, 2015). Depression has been most extensively investigated, especially as it coexists with diabetes. Individuals with diabetes are twice as likely to suffer from depression as patients without diabetes, and it is estimated that the prevalence of elevated symptoms of depression among individuals with diabetes is 31% (Anderson, Freedland, et al., 2001). Among those with coronary heart disease, 15–20% are estimated to meet criteria for major depression (Lichtman, Bigger, et al., 2008), and an additional 20% are estimated to have elevated symptoms of depression. But concern is not limited to depression. Hostility and anxiety are major risks for and complications of cardiovascular disease (Blumenthal, Sherwood, et al., 2012). Among cancer patients, the prevalence of anxiety is estimated to be 10%, and the prevalence of any mood disorder is estimated at 38% (Mitchell, Chan, et al., 2011).

As described in greater detail in the chapter on "Psychology, Mental Health, and Quality of Life" (Snoek et al., *infra*), broad social and economic contexts of family and social relationships, organizational, economic, and cultural factors influence both psychological and biological functioning. Those disadvantaged in a number of these areas are much more likely to develop some chronic disease and some psychological disorder. The particular diseases and disorders may be varied, but their likelihood is high. This "complex of developmental, biological, and psychosocial determinants" and the diseases and disorders to which it leads are, in turn, major contributors to avoidable emergency and hospital care in most health systems around the world.

If individuals are disadvantaged with regard to a number of factors in the "complex of developmental, biological, and psychosocial determinants," then developing some chronic disease and some psychological disorder are highly probable. The phenotypic expression of the complex may be varied, but the likelihood of expression is high. Thus, an important strategy is to develop interventions that address this underlying complex in order to reduce unnecessary burden of disease and associated costs (Fisher, Chan, et al., 2012, 2015).

There is much reason to think that peer support can be helpful in this area. In addition to psychological problems complicating other health problems, they are also themselves the object of peer support. Both the social isolation or lack of a confidant that often accompany psychopathology and distress (Fisher, Chan, et al., 2012, 2015) and the importance of simple social contact and emotional support discussed at the beginning of this chapter (Harlow, 1958) suggest that simple, frequent, affirming, and pleasant contact from a supporter may be especially helpful to those with emotional distress.

Data support this expectation. A meta-analysis by Pfeiffer, Heisler, and their colleagues found a pooled, standardized mean difference between peer support for depression and usual care of −0.59 favoring the peer support (Pfeiffer, Heisler, et al., 2011). The emotional benefits of peer support were illustrated in a study commissioned by the UK-based Stroke Association. Having a stroke can negatively impact on emotional well-being both in the immediate aftermath of a stroke, and in the longer term. In a small-scale study of the Stroke Association's peer support groups, supported by Nesta Health Lab and the Cabinet Office, some stroke survivors talked about "loss of the life and the person they were before their stroke." They highlighted significant changes to their personal and role identity, including a loss of independence and reduced ability to do things they had previously done, including taking care of others in their lives. For these stroke survivors, attending a group alongside supportive peers had a positive impact on their mental well-being. This was variously attributed to being among friends, to the creation of a supportive and social group atmosphere and to groups creating a space in which people could make sense of the ongoing emotional "ups and downs" that can follow a stroke.

In a striking cluster randomized evaluation in Pakistan, Lady Health Workers implemented a cognitive-behavioral, problem-solving intervention for women who met criteria for major depression during the third trimester of their pregnancies. Relative to controls, the intervention substantially reduced depression 12 months *postpartum* ($p < 0.0001$) (Rahman, Malik, et al., 2008). In India, peer support for depression, anxiety, and other mental health problems included education about psychological problems and ways of coping with them (e.g., deep breathing for anxiety symptoms) as well as interpersonal therapy (de Mello, de Jesus Mari, et al., 2005), all delivered by lay health counselors with backup by primary care and monthly consultations from psychiatrists. Results included a 30% decrease in prevalence of depression and other common mental disorders among those meeting criteria at baseline, 36% reduction in suicide attempts or plans, as well as reductions in days out of work (Patel, Weiss, et al., 2011).

A population-based study in the USA evaluated Medicaid enrollees who had made a claim for both community mental health and peer support services. A comparison group who had made only claims for community mental health services was matched by gender, race, age, urban/rural residence, and principle diagnosis. Those who had received peer support were more likely (OR = 1.345) to achieve crisis stabilization than the comparison group, and those who did not achieve stabilization were still less likely to be hospitalized (OR = 0.766) (Landers & Zhou, 2011).

Peer support also reduced distress and related hospitalizations among adults with diabetes in Hong Kong. The base of the program was JADE (Chan, So, et al., 2009a, 2009b), a standardized, systematic model of care incorporating many of the same emphases as Wagner's Chronic Care Model and the Patient-Centered Medical Home, e.g., quarterly reports to patients providing appraisal of clinical status and self-management recommendations. In addition to JADE, half of participants were randomized to receive PEARL, telephone-based peer support provided by trained peer supporters.

Reflecting patterns familiar to most in health policy and services, patients with elevated levels of depression, anxiety, and/or stress were more likely to be hospitalized (34%) than those without distress (20%). Among the group with heightened distress, the peer support intervention improved distress scores relative to standardized, high-quality care alone ($p = 0.03$) and reduced overall hospitalizations (relative risk =0.15, $p < 0.001$), a reduction to the "normal" level of those low on distress measures (Chan, Sui, et al., 2014). That is, among the fifth of patients with high scores on distress and who account for greatly disproportionate hospital care, the addition of peer support to standardized, high-quality clinical care reduced distress and lowered associated hospitalization rates to normal levels.

One of the striking aspects of these results of Chan and her colleagues is that the peer support intervention was designed to assist diabetes management, not to reduce emotional distress. Yet it had substantial effects on distress and associated hospitalizations. As discussed in an earlier section on the "Fundamental Value of Connection," the provision of peer support itself may have emotional and quality of life benefits, regardless of the particular curriculum or behavior changes the peer supporter is promoting.

Reaching Populations and Peer Support in Primary Care

Although exceptions are becoming more numerous (Bhutta, Lassi, et al., 2010; Patel, Weiss, et al., 2011; Perry, Zulliger, & Rogers, 2014; Rahman, Malik, et al., 2008), many studies of peer support continue to be based on samples of populations of interest. As much as these may illuminate important principles and intervention approaches, they are unable to address the challenge of reaching entire populations.

One approach to reaching populations is through primary care, therefore an especially important setting for peer support (Daaleman & Fisher, 2015). A number of the projects already cited have been conducted through primary care (Ayala, Ibarra, et al., 2015; Safford, Andreae, et al., 2015; Simmons, Cohn, et al., 2013; Simmons, Prevost, et al., 2015; Tang, Funnell, et al., 2014; Thom, Ghorob, et al., 2013). In one study, 12 group-based primary care office visits plus 12 individual phone contacts with peer coaches led to 4.5 kg losses among African-American adults with initial BMIs over 30.0 (Dutton, Phillips, et al., 2015). Recent development of the "Patient-Centered Medical Home" (Stange, Nutting, et al., 2010) emphasizes understanding individuals' in the context of their lives and comprehensive care addressing the person, not just the disease. This provides a context highly congruent with peer support (Bielaszka-DuVernay, 2011; Findley, Matos, et al., 2014; Volkmann & Castanares, 2011) as explored in a 2015 conference addressing varied approaches to applying peer support within the medical home (Fisher, Hacker, et al., 2015).

Turning to reaching populations through primary care, a program of Alivio Medical Center, a primary care, community health center in Chicago funded by the government to provide care for indigent people, set out to identify ways to provide peer support to the entire population of 3787 adults with type 2 diabetes whom Alivio serves. The project was also a collaboration with the National Council of La Raza and Peers for Progress.

In the program, *Mi Salud es Primero*, the intended audience of 3687 was divided into two groups. About 10% with elevated HbA1c values, apparent psychosocial distress, or who were referred by their primary care providers as needing extra support were placed in a "high-need" group. *Compañeros En Salud* reached out to these individuals through individual contacts and a protocol focused on self-management objectives and psychosocial and environmental barriers and implemented initially through biweekly phone calls, reduced to monthly and then quarterly as progress warranted. The balance of the population of 3687 with diabetes were approached with a less intensive protocol, including quarterly contacts by phone or group classes, activities, and contacts through regular clinical appointments. All participants were encouraged to participate in group classes and support groups and to contact the *Compañeros* when they felt that might be helpful. After 28 months, *Compañeros* had reached 90% of the high-need group of 468 and 91% of the balance of those with diabetes. This was associated with modest reductions in HbA1c ($p < 0.001$), from 9.36 to 9.12% in the high-need group, and from 8.05 to 7.94% in the rest of the population. Although modest, it is important to note that these were changes across the entire population, not just a selected study sample.

The program included nine *Compañeros* who worked with individual patients, yielding a case load of about 410 patients for each. At an annual salary of about $50,000 (including fringe), this yields a cost of $122 per patient per year, *not including* administrative and other expenses. Clearly, the challenges of reaching populations are substantial, but not insurmountable. As discussed earlier, for example, well-established peer support programs in Thailand with its Village Health Workers and in Pakistan with its Lady Health Workers show the feasibility of broad implementation of such programs.

Digital Peer Support

An important opportunity for extending peer support may lie in digital health applications. Through telephone, text, web-based, social media, and automated technology, digital resources can allow peers to deliver support across geographic distances, to larger numbers, and with more efficiency. As a complement to live peer support, digital tools can provide routine monitoring and even health messaging, using algorithms to prompt live outreach for those individuals or circumstances that may need it. Digital tools also respond in real time, making support more accessible and convenient. For patients with rare diseases, digital tools may present their only opportunity to find other patients with the same condition. Providers and researchers are pressing for the integration of e-applications and electronic medical records, which promises to improve patient monitoring and generate actionable data.

In the UK, Body & Soul, a charity working to promote the dignity and well-being of children, young people, and families living with or affected by HIV was funded by Nesta Health Lab and the Cabinet Office to expand their face-to-face peer mentor approach with young people through a new peer support digital offer. The grant has allowed the team to reach 435 young people across 74 local health authorities by mobilizing 25 volunteer peer mentors through over 3700 peer support calls. The digital peer support intervention showed positive impact including participants experiencing:

(a) Increased feelings of well-being and thinking about the future
(b) Less loneliness and isolation among young people living with HIV, with some clients highlighting an increased number of people whom they could talk to for support
(c) Increased confidence in their knowledge of HIV and their ability to communicate openly with health professionals, friends and romantic partners

Texting and telephone contact were used extensively in a peer support program in Uganda (Baumann, Frederick, et al., 2015), and automated text prompts were used in a South African program (Rotheram-Borus, Tomlinson, et al., 2012). In another study, automated telephone self-management support for low-income English-, Spanish-, and Cantonese-speaking adults improved reported self-care and SF-12 physical status (Ratanawongsa, Handley, et al., 2014).

In remote areas of Australia, Oldenburg and colleagues developed "Telephone-Linked Care" (Williams, Bird, et al., 2012). This provided messages and reminders that were personalized according to individual self-management and clinical measures, all monitored through data entered in patients' smartphones. HbA1c values declined from 8.8% to 8.0% and were accompanied by improvements on mental health indicators that exceeded those in a control condition. Medication costs were lower as well ($1542 vs. $1821 on average).

The four key functions of peer support provide a useful template for understanding the value of interventions such as the Telephone-Linked Care program. Consider the following ways in which features of the program fit with the four key functions:

- Assistance in Daily Management – Dialogues and individualized messages around self-management behaviors and medication adherence from among over 2000 prerecorded messages in the program library, facilitating great sensitivity to the nuances of users' reports, reminiscent of Bowlby's identification of the parent's sensitivity to the child's needs as key to attachment relationships (Bowlby, 1988).
- Linkage to Clinical Care – Program coordinator monitors patients' data to connect them with clinical providers as necessary
- Ongoing Support – Costs of adding additional users and extending use are quite modest once the system is put in place.
- Social and Emotional Support – Surprisingly, users reported that the system seemed to provide substantial social and emotional support; in addition to improvements in mental health outcomes, 79% strongly agreed that it gave them confidence to manage their diabetes better (Oldenburg, 2014).

Recent years have seen a boom in the release of smartphone apps for any number of chronic diseases. Though they began as tools to educate and build skills for self-management, the latest smartphone apps are designed around social connectivity. Developers of digital tools have realized that the main selling point of health smartphone apps is giving users the ability to connect with an online community of peers. App users trust the collective knowledge and experience of "patients like me," and they use these apps to actively seek out opportunities to give and receive support. For direct-to-consumer digital apps, endorsements from and coaching provided by peers can help patients overcome common barriers to initiating and maintaining app utilization.

Social Networking

Digital tools can recruit social networks and supports from individuals' family and friends. For example, in Piette's CarePartner program, patients received calls from an automated system, including information about ways to improve self-care. Information was then disseminated to (1) clinics, which received alerts about patients' signs and symptoms, and (2) family members/friends who received an email, IVR call, or SMS with updates on the patient's status. Results demonstrated significantly greater medication adherence among patients with a support person, as well as greater emotional benefits (e.g., fewer negative emotions) compared to those without a support person (Aikens, Trivedi, et al., 2015; Piette, Marinec, et al., 2016).

In another example, Valle and colleagues (2013, 2015) conducted an RCT of a behavioral intervention to increase moderate-to-vigorous intensity physical activity (MVPA) among young adult cancer survivors ($n = 86$) compared to a self-help comparison condition. Delivered primarily through Facebook, intervention participants received weekly Facebook messages with behavioral lessons, a pedometer, moderated social support discussion prompts within a Facebook group, and access to a goal-setting and self-monitoring website. Comparison group participants also received Facebook messages with general exercise information and a pedometer, but discussions within the Facebook group were unprompted (not moderated), and they did not have access to the website. After 12 weeks, the intervention participants significantly increased self-reported light physical activity compared with the self-help group. Both groups posted a comparable number of comments to their respective Facebook groups and increased weekly minutes of self-reported MVPA. Among all participants, social support from friends was associated with changes in MVPA. Overall findings from the study demonstrate the feasibility of messages and group functionalities of Facebook, the emergence of social support (both among intervention and comparison group participants), and the potential to enhance support for behavior change using social media, perhaps incorporating peer-led options as well.

Gamification

A promising digital approach entails embedding health messages and promotion within game formats (DeSmet, Shegog, et al., 2015; Miller, Cafazzo, & Seto, 2016). Gamification applies the elements of games in nontraditional gaming contexts in order to improve user engagement and experience (Deterding, Björk, et al., 2013; Deterding, Dixon, et al., 2011). In response to HIV disparities among young men who have sex with men, Lisa Hightow-Weidman and colleagues worked with the technology company Caktus Group (caktusgroup.com) to develop a technology-based "game" to increase HIV medication adherence. The result, *Epic Allies*, is a smartphone app for Android and iPhone platforms that utilizes game mechanics (mini-games, points, rewards, story-line, levels, competition, collaboration), behavioral tracking, tailored feedback, and social networking elements to increase uptake of and adherence to antiretroviral therapy (LeGrand, Muessig, et al., 2016). From 2015 to 2017, the efficacy of the app at achieving these goals will have been tested in a randomized controlled trial with men who have sex with men age 16–24 at 5 US sites (Florida, Illinois, Louisiana, New York, North Carolina). The app – including the main superhero theme – was iteratively developed through rounds of testing and feedback with end users (young, HIV-positive men who have sex with men). This process resulted in important changes and refinements to the app's gamification design features in order to draw clearer connections between the end user's actions in the game and their health behaviors (LeGrand, Muessig, et al., 2016). With the promise of promoting individual tailoring, 24/7 access, greater interactivity, and integration of gaming and social features, the *Epic Allies* app offers many benefits to participants, especially given the stigma surrounding HIV. Continued challenges for future researchers include gaining and maintaining user engagement and navigating how to capitalize on web/app development, especially given the rapidly evolving technology field and the different language and goals between researchers and developers.

Integrating Digital and Peer Support

"High tech" may be complementary to, not a replacement of, the "soft touch" of peer support. One can easily imagine individuals receiving both digital and live support interventions, the former addressing routine, redundant information and monitoring, and the latter engaging in problem-solving and attention to individual concerns. A current study (Tang, Peeples, et al., 2016) offers a digital tool for diabetes management, *BlueStar*®, as an enhancement of peer support. Participants took advantage of the flexibility with which peer support and the digital tool were offered. Some regularly used both and others used predominantly one or the other.

The blending of both digital and peer support may be advantageous. Patients at risk for nonadherence to antidepressant medication were offered support for adherence and symptom reduction through weekly interactive voice response technology. Among these, 61% opted for participating with a support person. Analyses indicated that only those who participated with a support person improved adherence and symptom remission (Aikens, Trivedi, et al., 2015).

The integration of digital and peer support suggests ways to enhance patients' choices, to titrate care and support according to patient need and preference, and to reach populations. All patients might be offered peer support, digital tools, basic diabetes self-management education (Powers, Bardsley, et al., 2015), online resources, and varied activities and promotional initiatives. Among these, combinations of digital and peer support might be actively promoted according to need. For those doing well (as gauged by blood glucose control, psychosocial status, and clinician appraisal), little more than offering the digital support might be indicated. For those doing only moderately well (again, gauged by clinical, psychosocial, and clinician indicators), the digital resource might be promoted more vigorously, perhaps through peer support contacts. For those not doing well (e.g., poor blood glucose control, abnormal values for blood pressure, lipids, heightened depression, anxiety or diabetes distress, and/or clinician identification), peer support might be offered proactively with digital tools as a resource within the peer support relationship. There are many ways in which such a plan might be varied by population, setting, and healthcare system, but the general model of combining intervention approaches to reach populations, meet varying needs, and support patient choices and preferences is an important direction for future research and program development.

Organizational Niches and Peer Support

A key issue for peer support is the organizational niche in which it should be placed. In what part of a community or clinical setting will peer supporters be housed, both organizationally and physically? Who will supervise the peer supporters? How will their work be linked with other services of the organization? How will they identify those to help? How and in what office will records of their work be developed and kept, and with whom will they be shared? The best answers to these questions will depend on the problems, settings, and populations to be served. They are, however, important to address.

In a program of New York-Presbyterian Hospital and Columbia University Medical Center, funds are given to cooperating community-based organizations to hire peer supporters who then work through those organizations while linking the organizations and those they help with the medical center's clinical resources (Center for Community Health Navigation). This supports the role of the community organizations as active collaborators in the program. In contrast, the Rhode Island Parent Information Network in the USA is based in the Rhode Island Department of Health and funds trained peer supporters who work out of cooperating pediatric practices (Rhode Island Parent Information Network). The program in New York is based in the clinical setting, but funds peer supporters in community settings, while the program in Rhode Island is funded through state government but places peer supporters in clinical settings.

In the program at Alivio Medical Center, described earlier, *Compañeros En Salud* was not part of clinical teams, but a separate group within the organization. The leader of the *Compañeros* reported directly to the head of the organization, not the medical director. At the same time, *Compañeros* were linked to clinical teams and spent part of their time in clinic to see patients during routine clinic appointments and coordinate with clinical care. This was intended to coordinate the peer support with clinical care but also provide patients a sense that the peer supporter was someone with whom they could comfortably share concerns, even about their clinical care. No doubt, what model best fits a setting may vary. What is important is that planning considers such organizational issues and their advantages and disadvantages for a particular program.

A number of other reports have raised valuable questions for consideration in developing a plan for the organizational home of a peer support intervention. Instead of setting up a new program, objectives can be incorporated into existing programs and structures. Haire-Joshu and her colleagues pursued this in several programs. One incorporated energy balance interventions into adult mentoring of disadvantaged, ethnic minority children (Haire-Joshu, Nanney, et al., 2010). A second incorporated obesity prevention and control into a program of home visiting and parent mentoring for adolescent mothers (Haire-Joshu, Schwarz, et al., 2015). Others also have pursued this strategy, including integrating healthy nutrition and physical activity into an after-school setting (Choudhry, McClinton-Powell, et al., 2011).

With its strong ties to broader community organization and community health promotion approaches, peer support has often been linked with community programs. The program among low-income African-Americans in rural Alabama in the USA, described earlier, drew heavily on community input for program planning (Cherrington, Martin, et al., 2012) and went on to exceed recruitment goals (Andreae, Halanych, et al., 2012) and achieve improvements on several clinical measures (Safford, Andreae, et al., 2015). A prominent community-oriented approach is to organize peer support through churches (Samuel-Hodge, Keyserling, et al., 2009; Simmons, Fleming, et al., 1998; Tang, Nwankwo, et al., 2012, 2014).

In Birmingham, Alabama, Cherrington and her colleagues established a searchable, interactive web-based resource providing details about local programs for diabetes prevention and management, intended both for individuals as well as peer supporters and professionals (Cherrington, Agne, et al., 2015). They then went on to develop a fee-for-service program through which local provider groups or other organizations may contract for peer support services (Fisher, Hacker, et al., 2015). Clearly, there are many ways in which peer support can be organized and sustained through community and healthcare settings. Implementation and dissemination research needs to articulate alternative approaches to enable programs to find those that best suit their purposes, settings, cultures, and populations served.

Peer Support as a Continuum

In February, 2016, representatives from diabetes peer support programs in Denmark, Finland, France, Holland, and the UK met in London, hosted by the Nesta Health Lab, by the Steno Diabetes Center of Copenhagen and by Peers for Progress. Although sharing a focus on diabetes, the range of programs was striking. It included individual, group, telephone, and web-based programs, those focused on newly diagnosed individuals and their families, those focused on sharing experiences among those with diabetes, and many more approaches. (A report from the meeting is available at peersforprogress.org.) Some might be viewed as "pure" peer support in which an individual with diabetes but no professional training or a family who has dealt with type 1 diabetes helps another family to cope with their new challenges following diagnosis of a child. Others, such as a mutual support website, or an automated digital app, or a peer support group facilitated by a trained nurse might be seen as including elements of peer support.

Toward the end of the day's discussions, one individual pointed out, "peer support is really a continuum." Expanding on this, it appears more worthwhile to examine the many ways peer support can be provided and woven through prevention and care than to spend effort worrying about what is and is not "real" peer support or who is and is not a "real" community health worker or *promotora*. This lays the ground for a robust view of peer support as a set of intervention emphases that can be integrated into a variety of settings and services, rather than a highly demarcated service that risks isolation and marginalization. A narrow definition would also tend to limit health system support to a similarly narrow range of interventions. The potential of other forms, varieties or levels of peer support to grow and reach and benefit those they may would be regrettably constrained.

That we best view peer support as a continuum is also suggested by the observation from Uganda, above, that the peer support program was not maintained as a distinct program but, rather, was incorporated into ongoing clinical routines such as in making appointments for patient dyads to encourage their continued mutual support.

Viewing peer support as a continuum encourages exploration of how it can be included in a wide range of programs and interventions and how a wide range of individuals, not just "real" peers, can adopt peer support strategies and approaches in their work, even if they do so as professionals, counselors, or in other roles. Just as promoting psychology is not limited to psychologists and promoting health is not limited to health professionals, so promoting social and peer support can reach far beyond those with titles denoting peer support.

Conclusions and Policy Implications

A 2014 international meeting hosted by Peers for Progress and addressing much of this work (Peers for Progress, 2014a) noted that, in addition to its contributions to effectiveness, reach to populations, including those often hardly reached, and benefits for quality of life as well as clinical status and prevention, peer support fills a critical role in *humanizing health care*. If not unique, this dual role of combining effectiveness and humanizing care is an important feature of peer support for prevention and health care of the future.

Beyond showing that "it works," emerging research shows that peer support is broadly feasible and sustainable. Dissemination can combine standardization, such as through the four key functions emphasized here, and adaptability to local circumstances. Keys to its success are becoming clear, including both person- and community-centered implementation, proactive offering of services, and attention to emotional as well as instrumental support. Most important, perhaps, peer support shows strong potential for addressing key priorities in "bending the curve" through healthcare reform (Rosenthal, Brownstein, et al., 2010): reaching those whom conventional services too often fail to engage, mitigating and reducing costs associated with co-occurring physical and psychological problems, and providing intervention models adaptable to diverse settings and populations. Future work should expand the individuals and groups providing support, the concerns and objectives for which it is useful, the organizational arrangements through which it can be implemented, the modes and channels by which it is delivered, the nuance with which it is employed, and, thereby, the individuals, families, and groups who benefit from it.

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23

Engaging Communities to Improve Health: Models, Evidence, and the Participatory Knowledge Translation (PaKT) Framework

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Introduction

A 1988 report from the US's Institute of Medicine (IOM) suggested that much decision-making in public health was driven by "crisis, hot issues, and concerns of organized interests" (Institute of Medicine Committee for the Study of the Future of Public Health, 1988). More than 25 years later, that concern still resonates, leading to repeated appeals to better link research evidence with community needs and preferences to improve population health in a systematic and strategic manner (Kohatsu, Robinson, & Torner, 2004). The process of leveraging evidence to promote changes in population health is often referred to as knowledge translation (KT). As described by The Canadian Institutes of Health Research (2004), KT encompasses the "exchange, synthesis, and ethically-sound application of knowledge – within a complex set of interactions among researchers and users – to accelerate the capture of the benefits of research for [populations] through improved health, more effective services and products, and a strengthened health care system." That is, effective KT is not simply a cognitive or intellectual process but entails action on the part of systems, groups, organizations, and diverse individual behavior. Effective KT approaches are expected to yield diverse benefits including increased utilization of successful programs and policies, increased program sustainability, heightened organizational efficiency/use of limited resources, and greater impact on health outcomes (Brownson, Baker, et al., 2011; Brownson, Fielding, & Maylahn, 2009; Canadian Institutes of Health Research, 2004; Rychetnik, Hawe, et al., 2004). Despite their potential, KT approaches are not the norm in public health settings at this time, resulting in lost opportunities and wasted resources (Brownson, Baker, et al., 2011).

A significant arena for the application of evidence to public health challenges is within local community institutions and organizations. Community-based organizations (CBOs) and nongovernmental organizations are vital – but often underutilized – channels and partners in the delivery of health promotion programs to the general public (Kerner, Gruiguis-Blake, et al., 2005; Maibach, Van Duyn, & Bloodgood, 2006; World Health Organization, 1999). These organizations are also the front line in translation of many large-scale efforts that reflect policymaking at the local, state, or federal levels and thus

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are vital to the success of those programs. CBOs targeting underserved populations are of particular importance as improved links between research and action in these organizations may be an important support for reducing and eliminating health disparities (Institute of Medicine, 2001, 2008; Viswanath, 2006).

Despite tremendous interest in the field, it is still unclear how best to leverage KT in community settings to create sustained social change (Owen, Glanz, et al., 2006). Important challenges include:

1. Limited practitioner access to and skills to use knowledge in a timely manner
2. Gaps between practitioner expertise related to the problem and researcher expertise related to potential solutions
3. A mismatch between evidence-based strategies/programs and adopting organizations (e.g., resource demands, lack of capacity within adopting organizations for implementation, problems defined based on academic divisions, rather than real-world issues)
4. Barriers related to implementation context (e.g., political opposition, lack of leadership, competing tacit knowledge from practitioner experience, complex program delivery environments, organizational inertia, lack of resources, etc.)
5. Inability to translate research results to practice settings (e.g., results that are not relevant to practice settings, lack of capacity among researchers to engage in translation activities) (Brownson, Colditz, & Proctor, 2012; Glasgow & Emmons, 2007; Harrop, Nelson, et al., 2012; Landry, Amara, et al., 2006; Stamatakis, Vinson, & Kerner, 2012; Woolf, 2008)

A major challenge with existing KT models is that most rely on top-down, centralized approaches, which restrict the ability of local institutions to leverage their expertise and underemphasize the fact that evidence-based strategies are being adopted in increasingly diverse settings. Translational efforts are often hindered or even halted by challenges of addressing local context or practice settings (Brownson, Fielding, & Maylahn, 2009). This is a particular challenge as an important part of the KT process is implementation or the integration of evidence-based strategies into practice settings. Most implementation occurs at the local level even if policies are formulated at the national or regional level. In this way, variation in local capacity to leverage the evidence base can lead to variation in outcomes, which can create or exacerbate disparities. Yet another challenge with current orthodoxy is that it does not always account for dynamic changes occurring at the local level, resulting in rigid prescriptions instead of taking an iterative flexible approach. Finally, assessments of implementation tend to focus on the movement of a given program or strategy through a system (with a treatment of the system as a fixed entity).

Following these considerations, this chapter seeks to review important approaches to creating change in communities, highlight gaps in current approaches, and propose a novel approach to creating social change in communities. In the section "Community Organization and the Evolution of Participatory, Ecological, and System Approaches to Creating Change", we draw on early community trials for cardiovascular health and describe recent advances in participatory, ecological, and systems approaches to KT. In the section "The Participatory Knowledge Translation (PaKT) Framework", we present the participatory knowledge translation (PaKT) framework and provide examples of its application. Finally, in the section "Conclusions and Next Steps", we discuss opportunities for future research and practice based on the PaKT framework.

Community Organization and the Evolution of Participatory, Ecological, and System Approaches to Creating Change

The Initial Cardiovascular Health Programs

The early community trials focused on cardiovascular health offer acute insight into the opportunities and challenges of creating social change in communities. In the 1970s and 1980s, the reduction of cardiovascular disease (CVD) and related risk factors were gaining attention as major public health priorities. In light of evidence that primary prevention through behavior change could be a feasible population-wide solution to lower CVD rates, in conjunction with the growing popularity of using community settings for behavior change, programs began using larger-scale strategies that intervened at the community level. The North Karelia Project was one of the first of this group of programs, and is one of the most well known, given its successes. The project was started in 1972 as a community-based project to address cardiovascular disease in North Karelia, a county in Eastern Finland (Puska, Nissinen, et al., 1985). The main objective of the program was to reduce coronary heart disease (CHD) mortality in the population, with intermediate objectives to reduce levels of major risk factors such as smoking, elevated serum cholesterol, and elevated blood pressure. Dietary changes to reduce cholesterol were an important target of the intervention. The program utilized a wide range of strategies, including mass media-based education, training of community residents, and provision of materials necessary for residents to implement simple, sustainable activities promoting lifestyle changes, with an emphasis on smoking and dietary habits. Training activities also targeted doctors and nurses and also social workers, representatives of voluntary health organizations, and informal opinion leaders. Attention to the health system included treatment guidelines and reorganizing treatment for hypertension as well as care following myocardial infarction (Puska, 2009). The intervention developers strategically involved the health services, voluntary, media, business, and policy sectors to create broad-based change. The breadth of these involvements was striking, including in the food industry, for example, not only grocery stores but dairies and sausage factories. Also, there was substantial interaction among the components of the campaign so that, e.g., mass media interventions interacted with local newspapers and community organizations.

The program resulted in significant changes in smoking, cholesterol, and blood pressure in North Karelia compared to the reference area, although differences by gender were observed (Puska, Nissinen, et al., 1985). About 20 years after program inception, CHD mortality among men declined significantly between the preprogram assessment (1969–1971) and 1995, with a decline of 73% in North Karelia compared to 65% across Finland. A similar decline in CVD mortality was also found. Among men, lung cancer mortality decreased significantly more in North Karelia in the 1980s and 1990s versus all of Finland. Among women, a marked reduction in CVD mortality and a small reduction in lung cancer mortality were detected (Puska, Vartiainen, et al., 1998). An assessment at the 35th anniversary of the program inception provides a sense of the scale of possible changes. In Finland, serum cholesterol levels declined strongly between 1972 and 2007. Blood pressure also declined through 2002. Smoking rates declined among men but increased among women until 2002 (at which point they leveled off). For body mass index, levels increased between 1972 and 2007 for men. For women, they decreased, until 1982, but increased through 2007. Overall, changes in risk factors were linked to a 60% reduction in CHD mortality for middle-aged men (in the context of an overall 80% decline) (Vartiainen, Laatikainen, et al., 2010).

Due in part to the broad community model and successes of North Karelia, the US National Heart, Lung, and Blood Institute (NHLBI) funded a series of large research and demonstration programs in the USA to explore the feasibility of implementing large-scale community programs targeting activities to lower both risky behaviors and subsequently CVD morbidity and mortality rates in the community (Viswanath, Finnegan, et al., 1991). These studies are described in rich detail elsewhere; key attributes of the projects are presented here:

- Stanford Five-City project: The program was funded from 1978 to 1996 and covered five California communities. The two treatment communities received 5 years of intervention, which focused primarily on delivering health education for behavior change through print and broadcast media programs, with other educational opportunities provided in community settings. The long-term goal was to establish locally-run programs that were tied to the investigators, but not supported by them, so that the programs could be maintained by the communities (Farquhar, Fortmann, et al., 1985). The program produced change in smoking rates, cholesterol, blood pressure, resting pulse and CHD risk (Farquhar, Fortmann, et al., 1990).

- Minnesota Heart Health Program (MHHP): Funded from 1980 to 1993, the program covered six communities in Minnesota, North Dakota, and South Dakota (Murray, 1995). The three treatment communities received 5–6 years of intervention, and strategies included the use of several mass media channels to deliver messages on healthy behaviors, a strong emphasis on building community advisory boards, and educational programs in schools, worksites, and community settings (Jacobs, Luepker, et al., 1986; Luepker, Rastam, et al., 1996). Community analysis and organization were important strategies used to engage community leaders and organizations, resulting in active involvement of groups to support risk reduction (Murray, 1995). Impact was demonstrated on smoking prevalence among women and increased physical activity for men and women (Luepker, Murray, et al., 1994).
- The Pawtucket Heart Health Program (PHHP): Funded from 1980 to 1996, the program covered two communities in the New England region of the USA. The treatment community received 7 years of intervention, with programming focused on targeting CVD risk factors (including smoking cessation, cholesterol reduction, and maintenance of a desirable body weight), building skills for behavior change, and fostering community activation (Carleton, Lasater, et al., 1995). The PHHP emphasized involvement of community volunteers to carry out program activities (Lefebvre, Lasater, et al., 1987). Reductions in obesity and CHD risk were the major outcomes (Carleton, Lasater, et al., 1995).

These trials had a number of common features, including the emphasis on harnessing the power of the community to create large-scale change. These trials also tended to rely explicitly on theories of behavior change, communication, and diffusion of innovations. As a group, the trials emphasized the complex, multilevel drivers of CVD and accordingly developed multilevel intervention strategies. Strategies included mass media campaigns, network interventions, community organization and mobilization, environmental changes (e.g., changes in supermarket offerings or clinical services), and policy change (e.g., encouraging the implementation of smoke-free policies for public areas, schools, and worksites). They utilized quasi-experimental controlled designs and utilized baseline surveys, panel follow-ups, and cross-sectional surveys (Viswanath & Finnegan, 2002).

Despite these similarities, the three US-based trials utilized different strategies in engaging communities and creating system change. Broadly, the Stanford project utilized mass media (television, radio, and print materials) and group programs implemented in community settings to support behavior change, whereas the MHHP emphasized face-to-face communication, community events, and television, and the PHHP emphasized community organization and action, health promotion campaigns, and activities supporting screening, counseling, and referral to services (Flora, Lefebvre, et al., 1993; Lefebvre, Lasater, et al., 1987; Winkleby, Feldman, & Murray, 1997).

The community prevention trials demonstrated the importance of using multiple interventions to influence individuals' knowledge, attitudes, and behaviors as well as institutional and environmental supports to promote and sustain behavior change (Finnegan, Bracht, & Viswanath, 1989; Finnegan & Viswanath, 1999). Another important strength of the four large cardiovascular prevention programs is that they were better able to approximate "real-world" environments than laboratory-based trials. Data from such trials are expected to be more relevant to practice than data from tightly controlled trials. Another advantage of the community intervention approach is that it does not require activated participants, such as those who might enroll in a clinic-based intervention. Instead, community members are exposed to the intervention and system changes as they go about their regular lives. Accordingly, these interventions may reach a broader audience than those served by the healthcare system directly (Fortmann, Flora, et al., 1995). Yet, these theoretical advantages were not always realized. Taking the Stanford project as an example, the protocol required intensive evaluation activities for some participants more characteristic of a laboratory trial, which may have altered the received dose of the program and also impacted participation rates, negatively impacting the expected population-wide reach (Leventhal, Safer, et al., 1980).

Ultimately, the early cardiovascular trial projects were deemed of limited success in terms of cardiovascular health-related outcomes, due at least in part to secular trends in comparison communities obscuring program effects. In fact, the lack of sufficient dose to overcome secular trends may have affected all three programs, a problem not uncommon with most public health programs (Viswanath & Finnegan, 2002; Hornik, 2002). A careful analysis suggests that changes in comparison communities may have been due to improved clinical diagnosis and treatment of heart disease, as well as increased adoption of preventive behaviors among the public. These changes in behavior may have resulted from mass media campaigns and increased attention to heart disease among the media due to the ability of scientists, policymakers, and others to place this issue on the media's and thus the public's agenda (Viswanath & Finnegan, 2002). Additionally, the traditional evaluation models were built under the assumption of little change in comparison communities and media systems (Viswanath, Finnegan, et al., 1991). Another evaluation challenge relates to the expected effect size and statistical power. The three US-based trials were powered to detect what may have been overly ambitious reductions in risk factors (10–20% declines) and also assumed very low rates of change in comparison communities (Viswanath & Finnegan, 2002; Winkleby, Feldman, & Murray, 1997).

From an outcomes standpoint, it was clear at the end of the trials that assessments should have included a wider range of targets, i.e., moving beyond immediate change in biological markers and risk factors. In many of the demonstration projects, although changes in CVD risk and biochemical measurements such as blood pressure and cholesterol were smaller than expected, focusing on these specific endpoints may have missed the range of positive change that rippled through the communities, setting the stage for change at a later time. The need for long-term monitoring to see change in population-based CHD mortality was noted in the North Karelia Project (Puska, Nissinen, et al., 1985). As critics of the Stanford project highlighted, the emphasis on clinical markers, rather than behavior change among individuals and communities, limited the impact of the trial on the field of preventive health (Leventhal, Safer, et al., 1980). Although intermediate markers, such as knowledge and awareness, and community impact markers, such as organizational or environmental changes, were included in the assessments of each of the three trials (Pirie, Stone, et al., 1994), greater emphasis on the impact of intervention components on behavior change processes would have supported greater application of the findings. While the overall findings may have been less than expected, several components of the interventions often interacted to produce parental involvement, increased social networks, and other positive changes within groups of the community; however, the challenges in testing many combinations of these components on a broader scale may have led to an underestimation of their success (Mittelmark, Hunt, et al., 1993; Schooler, Fortmann, & Flora, 1997). For example, at the close of the MHHP intervention, greater social connectedness was found in worksite organizations providing health promotion services (Weisbrod, Pirie, & Bracht, 1992), although this finding was not included as a main outcome to gauge study success.

Another challenge to the trials may have come from the way communities were defined and integrated into the theoretical base of the intervention. Researchers affiliated with the MHHP note that the working definition of the community may have been too narrow to achieve the program goals. The program focused intensively on residents of three selected communities but did not/was unable to control the larger social environment that impacted these communities. Investigators noted that changing the behavior of whole communities may require changing their broader social environment as well, which was beyond the scope of this program, but may have limited the program's ability to create change in community-level outcomes (Luepker, Murray, et al., 1994). An example of broader social change assessed, but not addressed, by the MHHP relates to state-level restrictions on tobacco use. Assessments of opportunities to change policy and public support for policy change were conducted, though the findings were not translated into action during the course of the initial trial (Mittelmark, Hunt, et al., 1993). For the Stanford project, critics highlighted the mismatch between the community trial goal and the predominance of individual-level behavior change theories in the intervention design, with insufficient attention to community processes and outcomes (Hawe, Shiell, & Riley, 2009; Leventhal, Safer, et al., 1980).

Based on the experience and findings of the early cardiovascular trials, suggestions for improving community-level interventions include the following:

1. A greater emphasis on creating interventions that suit the local context in terms of the population, culture, and social/political climate
2. An increased emphasis on multi-sectoral partnerships (particularly among non-health sectors) to allow for a sufficiently multilevel and integrated effort
3. Coordination of intervention activities across levels of influence
4. Ensuring a sufficient reach and dose across the target audience
5. Allowing sufficient time for community needs assessments, networking, and relationship development before the intervention starts
6. Tailoring programs for community characteristics, such as leadership, community participation, capacity, networks, community values and unification, and community ability to address problems (Goodman, Speers, et al., 1998; McLaren, Ghali, et al., 2007; Mittelmark, Hunt, et al., 1993; Papadakis & Moroz, 2008; Schooler, Fortmann, & Flora, 1997)

Overall, the initial cardiovascular trials highlighted the importance of multilevel, multiprong action to create change in communities. They also highlighted the potential to leverage the evidence base for large-scale program development and planning. At the same time, the modest results and challenges to sustainability point to the need to take a broad, long-term perspective on creating social change in communities. The required intensive investment and long-term solutions cannot be achieved simply through external agents' action. An important potential solution to these challenges lies in the use of participatory approaches to creating change in communities.

Participatory Approaches to Knowledge Translation

Many of the challenges with bringing research evidence to bear in community settings stem from the distance between research and practice settings. Early attempts at leveraging the evidence base often focused on a "push" from the research and funding communities. Current strategies proposed also include a "pull" approach, driven by the needs and capacity of practitioners and "system capacity" for supporting the use of evidence in practice (Green & Mercer, 2001; Lavis, Lomas, et al., 2006; Orleans, 2007). Another way to bridge this gap is to engage communities and other stakeholders using a participatory approach so that research produced is more relevant to communities and more widely disseminated (Glasgow & Emmons, 2007; Minkler & Salvatore, 2012; Woolf, 2008). Importantly, a participatory approach, such as that described by community-based participatory research (CBPR), can engage the end users of the knowledge early in the process, thus enhancing the probability of successful translation. That is, practice may influence the nature of research questions, study designs, and interpretation of results plausibly leading to more relevant research and sustained social change.

CBPR is an approach to research that is collaborative and involves all partners in a process of co-learning and capacity-building to create change and link knowledge and action to improve health and reduce health disparities (Israel, Schulz, et al., 1998; WK Kellogg Foundation, 2001). CBPR is vital for translational research as it allows researchers to leverage the rich knowledge of practitioners and community members and potentially improve intervention impact in a wide range of settings (Minkler & Wallerstein, 2008). By increasing the relevance of the research conducted and insights gathered, there is potential to increase the application of research evidence to practice settings. CBPR is particularly relevant for KT work as it emphasizes multidirectional flow of information between researchers, communities, organizations, and policymakers, not the typical unidirectional flow from researchers to communities (Minkler & Salvatore, 2012). In this way, the approach directly addresses a number of challenges related to translational research, including issues of external validity, privileging of academic versus practice-based knowledge, power dynamics in universities, limited attention to sustainability, difficulties with communication between academics and practitioners, and historical lack of trust between researchers and practitioners (Wallerstein & Duran, 2010). An example that addressed each of these issues comes from work conducted by Duran and colleagues in New Mexico (Wallerstein & Duran, 2010). Using participatory approaches, a team of researchers, service providers, and community partners integrated evidence-based, culturally appropriate services for Native Americans with/at risk for HIV into a new care center. The engaged approach was credited with leveraging indigenous knowledge, increased health impact, increased acceptability of services, and improved potential for sustainability.

An important aspect of CBPR for KT is its roots in action research, or the approach to research that studies the impact of a range of social actions, with the goal of producing practical knowledge to support further action (Lewin, 1946). The action research approach emphasizes democratic, participatory processes to develop practical knowledge to address important issues for individuals and communities. Researchers are expected to approach a problem with the understanding that others will know as much, or more, as they do about the issue and potential solutions (Brydon-Miller, Greenwood, & Maguire, 2003). The work proceeds in a "spiral of steps" composed of cycles of planning, action, and evaluation that feed the next set of steps in the spiral. The evaluation, or "fact-finding" components, is essential to understanding the impact of one set of actions and setting the stage for refinement for greater success in the next iteration (Lewin, 1946). The emphasis on iterative steps and feedback of the results into the system as well as to involved parties are seminal components of this approach. Outputs of research from this perspective allow individuals and communities to set up systems to create the change they value (Bargal, 2006; Brydon-Miller, Greenwood, & Maguire, 2003).

Ecological and Systems Perspectives

An important complement to the participatory approach to KT is the adoption of ecological and systems perspectives. As described by Bronfenbrenner (2005), the ecological perspective emphasizes the embeddedness of an individual in his/her environment and the mutual influence between the individual and environment. In typical public health applications for individual behavior change, the perspective prompts attention to micro-level influences, such as biology or interpersonal influences of individuals, family, friends, and colleagues; meso-level influences, such as community structures and organizations; and macro-level influences, such as policies and governing institutions. In the context of KT in community settings, we must consider the multilevel drivers that support or hinder the application of evidence to solve public health problems, as well as the multiple levels at which KT can have impact. Change requires individual change as well as linked social and structural supports. Change can be created more quickly and more sustainably if multiple actions work independently and interdependently to move a system toward a desired set of outcomes (Trickett, 2009). Accordingly, we take into account multiple influences and impacts of action by individuals and organizations charged with creating social change. We also consider interactions within and between levels, both directly and indirectly (Bronfenbrenner, 2005; Schensul, 2009; Trickett, 2009).

An evaluation of an international effort for diabetes prevention highlights the challenges and supports for an ecological approach to KT. A range of projects across the KT continuum were conducted in the USA, Vietnam, the Philippines, Sri Lanka, India, Australia, Guinea, Cameroon, and Jordan. Key barriers and facilitators to translation of diabetes prevention efforts existed at the following levels: target population, staff, and organizational/interorganizational. Potential solutions highlighted the importance of engaging end users in a different manner than traditional outreach efforts, investing time in relationship building and capacity building (among staff and supporting organizations), and preparing for dissemination activities to a diverse set of stakeholders as knowledge was gained. The review highlighted the complexity of intervening in systems but also highlighted the potential to create sustainable change if the challenges were met (Garcia de Quevedo, Siminerio, et al., 2012).

Ecological approaches can often be supported via community mobilization. Community mobilization refers to processes by which community groups and institutions convene and collaboratively identify health topics, create action plans, and then take action to support change (Minkler, Wallerstein, & Wilson, 2008; Roussos & Fawcett, 2000). The potential for community mobilization and collaboration in the arena of health promotion has been of great interest to private and public sector actors, resulting in an intense focus on the formation of coalitions, alliances, and other forms of interorganizational partnerships (Butterfoss, Goodman, & Wandersman, 1996; Lasker, Weiss, & Miller, 2001). A useful example comes from the Canadian Heart Health Initiative. For a provincial project in Prince Edward Island, the leaders of the initiative utilized techniques of community mobilization to engage coalitions to promote heart health. With this perspective, the effort increased research and programming capacity in the community, strengthened partnerships, increased investment into the activities by the community, and expanded the scope of the project to a multilevel effort (Robinson, Elliott, et al., 2005).

Intersectoral partnerships – relationships among actors from diverse sectors, such as education, public health, and criminal justice – offer an important target for creating sustainable change. This is in line with the social determinants of health perspective that acknowledges the contribution of different sectors – health and non-health to health outcomes. Intersectoral partnerships can marshal human and social capital from a wide range of partners and are one solution to problems that cannot be tackled by an organization or sector in isolation (Lasker, Weiss, & Miller, 2001; Provan, Nakama, et al., 2003; Provan, Veazie, et al., 2005; Roussos & Fawcett, 2000). Inclusion of diverse partners can increase the range of resources available, not only in terms of pooling of resources or resource exchange but creation of new and effective resources and the potential to impact a broad set of influences on health (Burt, 1992; Lasker, Weiss, & Miller, 2001). Despite the potential benefits of partnership in community settings, there are many barriers, including interorganizational differences in values, missions, goals and norms, competing interests, and challenges of competing for scarce resources (Provan, Nakama, et al., 2003). Thus, the challenges with creating interorganizational partnerships is non-trivial, though such efforts have successfully been applied to address health disparities overall (Hennessey, Smith, et al., 2005) as well as specific behaviors and diseases, such as diabetes (Giachello, Arrom, et al., 2003), HIV/AIDS (Parker & Aggleton, 2003), and substance abuse (Shults, Elder, et al., 2009).

An important challenge posed by ecological models and intersectoral partnerships relates to the scope of efforts to create change. For example, a comprehensive approach to obesity might include families, schools, neighborhood business, and local government. Yet, supporting and coordinating action among such diverse constituents would probably call for more resources than the typical local organization can bring to bear. Or, competition and conflict may derail or inhibit efforts to mobilize different sectors. This is particularly the case in large heterogeneous communities where conflict is part of the system (Tichenor, Donohue, & Olien, 1980). One important solution is in the form of broad-based coalitions that bring together public, private, and nonprofit sectors. These can be government sponsored or locally commissioned and can spread the burden of coordination across a range of agencies, rather than attempting to have a single organization attempt the task. For example, a recent partnership among researchers, community groups, and service providers in Tampa, Florida, highlighted the power of a diverse coalition to assess local needs related to mental health and substance abuse, identify appropriate evidence-based practices, and support their implementation. Through engaging with potential stakeholders from the needs assessment onward, the group was able to identify and implement acceptable and sustainable solutions (Rugs, Hills, et al., 2011).

The field of systems science is also vital to KT efforts in community settings. This area of inquiry focuses on complex systems, or those in which the functioning package of parts, or the whole, is different than the sum of its parts due to interplay between parts. A useful definition from the World Health Organization (WHO) highlights the following features of systems: self-organizing, nonlinear, dynamic, history-driven, tightly linked, counterintuitive, feedback-driven, and resistant to change. The WHO vision of systems science is inherently participatory, with explicit guidance for inclusion of diverse stakeholders in understanding systems, defining success and goals, and devising systems-based solutions to public health problems (de Savigny & Adam, 2009). An important idea is that the outcomes are durable and adaptive (Luke & Stamatakis, 2012). Given the complex and important interplay between elements, the study of KT thus requires a study of the whole system to understand opportunities to create change. This perspective addresses limitations in behavioral science that stem from roots in the biomedical tradition, which prompt seeking of results that are highly generalizable, assume linearity, and mask, rather than delve into, differences between groups (Livingood, Allegrante, et al., 2011). These ideas parallel the idea of complex/systems interventions, in which the overall impact is not a simple addition of the components (Hawe, Shiell, & Riley, 2004). A useful example of the application of systems science approaches for KT comes from the Prevention Impacts Simulation Model (PRISM), developed by the Centers for Disease Control and Prevention, with co-funding from the US National Institutes of Health. PRISM allows communities to model potential impacts of health policies that target chronic diseases, project time and effort required to create a given change, and assess the potential impacts of partially implemented changes. By integrating evidence and modeling capabilities and making them accessible to decision-makers, the tool is able to leverage the power of systems modeling for supporting evidence-based policy change (Homer, Milstein, et al., 2010).

Clearly, it is a complex task to intervene in communities and systems. The motivation to engage in work at the intersection of KT, CBPR, and multilevel/systems interventions is summed up nicely as follows by Brydon-Miller et al. (2003):

> Messes are complex, multi-dimensional, intractable, dynamic problems that can only be partially addressed and partially resolved. Yet most action researchers have disciplined themselves to believe

> that messes can be attractive and even exciting. We try not to avoid messy situations despite knowing that we do not have the 'magic bullet' because we believe that, together with legitimate community stakeholders, we can do something to improve the situation.

The Participatory Knowledge Translation (PaKT) Framework

Clearly, there are a number of challenges to creating evidence-driven, broad-based change in communities to improve health. It is our contention that a system that allows for ongoing translation of evidence/data into sustained community change efforts will address many of the barriers to improving health and addressing health disparities in communities. The success of such a system hinges on sustained engagement in a community with community stakeholders. Thus, we outline a *process* by which individuals and organizations can engage with communities to leverage KT and develop systems that promote social change over the long term. In this way, the framework we offer explicitly addresses a major challenge of many past efforts, which have typically relied on outsiders to kick-start or even attempt to control the change process. Lack of user engagement and ownership for these outsider-driven changes has been a major cause of failure for change efforts. We focus here on community engagement and mobilization, not just participation, with KT processes as the engine that fuels ongoing change. The framework also explicitly includes attention to health disparities and social/contextual drivers of those disparities, which also prompts a long-term perspective that addresses differing targets as health profiles and disparities shift. The goal of the outlined process is to build multilevel infrastructure for promoting change in communities to improve health. Our experiences with successes and challenges to application of this framework have served to refine it, and we discuss these experiences in detail below.

As seen in Fig. 23.1, there are three major inputs to the framework: institutionalized participation, investment in communities, and knowledge production/transfer, which are linked to infrastructure impacts by iterative Plan-Do-

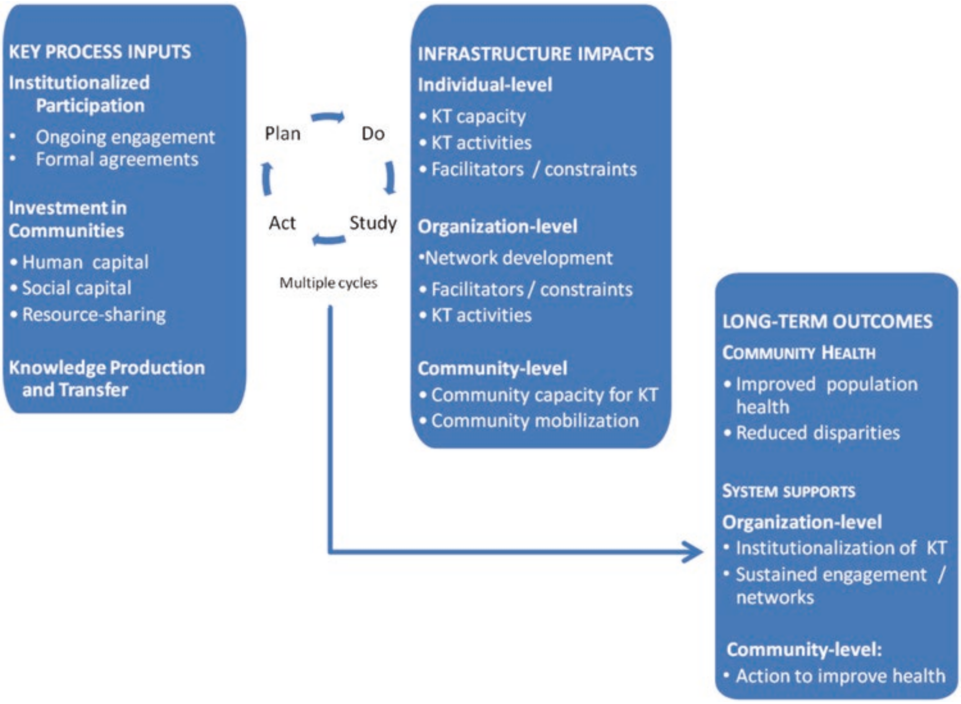


Fig. 23.1 The participatory knowledge translation (PaKT) framework

Study-Act cycles, which ultimately lead to long-term outcomes. At a high level, institutionalized participation refers to the activities and *infrastructure* that allow diverse partners to engage successfully to address a priority health issue. The focus on investment in communities emphasizes opportunities to share resources and build capacity and structures within communities that have sustained benefits that may extend beyond a given effort's focus. Finally, the emphasis on knowledge production and transfer highlights opportunities to produce and spread knowledge that is relevant, accessible, and useful for diverse partners. The infrastructure impacts, or initial markers of change, are expected to accrue at the individual level (e.g., capacity for KT), the organization level (e.g., intersectoral network development), and the community level (e.g., capacity for using KT to improve health). As noted in the figure, there are a series of Plan-Do-Study-Act cycles in the process. These cycles emphasize action-oriented learning through four steps: Plan (determine a course of action), Do (execute the plan), Study (assess outcomes), and Act (utilize the findings by acting upon them) (Deming, 2000; Institute for Healthcare Improvement, 2004). In the PaKT framework, the Plan-Do-Study-Act cycles provide the link between key process inputs and infrastructure impacts, which change through the iterative cycles. As cycles progress, we expect to see changes in long-term outcomes, such as improved community health and system supports to promote social change for improved health.

Background on Three Key Projects

We draw from our experiences with three recent participatory research projects to illustrate the components of the PaKT framework.

2005–2012: Massachusetts Community Network for Cancer Education, Research, and Training (MassCONECT)

MassCONECT was a transdisciplinary collaboration based on CBPR principles. This initiative was funded by the US National Cancer Institute (NCI) as part of the Community Networks Program. The program focused on reducing and eliminating cancer disparities in low SES communities through infrastructure development. The program utilized a social determinants approach and brought together relevant stakeholders – academics from a number of disciplines, policymakers, community leaders, coalition leaders, media, and local and state government – together to create sustainable solutions to reduce cancer disparities. This was achieved through making public health data available, engaging local media about health inequalities, supporting the dissemination of evidence-based strategies/programs, supporting coalition efforts related to health insurance, and training CBO staff to engage media about health inequalities. The program leveraged existing infrastructure and connections of four community coalitions in Boston, Lawrence, and Worcester, MA (Emmons, Viswanath, & Colditz, 2008; Koh, Oppenheimer, et al., 2010).

2008–2014: PLANET MassCONECT

PLANET MassCONECT was a KT project that grew out of the MassCONECT effort. The project was initially based in the MassCONECT communities – Boston, Lawrence, and Worcester and leveraged the existing connections and relationships between researchers and academics that were built during the MassCONECT project. The program infused three types of capital into partner communities. First, we focused on *human capital* – the program built capacity among staff members of community-based organizations (CBOs) to find, adapt, and utilize evidence-based programs (EBPs). Capacity-building efforts included a 2-day workshop and a tool kit that included a website (www.PLANETMassCONECT.org), a training manual, handouts, and case studies. Second, we focused on *financial capital*, including pilot grants to apply newfound knowledge, as well as financial support for partner institutions. Third, we focused on *social capital*, including networking opportunities to promote learning networks in which trainees could support each other. By enhancing capacity among local CBOs to use EBPs, the project was expected to improve programmatic quality and impact, ultimately reducing disparities. The original project was funded by the National Cancer Institute; additional funding allowed for the expansion of the intervention to two additional Massachusetts communities: Lowell and Brockton. Across the five communities, over 250 individuals were trained. The discussion in this chapter focuses on the intervention developed with and for the initial three communities.

2010–2015: Influencing the Media and Public Agenda on Cancer and Tobacco Disparities (Project IMPACT)

In contrast to the very broad infrastructure development of PLANET MassCONECT, Project IMPACT was created to build capacity among community groups in Lawrence, to change the public agenda on health- and tobacco-related disparities by changing the media agenda. The project started with a needs assessment, a community leadership analysis, and an assessment of the media environment, related to health disparities broadly and tobacco disparities specifically. The second step of the initiative was a capacity-building program for CBO staff members to help them advance their agendas, through strategic communication, around health disparities with special focus on tobacco-related disparities. About 60 individuals were trained through this program.

Description of Settings

The initiatives described here are set in three Massachusetts communities, Boston, Greater Lawrence, and Greater Worcester, constituted as a part of regional community health network areas (CHNAs). CHNAs are local coalitions that link public, private, and nonprofit sectors to engage in prevention and health promotion with the broad goal of building healthier communities. The CHNA effort was started in 1992 by the Massachusetts Department of Public Health and includes all Massachusetts towns and cities, organized into 27 CHNAs (Massachusetts Department of Public Health, 2013). These communities are diverse in terms of size and demographics and thus present a useful range of settings for KT activities. Table 23.1 summarizes the racial/ethnic composition of the three communities.

Component 1: Institutionalized Participation

Developing and maintaining partnerships that support sustained community action to improve health can be challenging, but a structured approach to participation can provide the scaffolding to support such an effort. One of the key ideas espoused by the participatory approach is stakeholder participation throughout the research process to leverage the strengths diverse partners bring to the table and ensure that the efforts meet the needs of diverse stakeholders (Israel, Schulz, et al., 1998). Joint infrastructure development has been identified as an essential element for success across a diverse set of CBPR projects (Lencucha, Kothari, & Hamel, 2010). Institutionalized participation, including plans for ongoing engagement and the use of formal agreements, is key to supporting the growth of effective, collaborative, sustained partnerships.

Ongoing Engagement

The process outlined by the PaKT framework assumes that engagement among those attempting to create change in communities and important stakeholders must occur before, during, and after a discrete project is conducted. This supports the goal of creating long-term collaborative structures to create change in a given community. Often, models focus on mobilization with the elite. The PaKT framework focuses explicitly on a wide range of stakeholders. This addresses challenges highlighted earlier with the potential disconnect between those creating and those required to adopt new solutions.

One opportunity to promote and sustain engagement comes from the formation of advisory committees that include diverse stakeholders, a strategy often used in participatory research. For each of our projects, we formed Community Project Advisory Committees (C-PACs) that

Table 23.1 Sociodemographic profile of three-study communities, 2007–2011 census data (US Census Bureau, 2013)

	Population	Race[a]					Economics	
		White (%)	Black (%)	Asian (%)	Other (%)[b]	Hispanic or Latino (%)	Median household income ($)[c]	Adults living below the poverty level (%)
Boston	609,942	56.7	27.8	9.7	9.8	17.3	51,739	19.8
Greater Lawrence								
Lawrence	75,761	35.1	5.8	3.3	59.6	72.9	31,478	23.9
Methuen	46,785	80.7	2.8	5.1	13.9	17.6	65,799	7.6
North Andover	28,156	90.7	1.9	6.0	2.6	2.9	95,199	4.0
Greater Worcester								
Worcester	181,045	79.2	12.1	6.3	5.4	19.3	45,846	16.6
Leicester	10,934	96.5	1.4	2.0	0.5	4.1	72,471	5.3
Paxton	4,767	92.7	4.8	2.5	0.6	0.9	105,072	3.0
Holden	17,197	96.4	0.9	2.8	0.6	1.2	89,660	3.7
West Boylston	7,660	90.4	5.4	0.3	4.8	6.9	73,600	3.8
Boylston	4,320	97.6	0.0	2.0	7.4	3.0	91,734	1.2
Shrewsbury	35,269	81.1	2.1	17.3	2.0	2.4	88,985	4.1
Grafton	17,472	89.5	2.4	8.4	0.6	2.2	89,950	6.3
Millbury	13,250	96.2	0.7	2.9	1.0	3.0	77,883	2.5
Auburn	16,183	97.6	1.3	0.6	1.8	1.0	73,559	4.9

[a] Reported alone or in combination with other categories
[b] Includes (alone or in combination): American Indian and Alaska Native, Native Hawaiian and other Pacific Islander, and some other race
[c] In 2011 inflation-adjusted dollars

included community partners, investigators, and study staff. The C-PACs are key decision-making platforms that ensure all stakeholders have input into and agree with all phases of a given project. C-PACs for each project meet in person quarterly to review progress, solicit feedback from all members, and make important decisions. Each C-PAC conducts additional business through conference calls or email as needed.

C-PACs are often complemented by project-specific *working groups* in each community. Each working group is time limited focused on a defined project and involves academic, community, and project-specific partners. Two coalitions (in Lawrence and Worcester) created a MassCONECT Working Group when the grant period began. These working groups brought together local CBOs working on cancer and health disparities. They met monthly to discuss the MassCONECT work occurring in their communities, as well as how best to work together to reduce disparities. Even though the grant has ended, these working groups still convene regularly to sustain the work started by these efforts.

Community assessments provide an additional opportunity for partners to engage actively as a new project starts or early in the project life course. This type of assessment is useful for collecting necessary data to inform an approach that is evidence-based and reflects the needs, goals, and resources of the community (Brownson, Baker, et al., 2011; Minkler & Hancock, 2008). An ecological assessment addresses the health profile of the community, the underlying power structures, the network structure of the community, norms that influence health-related behaviors, and community history and trajectory (Trickett, 2009). Community assessments also present an opportunity to support and develop partnerships. Though it comes in many forms, the ultimate purpose of the assessment is to highlight targets of intervention and identify resources and opportunities.

Engaging in a participatory needs assessment has a number of benefits, including codevelopment of priorities for action. Our research suggests that CBOs often face challenges leveraging data for priority setting (Ramanadhan, Crisostomo, et al., 2012; Ramanadhan & Viswanath, 2013). Key challenges include (1) integration and utilization of data along with community values and local social, cultural, political, and economic contexts; (2) the fact that CBO staff members may use different definitions of data and evidence and have different understandings of the role and utility of evidence, compared to academics and funders; and (3) barriers to using data for priority setting and decision-making, such as challenges in finding, accessing, and using relevant data. By negotiating these challenges as partners, the team can negotiate and cocreate a set of acceptable priorities, rather than approaching the process from separate directions.

Although needs assessments may provide the impetus for a project, communities have often already identified issues to be addressed, and there is an opportunity for collaboration where appropriate. For example, the PLANET MassCONECT project was developed based on a request from community partners to fill a gap in capacity at the community level for finding and using evidence-based programs. Community partners highlighted an important need, and a team of academics and community partners collaborated to create a research program around this need. Certainly, challenges exist in issue selection, including tensions between funding streams and community interests (Minkler & Hancock, 2008). However, long-standing partnerships with institutionalized participation provide a forum for resolution and mutual accommodation of interests and needs. Participation related to remaining phases of the research process (after the partnership has been created and the issue identified) are discussed under Component 3, knowledge production and transfer. Also, given the emphasis on long-term engagement in the framework, it is unsurprising that in each of our partner communities, we have one to two partners (leaders of organizations or coalitions) with whom we consistently collaborate, adding additional stakeholder partners as the projects dictate. In this way, ongoing engagement refers not only to participation throughout a given project but also across and in between projects, to ensure continuity of effort toward social change.

Formal Agreements

Formal agreements are a useful way to support institutionalized participation. At the beginning of each new project, we have signed a memorandum of understanding (MoU) with each of our partners, clearly detailing roles and responsibilities related to the project. These agreements provide a useful reference for all stakeholders. Again, given our interest in engagement beyond the life of a given project, these formal agreements provide an opportunity to renew the commitment to collaboration but also to define appropriate boundaries for a particular effort. Another important formal agreement is the Publication Policy. Often, community partners find that partners contribute different skills at different times, but in many cases, the academic partners are the only ones recognized in formal publications. To avoid this issue, we have developed a publication policy that ensures that diverse contributions are recognized, whether through individual contributions as authors or through a list of all members of the advisory committee in the acknowledgements section.

Component 2: Investment in Communities

Human Capital

Investment in human capital is essential to an engaged, systems-focused approach to using KT for improving health. For CBO staff members and leadership, to understand the value of leveraging the best health promotion evidence and to have the skills to do this supports not only health impact in the short term but inherently prompts ongoing attention to opportunities to apply the changing health promotion science to new efforts. Successful capacity building thus results in the improved ability of community partners, and local structures, to address current health issues, as well as those that the community is likely to face in the future (Hawe, Noort, et al., 1997). It is useful to consider Lewin's metaphor of action, research, and capacity building as the three points of a triangle that must be linked to remain whole (Lewin, 1946). It is clear that KT efforts require a great deal from CBO staff members; thus, it is vital to plan for the necessary support.

One example of capacity building for KT in community settings comes from the PLANET MassCONECT intervention, which tested a participatory model for knowledge transfer. By developing abilities to find, use, adapt, and evaluate evidence-based programs and strategies, CBO staff members were expected to be able to provide higher-quality services to the communities they serve. The program did not emphasize a specific health issue but instead focused on a broad set of skills that apply across disease categories. This was an important decision based on C-PAC guidance so that the program would best meet the needs of CBOs in the partner communities. Trainees were introduced in a 2-day workshop to the systematic approach to program planning, summarized in Fig. 23.2. As indicated by the funnel metaphor, the process supports organizations as they take stock of the large universe of potential EBPs available and systematically narrow this down to a set of strategic options for the adopting organization.

In addition to skills built during the training workshop, the program emphasized ongoing use of the skills through use of a customized website with resources to support each step of the process. Finally, trainees had opportunities to apply skills gained in the training to apply for pilot grants and were given detailed technical assistance throughout the application process, including post-decision feedback.

As we engaged in this capacity-building effort, the limits of applying highly prescribed EBPs in practice settings became evident, and we shifted toward the idea of evidence-informed programs and strategies, which is an important conceptual distinction. Rather than promoting a fixed, static EBP, which may or may not meet the needs of CBOs, we instead began to promote the incorporation of evidence and data throughout program planning processes. This is consistent with the evidence-based public health approaches put forth by Brownson and colleagues (Brownson, Baker, et al., 2011).

The PLANET MassCONECT systematic approach to program planning was developed to link evidence and action in community settings. First, when reviewing data, CBOs may face sev-

Fig. 23.2 The PLANET MassCONECT systematic approach to program planning

eral challenges in finding the data they need, based on issues of accessing relevant data or interpreting and acting upon the data that are found (Ramanadhan, Crisostomo, et al., 2012). We delivered explicit training focused on finding, evaluating, and using a range of data to support program planning. The second step of the process, finding partners, provides a useful example of the interactive exchange that drove program content. Our goal was to emphasize strategic selection of partners, with an emphasis on multilevel change and opportunities to select partners that brought needed resources to the partnership. We incorporated a tool codeveloped with partners for partnership assessment; the tool is discussed in detail in the section on social capital.

In the third step of the systematic approach, we introduced the US Centers for Disease Control and Prevention's (CDC) *Community Guide*, a resource that provides high-level guidance about evidence-based approaches to health promotion. Through this resource, trainees were introduced to ideas of systematic reviews and opportunities to make decisions about the appropriate strategies for their work based on large amounts of data. One challenge is that many reviews consider randomized control trials (RCTs) as the gold standard for evidence-based practices and exclude studies using other designs (Livingood, Allegrante, et al., 2011). This makes finding relevant data for strategies housed in community organizations a particular challenge. For example, trainees attempting to partner with schools often found that there are a number of strategies for which there is "insufficient evidence" to support the use of that strategy in schools. However, upon closer examination, the challenge with the data was often that there were too few trials conducted in schools to allow for a determination to be made. Trainees were encouraged to read the "insufficient evidence" marker as a situation in which the "jury was still out," but this required intensive discussion and support to move practitioners away from their initial reading that they should avoid strategies with this label. We also encouraged trainees to remember that an EBP could exist in a nonsupported category of strategies. As noted by Fisher (2008), compilation reviews present a few important challenges. First, a finding of "insufficient evidence" may simply reflect the challenge (in terms of design, expense, ethics, etc.) of conducting a certain type of study. However, the "insufficient evidence" finding may lead to concerns that there are no evidence-based actions to be taken, with the result of no action taken. Additionally, the designs of these reviews (e.g., categories used to distinguish one group of intervention settings from another) may be a function of the available eligible data, rather than an underlying scientific question of interest. Thus, while the findings have a place in evidence-based decision-making, they reflect a summary of a tightly restricted set of studies and should be applied accordingly.

In the fourth step, we supported staff members as they attempted to find an appropriate program or strategy. Through rich experience with over 250 trainees, we have found that an important challenge relates to finding a program that meets enough criteria for selection (e.g., program match with resources and target audience, availability of evaluation materials, and customization requirements). However, once we shifted toward ideas of evidence-based strategies and programming efforts, we found that we were able to point trainees to resources that summarized the best available evidence. At that point, they were charged with making the information usable locally, which brings us to the process of customization or localization, also called program adaptation. CBOs face the challenge of making a program relevant to the CBO's target audience, which may be quite different from the population with which a given program was developed. Mismatches between study and target populations are likely to become the norm in countries that are becoming increasingly diverse in terms of race/ethnicity, national origin, religious background, and other attributes, as is the case in the USA (Castro, Barrera, & Holleran Steiker, 2010; Humes, Jones, & Ramirzez, 2011). This is also a challenge when attempting to use a program that was effective in one country in another. Insufficient or ineffective adaptations can result in decreased participant engagement or a program that is not relevant to the participant, which can lead to program failure (Lau, 2006).

An important set of solutions for program adaptation focus on preserving the function, rather than the form, of the program. Drawing on the idea of interventions as events that take place in a system (rather than something that happens to a defined organization), it is clear that context is key, and the way a program interacts with the context will lead to success or failure. Rather than thinking of a static program, if one thinks of the program as a dynamic and complex entity, the underlying processes by change is achieved can be standardized across sites, even if the program looks quite different across sites (Hawe, Shiell, & Riley, 2004, 2009). At this time, the challenge is for program developers to identify core processes, or the function of the intervention, and develop methods for sharing those processes with CBOs, a marked shift from the earlier stance of packaged interventions that were to be implemented with exacting fidelity (Fixsen, Naoom, et al., 2005).

The final piece of the PLANET approach to program planning relates to evaluation. Again, the program promoted continuous evaluation and feedback loops to drive further action. While funders often require evaluations as a condition of funding, CBOs do not always see the utility of this often resource-intensive process (Ramanadhan, Crisostomo, et al., 2012). In our trainings, we emphasized quality improvement perspectives, highlighting the potential for evaluation to allow CBOs to maximize limited resources and increase impact. Given that KT requires a new way of work and organizational change, it is important to use evaluation as a tool to focus on quality and organizational improvement, as well as a means by which to bring about organizational change (Senge, 1990). In this context, the idea of connecting KT with improvement science to improve the quality of care and public health is increasingly gaining currency (Improvement Science Research Network, 2014; Institute for Healthcare Improvement, 2014). The same PDSA cycles highlighted in our framework were the focus of our efforts to encourage CBOs to leverage organizational data as part of continuous quality improvement processes.

Another example of investing in human capital comes from Project IMPACT. As part of this project, we planned to conduct a baseline survey and found that in order to get a sense of the depth and breadth of the community, we would need to do a door-to-door survey, rather than a phone- or web-based survey. While door-to-door surveys have been replaced by telephone-administered surveys for the reasons of cost and efficiency, the increasing penetration of cell phones is posing a significant challenge to the reliability and representativeness of usual random digit-dial surveys. This is particularly true in minority and low-income communities (Blumberg, Ganesh, et al., 2013). We therefore opted to administer face-to-face surveys. Rather than hiring an outside company, we recruited, hired, and trained 16 young adults from Lawrence High School and Northern Essex Community College to administer the survey. Not only were these young people engaged in the process (and supported by leaders at their institutions), but they also quickly built the necessary research and survey administration skills to field over 900 surveys. The survey administrators were paid and were also given opportunities to visit the Dana-Farber Cancer Institute/the Harvard School of Public Health and network with leading oncologists, nurses, and public health professionals. A subset also attended a voluntary meeting and performed a series of analyses on the preliminary data, which they presented to public health professionals in the community. Through participation, the survey administrators reported gaining professional and communication skills, learning about health disparities, and gaining self-confidence. Although the financial costs of hiring young people were within the expected range for costs for a survey research firm, this nontraditional approach required a much greater investment on the part of staff and community partners (Ramanadhan, Nagler, et al., 2016).

Social Capital

In addition to human capital, the PaKT framework also explicitly focuses on social capital. We take a network-based view of social capital, emphasizing the "resources embedded in a social structure that are accessed and/or mobilized in purposive actions" and focused on individuals and groups (Lin, 2001). Given our interest in supporting multilevel action, partnerships among diverse stakeholders become a vital target for action. A useful distinction comes from the concepts of bonding versus bridging capital. Bonding capital comes from similar others and helps organizations get their work done and maintain effectiveness. On the other hand, bridging capital comes from connections with dissimilar others and helps organizations move ahead, particularly when organizations have different levels of power. In this way network members gain access to a wide range of capital through their connections (Kawachi, Subramanian, & Kim, 2008) as well as enabling the flow of information (Viswanath, 2008).

Broadly, a network approach emphasizes the potential to leverage the knowledge and resources of diverse stakeholders in the development of practical and effective solutions to health problems (Israel, Schulz, et al., 1998; Lasker, Weiss, & Miller, 2001). Staff social networks can also be important to support a new way of work (Institute for Healthcare Improvement, 2004), here the use of KT approaches in community settings. Informal knowledge transfer can be particularly important in low-resource settings, such as the environments many CBOs operate in, to allow for diffusion of information without great expense related to training (Ramanadhan, Wiecha, et al., 2009, 2010).

Social capital should be viewed as a strategic investment. Resources must be invested to develop and maintain network connections, so there is an important opportunity to identify the network structures and members that will support the desired social change and then work toward that setup. One way in which to uncover a strategic set of partners is to use community leadership analysis. This technique draws on community reconnaissance, a set of methods that uncovers underlying power dynamics in communities (Nix, 1977; Nix & Seerley, 1971). In a recent study for Project IMPACT, we conducted such a leadership analysis to understand power dynamics in relation to health inequalities in the intervention community. We started with a seed group of community leaders and conducted a snowball sample, interviewing other individuals who were often nominated as leaders in the community. We conducted a total of 33 semi-structured interviews with participants from six sectors in the city. We analyzed the qualitative data (interview transcripts) and then mapped the resulting nomination network using UCINET (Borgatti, Everett, & Freeman, 2005), dedicated network analysis software. By combining the qualitative and quantitative data, we were able to create a number of network maps that (a) identified a core leadership group for the city, (b) assessed the extent to which a range of sectors were represented in the power structure of the city, and (c) highlighted connections that could be leveraged by our community partners to engender multi-sector collaboration to support their goals (McCauley, Ramanadhan, & Viswanath, 2015). This type of assessment is vital as public health practice efforts may include wide-ranging actors and systems including community members; community-based/nongovernmental organizations; entities from a range of sectors, such as housing and transportation; and governmental structures at local and higher levels (Trochim, Cabrera, et al., 2006). A major challenge is in translating this assessment process from an academic to a practice context, so that it is accessible and feasible for community partners.

In addition to conducting our own network assessments, we have developed a tool for CBOs to consider interorganizational networks in a selective and strategic manner. Working with the PLANET MASSCONECT C-PAC, we developed the "Assessing and Maximizing Partnerships (AMP) Tool," a four-step strategic planning process that allows CBOs to analyze their current and required partnerships for a given health promotion goal. The tool is meant for use by a team of CBO staff members and includes four steps: defining the health promotion goal, creating a partnership snapshot, analyzing the partnership snapshot, and developing an action plan to create a network of partners that will allow the organization to meet the targeted goal. The novelty of the partnership snapshot is that it prompts CBOs to assess partners' resources and determine what aspects of the relationships are/could be leveraged effectively. Resources are defined by the CBO and may range from granting access to space to providing access to a new or hard-to-reach population or even facilitating connections to policymakers.

Another example of explicit network development efforts comes from PLANET MassCONECT. We arranged a series of networking events for capacity-building trainees in our intervention communities and facilitated connection development both within and between the three communities where the intervention occurred. These events included additional trainings on requested topics, such as network analysis and evaluation and always included time for networking as part of the event. These activities supported our goal of building a network of KT specialists in each of the communities. This network was intended to be a sustained resource in the community long after the intervention concluded. We also wanted to take a network perspective because changing the "way of work" around EBPs is a difficult process, and staff members need support from their peers and opportunities to exchange information and resources to sustain the effort.

In addition to targeting networks, an important focus of our work has been to leverage existing networks. As mentioned, the members of the initial MassCONECT coalitions were selected because of their strength and activity. Through partnership with academics, a rich network was developed. Similarly, for PLANET MassCONECT, the team hired community health educators based in each of the three communities. These individuals were well connected in their communities and served as the face of the academic institution in the community. At the same time, they served as the face of the community in the academic institution. By hiring respected and connected staff members, we were able to build and strengthen relationships much more quickly than if the team had hired outsiders. In all of our participatory projects, our team also focuses on what is often referred to by partners as the "power of showing up." The investigators and study staff visited our three communities on a regular, almost weekly, basis at the outset of partnership development, and in-person engagement with community partners remains a part of our standard operating procedure despite staff turnover. As discussed elsewhere in the chapter, hiring local staff is also an investment in the community, a way of transferring resources by employing local people and investing in human capital by training them.

Another opportunity to encourage social capital development is through facilitating partnerships. For example, through MassCONECT, the academic team was able to link the City of Lawrence Mayor's Health Task Force with the Boston Mammography Van and fill an unmet need for mammography services. Additionally, a Mammography Working Group was created at the Task Force. This working group brought together representatives from each of the four hospitals and health centers in Lawrence with imaging centers. The partnerships were facilitated by the research project but then continued to flourish on their own.

Resource Sharing

Another key input in the PaKT framework is resource sharing. Key resources shared may include funds or other material resources, staff, and access to knowledge or individuals. Consistent with our emphasis on agreements, we plan for the sharing of funds and material resources during the grant application stage. In the series of meetings in which potential grant ideas are discussed, we also include opportunities to discuss the budget and ways in which funds can be distributed. We also plan for honoraria for partners who are engaging outside a funded partner organization, as well as stipends for travel to meetings. A great challenge often relates to the differences in funding allocation among partners. The research partners' budget is often inflated by indirect costs (the charge levied by many academic institutions to cover facilities and other expenses) as well as expenses related to formal research activities. Long-standing partners have come to appreciate the perspective our group takes to allocate as much as possible to community partners, both directly in the manner of funds that go to the organizations but also in other ways, such as directing resources into the community whenever possible. An example of this, described earlier in the capacity-building section, was the training of local survey administrators for Project IMPACT. The additional flow of resources into the community was important both in terms of sharing resources but also in generating capacity and strengthening relationships in the community.

Another important strategy within the resource-sharing approach has been the sharing of staff time. For example, with the PLANET MassCONECT project, we hired three full-time community health educators, one in each city. These individuals served as local study staff to support the program, conduct surveys, etc. on behalf of the research team, but a portion of their time was also allocated directly to a partner coalition in that community. In this other role, they provided project and programmatic support to community partners as needed. This had the advantage of further maintaining the integration of our staff members into the community. Finally, resource sharing has often included access. From a network perspective, one vital resource a network connection can provide is access to other individuals or additional resources (Lin, 2001). As an academic partner, we were often able to facilitate connections to researchers or experts in an area of interest for community partners.

Component 3: Knowledge Production and Transfer

Knowledge production is an important component of the PaKT framework and emphasizes the creation of practice-focused evidence. A participatory research process includes engagement throughout the research process, including problem definition, data collection and analysis, interpretation of results, and dissemination and application of results (Israel, Schulz, et al., 2008). The first activity (problem definition) was addressed in Component 1; we discuss the other phases of the research process here. Our engaged research process starts with the development of the research protocol and the evaluation plan. Through codevelopment of evaluation tools and plans, the key stakeholders' interests, needs, and definitions of success are incorporated explicitly. After all, there are diverse "ways of knowing" which have value to different parties (Minkler & Salvatore, 2012). In some cases, this may result in additional evaluation activities that have meaning to different parties, but the goal is to compare and contrast the variety of evaluation vehicles to determine what the broad picture looks like. This is a marked shift from traditional clinical trials methodology, in which a primary outcome is specified at the outset and success or failure rests on tests of that outcome. Instead, outcome assessment in this tradition is conducted with an emphasis on context, emphasizing assessment of what works, for whom, and under what circumstances (Pawson & Tilley, 1997). This is not to suggest that findings cannot be applied elsewhere in the field but instead that sufficient attention is paid to context to support spread of effective processes and strategies. This type of evaluation is necessary for action research, to ensure that stakeholders participate in, benefit from, and have needs met by the evaluation effort, with the goal of improving the situation.

A major challenge for leveraging KT to create change in communities is the evaluation of multilevel, systems-focused efforts. As described by McGrath (1981), the choice of study design often reflects a tension between generalizability to populations, precision of measurement related to behavior, and emphasis on measuring systems/context. Given the complexity of public health systems and the need to focus on external validity and the impacts of context and multilevel drivers, designs such as the traditional randomized controlled trial may not be appropriate choices (Luke & Stamatakis, 2012). Instead, multilevel modeling, social network analysis, agent-based modeling, geographic information systems, and mixed-methods designs may be better choices (Luke & Stamatakis, 2012; Trickett, Beehler, et al., 2011). These designs can allow researchers to disentangle patterns of interaction between heterogeneous, multilevel elements that make up the system, address context explicitly, and study nonlinear and long-term effects (Green, 2006; Schensul, 2009). The study of interactions between levels of influences is underscored by ecological approaches (Bronfenbrenner, 2005). Another important element in the design (that reflects action research and systems science) is the emphasis on continuous feedback loops so that KT activities can be refined through the life course of the effort, to adapt to changing context, new knowledge, and other inputs, with the goal of increased impact.

Mixed-methods approaches may be of particular use for assessing change in complex systems. This approach prompts collection and analysis of quantitative and qualitative data in response to research questions, with an emphasis on integrating the two types of data to develop novel and more complete understandings of the issue than possible from quantitative or qualitative data alone (Creswell & Plano Clark, 2007). This approach is particularly appropriate for efforts to create change in community settings given that new methods of creating change are being tested, and mixed-methods approaches allow for exploratory and confirmatory work to support the development of new hypotheses and the subsequent testing of those hypotheses. Additionally, mixed-methods approaches allow for the integration of end users' voices (Palinkas, Aarons, et al., 2011), which is vital for participatory, action-oriented approaches. Drawing on diverse data sources is also important for incorporating context into the assessment, which is an important driver of success (Berwick, 2008) and has been a major challenge for KT initiatives. Finally, mixed-methods approaches support development of a wide range of dissemination products that can meet the needs of the diverse stakeholders and consumers of project-related products.

For Project IMPACT, the research team developed a survey that focused on media use, perceptions of social determinants of health, and general health and well-being. Our partners noted that they were engaged in a series of obesity prevention activities but were unable to find necessary local data to support their efforts. Through collaboration, a series of obesity-related items were added to the questionnaire. This resulted in some items of interest to the research team being dropped from the survey to avoid increasing respondent burden. Preliminary obesity-related data were shared with community partners in a timely fashion, though scientific publications took much longer to produce.

Once data have been collected, we leverage the strengths of team members to analyze the data. Typically, because of resource and capacity constraints, the academic partners on the team shoulder the responsibility of analyzing the data. Then, the C-PAC participates in the interpretation of results for all key studies and relevant minor studies. As noted above, we take an inclusive approach for all major study publications and solicit participation from all C-PAC members in some format. Similarly, the C-PAC members jointly determine the appropriate dissemination vehicles.

The MassCONECT project provides an example of the benefits of engaging in evaluation in a participatory manner. As noted above, we conducted a social network analysis to assess network development and its impact for this infrastructure-building grant. The stimulus to use this analytic method came from a subset of the community partners on the C-PAC. They subsequently participated in the development of the research instruments, guided fielding of the study, and participated in the analysis, interpretation, and dissemination of data. These individuals found the tools of network analysis extremely useful for their work with coalition-building and partnership development and wanted to share this work with other colleagues in their communities. To support this goal, the group conducted a daylong training on social network analysis targeted at CBO staff members. This introductory workshop focused on potential applications and prompted the group to create the AMP tool, described earlier, which provides a structured method for CBOs to examine the resources they have/need within their organizational partnerships.

For academic partners, at the end of an intervention, typical dissemination vehicles often include scientific presentations and publications. However, these vehicles are not necessarily relevant or accessible to community partners, who may determine additional channels that can effectively reach intended audiences (Minkler & Salvatore, 2012). For the MassCONECT project, we created a Dissemination Working Group to support creation of useful products. A popular format for dissemination was a two-page "brief" that summarizes a project activity. For example, we created a brief to share results of the network analysis mentioned above.

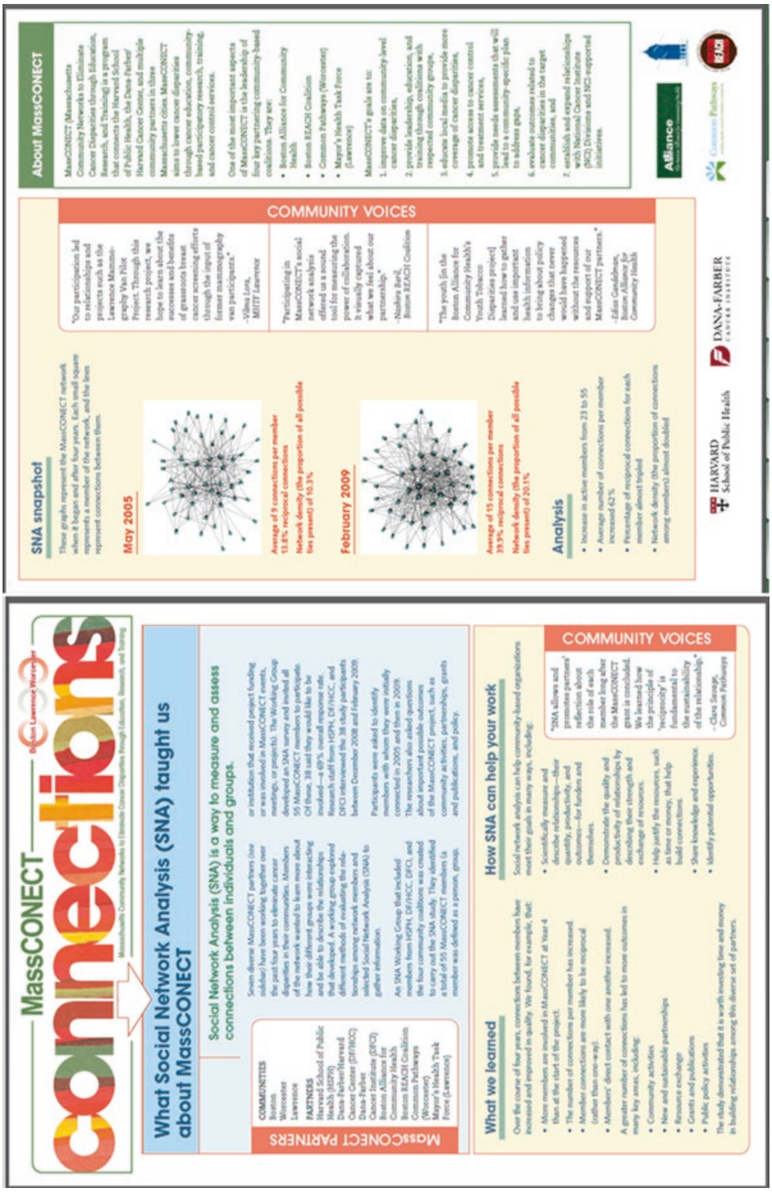
The brief was written for CBO staff members and contained three sections, as seen in Fig. 23.3. The first section provided an overview of the project. The second section provided highlights of the study. The third section emphasized the ways in which the findings might influence practice. Professional writers transformed academic findings into accessible, practice-focused information, presented in an appealing and easily digestible format. Another popular format was a poster. The academic team created a poster template, including background information about the project. Then, partners were able to adapt the template to suit their needs, which often included local conferences. A generic version of the poster also made the rounds in the three communities, displayed at venues for the public, such as public libraries. The poster template, as well as all project training materials, and additional content were put onto a CD and distributed to partners. Another strategy that has been effective is the joint presentation of results by academic and community partners at local and national events. Finally, the coproduction of journal articles has been another important strategy to ensure that the voices of diverse stakeholders are shared. Ultimately, the reach and application of the information contained in briefs, posters, and presentations are the markers of interest, and these provide an important area for future study.

Iterative, Action-Oriented Cycles

A broad goal for this approach is infrastructure development to create multilevel, ongoing change in communities that improves health and reduces disparities. As seen in Fig. 23.1, the key process inputs and a set of infrastructure impacts are linked by iterative cycles. Drawing on the spiral metaphor from Lewin (1946), evaluation is an ongoing process that leads to incremental improvements. For this reason, the framework includes the Plan-Do-Study-Act cycles (important feedback loops) so that the process inputs and infrastructure impacts work in concert to create a set of system-level changes driven and chosen by stakeholders and beneficiaries. Consistent with a systems science approach, planning is not something that simply happens at the outset of a program. Instead, continuous feedback loops allow for constant reevaluation and tinkering with strategies and inputs, and system action is understood to be a series of events over time (de Savigny & Adam, 2009; Trochim, Cabrera, et al., 2006). This continual adjustment reflects the importance of knowledge management and transfer to improve organizations' ability to keep up with and react to rapidly changing environments (Senge, 1990).

Infrastructure Impacts

The multilevel assessment captures progress toward the goal of creating change at multiple levels to support the use of KT to create change in communities. At the individual level, the framework highlights impacts among diverse stakeholders, such as researchers, practitioners, and/or other external change agents, depending on the project. An important impact is capacity for KT or the ability to generate and incorporate knowledge (Canadian Institutes of Health Research, 2004). In the tradition of capacity building, the goal is to support the ability to address current and future health problems (Hawe, Noort, et al., 1997). For practitioners, this may include understanding the value of the evidence base broadly as well as identifying needs, finding partners, choosing evidence-driven targets for action, adapting programs to local needs, and evaluating the results. For researchers and change agents, improved capacity may relate to deeper understanding of partnering communities, realities of practice, and realistic solutions (Glasgow & Emmons, 2007; Green, 2008). These outcomes will have important impacts on participatory processes, an example of the iterative interactions contained within the framework. The measures of capacity will shift based on the target of the effort and may reflect participatory decision-making



MassCONECT connections

What Social Network Analysis (SNA) taught us about MassCONECT

MassCONECT PARTNERS

What we learned

How SNA can help your work

COMMUNITY VOICES

SNA snapshot

May 2005

February 2009

Analysis

About MassCONECT

Fig. 23.3 Dissemination brief created to share results of MassCONECT social network analysis regarding markers of success. At the same time, stakeholders must be increasingly sensitized to issues related to health disparities and ideas of social determinants of health. After all, the causes of health disparities are myriad and complex. Moving beyond attention to healthcare access and individual behavior choices, researchers have identified key social determinants of health, such as race/ethnicity, income, education, social networks, neighborhood conditions, work environments, and social policies, that drive health outcomes and potential inequalities (Berkman & Kawachi, 2000; Phelan, Link, & Tehranifar, 2010). Although this conversation has taken root in academia, this perspective needs to be shared with other stakeholders to prompt attention to broad, multilevel change. One example of this conversation outside the academy are the workings of the World Health Organization's Commission on Social Determinants of Health – one way of using the knowledge transfer to promote policymaking among nation states (WHO Commission on Social Determinants of Health & World Health Organization, 2008).

Other individual-level impacts include increased application of research-based knowledge among knowledge users. In other words, success is defined as the application of scientific knowledge in practice settings. Measures that assess efforts to spread that knowledge are useful process indicators but are not sufficient to demonstrate success in this realm (Canadian Institutes of Health Research, 2004; Straus, Tetroe, & Graham, 2009). Finally, there are a range of individual-level facilitators and constraints of engaging in a given KT effort, such as their knowledge and beliefs, self-efficacy for required activities, identification with the organization, and other personal attributes (Damschroder, Aron, et al., 2009).

At the organizational level, we are prompted to assess networks between and within the range of key organizations and institutions in the system, which may include local agencies from a range of sectors, government entities, and others deemed vital to creating multilevel, sustainable change. The goal is to create strong, productive networks that include partners from multiple levels/sectors and support collaboration and collective action. As noted in the discussion of the Community Leadership Study from Project IMPACT, part of the goal for network development is to effectively engage with power structures, such as policy- and decision-makers. Through such network development, the flow of evidence and resources between key stakeholders can be improved (Canadian Institutes of Health Research, 2004).

As demonstrated earlier, social network analysis can be a useful tool by which to evaluate infrastructure development. Network analysis allows for assessment of relationships between parties of interest, such as members of a coalition or community group, as well as the impacts and outcomes of these relationships (Scott, 2000; Valente, 2010; Wasserman & Faust, 1994). Despite the potential utility of using network analysis to evaluate and intervene on community partnerships, this application is still underutilized for this purpose (Provan, Veazie, et al., 2005). A detailed description of potential measures is beyond the scope of this chapter. Instead, we highlight key questions of interest for building networks to support KT in communities, including the following: identifying central (or key) network members, assessing ways to leverage central members' position and power (such as access to external resources and influence on other members to support KT), determining whether or not relationships are formalized between organizations and thus sustainable, assessing trust among members and strength of relationships, examining subgroups of members and opportunities to mobilize them, identifying key benefits and drawbacks of partnership, and assessing the impact of external influences on the network (Provan, Veazie, et al., 2005; Shortell, 2004). By assessing networks, organizations can proactively shape and structure networks to reach their goals and increase impact.

An example of using social network analysis for assessing progress with partnerships comes from the MassCONECT project (Koh, Oppenheimer, et al., 2010). Again, the goal of this program was to develop an infrastructure to support collaborative research and practice efforts targeting cancer disparities in Boston, Lawrence, and Worcester, MA. Key stakeholders included community coalitions, researchers, policymakers, and others. At the end of the fourth year, the team conducted a social network analysis as one method of documenting the impact of the program. We studied the whole network of MassCONECT participants and were particularly interested in the impact of intersectoral connections or the relationships between network members from different sectors, such as CBOs and policymakers. The analysis demonstrated an increase in connections within the network, as well as the number of intersectoral connections and the extent to which intersectoral connections were reciprocated. Intersectoral connections were positively associated with outcomes of interest to diverse partners, including community activities, grants and publications, and policy engagement (Ramanadhan, Salhi, et al., 2012). Findings such as these underscore the importance of multilevel and multi-sectoral connections but also highlight the tremendous investment required to build and sustain such relationships.

At the organizational level, it is also important to assess impact in terms of organizational facilitators and constraints, such as the organization's structure, communication patterns, networks, culture, creation of internal systems for KT, climate for change, and readiness for change (Damschroder, Aron, et al., 2009; Fixsen, Naoom, et al., 2005). As with the individual level, engagement in KT activities is another important marker of infrastructure change. Examples of activities at this level include using data for programming and policy development, supporting policy changes, and interacting with the media. KT activities must also be assessed in terms relevance of solutions and creation of local change (Brydon-Miller, Greenwood, & Maguire, 2003).

At the community level, an important impact is the capacity of the community to use KT to improve health. The concept of community capacity includes (a) the characteristics (with an emphasis on assets) of communities that impact their ability to identify and address health and social issues of interest and (b) the capacity and resources to create change at the individual and community levels to support public health goals. In this application, community capacity specifically relates to the use of KT activities to improve health. Important components include citizen participation, leadership, skills, resources, networks, sense of community, understanding of community history, community power, community values, and critical reflection (Goodman, Speers, et al., 1998). Consistent with participatory and action research perspectives, we expect to see increased community capacity for advocacy and generating system changes that reduce disparities (Viswanathan, Ammerman, et al., 2004). Additional markers of interest may include social cohesion and social influence, trust, reciprocity, social capital, civic engagement, collective efficacy, and empowerment (Minkler, Wallerstein, & Wilson, 2008).

Community mobilization is another important community-level infrastructure impact. Mobilized communities can leverage existing social structures and resources to create change with varied goals, including increased access to services, improved health outreach, reformed policies, and a more health-promotive environment (Bracht & Tsouros, 1990). Mobilization around a particular set of health-related goals or in support of a population subgroup can provide the necessary support for taking action based on research evidence. Finally, as described earlier, a subset of community-level outcomes relate to development of necessary intersectoral networks, particularly connections with policy- and decision-makers who can support the translation of the community's agenda into change. Strengthening community capacity to change public agenda on health is an important strategy in mobilization such as we did in IMAPCT.

Long-Term Outcomes

The goal of the PaKT framework is to support systems-level change that has an impact on both health outcomes and health disparities. Thus, there are two types of long-term outcomes in this framework. One set of long-term outcomes includes community health impact, which can include markers such as community members' satisfaction, function, and symptomatology (Proctor, Silmere, et al., 2011). In addition to improved health, reduction of health disparities is an explicit goal of the processes described in the framework. Consistent with the iterative nature of the framework processes, it is understood that as disparities and underlying causes are addressed in relation to one issue, others will arise, prompting the next cycle of action in the community. As evidenced by the community heart health trials, these outcomes may require lengthy follow-up to demonstrate change.

The other set of outcomes are related to systems change, particularly within organizations and communities. These changes are expected to support sustainable efforts to change communities and improve health, including addressing social determinants of health (Wallerstein, Oetzel, et al., 2008). At the organization level, an important outcome is the institutionalization of KT approaches and activities in practice settings. These activities will create changes that improve health and address disparities and will sustain momentum in communities for continuous improvement. In this way, communities will be expected to yield the benefits ascribed to KT practices, including greater health impact and more efficient use of resources (Brownson, Baker, et al., 2011). Other important organization-level outcomes include networks to support KT activities. These networks must include a diverse group of engaged and committed stakeholders to providing the multilevel support required for sustainable change. The network structure can be a resource that is developed and strengthened as a community asset. The final set of long-term outcomes, found at the community level, focus on action to improve health. Through an engaged and participatory process, communities are expected to be able to identify and address pressing issues, leveraging the best available evidence from external and internal experts.

Conclusions and Next Steps

The PaKT framework offers a framework for a systems-focused, action-oriented, participatory approach to KT in community settings to drive multilevel, collaborative action for social change. The emphasis on institutionalized participation, investment in communities, and knowledge production and transfer is expected to lead to sustainable systems change to support the ability of communities to leverage existing knowledge to tackle health problems. Consistent with the participatory approach described, the framework is not highly prescriptive. Instead, it acknowledges the organic, evolving nature of engaged social change projects and highlights key areas for consideration. Those applying the framework are charged with adapting as needed to suit the change effort at hand.

Given the high-level, process-oriented nature of the framework, it can be utilized as a complement to other frameworks for the study of KT. There are over 60 frameworks and models addressing knowledge translation (Tabak, Khoong, et al., 2012). Many of the models assess the dissemination and/or implementation of a specific program or strategy in a defined setting, which is often clinical. The PaKT Framework provides a complementary perspective, placing a given study or implementation effort in the context of a strategic, long-term effort to create change that is driven and owned by those who will ultimately sustain the effort and benefit from it.

The framework highlights the intense investments required to create social change in communities. Although the examples presented in this chapter mostly come from research settings, a major strength of the framework is that social change efforts driven by others (whether internal or external change agents) can utilize many of the same principles. The framework highlights key areas for development to support the creation of change in communities to improve health. First, a systems approach is vital, which impacts not only the ways in which change efforts are constructed but also how they are evaluated. The use of multilevel assessments, systems modeling, network analysis, community leadership analysis, and mixed-methods approaches represents an important shift away from highly standardized randomized control trial designs, which are likely inappropriate for assessing the far-ranging impacts of systems change efforts. These methods of evaluating interventions are also an important way to gauge success with intermediate outcomes and project potential impacts on long-term outcomes. Second, a mindshift is needed to move away from external change agents conducting discrete projects in communities to long-term engagement of change agents (whether internal or external) with diverse stakeholders (from multiple sectors and with different levels of power). Such engagement not only will address existing barriers to creating practical, sustainable solutions but will also address the high cost of large-scale change efforts. Coordinated allocation/redirection of community resources provides an opportunity to engage in projects that would be far beyond the scope of a small number of organizations. As seen earlier, coalitions and networks of engaged stakeholders are key to the development of coordinated action. As highlighted in an IOM report on prevention-oriented interventions, the future of the field lies with collaborative development and execution of multilevel interventions (Smedley & Syme, 2000).

Training of researchers, change agents, and practitioners who can engage in a participatory KT process will address some of these challenges. On the research side, training in participatory approaches is limited, but steadily increasing, particularly with the recommendation by the IOM that CBPR be included as a core public health competency. As a complement, on the change agent and practitioner side, we have provided extensive details in an earlier section about the promise of building capacity among community partners to engage with scientific evidence more actively and ensure that available knowledge benefits their communities and constituents.

Conclusion

KT efforts are widely acknowledged as an essential part of promoting social change. While the mechanisms of knowledge transfer and utilization vary, resorting to classic "top-down" approaches to disseminate and implement evidence-based strategies and promote social change is unlikely to yield effective outcomes. It is increasingly recognized that involving the end user of the knowledge generation process may be a more effective approach. Leveraging the long and powerful history of community organization and engagement (including current manifestations as CBPR and other participatory approaches to research) presents an important opportunity to increase the impact of KT efforts. To this end, we propose the participatory knowledge translation (PaKT) framework, which emphasizes institutionalized end user participation, investment in human and social capital with resource sharing, and explicit end user engagement in knowledge generation and transfer as the means to develop sustainable systems to improve health and address disparities. The framework emphasizes the pacts made among stakeholders to address complex public health problems collectively and is intended to serve as a complement to top-down approaches. A return on investment in billions of dollars in research and developmental aid will come to naught if the change promoted lacks community buy-in and is not sustainable. This is particularly important in population health promotion where the disease burden is faced disproportionately by vulnerable groups. Though initial costs and timelines may be larger than traditional endeavors, such alternative models that promote infrastructure development and sustainability show great promise for creating effective and efficient change in the long run.

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24

Using Genomic Knowledge to Improve Health Promotion Interventions in the Developing World

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Introduction

Completion of the Human Genome Project has informed rapid advancements in technologies and discovery in the last decade. These advances have generated optimism that accumulating genetic discovery could be used to improve disease prevention efforts globally with many forecasting that affordable health applications will be available in the near-term (Burke, Burton, et al., 2010; Collins, Green, et al., 2003; Hingorani, Shah, et al., 2010). Much of this optimism rests on the potential to identify disease susceptibility early in life and the possibility to target interventions to *prevent* the occurrence of many health conditions. Indeed, the future is envisioned where health promotion applications could be targeted to improve health behaviors based on genetic susceptibility. However, the feasibility of these developments and the time frame for their realization continue to be widely debated (Burke, Burton, et al., 2010; Hingorani, Shah, et al., 2010).

Improved understanding of gene-disease associations indicates that most disease arises from the interrelationships of genes with each other and with the environment (including health-related behaviors) (Mabry, Olster, et al., 2008). Here we will refer to this perspective as "genomic." It also is widely agreed that the translation potential of most genetic discovery has yet to be established (Burke, Burton, et al., 2010; Hingorani, Shah, et al., 2010; McBride, Bowen, et al., 2010a). Thus, the immediate charge going forward for applying new genomic knowledge to health promotion interventions will be agnostic consideration of whether derived innovations add value to existing intervention approaches. This will be of particular importance in global health contexts with constrained resources and diverse social and cultural contexts (Daar, Singer, et al., 2007).

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Current Knowledge of Genetics and Role of Genetics in Health

The past two decades have witnessed impressive accomplishments in genomic discovery. For example, completion of the sequence of the human genome has now established that a remarkable 99% of the human genome is shared across individuals. Thusly, it is the 1% of unique code that accounts for most of the observable differences between individuals in height, skin and hair color, and innumerous other traits. The majority of this variation is accounted for by differences between individuals in code at specific sites in the genome, that is, single nucleotide polymorphisms or "SNPs." Genome-wide association studies (GWAS) have shown that common SNPs (>5% prevalence) are associated with the development of many common chronic diseases (such as diabetes, heart disease, high blood pressure, asthma). However, each of these SNPs individually conveys only small to moderate increases or decreases in disease risk (odds ratios 1.2–1.4) (Hindorff, Sethupathy, et al., 2009). Indeed, risk for common chronic diseases is influenced by many different genes (i.e., polygenic) interacting with each other and the environment (Frazer, Murray, et al., 2009; Mabry, Olster, et al., 2008).

Consider the example of the exceedingly high prevalence of Type 2 diabetes observed among Pima Indians. Yet, the prevalence of Type 2 diabetes is fivefold higher among Pima Indians living in the USA compared to those living in Mexico (Schulz, Bennett, et al., 2006). The two groups share common ancestry and a similar gene pool that is distinct from other Native American populations. This disparity in risk aligns with significant differences in lifestyle factors associated with weight (i.e., diet and physical activity) and the substantially higher prevalence of obesity among Pima Indians living in the USA compared with those living in Mexico.

Recent evidence is revealing how these environmental exposures "get under the skin," that is, interact with genes to influence disease development. Current evidence supports that exposures encountered in the environment and over a lifetime prompt chemical processes in the genome that turn gene expression on and off (Dolinoy & Jirtle, 2008). Emerging evidence is showing that these "epigenetic" processes are highly responsive to a broad array of environmental exposures that include health behaviors such as diet, physical activity, tobacco, and alcohol use (Mabry, Olster, et al., 2008; Wild, 2012). Add to this that the plasticity of one's "epigenome" is especially heightened at some stages of development including prenatally and in early childhood. Thus, environmental exposure may exact greatest harm and confer greatest during these periods.

Epigenetic modifications in gene expression can be passed down intergenerationally such that the influences of exposures on one generation can be conveyed to children and grandchildren (Adamo, Ferraro, & Brett, 2012). So-called natural experiments show how maternal exposures can influence epigenetic processes in the fetus and increase the offspring's disease risk in later life (Vaiserman, 2011). The Dutch Famine (1944–45) prompted by an embargo on the transport of food supplies in World War II. The Dutch population experienced a two-thirds drop in daily calories. This "Hunger Winter" was sandwiched between periods of optimal food availability. In addition, to a concordant drop in birth weight among babies born during the time frame of the famine, this cohort also experienced an increased likelihood of developing metabolic and heart disease later in life. Epigenetic explanations for this phenomenon build upon "mismatch theory" (Jackson, Niculescu, & Jackson, 2013). According to this line of thinking, the fetus's highly plastic epigenome has the ability to "retune" its metabolic needs to respond to anticipated food scarcity based on the mother's experience of famine and its effects on the uterine environment. Indeed, evolutionary pressure selects for those individuals who can adapt gene expression patterns (via epigenetic mechanisms) to a fluctuating environment. However, when the infant is born into an environment of privation (i.e., a nutritionally rich environment that characterized the time after the Hunger Winter), there is a mismatch in which the metabolic adaptations are not well suited to maximize fitness. This increases risk for pathological metabolic responses to adequate nutrition, responses that accrue over a lifetime and can lead to metabolic and heart disease.

With growing understanding of the complexity of the relationships among genes, epigenetics, environment, behavior, and health, there is optimism that genomic information could be applied to prevent and manage disease and promote health (Hingorani, Shah, et al., 2010). As knowledge of gene by environment increases, consideration of behavioral influences on gene expression and disease development will be the norm, rather than the exception. Genomic information is now being considered for use in risk communications to motivate individuals and families to take preventive actions to reduce disease risk (McBride, Bowen, et al., 2010a), for guiding screening schedules and treatment decisions among patients at high risk for a variety of health conditions (McBride, Koehly, et al., 2010b; Myers, Manne, et al., 2011), as well as for chemoprevention and surgery-based prevention options (Burn, Gerdes, et al., 2011; Rebbeck, Friebel, et al., 2004). However, it is important to note that utility has not been established for all new genetic information. For example, it has been argued that the utility of common disease genetics, an arena with the greatest potential for public health benefit, is years away from being demonstrated (Haga, Khoury, & Burke, 2003).

Genomics and LMIC

Skepticism is particularly high in applying genomic technologies in low- and lower-middle-income countries (LMICs) (Howitt, Darzi, et al., 2012), countries categorized by the World Bank to have gross national incomes ≤4035 dollars per capita (Price, 1976). As of 2008, over 100 countries met the criteria for LMIC. The list includes most of the continent of Africa, Central America, and East Asia (International Congress for School Effectiveness and Improvement, 2011). The World Health Organization (WHO), the United Nations, and other international organizations have generated several consensus reports to identify "grand challenges" and priorities for applying genomic advances to disease prevention in LMICs (Dandara, Adebamowo, et al., 2012). For example, over a decade ago, Singer and Daar (2001) recommended that genomics-based biotechnologies should be harnessed to improve global health equity. Most recently, the World Health Organization initiated plans for a list of policy and research priority target areas for genomics-informed innovations. These priorities included consideration of the ease of delivery of interventions in resource-poor clinical settings and the potential impact of genomics-based interventions for disease reduction and improving health equity (Singer & Daar, 2001).

However, these consensus-building efforts have heavily emphasized prevention of communicable diseases. For example, consistent with the World Health Organization's priorities, considerable effort already is underway to evaluate whether new understanding of the genomes of insect vectors can be used to develop vaccines for malaria (Prachi, Biagini, & Bagnoli, 2012). Similarly, increased evidence is suggesting the heritability of susceptibility to *Chlamydia trachomatis* infection, a sexually transmitted disease prevalent among adolescents in some LMICs. This research is informing new vaccine development and targeted prevention activities (Bailey, Natividad-Sancho, et al., 2009; Obasi, Balira, et al., 2001). Optimism about extending these approaches to prevent other communicable diseases also is high (Robinson & Hort, 2012).

Steep increases occurring in noncommunicable diseases worldwide, particularly chronic diseases (e.g., Type 2 diabetes and heart disease), are prompting the call for innovation in health promotion interventions (Yach, Hawkes, et al., 2004). Sixty-three percent of global mortality is from cardiovascular disease, cancer, chronic respiratory disease, and diabetes, of which 80% was in LMICs (Robinson & Hort, 2012). In LMICs, cardiovascular disease will kill five times more people than HIV/AIDS (World Health Organization 2012). By 2030, it is estimated that these chronic diseases will be the leading causes of death in LMICs (Robinson & Hort, 2012). Experts point to the globalization of industry including fast food, soft drinks, and the increasing reliance on motorized vehicles that together are shifting diets and activity patterns among those living in LMICs (Daar, Singer, et al., 2007).

Individuals in LMICs also develop chronic diseases at younger ages and die earlier than those living in high-income countries (Robinson & Hort, 2012). Increasingly, there is a call to maximize prevention efforts by targeting pregnant women and young children in LMICs, for promotion interventions (Hanson, Gluckman, et al., 2012). If these prevention efforts are to succeed in LMICs, applications of new genomic knowledge must consider and align with health behavior change interventions (Howitt, Darzi, et al., 2012; Yach, Hawkes, et al., 2004).

In this chapter, we describe how emerging genomic knowledge could lead to improvements in health promotion interventions that target risky health behaviors in the context of LMICs. We focus on two possible potential opportunities for genomics-informed health promotion efforts in LMICs: (a) risk stratification and health resource allocation and (b) targeted risk communications that heighten motivation to adhere to behavioral recommendations. We also consider these opportunities against the backdrop of social challenges presented by LMICs (Howitt, Darzi, et al., 2012; Yach, Hawkes, et al., 2004). To do so, we draw from the experiences of an ongoing program of research among genetically high-risk families in rural Ethiopia. We conclude with recommendations for future formative and comparative effectiveness research to consider potential opportunities for applying new genomic knowledge to health promotion globally. We provide working definitions of the terminology we use in Table 24.1.

Table 24.1 Key terms

Gene variation: the genetic differences within and among populations
Genetic variant: a difference in DNA code at a single location of the genome and often referred to as a "single nucleotide polymorphism" (SNP)
Genome sequencing: a laboratory process that determines the precise order of the complete DNA sequence of a person's genome at a single time
Stratification: where individuals are grouped based on genetic risk (e.g., family health history or genetic variant test results)
Targeted intervention: using a group characteristic to inform what type of intervention is provided
Genetic determinism: belief that genes determine, to the exclusion of environmental influences, a health outcome
Literacy: a complex set of abilities to understand and use the dominant symbol systems of a culture for personal and community development

Applying Genomics-Informed Risk Stratification in the Context of LMICs

Rose in his seminal article "Sick Individuals and sick populations" (Rose, 2001) was among the first to consider the relative value of targeting interventions to those at highest risk (often termed a clinical or high-risk approach) versus intervening with an entire population, the majority of whom would be at average risk (often termed a public health approach). The question Rose considered is whether there is greater public health benefit in achieving substantial risk reduction within a proportionately small, high-risk subgroup or to achieving modest health improvement (e.g., small blood pressure reduction) across an entire population.

The advent of improved multivariable risk algorithms is prompting new thinking that there may be utility in both approaches with the decision resting in the context under consideration (Ahern, Jones, et al., 2008; Zulman, Vijan, et al., 2008). For example, high-risk approaches may not be optimal when risk assessment must occur in clinical settings. However, the concern is that under these circumstances, targeted interventions may not reach those with inadequate access to health care (Frohlich & Potvin, 2008). On the other hand, public health interventions are highly in variable in cost, efficacy, and potential for adverse effects, all factors that influence their benefits (Ahern, Jones, et al., 2008; Zulman, Vijan, et al., 2008). Paradoxically, in contexts with limited resources, a low-intensity approach that is less expensive but also less efficacious may not be preferable to targeting a more effective intervention to those at higher risk (Frohlich & Potvin, 2008; McLaren, McIntyre, & Kirkpatrick, 2010; Zulman, Vijan, et al., 2008).

The post genomic era offers the capability to use genetics to guide risk stratification. Genomic research conducted internationally tells us that populations are not genetically homogeneous (Zimmern & Khoury, 2012) and accordingly, that disease risk is not equally distributed within a population. A study conducted in the USA (Williams, Hunt, et al., 2001) is frequently cited in which 14% of families ("high-risk families") accounted for more than 70% of early coronary heart disease (CHD) and 11% of families accounted for 86% of early strokes. Consider this scenario was occurring in an LMIC setting with limited health resources. Consider also that a portable approach to risk assessment is available that accurately identifies those at high risk, and adherence to moderately intensive behavioral recommendations (e.g., dietary restrictions, cholesterol-lowering pharmacotherapies, shorter screening intervals) has been shown to be efficacious in reducing risk. Given these considerations, targeting an intervention to high-risk families, particularly the children, arguably could be more effective than a population-based approach. Moreover, risk stratification will identify groups at especially low risk who will benefit less from some health promotion efforts.

Such stratification could be particularly useful in LMICs such as those in Africa, where the level of genetic diversity is exceptional (Tishkoff & Williams, 2002). Sub-Saharan Africa, for example, comprises 46 countries with enormous cultural, linguistic, geographic, and genetic diversity. This diversity of population genetics along with varying environmental exposures increases the likelihood that LMIC populations could be effectively stratified into risk categories, and the value of targeting interventions could be evaluated rigorously. However, these assertions rest on the assumption that reliable and valid risk assessment tools exist.

LMICs present unique opportunities and challenges for applying new genomics knowledge to health promotion that must be considered. A recent Lancet report (Howitt, Darzi, et al., 2012) outlines the complex nexus of infrastructure in which health promotion must occur in LMICs. Over two billion people lived on less than $2 a day (Howitt, Darzi, et al., 2012). Additionally, the number of health-care workers is extremely limited, with sub-Saharan Africa which accounts for 11% of the world's population, and 24% of global disease burden has only 3% of the world's health-care workers (Howitt, Darzi, et al., 2012). Intervention approaches that are portable and inexpensive, so-called frugal technologies, are required in these settings (Howitt, Darzi, et al., 2012). Concerns are that genomic applications will be too costly to be feasible (Burke, Burton, et al., 2010).

In the next section, we suggest a few examples of currently available genomics-based risk stratification tools, and we consider their potential utility for health promotion in LMICs and the challenges they present in these social and cultural contexts.

Potential Uses of Available Genomic Applications

Chronic disease risk clusters within families. Indeed, as an intergenerational set of related members, families share genetic, environmental, social, and behavioral factors. One genomics application that is widely available now is the Family Health History (FHH) assessment. While there is a considerable range of applications used to assess FHH, in principle, FHH comprises a systematic characterization of disease occurrence and age of onset among first- and second-degree blood relatives. Almost 60 studies have shown FHH to be predictive of disease onset across a variety of health conditions (Berg, Baird, et al., 2009; Qureshi, Wilson, et al., 2009). An individual's risk is highly predictive of disease risk for all members of a family (Claassen, Henneman, et al., 2010; Uusitupa & Tuomilehto, 2011; Yoon, Scheuner, & Khoury, 2003). FHH could be regarded as a "frugal technology" for identifying high-risk families.

However, an AHRQ review conducted in 2009 found that despite the ubiquity of its use, there were few examples and sparse empirical evidence concerning whether FHH assessment prompts individuals to adopt preventive behaviors (Berg, Baird, et al., 2009; Heideman, Middelkoop, et al., 2011; Qureshi, Wilson, et al., 2009). Like any risk assessment, the usefulness of the FHH also depends on the accuracy of the information obtained. In the case of FHH, individuals must be able to accurately report the occurrence and age of onset of diseases in their family members. However, the advantage of interview-based FHH is that it can be portable and adapted to the context.

For example, in the study of Utah families with coronary heart disease, Williams and colleagues (Williams, Hunt, et al., 2001) engaged students in health education classes to take home a FHH assessment for the family to complete. Students as part of the assignment transferred the FHH data to machine-readable data forms. The estimated cost of these assessments was $6.50 per survey. In the same way, lay health workers could be trained to collect FHHs. Thus low-cost administration of FHH assessment is feasible. Moreover, new applications of FHH are now being facilitated by smart technology where interactive computer increases the speed and ease of data collection. These innovations also could lower cost and extend their reach.

A few studies conducted in the USA have used FHH assessments with low-literacy populations to discuss inherited disease risk for chronic diseases (Ashida, Wilkinson, & Koehly, 2012; Kaphingst, Lachance, et al., 2011). Results suggest that risk reports generated using these tools are understandable to low-literacy target groups (Kaphingst, Lachance, et al., 2011) and feasible for use in low resourced settings (Ashida, Wilkinson, & Koehly, 2012). However, despite the strong predictive value of FHH in disease risk, and portability of the applications, FHH information has been underutilized for risk screening in public health practice (Berg, Baird, et al., 2009).

Genetic testing also is being used to characterize disease risk. Genetic tests for rare genetic mutations that cause familial cancer syndromes have been available since the mid-1990s. However, an ever-growing number of common gene variants associated with a host of common health conditions also are now being identified. Currently there are over 2000 genetic tests available related to health outcomes (National Library of Medicine, 2013). Some of these are panel tests that test for hundreds of genetic variants, and feedback is given to individuals on their disease risk and response to pharmacotherapies (Bloss, Darst, et al., 2011). These studies are also providing insight into how genetic variation may influence disease susceptibility and whether individuals with specific gene variants are more reactive to environmental exposures (Gilliland, 2009).

The availability of genomics-based risk information has raised concerns about whether the public will be able to accurately comprehend the meaning and limitations of this information. Concerns have been particularly heightened for genetic risk information related to common chronic disease where risk estimates will convey relatively low probabilities (Lea, Kaphingst, et al., 2010). Despite these concerns, there also has been considerable optimism that the high degree of personalization inherent in genetic risk information will make it especially salient to recipients and as such likely to motivate efforts to reduce risk.

Offerings of genetic testing in an array of contexts have evaluated whether individuals can understand the implications of having a risk variant of a single gene (McBride, Halabi, et al., 2000; Sanderson, Humphries, et al., 2008; Smerecnik, 2010) and having variants for multiple genes (Kaphingst, McBride, et al., 2012). Measures of comprehension have differed across these studies, ranging from assessments of whether an individual can recall results accurately (Lipkus, 2007) to indicators of misunderstanding reflected by attitudes endorsing genes as sole determinants of health (Smerecnik, 2010). These studies are consistent in showing that when evidence-based communication strategies are used and consideration is given to the literacy level of the target audience, lay audiences can understand the implications of genetic risk for common diseases. Studies showing the best outcomes in comprehension have used strategies including pictorial renditions of risk estimates (Lea, Kaphingst, et al., 2010), metaphors to convey the interplay of genetic susceptibility and exposure (McBride, Halabi, et al., 2000), and written material geared to the fifth grade level of literacy (Kaphingst, Lachance, et al., 2011).

Two systematic reviews have considered the evidence base concerning whether providing genetic risk information increases motivation and prompts concordant behavior change (Marteau, French, et al., 2010; McBride, Koehly, et al., 2010b). Both conclude that there is little evidence to support the assertions that genetic risk information alone will prompt behavior change. However, each also describes the numerous limitations of the research to date. By and large, most of the studies have targeted cigarette smoking, an addictive behavior. The study samples have been relatively small, and baseline levels of motivation for behavior change have been high in the targeted samples. Participants have been older individuals who are already experiencing health outcomes that are behavior-related. One future direction encouraged for this nascent field is to evaluate genetic risk communication with target groups such as young families where motivation levels for behavior change are low, and parent-child shared risk could be leveraged to motivate behavior change (McBride, Bowen, et al., 2010a).

It also is noteworthy that the common genetic variants identified in these studies each alone account for only modest increases in disease risk (e.g., 10–40%) (Frazer, Murray, et al., 2009). However, it is forecast that in the future these variants in aggregate could identify subgroups who are at substantially increased or decreased disease risk (e.g., as much as 2–5 fold). The rapid decrease in cost of such testing is also prompting efforts to consider whether integrating genetic variant testing with existing risk assessments including FHH could add value to risk stratification and inform targeted health promotion efforts (Pharoah, Antoniou, et al., 2008). Advancements too in technology enable genome-wide assessments to be conducted using saliva samples (without requiring refrigeration). Such developments further increase the feasibility for using genetic testing to assess disease risk in rural and often remote field settings that characterize LMICs.

Potential Challenges Presented by LMIC Contexts

The social-cultural context of LMICs presents numerous challenges for health promotion efforts. However, two key challenges quickly come to the fore as we consider evaluating whether integrating genomics-informed risk stratification and targeted risk communications could increase the effectiveness of health promotion interventions. First, widespread illiteracy, common in most LMICs, will present sizable communication challenges. Second, misperceptions about genomics (e.g., beliefs that such conditions are unpreventable) could foster social distancing and other stigmatizing behaviors and undermine adherence to behavioral recommendations. These challenges operate at multiple levels of influence to create a nexus of barriers that must be addressed in genomic translation research. Each of these challenges is discussed in turn below.

Literacy Challenges

The challenges of promoting genetic literacy in countries with *high* literacy rates are well documented (Pearson & Liu-Thompkins, 2012; Smerecnik, Mesters, et al., 2008; Syurina, Brankovic, et al., 2011). Thus, the challenges for promoting genomic literacy in LMICs are likely to be sizable (Nielsen-Bohlman, Panzer, et al., 2004; Raz, 2003; Tomatir, Ozsahin, et al., 2006; Wonkam, Njamnshi, & Angwafo, 2006). Literacy comprises skills that extend beyond the acquisition of knowledge and includes having the competencies to process, understand, and use information to make decisions and take requisite preventive actions (Rudd, 2013). World experts from 58 countries have identified public education in genomics as a high priority for LMICs (Daar, Singer, et al., 2007). Yet, an informal review of education programs for genomics-related diseases occurring in LMICs found few examples of programs.

In one study conducted in Tanzania, youth affected by albinism (McBride & Leppard, 2002) were provided with a health booklet describing the role of heredity as a cause of albinism and the importance of sun protection among those affected. Home visits were conducted in which health workers provided participants with sunscreen and hats. Unfortunately, few of the participants read the booklet and among those who did, the information was poorly retained and adherence to sun protection was quite low. Health promotion interventions have a long tradition of employing print-based education strategies that can be successful when designed specifically for low-literacy audiences (Michie, Jochelson, et al., 2009). However, high rates of *illiteracy* coupled with the high value placed on oral traditions of knowledge exchange may make print-based approaches less suitable for LMIC contexts.

High-income countries also rely on one-to-one genetic counseling services to accomplish educational objectives. However, genetic counselors are a limited resource internationally, and the majority of LMICs have no in-country genetic counselors (Pang, 2009). Thus, these efforts will likely fall to lay health advisors who themselves will have limited genetic literacy. How best to use oral education strategies to convey genomic information is largely unexplored.

Three decades of evidence suggests that bottom-up community involvement will be required in fostering genomic literacy in LMICs. It will be important when designing interventions to engage the community in advance in defining the primary objective for any literacy building efforts. For example, strategies may be targeted to improve a target community's capacity to appreciate the potential benefits and risks of participating in genomics-related research as a means to empower informed decision-making. Alternatively, literacy building may be directed to improve understanding of the role of heredity in disease risk as a means to justify resource allocation and motivate preventive actions. Thus, organized efforts involving the community in identifying conceptual knowledge needs, opportunities for using new knowledge, and fostering these essential competencies will be needed. Moreover, these processes likely will differ across LMICs and health contexts (Bhuyan, 2004).

In LMIC contexts of limited resources, systematic efforts to enhance genomic literacy also have the potential to divert limited resources away from other health promotion endeavors. Thus, health and community leaders will be important target groups for promoting genomic literacy. Again, information needs will differ based on the health context. For example, information needs may center on helping leaders develop skills to evaluate how and to what extent genomics-based innovations might be integrated with ongoing health education programs. Currently, there is sparse evidence to support what individuals, lay health workers, and community leaders need to know in order to build sufficient context-specific genetic literacy.

Labeling and Stigmatization

Another challenge of using genomic information to guide health resource allocation centers on the propensity for genetic risk to be misunderstood as signifying certainty, that is, deterministic of health outcomes. Misperceptions that health conditions with hereditary underpinnings are *unpreventable* are well documented and consistent throughout the developing world (Ayode, McBride, de Heer, Watanabe, Gebreyesus, et al., 2012). There also is mounting evidence in LMICs that such misconceptions increase social ostracism and other stigmatizing behaviors of families affected by conditions such as sickle cell disease, albinism, spinocerebellar ataxia, and certain neglected tropical diseases (Balgir, 2008; de Villiers, Weskamp, & Bryer, 1997; Kromberg, Zwane, & Jenkins, 1987; Lund, 2001; Lund & Gaigher, 2002; Marsh, Kamuya, & Molyneux, 2011).

Most of what is known about the association of these deterministic beliefs and increased stigmatizing behaviors is in high-income countries and based within the context of mental illness. Indeed, a review of 32 of these studies showed that beliefs in biogenetic explanations of mental illness tended to increase social distancing of those affected by mental illness and their families (Angermeyer, Holzinger, et al., 2011). Characteristics of LMICs present some additional and unique challenges that may intensify these consequences. Target groups in LMICs live predominantly in rural areas, often in remote settings where interpersonal affiliations have significant impact on daily living and economic livelihood. Thus, concerns that genomic risk-based resource allocation could result in social labeling and, in turn, could prompt associated social distancing behaviors with the potential for negative social consequences for affected families are justified.

Formative analysis of endemic causal beliefs about locally relevant disease caused by hereditary and environmental factors is needed in LMIC contexts. Novel health education strategies that convey the interplay of genes and environment in disease occurrence designed for oral delivery will be of particular import in reducing the likelihood that target groups will develop these misconceptions. Strategies most likely to be successful will layer new information about the combined contributions of heredity and environment on health onto individual's existing mental models, that is, the web of their beliefs and perceptions about the causes of a health condition (Fisher, Walker, et al., 2002; Roter, Rudd, et al., 1981). Accurate perceptions can be reinforced, and prevalent misunderstandings that discourage preventive actions could be corrected (Fisher, Walker, et al., 2002; Newman, Seiden, et al., 2009).

Use of Genomics-Informed Risk Stratification in LMICs

To identify examples of using genomics-informed risk stratification for health promotion efforts in LMICs, we conducted a literature search from 1960 to 2011 using keywords *genomics, genetics and family history* crossed with *health promotion, intervention, global health, and behavior change* and a third level of keywords including *allocation, stratification, effectiveness, adherence, equity, and social justice*. Studies were included if they used genomic-based knowledge or tools for health promotion. A total of 18 papers and 17 unique intervention studies were identified. Half described studies that targeted family members of patients with Type 2 diabetes or heart disease for improvements in diet and physical activity; half focused largely on promoting screening behaviors for early detection of cancer. The majority used FHH assessments, and a few relied on genetic testing for risk stratification. All publications were fairly recent (1999–2011), and none were conducted in LMICs.

Several of the identified studies targeted families at high risk for Type 2 diabetes (Kujala, Jokelainen, et al., 2011; Qureshi & Kai, 2008). Consistent with the broader literature, these studies relied on FHH assessments to identify target populations for health promotion interventions. FHH of Type 2 diabetes is associated with a doubling of individual risk; risk increases fourfold when both parents are diabetic (Heideman, Middelkoop, et al., 2011). There is evidence that those who report having a FHH of Type 2 diabetes have high levels of worry about their risk for the disease (Zlot, Bland, et al., 2009). Additionally, several studies of high-risk families show evidence that when adherence to dietary and physical activity recommendations is achieved, there are concordant improvements in disease risk factors (e.g., weight and blood glucose) (Kujala, Jokelainen, et al., 2011). However, these studies have not evaluated the relative benefits of informing high-risk families about hereditary risk as a means to enhance and motivate adherence, and average-risk comparison groups have not been included (Heideman, Middelkoop, et al., 2011).

Epidemiologic investigations also illustrate possible opportunities to stratify populations based on genetic testing for common variants and targeting interventions accordingly. One example comes from research with a cohort of asthmatic children recruited from families in Mexico City where exposure levels to air pollution are high (Romieu, Sienra-Monge, et al., 2004). The cohort was tested for gene variants in the *glutathione* *transferase (GST)* family of genes that influence the lung's ability to metabolize air pollution particulates. Evidence suggests that children with a null-null genotype for *GSTM1* may be especially vulnerable because their lungs are less efficient at metabolizing air pollutants (Gilliland, 2009; Yang, Fong, et al., 2009). Nearly 40% of children in the cohort had the null-null genotype. These children also had the most severe asthma symptoms (Romieu, Ramirez-Aguilar, et al., 2006). Antioxidant supplementation (vitamins C and E) improved forced expiratory flow levels more strongly among children with the high-risk genotype (i.e., *GSTM1* null-null) compared to children with at least one copy of the gene. This association was strongest among children with moderate or severe asthma (Romieu, Sienra-Monge, et al., 2004).

Again, this research has not evaluated how parents and affected communities might respond to risk stratification or targeted recommendations for antioxidant supplementation. It is also unclear how genetic testing and risk education might be integrated into existing asthma prevention programs. Moreover, even if deemed to be acceptable to target groups, it is unclear whether there would be cost savings and more efficient distribution of resources.

In summary, research in high-income countries suggests the feasibility of using genomics-informed risk assessments to identify those at highest risk and target health promotion resources accordingly. However, rigorous evaluation of these opportunities has yet to be conducted. Formative research will be required to consider how to communicate about genetic and environmental contributors to health conditions, to ensure adequate understanding of genomics, and to understand how to use genomic information in ways that motivate adherence to behavioral recommendations and reduce stigmatizing behaviors. This formative work also will require partnerships with communities to consider how best to integrate genomic innovations with existing health promotion interventions in varying social and health contexts. Lastly, comparative effectiveness research will be required to evaluate whether these efforts add value to health promotion efforts.

Genomic Translational Research in Ethiopia

In the sections to follow, we describe an ongoing program of translation research that began with formative research aimed to understand community members' receptivity to genetic research participation and their understandings and beliefs about the role of heredity in the development of podoconiosis, a nonfilarial elephantiasis. We applied these insights in a second phase of research to develop and pilot test health education materials about genetic susceptibility aimed to motivate consistent shoe wearing among genetically high-risk children. The research culminated in a community-based study to evaluate whether enhancing genomic literacy regarding the role of inherited susceptibility and environmental exposure as conjoint causes of podoconiosis improves upon standard health promotion intervention approaches. Each phase of the research is described below to illustrate how we built on opportunities and tackled inherent challenges of integrating genomics into efforts to promote foot health in rural Ethiopia.

Podoconiosis: A Neglected Tropical Disease

Podoconiosis, also known as "mossy foot," is a geochemical noninfectious lymphedema of the lower legs caused by prolonged barefoot exposure to red clay soil derived from volcanic rocks in highland areas (see Fig. 24.1) (Davey, Tekola, & Newport, 2007; Price, 1990). It is characterized by a gradually progressive and usually asymmetric swelling of the lower legs, with skin changes that include hyperkeratosis, papilliform ("mossy") lesions, and nodules. As the disease progresses, the lower legs become increasingly swollen and deformed, and the individual becomes increasingly disabled. Podoconiosis is an extremely stig-

Fig. 24.1 Podoconiosis, also known as "mossy foot," showing skin changes that include hyperkeratosis, papilliform ("mossy") lesions, and nodules

matized health condition in endemic areas (Tora, Davey, & Tadele, 2011; Yakob, Deribe, & Davey, 2010). The swelling in podoconiosis is disfiguring, and in the absence of deep cleaning, the oozing lymph fluid produces an unpleasant odor. Affected adults are often banned from churches, employment, and social events. Ostracized by peers and teachers, children drop out of school. Young people from affected families have very slim chances of finding a marriage partner, whether they themselves are affected or not. Those who get married and go on to develop the condition are likely to be discriminated against and divorced by their husbands.

Podoconiosis is an important public health problem in more than ten countries; there are at least four million people with the disease across tropical Africa, Central and South America, and northwest India (Davey, Tekola, & Newport, 2007; Price, 1990). In endemic areas, the number of people with podoconiosis outnumbers those with other diseases including HIV/AIDS, tuberculosis, malaria, and filarial elephantiasis (Alemu, Tekola Ayele, et al., 2011).

Most of the research on podoconiosis has been conducted in Ethiopia. With an estimated one million cases, Ethiopia bears the largest disease burden of any country (Destas, Ashine, & Davey, 2003). Podoconiosis develops in young adulthood when individuals are generally most productive economically and thus has catastrophic economic consequences. In Ethiopia it is estimated that the disease costs more than 200 million USD per year in lost productivity. In one quarter of patients, disease is advanced, substantially limiting their ability to work (Alemu, Tekola Ayele, et al., 2011; Tekola, Mariam, & Davey, 2006) Complications of the disease such as superinfection and acute lymphadenitis are associated with morbidity, reduced quality of life, and destitution aggravated by lost productivity in affected families. Most patients experience these acute episodes during the seasons of the year when agricultural activity is more intense (Alemu, Tekola Ayele, et al., 2011; Molla, Tomczyk, et al., 2012b; Tekola Ayele, Alemu, et al., 2013). For communities where an entire year's worth of income must be made in a matter of months, loss of a few days of work because of morbidity is a serious threat to their weakened economy and hurts the agricultural sector of endemic countries.

Genetic and Environmental Risk Factors for Podoconiosis

Podoconiosis is an example of a disease resulting from the interaction of genetic and environment risk factors (see Table 24.2). Areas endemic for

Table 24.2 Risk factors for podoconiosis in endemic areas

Factor	Description	References
Geography	Altitude: high altitude >1000 m above sea level Rainfall pattern and volume: seasonal rainfall, >1000 mm per year Soil: irritant red clay soil derived from volcanic rock	Davey, Tekola, and Newport (2007), Price and Plant (1990)
Socioeconomic status	Occupation: the majority are farmers Literacy: the majority are not educated Household economy: the majority are poor Gender: males and females are equally affected	Destas, Ashine, and Davey (2003), Kloos, Bedri Kello, and Addus (1992), Mengistu, Humber, et al. (1987), Price and Plant (1990)
Shoe-wearing behavior (lifestyle)	The majority of patients are barefoot	Davey, Tekola, and Newport (2007), Price and Plant (1990)
Familial factor/ genetics	Familial clustering, high heritability (63%), high sibling recurrence risk ratio (5.1), the most parsimonious genetic model being autosomal codominant major gene with age and footwear as significant environmental covariates. Genome-wide association study revealed significant susceptibility loci in the HLA class II loci (HLA-DQA1, -DRB1, -DQB1 genes)	Davey, Gebrehanna, Adeyemo, Rotimi, Newport, and Desta (2007), Price (1972), Tekola Ayele, Adeyemo, et al. (2012)

Adapted from Tekola Ayele, Adeyemo, and Rotimi (2012)

podoconiosis are characterized by altitude >1000 m above sea level and annual rainfall >1000 mm, factors that are important in the formation of the brownish red clay soil that contains mineral particles small enough to penetrate the skin of barefoot individuals (Price, 1974).

Barefoot exposure to the soil is common. Most do not regularly wear shoes from childhood and this habit begins in childhood, primarily because they cannot afford shoes (Yakob, Deribe, & Davey, 2008). The majority of people in highland Ethiopia are uneducated. Furthermore, the livelihood of adults in endemic areas predominantly depends on working the fertile clay soils for food crop production, which when practiced barefoot increases exposure to the environmental culprit.

Not all individuals who are exposed to red clay soil develop podoconiosis. Accumulating evidence shows the role of genetic predisposition in podoconiosis. Individuals in endemic areas enriched for the genetic risk factor(s), for example, through positive family history and barefoot exposure to clay soil, are at high risk for podoconiosis (Tekola Ayele, Adeyemo, & Rotimi, 2012). Familial clustering of podoconiosis in areas of red clay soil was first described by Price and based on his observations of high disease burden in some families in the tropical African countries of Ethiopia, Rwanda, and Burundi (Price, 1976). His segregation analysis of families with more than one affected child indicated significant familial aggregation and the possibility of a genetic factor(s) with an estimated risk genotype frequency of 15–40% (Price, 1972). Other community-based surveys since have also reported familial aggregation in a third to one-half of affected individuals in Ethiopia (Kloos, Bedri Kello, & Addus, 1992; Molla, Tomczyk, et al., 2012a; Tekola Ayele, Alemu, et al., 2013).

In 2005 a pedigree study conducted in multigenerational and multiple affected Ethiopian families showed that podoconiosis has a strong genetic basis. Siblings of an affected person were at five-times increased risk of developing podoconiosis when compared to a person in the general population, and 63% of the variation in development of podoconiosis was accounted for by genetic factors. The “best fit” model in the study revealed the contributions of a major gene, age, and history of use of footwear (i.e., genetic and environmental factors) to the pathophysiology of podoconiosis (Davey, Gebrehanna, et al., 2007).

In 2012, a genome-wide association study (a genomic approach that compares the frequency of common genetic variants in the genome between cases and controls) was validated using a family-based study method. This study confirmed that podoconiosis has a strong genetic basis and suggested that it is a T-cell-mediated inflammatory condition (Tekola Ayele, Adeyemo, et al., 2012).

Social Stigma and Its Effect on Genetic Research Participation

An initial qualitative study of podoconiosis-endemic areas showed that two-thirds of community members believed that the disease is hereditary and unpreventable (Tekola, Bull, et al., 2009a). Affected community members who reported experiences of social stigma and concern about being stigmatized were reticent to participate in genetics-related research on podoconiosis.

Community Engagement to Develop Informed Consent Processes

High rates of illiteracy in endemic areas make conventional informed consent processes virtually impossible. Yet little research is ongoing to guide alternatives. To this end, qualitative investigations were undertaken in podoconiosis-endemic areas prior to seeking consent for genetic research in Ethiopian families affected by podoconiosis. Results of focus groups with a variety of community groups showed that several social and cultural issues, if not properly handled by a research team, could affect the consent process for genetic research (Tekola, Bull, et al., 2009b). Among the concerns raised that were unique to participation in genetics research is that it was critical to have a comprehensive understanding of local terminologies and contexts for describing the hereditary nature (genetics) of podoconiosis. For example, the local vernacular term for podoconiosis, *gediya kita*, is a derogatory term (Tekola, Bull, et al., 2009a). Moreover, lay descriptions of genetics and heredity included concepts of “having it in the blood” or “the bone.” Given the strong social value of the bloodline in these communities, individual’s beliefs inclined them to associate genetic susceptibility with “unclean” blood. Additionally local decision-making structures and family ties needed to be considered in obtaining consent. And lastly, a more complete characterization of the stigma experienced by podoconiosis-affected families was needed to help the research team avoid exacerbating existing stigma.

The findings suggested the importance of using a hierarchical consent process in partnership with a local community health provider (CHP), the Mossy Foot Treatment and Prevention Association. The first part of the consent process involved community education and training of the CHP’s field workers. The components of the training emphasized providing information on genetic susceptibility to podoconiosis given environmental exposure. Results of the developmental study indicated that research involvement had to first be considered at the family level before an individual could agree to or decline participation. This was regarded as especially important in the context of podoconiosis because the stigma of research participation in a genetic study extended to the family as a whole. Moreover, affected individuals perceived that there would be increased stigma associated with participating in related research and felt strongly that they would have to consult their families before deciding. Thus, individuals were enrolled in the study only after they had discussed study participation with their family. Families were given information and adequate time to deliberate thus respecting complex intra-household decision-making processes. This comprehensive approach yielded great dividends during the recruitment process as most families reported less concern about privacy and social stigma, and 98.5% of approached individuals consented to enroll in the genetic study (Tekola, Bull, et al., 2009a).

Qualitative Research to Guide the Development of Interventions to Promote Shoe Use

Footwear may appear a relatively simple behavior to target to prevent podoconiosis. However, as with other behavioral interventions, the reality is complex. Recent evidence indicates that shoe-wearing prevalence is low and inconsistent (Yakob, Deribe, & Davey, 2008) and that the majority of school-aged children in these rural settings in Ethiopia wear inappropriate shoes that do not adequately protect the feet from exposure to the soil (e.g., flip-flops) (Tadesse, 2005).

Consistent with the PRECEDE-PROCEED approach to program development and evaluation (Green & Kreuter, 1991), we conducted a two-phase process for considering intervention strategies to promote consistent shoe wearing. The PRECEDE phase involves qualitative activities that enable diagnostic planning and focused on assessment of social, behavioral, environmental, educational, and ecological issues that may influence whether and when high-risk children wear shoes. In the PROCEED phase, information gleaned in the PRECEDE phase is used to guide and tailor program implementation and evaluation. The model has been used widely in developing and evaluating public health interventions across a wide variety of public health settings including interventions for rural populations in sub-Saharan Africa (Mbonu, Van Den Borne, & De Vries, 2011). Each phase of our activities is described in turn.

PRECEDE: Understanding Beliefs About Heredity and Their Effects on Shoe Wearing

As suggested earlier, we considered it critically important to understand individual's mental models about the role of genetics in health conditions. To this end, we undertook a second series of qualitative research activities including focus group discussions, semi-structured in-depth interviews, and extended case studies with community members. A total of 306 adults and children participated in these activities that explored participants' beliefs about the causes of podoconiosis, attitudes toward individuals affected by podoconiosis, attitudes toward wearing shoes, and optimal settings for promoting footwear among high-risk populations.

Heredity was spontaneously and frequently mentioned in participants' renditions of the cause of podoconiosis (Ayode, McBride, de Heer, Watanabe, Gebreyesus, et al., 2012). Those who believed podoconiosis was solely hereditary also tended to perceive that the condition was not preventable. Endorsement of heredity as a sole cause also aligned with acknowledgment that affected families experienced stigmatizing behaviors as well. However, denial that heredity had any role influenced stigmatizing behaviors. Those who perceived no role for heredity were concerned that podoconiosis was contagious and were concerned about being in close proximity to affected families (Ayode, McBride, de Heer, Watanabe, Gebreyesus, et al., 2012). Both belief systems led community members to conclude that interactions with individuals and families affected by podoconiosis should be avoided, thus exacerbating social stigma.

Beliefs about the involvement of heredity in the development of podoconiosis also were associated with shoe-wearing behaviors. Believing the condition to be inherited and thus not preventable diminished the perceived importance of wearing shoes; whereas believing that heredity was not involved and that contagion was at play also diminished the importance of wearing shoes in favor of avoiding physical contact with those who were affected. These misconceptions and attitudes were present among affected and unaffected families. Thus, improving community levels of genetic literacy will be required to shift attitudes and motivation to adopt foot protecting practices.

Adherence to most behavioral recommendations is impeded by a host of social and contextual factors as well. Indeed, our qualitative work identified a range of barriers to compliance among those who considered it important to wear shoes (Ayode, McBride, et al., 2013). Financial barriers were among the most important, but other issues such as suitability for farming activities, fit of shoe, and fear of labeling were also significant deterrents (Ayode, McBride, et al., 2013; Yakob, Deribe, & Davey, 2008). Several investigations have documented reluctance to wear shoes while farming or in the rainy season (Alemu, Tekola Ayele, et al., 2011; Molla, Tomczyk, et al., 2012b; Yakob, Deribe, & Davey, 2008) and use of poor-quality sandals or low-cut shoes likely to afford little protection from the soil (Alemu, Tekola Ayele, et al., 2011; Molla, Tomczyk, et al., 2012b; Yakob, Deribe, & Davey, 2008). These findings suggested that interventions to promote footwear will need to build participants' confidence and skills to overcome these barriers.

Shoe Distribution Targeting High-Risk Families

Promoting foot protection practices in podoconiosis-endemic areas of Ethiopia also is limited by the availability of health workers to distribute shoes. In turn, demand for shoes is high – half of the Ethiopian population is under the age 12 and could benefit from wearing shoes. Accordingly, the community health provider, Mossy Foot Treatment and Prevention Association, has used FHH to identify children at high risk of podoconiosis (Ayode, McBride, de Heer, Watanabe, Gebreyesus, et al., 2012; Davey & Burridge, 2009) and target them for distribution of shoes. This service delivery model that uses the limited infrastructure to distribute free shoes to genetically high-risk families is defensible given that podoconiosis is a highly prevalent disease, with an identifiable phenotype and high heritability, and that shoes are a relatively scarce resource (Tekola Ayele, Adeyemo, & Rotimi, 2012). However, the efficiency of targeted shoe distribution must be balanced against concerns that in the absence of programs aimed to improve understanding of the rationale for targeting, these approaches could backfire by exacerbating stigmatizing behaviors toward affected families.

Thus in the PRECEDE phase of the research, we solicited community members' beliefs and attitudes regarding targeted shoe distribution and their association with understanding of the role of heredity in the development of podoconiosis. Our focus groups suggested that perceptions that inherited diseases were not preventable needed to be countered by efforts to reinforce and deepen understanding of individual variation in susceptibility, a concept acknowledged by many participants, but only superficially understood (Ayode, McBride, de Heer, Watanabe, Gebreyesus, et al., 2012). Our results also suggested that this could be used to bolster target groups' confidence that risk can be reduced. Indeed, these initial findings suggested that education strategies were needed. However, it was not clear how best to convey a nuanced understanding of the interaction of inherited susceptibility and environment as joint causal factors in podoconiosis or whether these efforts would decrease the occurrence of stigmatizing behaviors.

PROCEDE: Developing a Theory-Based Genetic Susceptibility Education to Motivate Consistent Shoe Wearing

Theory Considerations

There is consensus that public health interventions that are most effective are grounded in social and behavioral theory (Michie & Johnston, 2012). Theory may be especially important for developing interventions for LMICs where public health infrastructure is limited and literacy levels are low. In these contexts, theory can be useful for considering how best to incorporate emerging genomic knowledge into existing health promotion efforts and to attain parsimony in assessments of intervention response. Theory also could be informative in deciding what genomic information could uniquely bring to behavior change interventions aimed for LMICs' specific health promotion challenges.

Accordingly, we drew on several theories in designing an intervention to promote shoe wearing among high-risk families. We first considered individual-level conceptual models including social cognitive theory (SCT) of self-regulation (Bandura, 1986). SCT argues for the importance of targeting individual's beliefs and attitudes about genetic susceptibility and its association with shoe wearing, how these beliefs about genetics influence their perceived capabilities to prevent podoconiosis, and whether wearing shoes can be effective in reducing their risk for the condition.

Additionally, we considered interdependence models including the concept of "communal coping." Interdependence theory argues that an individual's motivation to engage in health behaviors may be influenced by their affective relationships (e.g., spouses, parent-child relationships) (Lewis & McBride, 2004). Motivation may be enhanced in circumstances in which a health threat is perceived to be shared or that remediation of the health threats is a relational responsibility. Indeed, individuals will take preventive actions on behalf of important others that they may be less willing to adopt on their own behalf. In this line of thought, understanding of shared genetic risk could be capitalized on, for example, to motivate parents to encourage their children to wear shoes.

Misunderstandings that inherited diseases are unpreventable also are socially influenced. These misconceptions represent shared beliefs about illness that are maintained through interpersonal communication in social contexts (Landrine & Klonoff, 1992; van Oostrom, Meijers-Heijboer, et al., 2007). Intervention activities can capitalize on interpersonal relationships at the family, neighborhood, and societal level to correct misconceptions and empower community members to communicate accurate information within their social networks. Engaging community members in this way also would increase the potential for the intervention to be sustained over time.

Intervention Target Groups

Interdependence theory also guided the selection of our target group for the intervention. Our qualitative work suggested that parents from affected families felt strongly that wearing shoes could improve their children's chances for social advancement by offering them opportunities to attend school (Ayode, McBride, de Heer, Watanabe, Gebreyesus, et al., 2012). Thus consistent with interdependence theory, we proposed to capitalize on parent's desire to improve their child's social standing to encourage and empower parents to help their young children wear shoes consistently.

Also consistent with interdependence theory, our qualitative work suggested that community misperceptions were reinforced within the community by those who were unaffected by podoconiosis. Affected and unaffected individuals had similar misperceptions about the role of heredity in the development of podoconiosis. However, the two groups were not comfortable discussing these beliefs in mixed groups (Ayode, McBride, de Heer, Watanabe, Gebreyesus, et al., 2012). Thus, we concluded genomics education would be targeted to affected families and their neighboring unaffected households. However, this would require that separate health education sessions be conducted with affected and unaffected families.

Additional efforts to promote broader public awareness of the shoe distribution would be conducted by distributing posters and other promotional materials and development of a song to provide a supportive context to the educational efforts. Lastly, it was decided that to maximize long-term sustainability, the intervention should be delivered by local individuals identified by community leaders as lay health advisors.

Inherited Susceptibility Education

Our choices for discussing inherited susceptibility as a means to motivate high-risk individuals to take preventive actions were limited by high rates of illiteracy in the target population. Additionally, residents of the targeted communities speak a variety of different dialects, making it difficult to standardize text. Thus, we concluded that our health education materials would have to rely on oral delivery with visual aids used to support key learning objectives. Under these circumstances, use of visual metaphors has been recommended to enhance the cultural sensitivity of the messages (Freimuth, Linnan, & Potter, 2000). We drew on one example used to characterize genetic susceptibility to mental illness (Peay & Austin 2011). The metaphor for genetic susceptibility relies on a jar of marbles where one color of marble is used to represent individual's genetic risk and another color represents environmental risk. The notion conveyed is that individuals who start out with their jar holding more genetic risk marbles require less environmental exposure (fewer marbles) to significantly increase their risk for a negative health outcome.

Building on this metaphor, we first considered examples of environmental sensitivities that were not stigmatized in the targeted Ethiopian communities. The high elevation of highland Ethiopia, limited tree cover, and necessity of walking long distances to get water or travel to market mean that individuals experience long spells of sun exposure. It is common to see variability in individuals' sensitivity to this sun exposure. Some use umbrellas to shield from the sun, others wear scarves, and some walk without any sun protection. We used this example of variation in sensitivity that is well accepted by the community to illustrate how subjective sun sensitivity might influence the use of sun protection. We then linked this example to inherited sensitivity to soil. The development of foot and leg swelling among family members was an indication that individuals may have inherited this sensitivity to soil exposure, and these individuals would benefit from consistently wearing shoes to protect the feet. We tested this conceptual approach with the target audience in sessions with community health leaders and found it to be well accepted.

Skills Training to Overcome Barriers

Consistent with SCT, it was also clear that parents would benefit from having the opportunity to develop requisite skills to overcome key barriers to their child wearing shoes. Thus an important component of the intervention was to conduct oral educational sessions in households and give parents' the opportunity to build confidence to overcome impediments to their child wearing shoes. A booster education session and shoe distribution were included to sustain intervention benefits. The developed intervention is currently being evaluated with parents of young children who are receiving free shoes from MFI in six communities in highland Ethiopia.

Implications of Podoconiosis for Using Genetics to Promote Health Globally

The case of podoconiosis offers a valuable example of the opportunities and challenges of using genetic information for risk stratification and targeting scarce resources to those at highest risk for negative health outcomes. Results of this project suggest the critical role that genetic education strategies can play in promoting health and reducing the stigma of preventable hereditary health conditions. This example is relevant to the broader global health context as world experts from 58 countries have recommended the development of public engagement strategies to inform and educate the public about genomics (Daar, Singer, et al., 2007). These activities are being given priority in recognition of their potential to build the capacity needed to weigh the ethical, social, and cultural issues that come with efforts to apply emerging genomic knowledge for health improvements (Daar, Singer, et al., 2007). Currently there are very few examples of health education interventions in development or that have been evaluated in the developing world. Indeed, there are few examples of these approaches in developed countries (see, e.g., (Kaphingst, Lachance, et al., 2011)). Development and evaluation of health education approaches that can be readily incorporated appropriate to the needs of LMIC settings will be critical in the coming decade.

Additionally, the conditions for whether and how to use genomics in risk stratification and for targeting intervention also need more careful consideration and evaluation. The risk stratification approaches employed in the podoconiosis project were based on extensive efforts to build relationships with the communities and target groups. At each step of the research, the community was consulted about the approaches being taken. Even so, community members were frustrated that footwear could not be made available to all. Thus, reliance on targeting those at high risk will have social costs and could influence the likelihood that interventions are sustainable for the long term. Considering the optimal complement of targeted interventions and population-wide activities will be especially critical for promoting health in LMIC settings.

Conclusions and Recommendations

In this chapter, we have suggested examples of what may be unique opportunities and challenges for applying genomic discovery to promote health in LMICs. We specifically considered how targeting genetically high-risk families for health conditions in LMICs might be used to allocate scarce health promotion resources and to motivate adherence to behavioral recommendations. We suggested how social and behavioral sciences could be brought to bear in conducting formative research to develop and evaluate genomics-informed innovations in interventions to promote health. We considered this potential alongside concerns about high rates of illiteracy in LMICs and the potential that community misunderstandings about inherited susceptibility to health conditions could exacerbate stigmatizing behaviors. We described our formative research in developing novel approaches to conveying information about genomics to a low-literacy audience in the context of podoconiosis. We described our efforts to develop a footwear promotion intervention aimed to reduce the likelihood of social stigmatization arising from targeting shoe distribution to genetically high-risk families.

Our discussion of opportunities and challenges for genomic translation research touches on only the tip of the iceberg. Predictions of increased technological capacity to generate large volumes of genetic data faster and at lower cost have been largely on track (Green & Guyer, 2011). However, the global health research, that is, the "collaborative transnational research and action for promoting health for all" that is being called for to apply new genomics knowledge, is nascent (Beaglehole, Bonita, et al., 2011; Dandara, Adebamowo, et al., 2012). Moreover, it is being argued as a matter of social justice and commitment to fundamental human right to health that LMICs should be in the vanguard of receiving the benefits of genomics (Bozorgmehr, Saint, & Tinnemann, 2011). However, to be in the vanguard, LMICs must be fully engaged in translation research now.

Most agree that the agenda for genomic translation research must align with critical public health needs in LMICs (Williams & Tishkoff, 2011). As the epidemic of noncommunicable diseases like Type 2 diabetes and other chronic diseases grows, the health priorities of LMICs are converging with the priorities of high-income countries. This provides both the impetus and ideal social climate for the transnational collaborations in disease prevention efforts (Dandara, Adebamowo, et al., 2012).

Efforts to foster these collaborations will face numerous challenges. First and foremost will be the need to build scientific capacity in LMICs. Initially it will be critical that LMIC leaders see a clear path to concrete applications of genomic advances that lead to health improvements where ethical, social, and legal implications have been thoroughly considered (Dandara, Adebamowo, et al., 2012). Programs like the Human Heredity and Health in Africa (H3Africa) Initiative are beginning to lay the groundwork for these transnational collaborations (Williams & Tishkoff, 2011; Wonkam, Njamnshi, & Angwafo, 2006). The Initiative aims to develop expertise among African scientists and establish networks among these investigators to build needed research infrastructure (Price, 1976). Currently, these efforts are focused largely on the development of biorepositories and engaging target populations to participate in epidemiologic research to explore gene-disease associations (Williams & Tishkoff, 2011). Social and behavioral science perspectives will be essential in these efforts. However, the prevention of chronic disease, with the goal to promote healthy behaviors as the cornerstone, is *the* pressing issue internationally.

The case of podoconiosis is just one of an increasing number of health contexts in which health behavior change is needed. The charge for any genomic translation research in health promotion interventions will be to consider agnostically whether genomics-informed innovations add value for unit of cost to existing approaches. The knowledge base and tools for advancing this research agenda are well within the purview of social and behavioral scientists. They include community engagement strategies, state-of-the-science risk communication approaches, understanding of social and behavioral theories, and evidence-based behavior change approaches. Early involvement of an international cadre of social and behavioral scientists in translational research is critical if we are to shape genomics-informed innovation to promote health globally with maximal benefit and minimal negative social impact.

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25

Policy and Policy Research for Behavioural Medicine

Vivian Lin, Bronwyn Carter, and Yan Guo

Introduction

Health behaviours are shaped by a multiplicity of forces. The policy environment is one of the factors that can influence behaviour, either for better health or to damage health. In other words, the right set of policies can make healthy choices easier choices, and policy instruments – such as financial subsidies and incentives, regulation, information and service provision – are commonly used to address behavioural health issues. While these same instruments can provide incentives for better health through better use of health services and adoption of health-promoting behaviours, they can also act as disincentive for health service use and healthy behaviours.

This chapter will be concerned with the design and research of policy interventions that positively alter health behaviour. How healthcare policies and intersectoral policies for health influence behaviour will be considered. However, insofar as policy research in relation to behavioural health is a relatively new and evolving field, the chapter will focus on policy research methods for behavioural health, as policy research methods are important both for assessing policy impact as well as helping to design policy interventions.

What Is Health Policy?

The term policy is commonly used in relation to how we are governed but does not have a clear and unambiguous definition. 'Policy' may be used to mean a broad orientation, an indication of normal practice, a statement of values or a specific commitment. The work of government is understood by Colebatch to involve 'managing… problems by means of explicit courses of action – its policies' (Colebatch, 2009). The term 'policy' is used in this chapter in reference to how governments manage the course of events in order to solve and prevent health problems.

The World Health Organization conceives of health policy in two respects (World Health Organization, 2000): policies for delivery of healthcare services and policies to protect and improve population health and well-being. Healthcare policy is primarily concerned with the health sector and the service delivery system, whereas policy for health, as defined by The Ottawa Charter for Health Promotion (World Health Organization, 1986), proposes actions on both population level interventions by the health sector, as well as public policies in all sectors that

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shape health and well-being. As a core action in the Ottawa Charter, healthy public policy puts health on the central agenda of government, making policy choices in support of health easier choices at the macro level. The Charter makes policy-makers in all sectors aware of the health consequences of their decisions, directing them to accept their responsibilities for health and making it easier for them to make policy decisions in support of the health of the population. The determinants of health are addressed specifically as a core action in the Bangkok Charter (World Health Organization, 2005), which requires governments to regulate and legislate to protect from harm and enable equal opportunity for health and well-being for all people.

Process of Policy-Making

All governments have formal processes of policy-making, although the specific institutions and processes vary depending on the constitution and structure of government, including the relationship between the legislative and executive arms of government. Governments will typically express their policies through instruments such as plans, legislation and regulation, budgetary allocations, service provision and financial subsidies and incentives.

While formal institutions of policy-making are important, in most countries, policy-making is the result of complex interaction among a wide array of stakeholders which takes account of the formal process of policy-making, the specific technical issues involved in a policy arena and the context within which policies are being proposed and debated (Buse, Mays, & Walt, 2012). The moment of policy decision relies on the confluence of major streams of policy-making: (1) the definition of the policy problem, (2) the agreement on the appropriate policy solutions and (3) the political window of opportunity (Kingdon, 1984). Evidence is important in policy-making. However, policy-makers rely on a broad range of evidence – from scientific research to political polling to budgetary projections for government to community acceptance. The uptake of research evidence into policy occurs when there is concurrence of interests and understanding among the researchers, the policy-makers and the community at large (Lin & Gibson, 2003).

Policies have effect – whether using financial, regulatory or information instruments – when they are implemented. Implementation, however, rests not only on government capacity but also on the extent of stakeholder ownership. This points to the importance of participatory processes – both across sectors and with non-state actors – in policy-making, as well as having sound evidence. For public health advocates within and outside of government, policy advocacy strategies become important, as well as getting the appropriate governance structures for policy-making. Whole-of-government and whole-of-society approaches are recognized as important for health policy-making (World Health Organization, 2013a), with six models for ‘smart governance’ proposed including collaboration with sharing of power between at least one public agency and non-state stakeholders; formal partnerships among different government departments and other sectors; formalized citizen engagement in decision-making to facilitate innovation; a mix of regulation and persuasion; independent expert bodies to provide evidence and watch ethical boundaries; and governance by adaptive policies, foresight and resilient structures to enable flexibility and timely response by stakeholders to issues as they arise (World Health Organization, 2011b).

How Is Policy Relevant to Behavioural Medicine?

Policy measures that shape health behaviour may relate to primary prevention at the population level as well as healthcare for individuals and communities. Policy measures directed at healthcare provision are needed to ensure access to quality health services, for at-risk and for ill populations with targeting for disadvantaged communities. Policy measures outside the health sector are also needed for primary prevention, particularly to address the social determinants of health.

Figure 25.1 provides a framework for policy interventions related to behavioural medicine. The framework shows how policy is used for behavioural medicine in sectors other than health, to provide interventions at the population level. The main policy instruments for behavioural medicine in use across sectors are 'health in all policies' (HiAP) initiatives and policies to reduce harmful behaviours and increase healthy behaviours at the population level. Such policies provide financial disincentive/incentive, regulation or information. The framework shows how policy is used for behavioural medicine in the health sector, to provide interventions at the level of the individual and for targeted groups. Within the health system, policy instruments for behavioural medicine relate to financing – for screening and referral, access to services, service models and workforce development. Health policies are, however, distal (rather than proximate) interventions. They do not have the same effects on all persons. Policies designed for health purposes interact with, and may be in contradiction with, policies in other sectors. Policy research for behavioural medicine therefore relates to agenda setting, policy design, policy implementation and evaluation of the impact of policy, within the health sector as well as other sectors.

Healthcare Policies

Access to health services is a policy area relevant to behavioural medicine as this influences care seeking and adherence. This is particularly important for disadvantaged groups. For healthcare policies, the key question is what policies are most likely to encourage appropriate care seeking and adherence – policy measures and research questions are therefore likely to be related to system characteristics such as financing incentives, service models and workforce competencies, and demand side issues such as health literacy, and social and cultural influences on access. Policies in relation to financial barriers to access are important, as are policies that are non-discriminatory and promote diverse service models and diversity in the health workforce

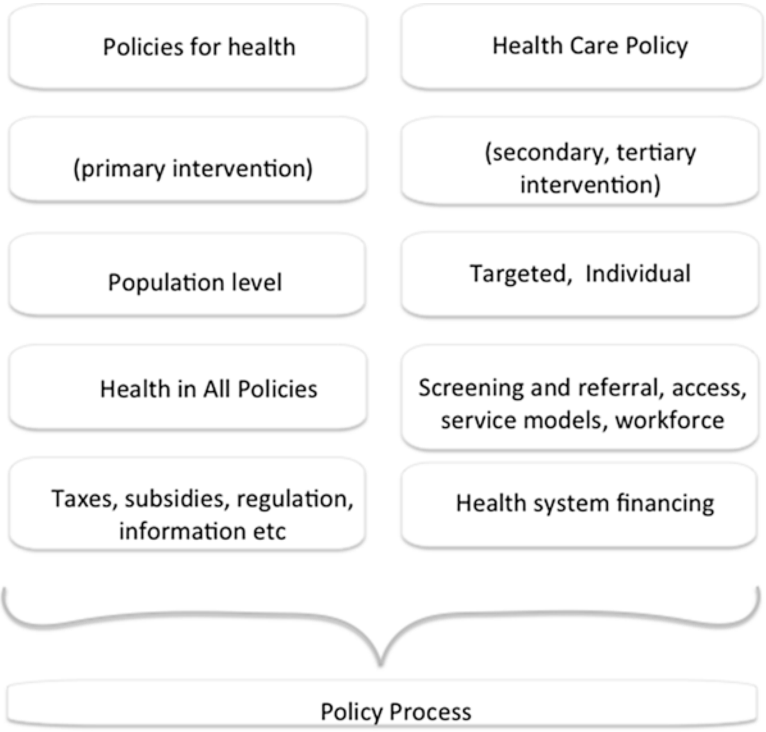

Fig. 25.1 Organizational framework for examining policy and behavioural medicine

which engender trust by the community. In the post-2015 development agenda, policies for ensuring universal health coverage will be a core concern globally (Lin & Carter, 2014; World Health Organization, 2013b, 2014).

Financing Incentives

Key policy areas for health system financing relate to health insurance, patient and provider incentives for preventive care and the effects of out of pocket costs. Policy questions for behavioural medicine include Is there a health insurance system that assures people having access to care, including both preventive services as well as treatment and rehabilitation services? Is there specific financing for systems to underpin preventive care, such as screening registries and recalls, or social marketing campaigns? Does the payment system for the provider give incentive for preventive interventions such as regular screening, lifestyle advice and referral to counselling and support services? Does the financing or payment system require substantial out of pocket payment from consumers such that they can fall into poverty, or delay care seeking, or not take the necessary drugs? One example of a financing incentive to promote access to services is blended payment systems which increase access to care by combining capitation, allowances and fee-per-item payments. A study of oral healthcare found that blended payment systems promote balance between over-provision or under-treatment, patient selection or 'cherry picking' by dentists and overconsumption and equitable coverage and access for patients (Woods, 2013). Public funding of family planning services for low-income women (Gerstein & Markus, 2013) is an example of financial incentive to promote access to care and preventive services.

A review of systematic reviews of financial incentives for health-related behaviour examined characteristics of effective programmes (Lynagh, Sanson-Fisher, & Bonevski, 2013) and proposed the following principles:

- Reliable, accurate and acceptable measures of behaviour change should be used such as uptake of immunization, participation in screening and treatment programmes, smoking cessation and physical activity (validated by pedometer readings).
- Incentives are more likely to be effective with disadvantaged or vulnerable groups, for example, low socioeconomic groups, drug users and teenage mothers, but more studies are needed of the general population.
- Incentives need to be sufficient in size, for example, return visits to a tuberculosis clinic were higher in patients receiving a larger cash incentive.
- The size of the incentive required may vary with financial status, for example, more favourable results were achieved in treatments for obesity with incentives greater than 1.2% of personal disposable income.
- A frequent and incremental reinforcement schedule with reset contingency is needed (when a relapse in behaviour occurs the size of the incentive returns to its initial value), particularly for behaviours where maintaining an initial change is critical to sustaining change over the longer term, such as with smoking abstinence.
- Minimal delay between behaviour and reward is needed, for example, in drug treatment programmes immediate rewards have been shown to be more effective.
- Carrots work better than sticks because negative incentives may reinforce personal failure and may be viewed as punishing the most vulnerable.

Service Models and Workforce Policies

Policy for healthcare service models for behavioural medicine relate to policies which encourage services to be patient and community centred and offering seamless care that links community health and hospital care (World Health Organization Western Pacific Region, 2007). Prevention of unnecessary admissions, health maintenance in the community setting and satisfaction with services are some of the major policy objectives. Improved service coordination and responsiveness to the needs of patients will be achieved through further development of models of care, such as integration of patient education, family involvement, self-management and counselling. So policies need to encourage multidisciplinary teamwork, involve families/carers and recognize the use of complementary healthcare. The use of e-health records to promote continuity of care and web-based services to promote self-management (Ramadas, Chan, et al., 2014) is a recent example of service models for behavioural medicine.

People-centred healthcare rests, in part, on healthcare providers who can communicate effectively with patients and their families and work effectively in teams and on institutions that are trusted by the community and can develop tailor-made interventions. Policies are required to ensure the health workforce has the requisite competencies to practice behavioural medicine – to provide counselling and brief interventions and to refer to other disciplines for support services. With recognition and support, clinical educators and role models who espouse professionalism and humanism in healthcare can transfer to trainees such values and skills important in behavioural medicine. So workforce policies for behavioural medicine are about leadership, curriculum, multidisciplinary education, clinical training in community settings and cross-cultural awareness training. For example, workforce policies for curriculum support inclusion of training in socio-behavioural medicine as well as biomedical paradigms (Ding, Zhong, et al., 2014) and development of specialist postgraduate training in particular areas of need such as public health nutrition (Hughes, 2006). Additional measures to promote non-discrimination of particular patient groups may also be important for access, such as targeted information or workforce competency development.

Policies for Health

Policies which address social determinants of health – the conditions in which people are born, grow, live, work and age – are important in behavioural medicine. There are multiple examples of the use of policy to address behavioural health issues such as smoking, alcohol and nutrition. Key policy areas for sectors other than health relate to financial incentives, regulation and information.

Legislation and regulation are core policy instruments used by governments around the world to promote population health. For example, the National Alcohol Strategy enacted in Chile in 2012 increases regulation of drunk driving (found to be in charge of a motor vehicle while over the legal blood alcohol limit) (Pena, 2012). Other examples of the use of regulation in behavioural health policy include limits placed on advertising, promotion, sponsorship and sales of tobacco, alcohol and unhealthy food, tobacco plain packaging laws, increases in smoke-free public places and worksites, bans on tobacco flavourings, regulation of salt content of foods, replacement of trans fat with polyunsaturated fat, labelling of ingredients, and policies to support breastfeeding such as breastfeeding rooms (Framework Convention Alliance, 2015; Lin, Jones, et al., 2014). Besides well-established measures in tobacco control, there is increasing experimentation with regulation such as bottle-size bans for sweetened drinks (Mytton, Clarke, & Rayner, 2012), zoning to control fast food and ensure access to quality early childhood education (Friedman-Krauss & Barnett, 2013).

Governments also exert influence through the use of financial tools. Examples of financial incentives in policy for behavioural health include tobacco and alcohol taxes (Framework Convention Alliance, 2015; Lin, Jones, et al., 2014; Pena, 2012), subsidies to increase availability and access to healthy food and health insurance incentives for keeping physically active (Lin, Jones, et al., 2014). 'Fat taxes' such as tax on sugar sweetened drinks have also been trialled in Denmark (Mytton, Clarke, & Rayner, 2012).

Examples of behavioural health policy supporting the provision of information and persuasion include warnings on tobacco packets, mass media and public education to raise awareness of tobacco harms and the benefits of diet and physical activity in disease prevention (Framework Convention Alliance, 2015; Lin, Jones, et al., 2014).

For policies for health relevant to behavioural medicine, the concern is to effect the adoption of healthy public policies across all sectors involving policies and programmes that have an impact on the social and behavioural determinants of health. Increasingly, health in all policies approaches are becoming a focus for action on social determinants of health (European Observatory on Health Systems and Policies, 2006; Howard & Gunther, 2012; Government of South Australia, 2013; McQueen, Wismar, et al., 2012; Shankardass, Solar, et al., 2011).

Healthy public policies can be adopted at various levels to address behavioural health issues. Well-established examples include broad-based healthy settings policies such as 'health-promoting schools', 'age-friendly cities', 'safe communities' and 'healthy cities'. Healthy city policy enables local policies such as for green spaces and physical activity as part of housing development, active transport and policy for maintaining land for agriculture and local food production (Lin, Jones, et al., 2014).

The importance of acting at multiple levels is recognized in policy areas related to behavioural medicine including tobacco control, nutrition and physical activity, alcohol-related harm, drug dependence, healthy ageing, preventing accidents and injuries and sexual health (Lin & Carter, 2013). In 2007 European Union (EU) health ministers recognized the importance of behavioural and lifestyle factors in determining the health of the population and committed to addressing such health issues at local and international levels through adopting the HiAP approach. HiAP is defined as a policy principle to improve population health by including, integrating or internalizing in the policies of other ministries and sectors, health policies that shape or influence the social determinants of health (McQueen, Wismar, et al., 2012).

Getting appropriate policies adopted and implemented for behavioural health is often a challenge for public health advocates, particularly in the face of either industry power or lack of understanding of the evidence base on the part of policy-makers.

The importance of policy governance for behavioural health can be seen particularly in HiAP. In South Australia, the key governance elements included state strategic plan with key performance indicators that held government agency heads accountable, a process coordinated by the cabinet office and supported by analytical work of the health department (South Australia Health, 2012). Intersectoral governance structures effective in achieving HiAP were examined by the European Observatory on Health Systems and Policies (McQueen, Wismar, et al., 2012) and shown to include committees at the levels of parliament, government and the public service, engagement with stakeholders and particular funding arrangements. Achieving policy coherence across agencies and across all levels of the system has been shown to be important in addressing behavioural risk factors (Lin, Jones, et al., 2014).

Policy Research: Why and What?

Behavioural health policy can prevent potentially harmful effects and minimize unintended adverse consequences of policy in the health sector and other sectors, as well as address inequalities in behaviour-related health issues. Hence the importance of policy research for behavioural medicine. The current evidence base for behavioural medicine policy is stronger, however, than achievements to date in implementation would indicate (European Observatory on Health Systems and Policies, 2006). At the same time, there is still much research to be done to understand the impact of specific policy measures. Challenges in policy research in relation to the availability and appraisal of evidence for policy-making, including the requirements of the evidence-based medicine and evidence-based policy movements, are discussed later in the chapter.

What Does Policy Research Focus On?

Policy research aims to understand the nature of policy work: how policies are made, how policies are implemented, how policies might be designed and how policies can be influenced – these central concerns apply to both healthcare policy and policy for health. Policy research can focus on both the content and the processes of policy-making. A critical problem for policy-makers is under what conditions will policies be effective in delivering desired policy objectives. The preconditions and the infrastructure necessary for policy interventions are also important for understanding policy effectiveness.

Policy Content and Design

Typical questions in relation to the content and design of policy can be oriented towards analysis *of* policy or analysis *for* policy (Parsons, 1995). Key aspects of analysis *of* policy are concerned with policy determination – how policy is made, why, when and for whom and also policy content – which may describe a particular policy and how it developed or may be informed by a theoretical framework which offers a critique of policy. In the case of analysis *for* policy, this relates to advocacy intended to influence the policy agenda and also to information that may provide evidence for policy decisions. Policy analysis also includes policy monitoring and evaluation, which examines the impact on the population and decides what works.

Questions asked by health researchers when examining the content of policy for behavioural medicine may include Did health or access to services improve? What is the appropriate mix of interventions? Which policy instruments are the most cost-effective? What level of coverage or targeting of funding is necessary to have an impact? What processes and resources would assure effective implementation? Who benefits and at a cost to whom? What is the equity or distributional impact?

Policy Analysis/Policy Evaluation

Policy evaluation studies are comparable to programme evaluation studies, but the attribution of result is often more difficult given the interaction of policy measures with other complex societal forces, including other policies, social institutions and locational differences in any jurisdiction.

Nonetheless, tools are being developed for use in studying what health impacts may arise from various public policy measures. Such tools include, for example, health impact assessment (HIA) (the systematic screening, scoping, appraisal, reporting and monitoring of anticipated health impacts) (European Observatory on Health Systems and Policies, 2006), Health Lens Analysis (a cross-sectoral process of gathering evidence of health impacts, generating policy recommendations aimed at mitigating health impacts, navigating recommendations through decision-making and governance processes and evaluating the effectiveness of the health lens process) (South Australia Health, 2012) and health equity gauge (a community development and social justice approach including social/political/economic assessment, advocacy and community empowerment) (Pauly, MacDonald, et al., 2013). One example of a tool developed to evaluate equity impacts of behavioural health interventions is the framework used to identify whether smoking cessation programmes reduce or exacerbate inequities in smoking rates between socio-disadvantaged and affluent smokers (Pauly, MacDonald, et al., 2013). The application of this equity evaluation tool in a programme in the United Kingdom demonstrated that although overall smoking rates dropped, affluent smokers benefited more from the programme, so the programme was not contributing to a reduction in health inequalities.

Policy Process

Typical questions in relation to the processes of policy-making revolve around agenda setting, decision-making and implementation (Parsons, 1995). The focus is on the key issues related to the policy process – the underlying factors and actors in policy-making, such as how power is exercised, how decisions are made, how values/knowledge/ideas have been used, how advocacy and negotiations have been undertaken, what contextual influences are important and what roles are played by diverse stakeholders and networks.

Research related to agenda setting seeks to explain stability and change in policy-making.

Topics in agenda setting relevant to behavioural medicine include the role of a mixture of empirical information and emotive appeals, termed 'policy images', in dampening or exacerbating mobilizations against entrenched interests; how policy change is born out of belief systems common to participants in the policy process and also results from shifts in attention, as described by the Advocacy Coalition Framework and Punctuated Equilibrium Theory; how and why political agendas change as a result of the unequal agenda-setting power of different political parties; as well as timing of changes in agenda according to how governments respond to and process new information about changes in their environment (Sabatier & Weible, 2014).

Using the Advocacy Coalition Framework, studies of how advocacy is undertaken have shown that substantial compromises and important changes in public policy can be achieved through 'opposing groups …modifying… certain elements of their belief structures through policy learning born of continual interactions within policy subsystems' (Sabatier & Weible, 2014). Such policy-oriented learning is understood to occur when there is an intermediate rather than extreme level of informed conflict between the coalitions; accepted quantitative evidence exists in relation to the policy question; and due to the feasibility for controlled experimentation, when the problem relates to a natural system rather than a purely social or political system. Even when the views of the opposing coalition are not changed in the face of the available evidence, important impacts on policy can be achieved through alterations achieved in the views of policy brokers – actors who act as intermediaries between opposing coalitions mitigating conflict and seeking agreement on common ground. Such achievements indicate potential for the prioritization of policy to address behaviour-related public health issues.

Studies of policy decision-making seek to understand how changes in policy occur. 'Policy shifts' are understood by researchers to spring from shifts in attention, and non-incremental shifts or rapid changes termed 'serial shifts' are described as resulting from two shifts, the first shift occurring when a decision rule is temporarily set aside (called a deviant case) and the second shift occurring when a new decision rule is adopted (called a shift point).

Understanding of policy implementation has received less attention from researchers but is a central concern for practitioners, as seen through the recent rise of implementation science (Glasgow, Vinson, et al., 2012). Early policy implementation studies revealed how policies are not always implemented as designed or intended. The notion of 'street bureaucrat' (Pressman & Wildavsky, 1984) has been very important in highlighting the role of front-line workers in any policy and service delivery system in exercising discretion.

The need for further research of the policy process in relation to behavioural health is recognized as a core action of the Bangkok Charter, which declared a commitment to build capacity for research to address the determinants of health.

What Are the Common Approaches Used in Policy Research?

Methodologies commonly used in policy research include controlled/quasi-experimental, comparative or historical analysis and participatory action research (PAR). Both quantitative and qualitative methods may be used or used in combination. Common study designs used include rigorous impact evaluation and case study, using survey and interview as data collection instruments. A prospective approach to the study of the policy process is not commonly undertaken due to difficulty accessing information in relation to the processes which occur in policy-making. With retrospective studies the difficulty is access to key players and their memories (or the need to construct history).

The appropriate study design and methods to be used will be determined by the research question under investigation. This approach is well recognized in public health and public policy research (Baum, 2008a; Carter, 2009; Dunn, 2012; Saks & Allsop, 2013) and is consistent with good political science (Moses & Knutsen, 2007). For example, in studies of the cross-sectoral policy process, the use of an empirical methodology provides access to the various actors involved and provides insight into the various roles of different sectors and the importance of leadership in developing and implementing policies for health. The use of intensive methods such as case study and interview enables the collection and analysis of relevant data. The integrated use of both qualitative and quantitative data enables recording of the views of various actors and stakeholders as well as demonstration of changes occurring over time (Shankardass, Solar, et al., 2011). The strengths and limitations of each of the approaches commonly used in policy research are discussed below and summarized in Table 25.1.

Before describing policy research methods in detail, it is important to note that these methods are not mutually exclusive but may be used with each other and in varied combinations. Examples in the following pages recur as illustrative of several methods. This reflects an important aspect of policy, that is, its need to bring together and integrate diverse evidence, observations, as well as perspectives and interests of varied individuals, groups, and organizations.

Experimental and Quasi-Experimental Methodologies

Rigorous impact evaluation is a quasi-experimental methodology used in research to inform public health policy. Quasi-experimental and other controlled methodologies are used, often in combination, due to the capacity of these approaches to minimize bias. Experimental methodologies and study designs such as randomized controlled trials (RCTs) are not used due to issues with feasibility and/or ethical barriers often present in studies of policy interventions. Also, the plausibility of extrapolation of evidence produced by RCTs across complex causal chains underlying public health interventions is considered insufficient to inform policy decisions regarding such interventions (Victora, Habicht, & Bryce, 2004).

Policy evaluation using rigorous impact evaluation approach may use randomized and controlled study design features when feasible. However, other design features are used in conjunction with these, such as observational and analysis techniques, in order to generate evidence of plausibility. Evaluation studies using such a study design can inform policy decisions in relation to ongoing funding, changes to or cancellation of public health programmes. The World Bank, for example, uses this approach to measure the effectiveness of development programmes in poor and vulnerable populations in the areas of child development and nutrition, education, health systems, water supply, sanitation and hygiene. This type of study design is used to investigate how health-related behaviours can be improved by reforms and interventions that focus on areas such as social norms and practices, education, economic assets and cash transfers, reducing violence and accountability mechanisms (World Bank, 2015b).

The key advantage of this approach is the strength of the evidence provided through the use of baseline data and a control group. Without the use of such a rigorous approach to programme evaluation, health improvements in developing countries, for example, may be attributed to improvements in economic growth and public service delivery rather than to programme interventions (World Bank, 2015c). Studies undertaken of such programmes have demonstrated that rigorous impact evaluations can be conducted in a cost-effective and timely manner. However, this approach requires that the relevant evaluation is planned in advance, prior to programme implementation, including the methodology to be used. Such forward planning allows for collection of baseline data, identification of study groups with similar characteristics and random allocation to programme implementation and non-intervention groups.

A natural experiment methodology may be adopted, where random or controlled allocation of population groups is not feasible (Des Jarlais, Lyles, & Crepaz, 2004). In such studies, standardized reporting of results is important, in order to facilitate synthesis of findings to inform policy decisions.

Table 25.1 Common approaches in policy research: advantages and limitations

Policy research approaches	Advantages	Limitations	Examples
Rigorous impact evaluation Compares programme outcomes with outcomes of control group	Provides rigorous evidence of programme effectiveness to inform policy decisions regarding ongoing programme funding. Can be conducted in a cost-effective and timely manner	Allocation to control and programme recipient groups must be in place prior to programme implementation and a systematic and transparent method must be adopted	• Strategic Impact Evaluation (World Bank, 2015b) • Building Parental Capacity to Help Child Nutrition and Health: A Randomized Controlled Trial (World Bank, 2015a)
Comparative and historical analysis Identifies and explains differences and similarities among cases using shared concepts and seeks to make inferences in relation to generalizability	Enables comparison of policy initiatives in different contexts and sheds light on implications for application in other contexts	Inferences drawn in relation to policy factors in one setting may not apply in other contexts/populations, managing complex data can be a limitation	• Getting Started with HiAP: Results of a Realist-Informed Scoping Review (Shankardass, Solar, et al., 2011) • Towards the integration of HiAP: a Québec–South Australia comparison (Department of Health South Australia, 2010)
Participatory action research (PAR) All participants and researchers work together as fellow subjects in a collaborative and cyclical process, reflecting on their own experience and taking action based on understanding of context in order to achieve common goals	Allows for development and refinement of new policy based on issues arising during policy design, implementation and evaluation, by policy-makers and other stakeholders working together	May require long and complicated negotiation and reflection to reconcile values and demands of various participants – community members, practitioners and policy-makers	• Using participatory action research to build healthy communities (Minkler, 2000) • Participatory action research on public health policy development for physical activities in local administration organizations, Chiang Mai Province, Thailand (Sarobol, 2012) • Challenging HiAP, an action research study in Dutch municipalities (Steenbakkers, Jansen, et al., 2012)
Literature review and systematic review Primary studies relevant to the particular research question are identified and appraised	Generates evidence to inform policy decisions, can also identify need for further primary studies to address particular policy questions	Primary studies may not have been conducted or may not have produced evidence which answers particular policy question	• Effective drunk driving prevention and enforcement strategies: approaches to improving practice (Australian Institute of Criminology, 2014) • Effectiveness of Mass Media Campaigns for Reducing Drinking and Driving and Alcohol-Involved Crashes: A Systematic Review (Elder, Shults, et al., 2004) • Increased police patrols for preventing alcohol-impaired driving (Review) (Goss, Van Bramer, et al., 2008) • Interventions in the alcohol server setting for preventing injuries (Review) (Ker & Chinnock, 2008)

Case study Empirical research drawing on multiple sources of evidence in context, can be descriptive or explanatory	Provide detailed view of policy in context, can describe complexities of how particular policies are developed or implemented and explain how and why they are effective. Allows development of research methodology, as more is known about the context	Inferences drawn in relation to policy factors in one setting may not apply in other contexts/populations	• Case studies of HiAP implementation from South Australia, Finland, Norway, France, Wales and Thailand (Department of Health South Australia, 2010) • A case study of the role of HIA in implementing welfare strategy at the local level (European Observatory on Health Systems and Policies, 2006) • Case study South Australian HiAP Initiative (Government of South Australia, 2013) • Case studies of HiAP as a strategic policy response to NCDs (Lin, Jones, et al., 2014) • Case studies of governance mechanisms for HiAP (McQueen, Wismar, et al., 2012) • Case studies of equity-focused HiAP activities (Shankardass, Solar, et al., 2011)
Quantitative methods Data on single variables expressed in numbers, useful for understanding cause and extent of behaviour-related public health issues	Descriptive data can be summarized graphically, inferential statistics can be used to support generalization	Provides limited contextual data, missing data can introduce error or bias, sparse categories can limit basis for comparative analysis	• Using social network analysis to examine decision-making on new vaccine introduction in Nigeria (Wonodi, Privor-Dumm, et al., 2012)
Qualitative methods Data on multiple variables expressed in words, enables detailed exploration and increased understanding of issues effecting population groups	Allows for description, understanding and interpretation of complexities, such as roles of multiple stakeholders and variations in political, economic and social context	Missing data can introduce error or bias and limit generalizability	• HiAP: An EU literature review 2006–2011 and interview with key stakeholders (Howard & Gunther, 2012)
Mixed methods Integrated use of qualitative and quantitative methods	Allows for measurement of complexity and variation inherent in public health policy processes and content	Methodologically complex	• Racial and Ethnic Approaches to Community Health project (REACH) United States (Blas & Kurup, 2010; Institute for Family Health, 2014) • Developing and Evaluating Best Practice in User Involvement in Cancer Services (Tritter, 2013) • North Karelia Cardiovascular Study (Baum, 2008a) • Evaluation National HIV/AIDS Strategy (Feachem, 1995)

Sources: Halperin and Heath (2012), Baum (2008a), Padgett (2012)

For example, in evaluation studies of interventions for HIV prevention, a non-randomized trial design is used together with agreed guidelines for reporting research design, theories used, intervention and comparison conditions and methods of adjusting for possible biases.

Comparative and Historical Analysis

Comparative and historical research is also increasingly recognized as important in health policy research. Policies are often context specific yet there are features and dynamics that are shared across countries and communities, so comparative analyzes can help tease out the context specificity and universality (Halperin & Heath, 2012). Comparative studies have examined policies to promote behaviour to prevent non-communicable chronic diseases such as heart disease and diabetes and to control the spread of communicable diseases such as HIV and SARS.

In comparative research the purpose of comparison may include exploration, explanation or evaluation (Saks & Allsop, 2013). Explanatory studies make best use of the analytical potential of the comparative research design, although exploratory comparative studies indicate differences and similarities observed. Evaluation

HiAP: Results of a Realist-Informed Scoping Review of the Literature

The comparative analys`is of HiAP cases conducted by the research team at St Michael's Hospital Canada (Shankardass, Solar, et al., 2011) compared the success of the implementation of particular HiAP activities across 16 different countries. This study was commissioned as part of a broader set of studies and consultations by the Ministry of Health and Long-Term Care to assess the feasibility of a government-wide HiAP approach to reducing health inequities in Ontario.

An international scoping review of scholarly articles and grey literature on equity-focused policy initiatives produced 163 documents describing intersectoral health policies in 43 countries. A total of 16 cases of the use of specific HiAP approaches were identified in the following countries: Australia, Brazil, Cuba, England, Finland, Iran, Malaysia, New Zealand, Northern Ireland, Norway, Quebec, Scotland, Sri Lanka, Sweden, Thailand, and Wales.

Adopting a comparative analysis approach as well as a systematic realist approach in this study facilitated comparison of programmes in different countries and discussion from an explanatory perspective, unpacking how implementation of HiAP policies had been found to work in addressing 'lifestyle or behaviour' factors and working and living conditions. The researchers reported that no single design feature leads to successful implementation of the HiAP approach, but the following trends were observed:

- HIA or other tools or mechanisms were used to assess impact and evaluate interventions in the health sector or other sectors outside healthcare.
- Midstream interventions were aimed at reducing behavioural factors, and the effects of these factors were also mitigated by healthcare service-related interventions (downstream interventions).
- Universal policy initiatives were combined with targeted policy initiatives, but most policy activity was related to the target group.
- Recognition of the social determinants of health at the level of government enabled involvement of sectors outside healthcare and non-governmental stakeholders.
- Interdependence across sectors such as sharing of budgets was considered important rather than simple information sharing or cooperation.
- Use of purpose developed and existing tools and structures to support coordina-

tion for HiAP including formal intersectoral committees, budget development processes and decision support tools.

- HiAP appeared feasible for improving population health inequities in both strong and weak welfare states.
- Fewer HiAP cases focussed on outcomes across the entire population, most were focussed on reducing health disparities between subgroups.
- A mix of horizontal and vertical integration management strategies were used, approaches were varied but tended to be linked to the management and delivery of primary health care where this was aimed more broadly, that is, towards social and economic development, or in other cases intersectoral strengthening was itself a government goal, for example, in UK Health Action Zones.
- The leadership role played by the health sector varied, as did rationale for improving health inequity, including national development goals to address political turmoil, a tradition of cross-sectoral approaches to development as part of political ideology and a drive for state efficiency.

The researchers recommended that more studies of HiAP are needed, using interview and case study methods, in order to understand variations in roles of different sectors and the importance of leadership in HiAP and to examine the types of relationships and mechanisms that support HiAP in particular settings, which can then inform the initiation and implementation of HiAP in other settings.

studies assess the implementation or impact of particular policies of interest such as HiAP.

In another study comparative analysis was used to benchmark jurisdictions with the highest levels of health and the best health behaviours in Canada and internationally (Manuel, Creatore, et al., 2009). Studies of the Racial and Ethnic Approaches to Community Health (REACH) programme in the United States and the Communities for Health programme in England provide an example of the use of comparative analysis for evaluation of behavioural health programmes (Blanchard, Narle, et al., 2013). This comparative analysis resulted in suggested priority areas of action for policy to address behavioural risk factors for NCDs and provided strategies and actions for NCD reduction globally.

The comparative analysis of HiAP in Quebec and South Australia identified similarities in both settings (Department of Health South Australia, 2010). In Quebec HIA is a legislative requirement, and in South Australia the State Strategic Plan gives the Department of Premier and Cabinet a key role in health. Through the use of the comparative analysis method, the implementation of HiAP was shown to benefit from similarities of context in the two countries, including (a) high-level government mandate, (b) engagement of a central government agency, (c) high-level cross-sectoral governance structures and actors, (d) working ‘upstream’ as early as possible in the policy process and (e) policy focus based on a determinants approach to health.

Policies are often path dependent and therefore an understanding of history can explain not only the present but potentially predict dynamics into the future. A study of alcohol policy in the European Union (European Observatory on Health Systems and Policies, 2006) is an example of the use of historical and comparative analysis to inform policy for health. This study was undertaken following policy developments which had been taking place over a number of years including loosening of EU alcohol policies and opening up of alcohol markets in Nordic and Baltic states. The researchers analyzed the history of policy developments leading to increased alcohol consumption and compared potential policy options to limit alcohol consumption including ‘hard law’ such as legislation and regulations and ‘soft law’ such as recommendations and strategies.

Policy studies are often event or decision based as they may be the embodiment or culmination of a set of policy processes. The study of alcohol policy in the European Union discussed above is such an example, as this study was undertaken to address increasing alcohol-related harm in Finland and to inform a submission on the EU alcohol strategy.

Recognized limitations of comparative studies include (Saks & Allsop, 2013):

- When choosing comparable cases, using cases with functional equivalence is important. This depends on the particular framework of the research design, cases with multiple characteristics which are identifiably similar or different. Countries with broad similarities are best – similar economic wealth, stable democratic political systems and developed welfare states.
- Identifying comparable units for comparison can be problematic, for example, specific health policies, health outcomes and health services.
- Managing complexity of data can be problematic.
- The use of ideal types and typologies; these need to be employed cautiously.

Participatory Action Research

Participatory action research (PAR) has been increasingly adopted as a way of engaging with and improving policy interventions as they unfold. Realist approaches framed around theories of change are an important underpinning of participatory action research, straddling the natural and social sciences and naturalist and constructivist methodologies (Moses & Knutsen, 2007). This method allows for the development and refinement of new policy based on issues arising during policy design, implementation or evaluation (Baum, 2008a). This approach is used in policy research to understand how policy works in context and the mechanisms at play in policy implementation and policy outcomes, focusing on necessity and contingency.

Using this methodology in social research, various stakeholders, such as academics and community members, work together for mutual benefit. The contradictory role of power and privilege is recognized in this approach, which can challenge these issues and integrate education and social action to improve health and reduce health disparities (Wallerstein & Duran, 2006). When using this participatory methodology, fellow researchers work in a collaborative and cyclical process, reflecting on their own experience and taking action based on understanding of context in order to achieve common goals. The cycle is described as a spiral of processes involving planning, acting, observing and reflecting (Baum, 2008a).

Examples of the use of the participatory action research method are found in the Healthy Cities and Healthy Communities Projects. This method has been used in many of these projects, with ‘experts’ and citizens working together incorporating high-level community participation in various aspects of the research process (Minkler, 2000). The usefulness of the participatory approach is recognized in cultural competency research. Community input to design, implementation and evaluation of programmes was recommended by the US Office of Minority Health and Agency for Healthcare Research and Quality in the report on research on cultural competence in healthcare (Fortier & Bishop, 2003). However, in order to measure and validate elements of culturally competent health promotion programmes (CCHP), controlled studies are also recommended.

The work of the National Health Assembly in Thailand is another example of PAR. This legislative body acts as part of a learning process as well as an instrument to develop participatory public policies on health at local and national levels (Lin, Jones, et al., 2014). Behavioural health issues considered in the 2012 National Health Assembly include food safety, air pollution, systems to support walking and cycling, children and IT, among others. The NCD prevention project conducted in Chiang Mai Province in Thailand is a particular example of the use of participatory action research. Public health policies to promote physical activity were developed, as well as a model for development by the community of public policies for health. Local community members and local organization officers in two municipalities used PAR at all steps of the process to develop policy to address NCDs in working and elderly people (Sarobol, 2012). In Holland PAR was used in the evaluation of implementation of HiAP interventions targeting obesity and showed that coaching for municipalities by the regional public health service stimulated the development of HiAP (Steenbakkers, Jansen, et al., 2012).

Limitations of participatory action research as a method in policy research include the long and complicated negotiation and reflection required to reconcile values and demands of various participants – community members, practitioners and policy-makers (Baum, 2008a).

Case Study

The usefulness of the case study method in policy research is recognized (Baum, 2008b; Halperin & Heath, 2012) as this method can provide a detailed view of policy in context, describe complexities of how particular policies are developed or implemented and explain how and why policies are effective. The case study method also allows development of research methodology as more is known about the context. The intensive methods used in case studies are recognized as useful in providing much needed information about the practicalities of implementing the HiAP approach successfully. For example, the findings of the global review of 16 cases of HiAP activities described above (Shankardass, Solar, et al., 2011) highlighted the importance of budget sharing and tools and structures to support HiAP. The case studies of governance mechanisms for HiAP in the European Union, North America and Australia (McQueen, Wismar, et al., 2012) found that structures effective in achieving HiAP include committees at the levels of parliament, government and the public service, engagement with stakeholders and particular funding arrangements. Such structures were found to facilitate governance actions in relation to planning, implementation and management, research and legal mandating.

Case studies conducted of HiAP initiatives worldwide have examined policy for behavioural health in the European Union, the United Kingdom, North America, Australia and Thailand (Department of Health South Australia, 2010; European Observatory on Health Systems and Policies, 2006; Government of South Australia, 2013; Lin, Jones, et al., 2014; McQueen, Wismar, et al., 2012; Shankardass, Solar, et al., 2011). Case studies have addressed topics related to behavioural health including:

- The use of the HiAP approach to address behavioural health risk factors such as physical activity, healthy eating, alcohol and tobacco
- Recognition of social determinants of health in addressing behaviour-related health issues
- HiAP case studies from health, work, digital technology, food and agriculture, alcohol and environment sectors
- Benefits of the HiAP approach for sectors other than health
- Systemic approaches to policy-making
- Equity-focused intersectoral policy initiatives
- Implementation challenges, effective strategies, governance structures, mechanisms and instruments for HiAP
- Mobilizing community action for healthy policy

Case studies demonstrate the utility of tools such as HIA and Health Lens Analysis in implementing HiAP. For example, the case study of the use of HIA to implement welfare strategy in a city in Finland (European Observatory on Health Systems and Policies, 2006) highlighted the importance of a procedural link between HIA and the decision-making process.

Case studies are also often undertaken as a way of using particular instances to elucidate the general. For example, the study of 158 cases of the use of HIA concluded that, in principle, it is possible to use HIA as a tool for implementing the HiAP approach, although due to the limited activities observed at national level, it was difficult to assess the effectiveness of HIA for this purpose (European Observatory on Health Systems and Policies, 2006). This research for HiAP policy analyzed case studies from the health, work, food and agriculture, alcohol and environment sectors in the European Union and identified benefits of HiAP for sectors outside

Health in All Policies Prospects and Potentials

This report forms part of a project under the auspices of the European Observatory on Health Systems and Policies, exploring the prospects and potential of HiAP to improve population health in Europe. The project took place against the background of the Lisbon Agenda which recognizes the importance of population health for economic stability and social cohesion in Europe and in the context of decreasing fertility rates, the ageing population, the obesity crisis, increasing chronic disease and healthcare costs and health workforce shortages.

This work was undertaken in the context of the Finnish Presidency of the European Union and aimed to emphasize the unique mandate and obligation of the EU to protect health in all its policies and to examine principles and challenges of the use of HIAP in moving health higher up the European agenda. The scope of the studies reported includes review of the theories, concepts and challenges in regard to HiAP in the European context, analysis of concrete examples of the use of HiAP in various fields and review of governance mechanisms used for HiAP with particular focus on HIA.

Methods used included reviews and case studies. Case studies were conducted of the use of HiAP in various fields including heart health promotion, working life, food and agriculture, alcohol policy and the environment. A review was conducted of governance mechanisms for implementation of HiAP, and challenges of horizontal health policy were examined. The Finnish experience of the preparation of national health reports was reviewed as an example of getting other sectors involved with and committed to intersectoral cooperation. Case studies of the use of HIA as a tool for HiAP were analyzed in 158 instances across Europe, with a focus on the implementation and institutionalization of HIA. A Finnish case study describes the role of HIA in implementing welfare strategy at the local level.

The findings of the project identified benefits of HiAP for sectors outside health as well as challenges and barriers to HiAP. Mechanisms and instruments for HiAP required to keep health high on the agenda are also discussed. Benefits of HiAP identified include healthier workforce, increased productivity and economic benefits – policies can affect the relationships among health, work and productivity, and health is a prerequisite for the latter two; advances in health made through policies in other sectors including education, environment, water and sanitation, planning, labour, housing, traffic, agriculture and nutrition. In principle, HIA was found to be a useful tool for implementing the HiAP approach, although the researchers concluded that further development of the use of HIA is needed. The study of heart health concluded that population health can be improved through policies, legislation and regulations in relation to tobacco smoking, physical activity levels and food quality.

Challenges and risks identified for the use of HiAP include conflicting priorities of other sectors in relation to agriculture, food and alcohol; the need to strengthen the analyzes of health impacts as well as the consideration of impacts on policy-making; the impact on costs of healthcare of other policies, for example, international trade; the need to consider health equity and the distribution of the impact of policies of other sectors across populations such as alcohol on low SES groups; the need for policy coherence – sectoral and organizational barriers need to be addressed; public support for HiAP is needed so public information and knowledge, civil society consultations and involvement of NGOs are all important, and in order to secure necessary political support, political ownership of HiAP is required at the highest level.

Mechanisms and instruments needed for HiAP include legal mandates for HIA and health surveillance to keep health high on the agenda; partnership and alliance building such as permanent intersectoral committees for transparency of policy process, timely HIA and comment and dialogue on policy proposals; availability of relevant knowledge and evidence; and identification of alternative policy options (European Observatory on Health Systems and Policies, 2006).

health including healthier workforce, increased productivity and economic benefits.

Another example of the use of the case study method to develop useful generalizations is the collective evaluation of five cases of the use of Health Lens Analysis for HiAP conducted in South Australia (Government of South Australia, 2013). This study enabled identification of common themes in implementation of the HiAP approach including:

- Policy changes which impact on the social determinants of health
- Greater understanding and stronger partnerships between health and partner agencies
- Increased understanding by policy-makers of the impact of their work on population health and health equity
- Development and dissemination of policy-relevant research
- Willingness to use the Health Lens Analysis process and adopt HiAP philosophy in future work
- Learning for all involved about redefining goals for HiAP, problem definitions and strategies, as well as dialogue and interaction among stakeholders.

One of the case studies described the use of the Health Lens Analysis in a project aimed at raising parental engagement with literacy to improve literacy outcomes for children and ultimately improve their health, with a focus on low socioeconomic families. Another of the Health Lens Analysis case studies demonstrated that the use of the HiAP approach enabled consideration of the health and well-being implications within the core business of a non-health government sector. Working together, the health department and the department of education, science and technology considered social and equity issues associated with increasing broadband uptake, together with the associated technological issues. Both positive and negative health impacts were associated with the use of digital technology, and use was linked to socioeconomic indicators such as education and literacy, employment status and income. Even when there was access, use was limited by individual capacity, digital literacy and confidence and insufficient financial resources.

Limitations of the case study method recognized in public policy research relate to transferability of findings, as inferences drawn in relation to policy factors in one setting may not apply in other contexts/populations (Halperin & Heath, 2012). The use of various pattern-matching methods (Dunn, 2012) such as comparative analysis discussed below enhances potential for generalizability of case study findings. Selection bias can be an issue in case studies. For example, as only 13 of 18 invited countries participated in the study of opportunities and barriers for the implementation of HiAP (Howard & Gunther, 2012), the researchers recognized that selection bias may have occurred, as those countries with more positive experiences of implementing HiAP may have been more likely to participate.

Systematic Reviews

Reviews of primary studies are often conducted in order to generate evidence to inform policy decisions, for example, in relation to behaviour-related health issues such as tobacco (Fichtenberg & Glantz, 2002) and drink driving. The Australian Institute of Criminology reviewed Australian and international literature on drunk driving countermeasures with the aim of identifying implications for policy and practice. This review made recommendations in relation to policy for random breath testing, publicity campaigns, penalties and targeted interventions for the general population and for recidivist drink drivers (Australian Institute of Criminology, 2014).

Systematic reviews are used to inform policy for behavioural medicine. For example, systematic reviews of studies of effective interventions to prevent alcohol-impaired driving are used to inform policy to reduce road trauma (Elder, Shults, et al., 2004). Systematic reviews include studies of various types, depending on the particular research question and also depending on the availability of evidence. Evidence is drawn from primary research studies and also potentially from a broad range of other sources. Other types of evidence may include policies and opinions of experts and consumers and other stakeholders, depending on pragmatic and contextual relevance (Carter, 2009; Lin & Gibson, 2003). For example, evidence drawn from various sources is to be included in the impact assessment of the World Health Organization Framework Convention on Tobacco Control, such as reviews of changes in legislation, as well as reviews of published studies and also stakeholder interviews and country case studies (WHO Framework Convention on Tobacco Control, 2014).

Systematic reviews are reviews conducted with the aim of summing up the best available evidence in relation to a particular research question. Essential to this process is the use of an explicit search strategy, coding and analysis of included studies, peer review and where possible meta-analysis of findings. The Cochrane Collaboration and the Campbell Collaboration conduct such reviews in fields related to behavioural medicine, such as healthcare, consumer advocacy, education, crime, social welfare and international development. The reviews which are freely available online are conducted by a global independent network of researchers, experts and stakeholders.

The capacity of systematic reviews to inform policy can be limited, however, due to lack of available or applicable evidence, particularly as published research tends to be focused on high-income (and often English-speaking) countries. Nevertheless, one key advantage of the use of this approach in policy research is the capacity of the systematic review to identify the need for further research in relation to a particular policy question. For example, systematic reviews of police patrol programmes and interventions in alcohol server settings identified insufficient evidence and recommended that further studies were required (Goss, Van Bramer, et al., 2008; Ker & Chinnock, 2008).

For policy research, the best available evidence includes evidence from the most rigorous studies, integrated with the most relevant evidence from other related sources, including the views of stakeholders. For this reason, the use of systematic reviews in which evidence is included from academic as well as colloquial sources is the preferred approach in health policy decision-making (Carter, 2009; Lin & Gibson, 2003). Policy research is complex and the key question is 'under what conditions will a policy intervention deliver the desired result'. This central concern for conditional effectiveness means that the questions of what is the best available evidence and what evidence is relevant must be considered in relation to any particular policy question.

Qualitative Methods

Using qualitative methods in policy research, data can be collected at organizational, community and individual levels through observation, interview or by accessing policy-related documents. Data analysis can be done using various approaches (Padgett, 2012) such as case study or participatory action research as discussed above, ethnography, grounded theory, phenomenological analysis, a mix and match of different qualitative methods or narrative approaches discussed in more detail below. Examples of the use of grounded theory in policy-related research are found in the review conducted of qualitative studies relating to tobacco control (Schultz, Bottorff, & McKeown, 2009). This method has also been identified as useful in the study of social determinants in women's health (Wuest, Merritt-Gray, et al., 2002). Phenomenological analysis has been used to identify factors that influence the utilization of research findings by policy-makers (Albert, Fretheim, & Maiga, 2007).

Textual analysis can also be done through a range of narrative analysis approaches (Padgett, 2012; Saks & Allsop, 2013) such as thematic coding for describing content, or through attention to form by identifying distinctive forms or stories for interpretation of meaning, or by meta-synthesis. Meta-synthesis of data is achieved through systematic review and can include integration of both qualitative and quantitative data. In some approaches qualitative data is converted into quantitative data to enable aggregation of the two different types of results, which can both then be interpreted in the meta-analysis. Different approaches to meta-synthesis are used for systematic reviews in policy research, depending on the underlying aim, particular research question, nature of the evidence and stage of policy development. Examples of systematic reviews in policy research for behavioural medicine include the Bayesian synthesis of qualitative and quantitative evidence for factors affecting the uptake of childhood immunization, the use of meta-ethnography in the study of medicine-taking behaviour, the quantitative case survey method used in the evaluation of crime prevention programmes and

Intersectoral Governance for Health in All Policies: Structures, Actions and Experiences

This project examined how countries in Europe, the Americas, Asia and Australia use intersectoral governance structures for HiAP and explains the processes that lead to health in all policies. The project was undertaken by the European Observatory on Health Systems and Policies (EOHSP) in partnership with the International Union for Health Promotion and Education (IUHPE) and encapsulates the research on how intersectoral governance structures for health operate.

The project involved an initial planning phase allowing for development of the study proposal and research framework to be adopted. During this phase fundamental conceptual issues in relation to methodological issues and governance for HiAP were discussed and clarified. Multiple qualitative methods were used including consultations with international experts, snowballing methods, an author's workshop, literature reviews, internal and external reviews of all case studies and critical reflection, revision and modification of the methodological framework developed for the study. Potential authors and HiAP cases to be included in the study were identified via the networks of the IUHPE and the EOHSP policy dialogue group.

Challenges and opportunities presented by the cultural and political diversity of the contexts of the authors and the case studies were discussed and taken into consideration. More than 20 mini case studies from Europe, the Americas, Asia and Australia were analyzed and reviewed in the context of the relevant literature; reviews were conducted by internal and external stakeholders in order to gain both perspectives. The validity of the methodological framework developed for the study was confirmed by the editors and other partners, following revision and modification based on the reflection and critical perspective of the authors and their cases.

The findings of the project include how governments and ministries can initiate action and how intersectoral governance structures can be successfully established, used and sustained; examples for policymakers of the governance tools and instruments available; and case studies which show how countries currently use intersectoral governance for HiAP. Key intersectoral structures and how they facilitate intersectoral action were identified including cabinet committees and secretariats, parliamentary committees, interdepartmental committees and units, mega-ministries and mergers, joint budgeting, delegated financing and public, stakeholder and industry engagement (McQueen, Wismar, et al., 2012).

the qualitative and quantitative narrative review of barriers and facilitators of health-related behaviour in young people (Mays, Pope, & Popay 2005).

Another example of the use of multiple qualitative methods is the study of HiAP implementation in the European Union (Howard & Gunther, 2012). Interviews provided a perspective not gained from the literature review on how things operate in practice and on the role of culture and values. Culture and values were not widely commented on by stakeholders, although in the literature review culture and values were recognized as an important factor in HiAP, with alcohol consumption shown to be higher in male study participants with less education. Also, notwithstanding the low rate of comment by stakeholders on culture and values, interview data did show that some stakeholders did see how

Health in All Policies: An EU Literature Review 2006–2011 and Interview with Key Stakeholders

The study of HiAP implementation in the European Union was undertaken as part of the Equity Action programme which aimed to develop an action plan to address increasing health inequalities in Europe. The programme aimed to identify what works and why for implementation of HiAP, build capacity in EU member states and develop practical guidance and consensus for adopting a HiAP approach to address health inequalities in the EU.

Following a decade-long reduction in poverty in Europe, in 2010 major health inequalities had been identified within and between countries in the WHO European Region. In 2011 the European parliament resolved to tackle the problem, calling upon all European Union member states to prioritize policy action to address health inequalities, taking into account the social determinants of health as well as lifestyle-related risk factors, such as alcohol, tobacco and nutrition. In keeping with this 'HiAP' approach, the response to such a call required action in policy areas such as consumer policy, employment, housing, social policy, the environment, agriculture and food, education, living and working conditions and research.

The literature review and stakeholder interviews were undertaken as a first step in the programme, in order to review the evidence in relation to opportunities and barriers for implementation of HiAP, to assess opinion on the implementation of a HiAP approach across a range of member states, countries and regions and in particular to assess how heath inequity was being incorporated within the HiAP approach and the use of HIA as a tool to implement HiAP.

The conclusions reached in the study in relation to opportunities and barriers to the implementation of HiAP related to political commitment which is needed at the highest level especially given the economic climate, the need for overarching strategies and action plans that endorse a HiAP approach and the use of dedicated people and resources to implement HIAs, the need for more partnerships particularly with communities, more skill development not only technical skills but also the softer skills such as negotiation and relationship building, prioritization of HiAP initiatives with an equity focus and a truly collaborative approach – 'health *for* all policies as well as 'health in all policies' (Howard & Gunther, 2012).

In this study use of interviews together with literature review provided fuller insight as interview findings provided a richer description of barriers and solutions for implementation. Specific pleas for support were heard, including simpler tools to support implementation and recommendations and tips for progress including the use of case studies to help raise awareness and sell the concept of HiAP. Also, few concrete examples were found of successful HiAP work undertaken with a strong equity focus. It was identified that a better understanding is needed of the difference between health inequity and health inequality/disparity (health inequity exists when population groups with differing health needs do not have fair and equal access to the basic requirements to address their particular health needs such as appropriate health services, healthy food and drink and effective help to quit smoking, whereas health inequality or disparity refers to unavoidable differences in health status among population groups). The findings of this study also identified the need for more case studies of HiAP to address behavioural health issues.

the history and tradition of public health could influence the acceptability of an interventionist approach to social determinants of health.

Another qualitative method used in policy research is realist systematic review. This model of research synthesis is used to evaluate complex social interventions (Pawson, Greenhalgh, et al., 2005) and has been recognized as particularly suitable for understanding complex policy processes such as HiAP. The realist methodological lens adopts an explanatory perspective rather than a judgemental one, unpacking how 'x' works and under what circumstances rather than asking how well did 'x' work. The use of this method facilitated identification of trends for successful implementation of HiAP interventions to address 'lifestyle or behaviour' factors and working and living conditions in 16 countries and subnational areas worldwide (Shankardass, Solar, et al., 2011).

In summary, advantages of the use of qualitative data in policy research include (a) the measurement of multiple variables and expression of the data in words, (b) detailed exploration and increased understanding of issues effecting population groups, (c) description, understanding and interpretation of complexities such as roles of multiple stakeholders and (d) variations in political, economic and social context (Baum, 2008a).

Quantitative Methods

Quantitative data in policy research can be collected at the organizational, community, network and individual levels (including polling). In the United States social network analysis was used to study how alcohol addiction is influenced by social environmental factors (Rosenquist, 2011). In Kenya, this method proved a useful instrument in understanding the social and health status of scavenging street children (Ayuku, Odero, et al., 2003).

Social network analysis has become increasingly important in understanding actor influences on policy decision-making. It can be used to identify how information is exchanged and who is included or excluded from the decision-making process. For example, in the study of vaccine decision-making in Nigeria, using data culled from interviews with government officials, as well as from partner organizations and other stakeholders such as health providers and the media, relationships were mapped and analyzed to show the distribution of influence among decision-makers and to explore linkages and pathways to stakeholders who can influence critical decisions in the policy process (Wonodi, Privor-Dumm, et al., 2012).

Quantitative methods are also important in rigorous impact evaluation and the use of big data for understanding policy impact. For example, in the evaluation of the North Karelia Project, large-scale quantitative methods were used to measure the impact on behaviour-related NCDs. Methods used included population prevalence rates for specific behaviour-related risk factors, mortality rates for particular NCDs and life-expectancy projections (Puska, 2002).

Cross-impact analysis (Dunn, 2012) is a quantitative method used in the analysis of public policy-related to behavioural health. This method has been used to study interdependent relationships among economic and health policies and outcomes. Cross-impact analysis is used to identify events that will facilitate or inhibit the occurrence of other related events, taking into account three aspects of any linkage including mode of linkage (positive or negative direction), strength of linkage and elapsed time of linkage. For example, this method was used to study the impact of increased motor vehicle production on family and community relationships, crime and alcohol addiction and identified linkages among these involving elapsed times of several decades. Some of the recognized advantages of this method include the ability to discern interdependencies that otherwise may go unnoticed and the revision of probabilities based on new evidence. Recognized limitations of this method include exclusion of relevant interdependent events due to the pragmatic problem of including a greater number of events and costly and time-consuming complex process, even with the use of high-performance computer technology. To address such limitations Dunn (2012) recommends the use of problem structuring methods to expose and debate conflicting assumptions and arguments, theory mapping and relevance trees.

In summary, advantages of the use of quantitative data in policy research include the expression of variables and factors in terms of numbers, portrayal of descriptive data such as in graphical summary and use of inferential statistics to support generalizations (Halperin & Heath, 2012). This approach can contribute to understanding the causes and extent of public health issues that are related to behaviour. The usefulness of quantitative data, however, can be limited by a lack of contextual data needed for understanding of policy processes and social determinants of health-related behaviour. Also, missing data can introduce error or bias and sparse categories can limit basis for comparative analysis.

Mixed Methods

Both qualitative and quantitative methods are used in policy research, and often it is important to use a combination of these methods. Mixed methods, the integrated use of qualitative and quantitative methods, allows for the measurement of the complexities and variations inherent in public health policy issues such as health-related behaviours. In a study of HiAP in South Australia (Government of South Australia, 2013), qualitative methods were used to include community views in policy development. The study then integrated qualitative and quantitative methodologies to identify solutions for complex policy issues such as behaviour-related health issues. In mixed methods studies, one or other methodology may dominate or the methods are used equally, in sequence or concurrently (Padgett, 2012).

Both qualitative and quantitative methods are used in the evaluation of the *Racial and Ethnic Approaches to Community Health* project in the United States. A community-based participatory approach is used that incorporates quantitative methods such as surveys and analysis of programme records as well as qualitative methods such as interviews and focus groups (Blas & Kurup, 2010; Institute for Family Health, 2014).

Well-known examples of studies using mixed methods to study behavioural health-related issues include the *North Karelia Cardiovascular Study* (Baum, 2008a) and the *Evaluation of the National HIV/AIDS Strategy* (Feachem, 1995). Another example of the use of mixed methods research to inform behavioural health policy is the study *'Developing and Evaluating Best Practice in User Involvement in Cancer Services'* (Tritter, 2013). Drawing on the expertise of the academic and voluntary sectors and health service partners, the study used a range of qualitative and quantitative methods to map and analyze user involvement, attitudes and experience.

Access to valid and reliable data of both types, qualitative and quantitative, is a challenge in public health research (Padgett, 2012). Do answers to a limited number of open-ended questions provide sufficient and valid data? Will a scale or index used in the quantification of qualitative data obtained in in-depth interviews produce descriptive statistics of limited value? Triangulation of data can present a conundrum, either when results from both sides are in accord or disagree. Despite the advantages of the use of mixed methods in policy research in allowing for the measurement of complexities and variations, this approach is methodologically complex. Researchers are advised to exercise caution and practice transparency. Trade-offs and opportunity costs involved in the use of multiple methods are recognized in public policy research, particularly in relation to time and financial constraints (Dunn, 2012). Knowledge gaps in research methods for HiAP may also be an issue, given the observation made by Dunn, that economists traditionally are not trained in data collection and the consideration of context, which is enabled through the use of qualitative methods.

What Are the Challenges in Policy Research for Behavioural Medicine?

Approaches to Policy Research

Challenges faced globally in approaches to policy research for behavioural medicine relate to approaches to research including theoretical understandings of the policy process, the use of applicable methodologies and methods and issues with data, as well as the use of evidence to inform policy.

Theories of the Policy Process

Policy theory is often derived from empirical studies rather than theoretical or review articles (Sabatier & Weible, 2014). As such, policy studies may be context dependent – so a flexible and synthetic approach to theory is advisable. The need for empirical studies of policy-making processes is recognized in the policy research literature. The findings of the international survey of policy work undertaken by Colebatch have highlighted that more empirical research is needed to study how policy workers (and which sort) get a place at the table, how the question is framed, what discourse is accepted as valid and how this work relates to the outcome at any point in time (Colebatch, 2006).

Methodology

In order to address the ‘wicked’ problems posed by the social determinants of health, countries must work together (European Observatory on Health Systems and Policies, 2006) to further develop methodologies for assessing impacts of proposals on health systems and determinants of health, such as the impact on nutrition and public health of policies which influence food supply and demand. Development of methodology for surveillance of determinants is also needed.

To address the ‘wicked’ nature of behaviour-related public health problems, researchers have identified the need for new forms of learning and knowledge management and can draw upon the foundation of HiAP in public health sciences to further develop methodology for the study of HiAP (European Observatory on Health Systems and Policies, 2006). The International Meeting on Implementation of HiAP (Department of Health South Australia, 2010) has highlighted that new approaches to health policy must encompass the global industry of health-related products and services, with consideration given to trade regimes, and industry approaches to innovation and corporate responsibility. Therefore there is a need to study a ‘different logic’ – the logic of the decisions of other sectors – as described by the World Health Organization’s 2008 World Health Report on Primary Healthcare, so that working within their frameworks, using their language, and based on their desired outcomes, equity and social determinants of health can be addressed.

Further development of evaluation methodology is needed, and methodology that captures HiAP’s need to be flexible, sensitive and responsive (Department of Health South Australia, 2010). The development of policy evaluation methods needs to be done before policies are introduced (European Observatory on Health Systems and Policies, 2006) – this is important from a logistical standpoint. Also, future studies need to accommodate lack of consensus on fundamental concepts and definitions and where possible build consensus (McQueen, Wismar, et al., 2012).

The use of more intensive research methods is needed, such as case studies to evaluate equity-focused HiAP initiatives (Howard & Gunther, 2012) and interviews and case studies to understand variations in roles of different sectors and the importance of leadership in HiAP (Shankardass, Solar, et al., 2011). The integrated use of qualitative and quantitative methods is needed to capture changes in sectors outside health and also to include community views in policy development (Government of South Australia, 2013). Methods are also needed to capture less tangible outcomes of HiAP work, outcomes such as long-term changes in policy culture in agencies outside of health, including relationship building and knowledge transfer among project group members (Government of South Australia, 2013). Improved access to relevant data and wider consultation with stakeholders have been identified as important, as well as increased capacity and capability in data analysis (McQueen, Wismar, et al., 2012) (Howard & Gunther, 2012).

The most critical lesson from policy research is to draw out what may be generalized from one setting to another. Policies can seldom be replicated, transferred or scaled up as if realities were comparable everywhere. Consideration of the use of appropriate methodology and research methods, together with consideration of context, social determinants of health and the involvement of health users, are all important. A pragmatic integrated approach is needed in policy research, using methodologies drawn from both constructivist and positivist paradigms. A constructivist approach understands knowledge to be a human construct and sees the researcher as an active participant in the research process, drawing conclusions by induction, moving from specific observations to broader generalizations and theories. A positivist approach understands knowledge as obtained through independent observation of naturally occurring phenomena. Together these approaches are capable of generating rigorous evidence including sufficient relevant detail in relation to the particular intervention or policy under evaluation. A description of the research methods used and the context of the intervention/evaluation are also required (Lin & Gibson, 2003).

Use of Evidence to Inform Policy

For policies to have the desired effect on behaviour, research evidence needs to underpin policy development and implementation. However, research evidence in relation to the prevalence and cause of behaviour-related health issues – and even evidence for effective interventions – is no assurance for policy adoption or implementation. For this reason key challenges for policy research for behavioural medicine include knowledge translation. Numerous strategies including knowledge brokerage, change agendas, diffusion networks, long-term liaison and communication training can be used to promote the uptake of research findings by policy-makers and policy managers charged with the implementation of innovative policies for behavioural medicine (Lin, 2008).

Good information infrastructure is important to track policy impacts over time and to understand the complex interactions among policy measures and other social, economic, environmental, cultural and political factors that affect behaviour of individuals, communities and social institutions.

Besides the importance of information, end users of policy research (be they politicians, bureaucrats, community leaders or health service providers) must be engaged – to inform prioritization of research questions, to shed light on potential unanticipated consequences of policies, to contribute to interpretation of results and to deliberate on implications of research for action.

The Nature of Evidence

Policy-makers are typically concerned with making decisions of a practical nature at a community level and so look to the available evidence as to what interventions are most likely to work in the population in question (Lin & Gibson, 2003). Given the realities and constraints of situations in which policy-makers are required to intervene, and the need for immediate resolution, the relevance of the available evidence at hand is of most importance. So the nature of evidence required by policy-makers is not what works or does not work on average for individuals with particular conditions derived from research and irrespective of context, as constructed in the study of clinical interventions. For this reason the adoption of a narrow application of evidence-based medicine to health policy may not accord with the reality of different communities and population groups. For example, according to the 'what counts is what works approach' adopted under NICE policy in the United Kingdom, there is an expectation that funding will not be continued where there is no evidence of effectiveness. Yet, policy interventions are typically adapted during implementation to suit the needs and contexts of different population groups. Furthermore, policy evaluation may not address the complexities of policy implementation (Pressman, Wildavsky, & Oakland Project, 1979). Evidence in relation to why particular policies are not effective can be used to make recommendations for further policy development. For example, the evaluation of coordinated care trials in Australia identified failures in both policy design and implementation and made recommendations for health system reform in order to improve care coordination (Segal, Dunt, & Day, 2004).

In adopting an evidence-based approach to health policy, cross-discipline thinking is required within the health sector, and beyond the health sector, cross-sectoral thinking is required, in particular, economic thinking. Increasing costs to the health sector as well as other sectors are attributed to issues in the delivery of healthcare, such as lack of cost/benefit analysis in terms of gains in quality of life, employer-funded insurance, overdiagnosis and lack of attention to patient preferences (Kaplan & Porzsolt, 2006). More empirical research is needed to study how policy workers (and which sort) get a place at the table, how questions are framed, what discourse is accepted as valid and how this work relates to outcomes at any point in time (Colebatch, 2006).

Involving Health Users in Research

Involving health users and community interest groups in research is another challenge for behavioural health policy research. The benefits of including healthcare users in research that aims ultimately to change their behaviours may appear self-evident. Research findings demonstrate that including the perspective of health users in research is important in increasing compliance with medical advice (Tritter, 2013). Involvement of healthcare users in research is also recognized as improving health outcomes, through improving the relevance, applicability and implementation of findings (Hill, 2013). Involving health users in research is recognized as important in generating evidence required by policy-makers in relation to the values and interests of community groups, as well as the relative efficacy of different policy options and the distribution of costs and benefits across different interest groups. A further challenge is to strengthen community capacity to engage in policy dialogue and demand evidence-based health policies (Lin & Gibson, 2003).

Involving healthcare users in policy research is recognized as a complex process, which may require some reorganization and structuring within the health sector, expansion and diversification of health consumer groups and associated organizations, as well as workforce training in particular research knowledge and skills (Hill, 2013).

Agendas in Policy Research for Behavioural Medicine

There are many issues about policies for behavioural health that warrant further research. These include policy process, policy tools and policy designs and impact. The global epidemic of chronic, non-communicable diseases is central to this agenda. Although it is important to consider best buys in interventions for specific diseases and risk factors (World Health Organization, 2011a), it is important also to consider the equity impact of interventions. The need for more case studies of policy initiatives targeted to address health inequalities and with a particular focus on determinants has been highlighted by both the review of implementation of HiAP in the European Union (Howard & Gunther, 2012) and the global review of equity-focused intersectoral initiatives (Shankardass, Solar, et al., 2011). Similarly, while there is much interest in adopting HiAP as a whole-of-system approach, there are many research gaps about the process and the effectiveness.

As part of the process, there are tools being developed, such as health impact assessment, but their use and effectiveness still need to be better documented and understood. Besides policy process, there is still a need to understand the policy advocacy dimensions better. The challenge for behavioural health policy is to understand how decisions to change priorities are made and how to raise the profile of the social determinants of health on the central agenda of government.

Policy research can be focused on policy as an intervention or as a context for other interventions, so sorting out complex intermingling relationships is difficult. There is a need to be clear about the circumstances, the relationships among actors, the frames of reference of actors, the object of intervention and the relationships among various interventions.

The mandate and responsibility of organizing health services exists at national or even local level; however, the framework in which it can be done is increasingly determined at levels beyond the national. For example, policies on international trade, markets, competition, industry and linked policy objectives on taxation and the size of the public sector and its services may all have important direct consequences for the health sector and its costs.

Addressing Chronic Diseases

One central challenge in behaviour-related health research is to develop an assessment approach for chronic disease. One possible model is the World Health Organization assessment approach, suggested by the policy think tank, Mitchell Institute in Australia (Mitchell Institute, 2014). The selected approach would be adopted to report quantitative trends in behavioural risk factors for chronic disease and provide qualitative assessments on the infrastructure required to prevent chronic diseases, such as public commitments, funding and the range of interventions including future priorities for action. The use of such an approach which could assist in turning theory into practice in health behaviour for chronic diseases such as cardiac disease presents the greatest challenge (European Observatory on Health Systems and Policies, 2006).

HiAP Policy Processes

Understanding policy processes is important when new policy approaches are adopted, such as HiAP. The key issues relate to governance structures and actions and degree of policy coherence and design of effective policy interventions – including return on investment and distributional consequences (Department of Health South Australia, 2010; European Observatory on Health Systems and Policies, 2006; Lin, Jones, et al., 2014; McQueen, Wismar, et al., 2012). Examples of policy research for HiAP are summarized in Table 25.2.

Design of Effective HiAP Interventions

No single design feature has been found to lead to successful implementation of the HiAP approach. Instead, a variety of trends have been observed such as in the review of 16 cases of HIAP interventions to address 'lifestyle or behaviour' factors, described in detail earlier (Shankardass, Solar, et al., 2011).

Preconditions for effectiveness of intersectoral policy interventions have been identified (Lin, Jones, et al., 2014). Factors essential for success of HiAP interventions include political context, horizontal governance, leadership, political commitment, human and financial resources, information and research, policy analysis tools, health sector role, partnership management, stakeholder engagement including across portfolios as well as outside government including civil society, immediacy of the problem, political importance, expectations and prospects of a workable policy solution, entry points and monitoring and evaluation of policy effectiveness.

Research has highlighted potential returns on investment offered by effective HiAP interventions, including improved productivity, economic growth and stability (European Observatory on Health Systems and Policies, 2006). The European Public Health Programme study to address the considerable burden on the economy attributed to obesity, tobacco use and

Table 25.2 Studies of health in all policies (HiAP)

Title	Policy focus	Findings in relation to HiAP policy processes	Findings regarding challenges in policy research
HiAP as a strategic policy response to NCDs. Health, Nutrition and Population discussion paper (Lin, Jones, et al., 2014)	Review of recent developments in HiAP policy initiatives including intersectoral mechanisms and partnerships to address NCDs including behavioural risk factors	HiAP offers an approach to secure coordinated action on behavioural health risk factors such as physical activity, healthy eating, alcohol, tobacco and also mobilizing community action for healthy policy	In order to effect and secure HiAP, there is a need to better understand: governance actions and their relationship to governance structures and processes, agenda setting, policy formulation, implementation and evaluation and effectiveness of interventions
South Australian HiAP Initiative Health Lens Analysis Case Study (Government of SA, 2013)	This case study aimed to evaluate the effectiveness of the Health Lens Analysis model in identifying evidence-based public policy to address social determinants of health and build capacity for HiAP implementation and also to benchmark with other models	Outcomes of Health Lens Analysis included policy changes which impact on social determinants of health, stronger cross-sectoral partnerships, development and dissemination of policy-related research and willingness to adopt HiAP in future work	Need to integrate qualitative and quantitative methods to capture changes in sectors outside health, need to identify ways to include community views in policy development and also to adopt HiAP at programme and service delivery levels
Intersectoral Governance for HiAP. Structures, Actions and Experiences (McQueen, Wismar et al., 2012)	An analysis of effective intersectoral governance mechanisms for HIAP in the European Union, North America and Australia	Identified intersectoral governance structures effective in achieving HiAP	Access to information is an issue, either limited information or too much. Future studies need to identify factors influencing action in and on HiAP and accommodate lack of consensus on fundamental concepts and definitions and where possible build consensus
HiAP: An EU literature review 2006–2011 and interview with key stakeholders (Howard & Gunther, 2012)	Identifies opportunities and barriers to HiAP implementation in the European Union in order to tackle health inequalities by addressing social determinants of health and lifestyle-related risk factors	Policies are needed which support development of overarching strategies and action plans which endorse a HiAP approach and promote working in partnership particularly with communities	Wider consultation and increased capacity and capability in data analysis and interpretation may strengthen findings. More case studies are needed, in particular, examples of equity-focused HiAP
Report to the Ministry of Health and Long-Term Care. Getting Started with HiAP (Shankardass, Solar, et al., 2011)	Global review of initiation and implementation of equity-focussed intersectoral health activities, to inform policy for Ontario	Behavioural factors addressed by midstream interventions, findings highlighted importance of recognition of social determinants of health, budget sharing and tools and structures to support HiAP	Intensive methods needed such as interviews and case studies to understand observed variations in role of different sectors and types and importance of leadership in initiation and implementation of HIAP

(continued)

Table 25.2 (continued)

Title	Policy focus	Findings in relation to HiAP policy processes	Findings regarding challenges in policy research
HiAP prospects and potentials (European Observatory on Health Systems and Policies, 2006)	Analysis of the benefits of the HiAP approach for sectors other than health and the whole of society	Benefits of intersectoral action identified, HiAP contributes to 'win-win' opportunities. Risk assessment methods are effective for HIAP but have limitations	Need to develop specific methodology for assessing impact of proposals on health systems, need to work together on methodological issues related to determinants of health
Implementing HiAP (Department of Health South Australia, 2010)	Analysis of HiAP implementation – discusses concepts and provides practical examples of national and sub national country case studies	Need to identify how and why other sectors would share HiAP goals, find a new balance among responsibilities, identify roles and accountabilities	New forms of learning and knowledge management required to address 'wicked' problems, encompassing global industry of health-related products and services, considering trade, industry innovation and corporate responsibility

alcohol-related conditions recognized that investment in health contributes to a 'virtuous cycle' of improved heath as well as economic outcomes.

Examining distributional consequences of policy interventions is a topic for healthy public policy research. As detailed in the descriptions of European studies of HiAP earlier in this chapter, HIA studies of distributions of impacts point to the value of HiAP in reducing inequities (European Observatory on Health Systems and Policies, 2006) The researchers concluded that HIA could be used to predict how different segments of the population would experience health impacts if different policy options were implemented. The review concluded that this approach has potential to address inequities between countries as well as within countries. A subsequent study (Howard & Gunther, 2012), however, found few examples of successful policy work undertaken with a strong equity focus. This research identified the need for better understanding of the differences between health equality and health equity and the need for better data to understand health inequities at a national and local level.

In healthcare policy as well as policy for health, the question of elites, including industry influence, is important, as is the question of the conditional effectiveness of policies. An example of the importance of industry influence is found in the study of HiAP for non-communicable diseases (NCDs) (Lin, Jones, et al., 2014). Opposition from industry and property developers was identified as potentially limiting the effectiveness of policy interventions such as excise duty on tobacco and alcohol, advertising bans and restrictions, promotion of healthy food products and planning restrictions to increase recreational space and promote active transport.

Infrastructure for HiAP

More research is needed of infrastructure to support HiAP, to better understand governance actions and their relationship to governance structures and processes, agenda setting, policy formulation, implementation and evaluation and effectiveness of interventions (Lin, Jones, et al., 2014). Researchers also report the need to identify ways to adopt HiAP at program and service delivery levels (Government of South Australia, 2013). Additionally, future studies are needed to identify factors influencing actions to develop HiAP initiatives as well as actions within HiAP initiatives (McQueen, Wismar, et al., 2012).

Conclusion

Policy measures are increasingly being advocated for and adopted for behavioural health. Policy instruments such as regulation may have a direct influence on health behaviour. Policies such as financial incentives can create enabling conditions for behavioural interventions to be effective or ineffective. However, evidence about policy effectiveness for behavioural health is still evolving. Research about policy effectiveness is challenging due to the complex nature of the policy-making process. For this reason, research about policy effectiveness needs to be concerned about policy process as well as policy impact. Understanding about policy process can help with better policy advocacy and better policy implementation. For example, better understanding of policy advocacy can help with placing the social determinants of health on the central agenda of government.

Development of good information infrastructure is required to gather evidence over time to inform policy development and revision, including evidence from a range of health disciplines and health users, as well as from across industry and government sectors. To address global factors in behavioural health issues, the development of cross-national infrastructure for comparative analyzes will be required. Such developments in approaches to policy research and information infrastructure will enable the generation of evidence required to inform future policy for behavioural medicine.

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Part V

Key Areas of Application in Prevention and Disease Management

Tobacco Control: Preventing Smoking and Facilitating Cessation

26

Ron Borland and Hua-Hie Yong

Introduction

Tobacco became the single largest cause of premature death and disease in the second half of the twentieth century, and unless stronger action is taken, it is on track to prematurely kill one billion people in the twenty-first century. It is currently estimated to kill over five million people each year (WHO, 2008). On average, it takes more than 10 years off the life of the smoker, and even more if they smoke heavily (Jha, Ramasundarahettige, et al., 2013). This means that smokers lose more lifetime than the total time they actually spend smoking (i.e., with a lit cigarette).

Tobacco is a product grown and manufactured for human consumption, and thus the harms it causes can be seen as an epidemic of harm created in large part by human activity. As such, it should be easy to solve, by reversing some of the harmful innovations and finding technological fixes for others. One of the aims of this chapter is to analyze why, even though considerable progress has been made to reduce the death and disease it causes, progress has been slower than desirable and may be slowing further. Behaviors can be very hard to change when they meet immediate human needs. Tobacco control is a story of how concerted action can make a difference, but also of the need to adapt strategies as the nature of the problem changes, changes that are in part generated by our attempts to control it.

The approach taken in this chapter is one that requires an ecological model of behavior change (Sallis, Owen, & Fisher, 2008). It requires consideration of broad environmental determinants that can nudge people away from smoking (Thaler & Sunstein, 2008); but this is not enough, it also needs to consider intrapersonal factors, both conscious beliefs and more reactive process (Friese, Hofmann, & Wiers, 2011; Borland, 2014). The factors that are available to consciousness include beliefs about self-efficacy, outcome expectancies, goals, and other beliefs. The more reactive aspects include consideration of how conditioning, both classical and operant, can influence behavior in response to the person's immediate environment.

Tobacco control has some unique features as well as some commonalities with other preventive activities. Because tobacco contains nicotine, it is a form of drug use, but unlike alcohol and some other drugs, it is not intoxicating, so the harms are virtually all associated with long term, not short-term use. In this, it is similar to the health harms associated with diet and physical activity. However, unlike diet, physical activity, and alcohol use, there is no desirable level of use (at least of smoked tobacco), so the aim is to

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reduce or preferably eliminate use, rather than find the appropriate level of use (moderation). Like diet, overuse has been stimulated, at least in part, by mass marketing. Finally, unlike some other behaviors, there are no user groups advocating for help. All of this should be kept in mind when relating the lessons learned in this chapter to other areas of prevention.

The way science has responded to behavioral challenges like tobacco control has been largely reactive. Science tends not to study easy-to-change behavior (except in the field of commercial marketing), so many scientists hold the false perception that behavior change is difficult. In fact, much behavior change is easy – think about the changes in behavior associated with the uptake of mobile phones and other technologies. However, the exceptions, the hard-to-change or more correctly hard-to-maintain behaviors like quitting tobacco use are the ones where change does not just happen (Borland, 2014). The way science develops is by developing an increasingly sophisticated understanding of the problem, a process that will continue until the understanding is sufficient to produce the interventions that allow us to effectively eliminate the problem.

The Addictive Nature of Tobacco Products

Tobacco use, particularly of cigarettes, is addictive; i.e., a proportion of the people who start to use regularly find that it is extremely difficult to stop even when they commit themselves to trying. Researchers and clinicians have tried to define addiction more clearly, and to find indicators that will predict future failure to abandon the behavior, but have had limited success. While there have been many scales developed to measure aspects of nicotine dependence, the only measures that have reliably predicted future quit success are two measures of habit strength: the amount smoked per day and the time to first cigarette of the day (Baker, Piper, et al., 2007; Borland, Yong, et al., 2010a). To these might be added reported strong cravings, particularly if measured after quitting (Herd, Borland, & Hyland, 2009) and a past history of failed attempts, especially short-duration ones (Partos, Borland, et al., 2013). All these measures only predict weakly, so none should really be thought of as a measure of addiction, but more as indicators of some of its characteristics. Currently, the only way to really measure addiction is after the event, i.e., still smoking in the face of prolonged interest and attempts to quit. There is much we do not know.

Addiction is a biopsychosocial phenomenon, meaning that smoking is maintained by a complex mix of biological, psychological, and social factors (West & Brown 2013, for a good summary of many of the theories of addiction). The biological component relates to the effects on the brain of nicotine, the main chemical responsible for tobacco's appeal (Henningfield & Benowitz, 2010). These effects differ as a function of how the nicotine is delivered, particularly how quickly it gets to the brain. If it is delivered rapidly, it provides a "hit" which many find pleasant. This hit is not present (or is much reduced) when the nicotine is delivered slowly, as is the case with nicotine patches (used to help smokers quit), and thus users do not develop an addiction to nicotine patches. It appears to be the sudden pulse of nicotine that provides the experiences that support addiction.

Two main factors influence the rate of uptake of nicotine: the pH of the environment and where in the body the nicotine is delivered. Cigarette smoke is mildly acidic and results in ionized nicotine that is absorbed into cells with difficulty. However when delivered into the lungs, it can be taken up rapidly. At higher pHs (mildly alkaline), nicotine is more readily absorbed, so enough can be absorbed through the oral mucosa to provide a psychologically satisfying dose. Cigar and pipe smoke can achieve this, but still at rates lower than for lung inhalation. The acrid smoke is harder to inhale; however, cigarette smokers, who have become expert in inhaling cigarette smoke, tend to inhale even when smoking pipes or cigars, while never cigarette smokers tend only to puff on these products. Unfortunately, for cigarette smokers, lung ingestion of smoke is the most harmful form of tobacco use because it delivers highly toxic and carcinogenic tar to the sensitive tissues of the lungs.

The immediate biological effects of nicotine provide rewards that are the basis for conditioned associations developing to the act of smoking, and the act gradually comes to be enjoyed – it typically starts out as being experienced as unpleasant, or at least some aspects are experienced that way, but this adjustment is usually rapid and most users come to experience positive effects quite quickly. From the perspective of behavioral theory, the addiction to smoking develops as a result of a combination of classical and operant conditioning. Cues associated with use, from the sight of cigarettes, through the act of lighting up to the experiences of taking in a puff of smoke, all of which occur before any desirable physiological effects of the nicotine are felt, become conditioned and over time become rewarding in their own right, especially those closest to the physiological response, such as the experience of the smoke on the back of the throat. Operant conditioning processes then build on these desired outcomes (rewards) by acting to find and use cigarettes more frequently. Indeed, according to some contemporary theories of addiction (Robinson & Berridge, 2003), the repetition of the behavior is reinforced more by the positive emotions associated with the anticipation of getting the drug, than by the actual effects of the drug itself. Because of these cues associated with regular use, drug users, *including* smokers, tend to prefer to use their drug in regular situations even though this means that the physiological effects of the drug are lower (something known as tolerance). That is because using in a novel situation leads to a stronger physiological response as the body is less prepared for the drug, because it is not expecting it. Part of the anticipatory response involves the body preparing to counter the effects of the drug, so if the drug effect was primary, smokers should prefer to smoke in unfamiliar context, but they do not.

Desire to smoke is not just determined by contextual cues, it tends to be greatest when the person is in a negative mood state. Thus both internal and external cues can come to trigger the desire to smoke, which is experienced as a craving, when the desire cannot be immediately fulfilled.

Initially addiction is simply experienced as a desire to smoke, but from the time smokers decide they should quit but are unable to do so, they can become aware that smoking is no longer a simple choice. However, addiction is much more than a simple conditioned habitual response. The biological aspects are associated with particularly strong rewarding consequences of use, which help maintain the behavior, and social and psychological aspects are also important. The social factors maintaining addiction range from the effects of social norms (both of the society as a whole and of friends and family), through any relevant laws and cultural traditions (e.g., in some parts of the world it is still considered polite to offer cigarettes as a gift). As tobacco control efforts have developed and the social determinants of smoking have been reduced in strength, we think conditioned and biological factors (and their interactions) are becoming more important factors maintaining smoking, although social context and beliefs can still have some influence.

The psychological aspects of addiction include the largely unconscious build-up of habits associated with the drug which create regular desires to smoke and beliefs about the utility of use, which when combined with conscious beliefs about the harms associated with long-term use create conditions of ambivalence about use. The habitual aspect of smoking is critical to its maintenance: By the age of 40, the average smoker will have smoked around 150,000 cigarettes (15–20 per day, by 365 days, by 25 years) and, if they take around ten puffs on each, will have inhaled tobacco smoke 1.5 million times. No other habits are anywhere near as practiced, and even if smoking were not addictive, suddenly eliminating this habit would still be likely to be difficult. The ambivalence is manifest in the rational self-being committed to quitting to avoid the adverse effects, but part of the emotional self, the part driven by the physiological need for the drug, wanting to smoke whenever cues to smoke trigger cravings. This conflict results in oscillations in reported motivation to quit, to avoidance of the issue, and to beliefs such as that if one really wanted to quit (e.g., resolved the essential psychic conflict) then quitting would be straightforward (Balmford & Borland, 2008). This last "excuse" focuses attention on the extremely difficult task (at least while still a smoker) of resolving the psychic conflict, and distracts attention away from strategies that are known to be effective, such as use of cessation aids. We think it is not possible to understand addiction from a purely social or behavioral perspective, but it requires an analysis that incorporates both operational (reactive) functions and executive or conscious deliberative ones along with the influences of environmental conditions. Stopping an addictive behavior can be seen to belong to a class of hard-to-maintain behaviors, which are those for which the simple desire to engage or desist is not enough to result in sustained change (Borland, 2014). In this regard, addictions should not be thought of as an all or none phenomenon, but one where the strength of the urges to engage in the problematic behavior varies across individuals, and within the individual it varies as a function of the person's underlying physiology, his/her beliefs and emotional states, and the environmental conditions he/she is in.

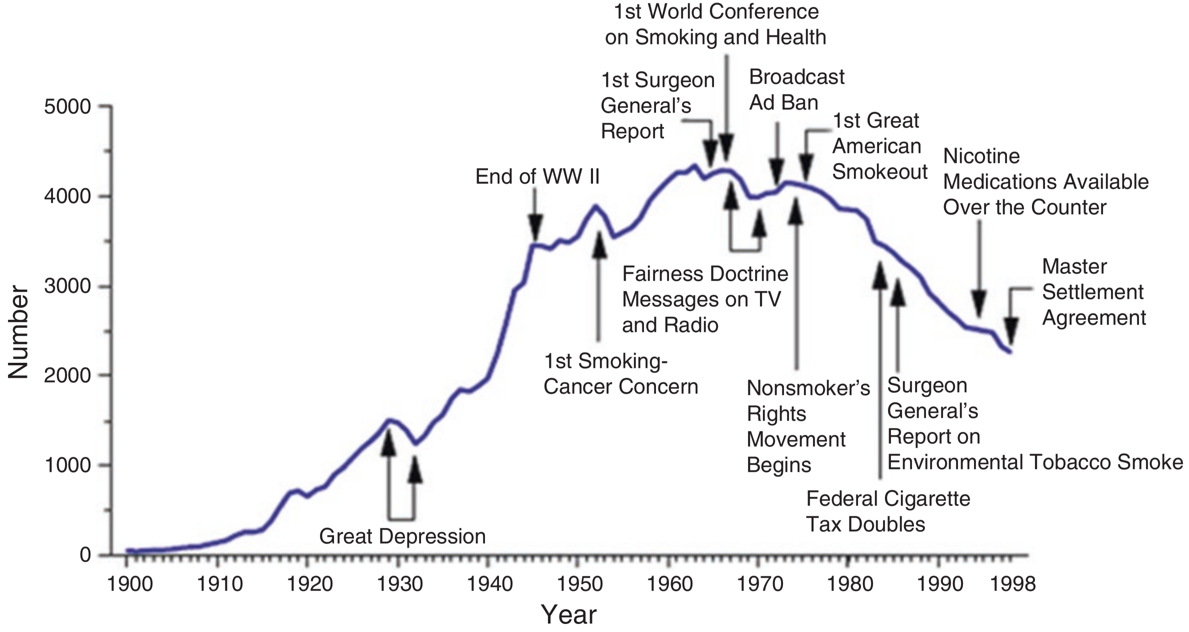
A Brief History of Tobacco Control

Tobacco had been used in North America for many generations before it was brought to the rest of the world in the sixteenth century following the European colonization of the Americas. It was used in a variety of forms, among which, what we would today recognize as, a cigarette (all hand-rolled, either by the user or in factories) was only a minor form of use. This all began to change in the second half of the nineteenth century.

The rise in tobacco use is a story that mirrors the rise of capitalism and, in particular, mass production and mass marketing as means of growing the market for certain kinds of products. Many of the standard techniques of modern marketing were pioneered by the tobacco industry (Brandt, 2007; Proctor, 2012). The invention of the automated cigarette rolling machine by Bonsack in the 1880s provided the basis for mass marketing. One other factor that was also important to the growth of the cigarette was the development of flue-curing of tobacco (Proctor, 2012). Flue-cured tobacco retains more sugar than traditionally cured tobacco and produces smoke with a lower pH, making it less acrid and allowing it to be inhaled into the lungs relatively easily. Lung inhalation is necessary as the lower pH reduces the uptake of nicotine from the oral mucosa. Absorption of the nicotine into the lungs results in it getting to the brain faster – within seconds of inhalation, providing a more powerful psychological experience and thus one that over time most tobacco users came to prefer. With mass production, it became cheaper to provide cigarettes and enterprising companies started making a lot of money from it, and gradually cigarettes came to dominate the tobacco market. Tobacco companies in the USA promoted their products extensively and had them included in rations for World War I soldiers, which hastened their spread. After the war, tobacco use expanded rapidly. The growth of factory-made cigarette use per capita in the USA is shown in Fig. 26.1. Note that in the early years, most tobacco use was of loose tobacco, often used in pipes, but there was still growth in overall tobacco use. Other Western countries had similar growth. Growth slowed at the start of the Great Depression, but then increased again over the period of World War II and beyond, until people started to become concerned about its harms.

Concern that tobacco smoking might be associated with serious health harms began to grow from the 1930s, albeit slowly. Two of the biggest and most influential studies were published in 1950, one by Doll and Hill in the UK and the other by Wynder in the USA, both showing compelling evidence of strong links between smoking and lung cancer. Publicity associated with these studies was considerable, but there was no consensus as to whether the harms were real, a debate artificially flamed by tobacco-related interests with a vested interest in undermining the evidence.

Institutional acceptance of the harms from tobacco can be dated from the 1961 report of the UK Royal College of Physicians and the 1964



Sources: United States Departmet of Agriculture; 1986 Surgeon General's Report.

Fig. 26.1 Annual adult per capita cigarette consumption and major smoking and health events – United States, 1900–1998 (Reproduced from MMWR, November 5, 1999, p. 986)

Report of the US Surgeon General. The problem could no longer be denied. The first international conference on tobacco or health was held in New York in 1967 and was addressed by US Senator Robert Kennedy. In the 1970s, led by Nigel Gray, the UICC (*Union for International Cancer Control*), supported by the American Cancer Society, built the framework for the global tobacco control movement. However, there was little coordinated action to stem the epidemic until the late 1970s and 1980s, and even then such effort took place only in a few countries.

Countries have varied greatly in terms of their response to the epidemiological evidence demonstrating the nature of the problem. It is impossible in one chapter to cover all of this diversity or the reasons for the varying levels of action, so what follows are largely generalizations. Two key reasons for the lack of concerted action were the counter-response of the tobacco industry, which contested the evidence and was successful in maintaining a debate over the harms for several decades, and the lack of expressed concern by smokers, those most directly affected. Indeed it was not until the end of the last century (nearly 50 years after the first definitive studies) that major tobacco companies were prepared to publicly acknowledge, something they had known at least as early as health researchers, that smoking was extremely harmful to health. Prior to this, tobacco companies took extraordinary steps to deny the evidence, create misleading evidence, and to challenge all attempts by governments to control use (Proctor, 2012). The false controversy, probably exacerbated by the reality that smoking does not seem dangerous, has meant that smokers have been reluctant to believe it is as harmful as scientists have claimed, and since most smokers who tried to quit found it too difficult to do so, they developed an ambivalent relationship with smoking even when they accepted that it was harmful. Without pressure from smokers, and with strong advocacy from a politically powerful and rich tobacco industry, and also perhaps diverted by the large income they receive from taxes on tobacco, governments largely failed to act.

For the first decade or so following the first conclusive reports in the early 1960s there was little governmental action in most places, although warnings were placed discretely on cigarette packs in some countries and some restrictions were placed on tobacco advertising, mainly in the electronic media (in those days, TV and radio). Over this time it also became clear that smoking was even more harmful than the early reports indicated. Links between smoking and heart disease were established as were links with a range of other diseases (several other cancers, stroke, and peripheral vascular disease being among the most important). Estimates of premature mortality from smoking started off at around one in four smokers, but grew as the epidemic matured to around one in two, and more recently the best estimates are more like two in three smokers will lose on average 10 years or more of productive life if they smoke (Doll, Peto, et al., 2004; Pirie, Peto, et al., 2013).

As the evidence grew, pressure for more action began to build. In some countries, the need for action was galvanized by a mixture of nongovernmental organizations (NGOs) advocating for action and activists taking high publicity action. One well-known example is the organization BUGA-UP (Billboard Utilising Graffiti Against Unhealthy Products) in Australia which defaced tobacco company billboard advertisements in often humorous ways to highlight some of the harms the advertisements were designed to ignore (see Fig. 26.2; Chapman, 1996).

Starting mainly in the 1980s, some countries began to take more comprehensive forms of action, with strategies varying somewhat by country. Most of this action was in affluent countries, including English-speaking countries (e.g., the USA, the UK, Australia, and Canada), much of Scandinavia, and small places like Singapore and Hong Kong. Most began to tighten up legislation, imposing restrictions on the ability of the tobacco industry to advertise its products, initially focusing on electronic media, but subsequently spreading to other forms of promotion. In the USA and Finland, a lot of initial action was stimulated by large community-based trials to reduce smoking, in some cases in conjunction with an integrated effort to encourage healthier lifestyles.

Fig. 26.2 Examples of the activities of the Australian activist group BUGA-UP. This was a group of mainly health professionals concerned about the ongoing promotion of tobacco products (Photo provided by Simon Chapman)

As the success of these initiatives became known, momentum for more action began to build. This was stimulated greatly by institutional conclusions that passive smoking was harmful, most notably in the conclusions to this effect in the 1986 US Surgeon General's report. This galvanized many nonsmokers to be concerned and validated tobacco control efforts as involving the protection of innocent bystanders, including children, rather than one of protecting smokers from their own behavior. This was closely followed by the 1988 Surgeon General's report concluding that smoking was addictive. Together, they helped change the discourse away from the position the industry had adopted of a freely chosen activity to one that smoking is not freely chosen and that it can also harm others. Tobacco control forces in those countries that were already trying to take actions became stronger, and other countries began to take action. One notable case was Thailand, which began with strong restrictions on promotion and attempts to prevent international tobacco companies from entering the market under the provisions of international free-trade agreements.

Since then, the impetus for tobacco control was stimulated by regular World Conferences on Tobacco or Health, and more recently by scientific journals: first *Tobacco Control*, then *Nicotine and Tobacco Research* following the formation of the Society for Research on Nicotine and Tobacco (SRNT). Both provide dedicated outlets for research to complement publication in more generalist journals. This has helped strengthen and disseminate the evidence base, while also facilitating sharing of advocacy successes. These developments have strengthened the case for tobacco control and for specific strategies, and thus increased the influence of tobacco control advocates, leading to increased action.

From the mid-1980s, Australia pioneered the extensive use of regular mass media campaigns and was able to demonstrate their benefits. In 1994, US researcher and activist Stanton Glantz received a box of tobacco industry documents sent anonymously (Glantz, Slade, et al., 1998), which was the start of a mass of such material becoming public in various ways, mainly through the US Courts and through a negotiated settlement by the government with most tobacco companies to pay for costs incurred in treating tobacco-related diseases. Among other things, this showed that the tobacco industry concealed research they had done showing that tobacco smoke was both carcinogenic and addictive. These documents have greatly enhanced our understanding of the industry and have helped convince decision-makers that they are no longer a respectable part of corporate society. They had been one of the most powerful lobby groups, but publicity about their unethical behavior has considerably weakened their power with politicians who now run considerable risks to their reputations if they are publicly identified as supporters of the industry. They still retain considerable power behind the scenes as they are large and profitable enterprises. Their power means that many governments still feel constrained from doing all that is needed to properly tackle the problem. The other main challenge for governments is that while so many people continue to smoke, prohibition is not a viable option.

Major Institutional Responses Shaping the Future: WHO FCTC and US FDA

In February 2005, the World Health Organization's (WHO) first piece of international law, the Framework Convention on Tobacco Control (FCTC), came into force for those countries that were party to it. As of January 2015, 180 of the 195 countries of the world are parties, the main exceptions being the USA and Indonesia. This convention calls for, and in some instances mandates, actions that represent an integrated approach to dealing with this major public health problem. The implementation of the FCTC has been complemented by WHO's MPOWER framework which picks up on several key articles and provides guidance for countries on implementation of tobacco control policies and programs that complement the formal text of the treaty and its negotiated guidelines. Implementation has also been supported by civil society through a coalition of NGOs called the Framework Convention Alliance, allowing the voices of tobacco control activists and researchers to be heard independent of governments.

The other major recent event that is likely to have international significance was the passage of legislation in the USA to give its Food and Drug Administration (FDA) powers to regulate tobacco products, but not to prohibit them. Even though the USA has not ratified the FCTC, the FDA legislation means that it will soon become compliant with FCTC requirements. Perhaps more importantly, it provides an agency that has the capacity to begin to properly regulate tobacco products, something that most FCTC parties lack the resources to effectively tackle.

Trends in Tobacco Use

Most of the tobacco used in the world today is in the form of factory-made cigarettes. However, in some places hand-rolled tobacco is an important source of smoked tobacco, and in others smokeless tobacco is also important. The greatest diversity in tobacco use is probably in India, where a wide range of tobacco products are either smoked, sucked, sniffed, chewed, or even used in toothpaste. In South Asia and parts of Africa, women who use tobacco predominantly use forms of smokeless tobacco. In Sweden and Norway, smokeless tobacco is the dominant form of use among men, but not used much by women.

Smokeless tobacco is less harmful than smoked tobacco, and smokeless forms can be reduced in toxicity far more than smoked forms (Foulds, Ramstrom, et al., 2003). In some parts of the developed world, there is some evidence of increased use of cleaner forms of smokeless as a consumer-initiated harm-reduction strategy. This chapter focuses on cigarette use, but does discuss the potential of cleaner forms of smokeless as part of the solution to the huge epidemic of tobacco-related harm, which is mainly due to the use of smoked tobacco.

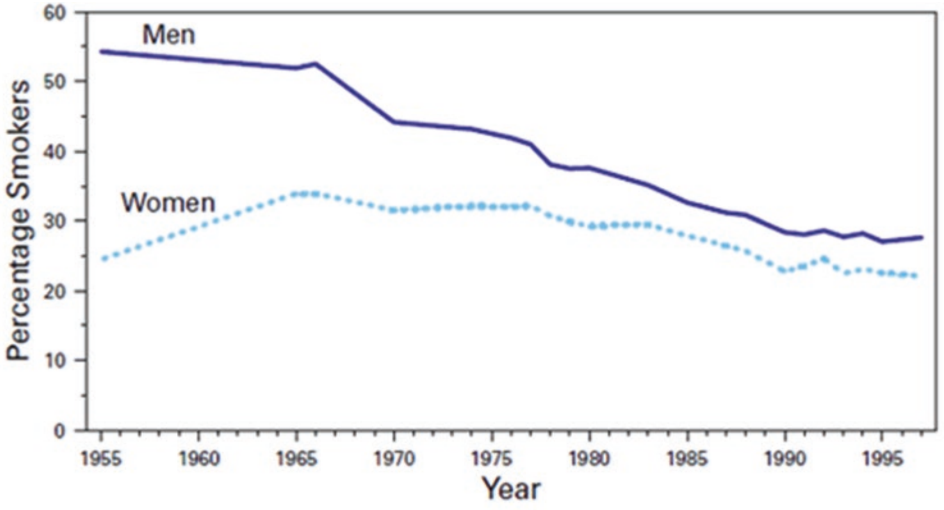
In this section, we have selected examples to illustrate both the diversity and the potential for progress of tobacco control efforts. We first focus on the early adopter countries, then briefly consider the early adopters among the less developed countries, and then describe the situation in two of the largest tobacco markets in the world: China and India.

Trends in Tobacco Use in Early Adopter (and Affluent) Countries

In the USA, tobacco use increased almost exponentially from the 1800s to the mid-1960s (DHHS (US Department of Health and Human Services), 2000). The dramatic rise in tobacco consumption was largely fuelled by the invention of the factory-made cigarette and cigarette smoking quickly outpaced the use of any other forms of tobacco product (Brandt, 2007). At the peak of tobacco use in the mid-1960s, more than 40% of the US adult population smoked cigarettes, more men than women (National Center for Health Statistics, 2005). However, starting from the early 1950s, cigarette consumption in men began to fall, perhaps as a result of health scares associated with tobacco use. The publication of the first US Surgeon General's report in 1964, concluding that smoking caused lung cancer, was associated with an increased decline for men and the start of a decline for women.

To mollify the public's growing concern about the health effects of smoking, tobacco companies introduced filtered cigarettes in the 1950s and the so-called low-tar cigarettes in the 1960s. As a result, the market share of both filtered cigarettes and so-called low-tar cigarettes increased dramatically. By 1960, more than half of all cigarettes consumed had filters (Giovino, 2002) and by 2005, 99% had filters (FTC (Federal Trade Commission), 2007). Similarly, the market share of low-tar cigarettes increased from 2% in 1967 to 85% of cigarettes distributed within the USA (Giovino, 2002). Menthol, an additive with an anesthetizing effect that was claimed to sooth the throat, was also added to cigarettes in the 1960s and its market share peaked in the 1980s when just under 30% of all cigarettes sold in the USA contained menthol (Giovino, 2002).

US adult smoking prevalence fell from 42% in 1965 to 21% in 2009 (see Fig. 26.3), with the rate for men (21%) being higher than for women (16%) in the latest estimate (Centers for Disease Control and Prevention, 2014). Among those who smoke, daily cigarette consumption began to fall around 1979 and smokers, on average, are smoking less than they did three decades ago.



*Before 1992, current smokers were defined as persons who reported having smoked ≥100 cigarettes and who currently smoked. Since 1992, current smokers were defined as persons who reported having smoked ≥100 cigarettes during their lifetime and who reported now smoking every day or some days.

Sources: 1955 Current Population Survey; 1965–1997 National Health Interview Survey.

Fig. 26.3 Trends in cigarette smoking* among persons aged ≥18 years, by sex – United States, 1955–1997 (Reproduced from MMWR, November 5, 1999, p. 988)

Most of the fall in daily consumption is due to reduced smoking among heavy smokers. This picture is replicated in other early adopter countries, with some doing better, particularly those that have complemented public education with the stronger forms of restriction on tobacco promotion, and restrictions on where smokers could smoke. Australia has done particularly well in this respect (overall, at least weekly smoking prevalence has more than halved from 34% in 1980 to 14% in 2013), as have the city states of Singapore and Hong Kong (2010, overall smoking prevalence of 14% and 12%, respectively), where because of historically low levels of smoking among women (about 4% in both countries), overall prevalence is even lower than countries like Australia.

In the UK, like the other early adopter countries, the overall smoking prevalence among adults (aged 16 and over) fell steadily between the mid-1970s and early 1980s. After 1982, the rate of decline slowed and between 2007 and 2012, overall smoking prevalence leveled out at 20% (Action on Smoking and Health (ASH), 2013).

Among youth in the UK, smoking prevalence has declined more recently. From the 1980s, where the first surveys occurred, uptake of smoking in youth fluctuated, but did not overall decline much till the mid-2000s (Action on Smoking and Health (ASH), 2013). However, in the USA from 2000, smoking rates among middle-school students almost halved by 2009 (see Fig. 26.4), and the rates of older students also declined from a higher baseline by a similar amount (but less proportionately) (Centers for Disease Control and Prevention, 2010). In Australia, the same pattern of decline occurred, but it may have happened slightly earlier.

Trends in Developing Countries

Thailand was among the first developing country to take action. As a result, it has reduced its smoking prevalence among those aged 15 years and older from around 35% in 1981 to 24% in 2011 from the latest available estimate (Global Adult Tobacco Survey (GATS), 2011). Rates in

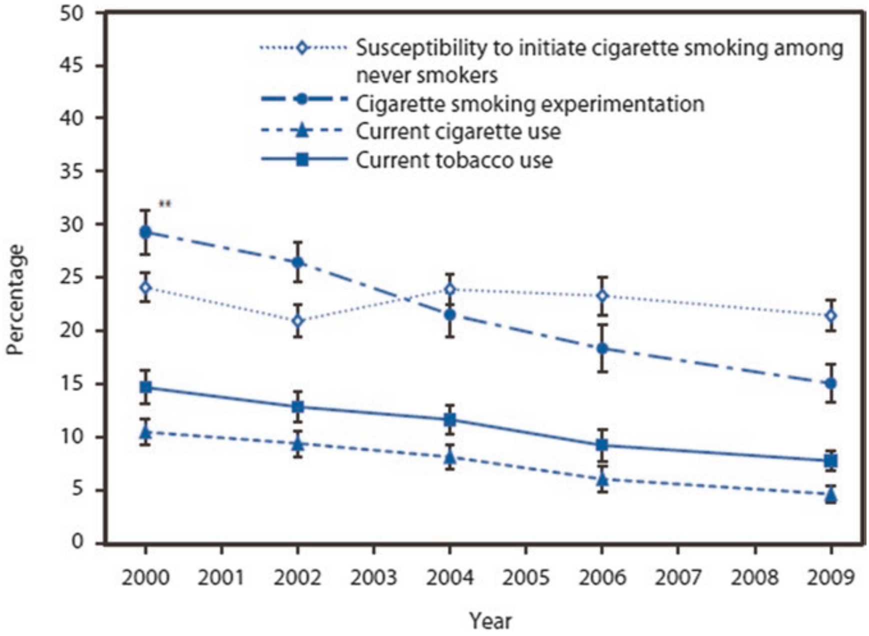


Fig. 26.4 Susceptibility to initiate cigarette smoking among never smokers, cigarette smoking experimentation, current cigarette use, and current tobacco use among adolescents in middle school. National Youth Tobacco Survey, United States, 2000–2009 (Reproduced from MMWR, August 27, 2010, Vol. 59, No. 33, p. 1066)

men fell from 63% to 46.6% and among females fell even further from the low 5% in 1981 to 2.6% in 2011 (GATS, 2011).

One stand-out case is Bhutan, a small Buddhist country in the Himalayas, which banned the sale of tobacco products in 2006 (but not possession or use), completing a process that began in one district in 1989 (ITC Project, 2011). Action in Bhutan was largely due to long-standing discouraging of smoking by the dominant Buddhist sect in Bhutan, with the legislative action triggered by publicity about the epidemiology. Bhutan has had very low tobacco use, with smoking rates estimated at less than 4% in 2010, making it relatively easy to implement a ban. Smuggling of tobacco remains a problem, although stronger laws were enacted in 2010 to try to reduce it. How successful they will be remains to be seen.

While the trend of tobacco use is on the decline in many developed Western nations, there have been concerns that this may not be happening in many developing countries like China and India. China has 350 million smokers representing about a third of the world's smokers. China ratified the FCTC in October 2005 and has slowly begun to take steps toward implementing the FCTC. Based on a 1996 survey, overall prevalence rates for Chinese smokers were around 67% for males and 4% for females, with an overall prevalence of 38% among those older than 15 years of age (Yang, Parkin, et al., 2004). The GATS conducted in 2010 estimated the current smoking prevalence of around 53% for men and 2% for women with the overall prevalence at 28.1%, an overall decline of nearly 10%. This reflects the early progress that can be made with public education in encouraging (mainly) less addicted smokers to quit.

The Chinese population is now better educated about the harms of smoking with smokers reporting higher levels of information from most communication channels (Li, Borland, et al., 2013), although levels of awareness still remain far too low (Yang, Hammond, et al., 2010). However, some interventions may not have been as effective as desirable. For example, in October 2008, the Chinese government introduced the new larger text-based health warnings on cigarette packaging to replace the old warnings, but unlike most other countries, they remain text only and do not require a standard background, and on one side are in English (which very few Chinese read). Experimental studies show that these warnings have low immediate impact as compared with stronger graphic or text-only warnings as used elsewhere (Fong, Hammond, et al., 2010), so the population-level effects are likely to be small. In May 2009, tobacco tax was increased by 3.4%, but the China National Tobacco Corporation (CNTC, the national monopoly) simply kept prices constant by absorbing the tax increase, thus it can have no effect on consumers (Hu, Mao, & Shi, 2010). Despite the efforts made to date, the FCTC commitment has not been fully fulfilled. There is also no national ban on tobacco use in public places, and in cities with restrictions, many do not cover all indoor work and public spaces. The restrictions on tobacco advertising, promotion, and sponsorship are also far from comprehensive. That said, there continues to be progress with many places becoming smoke-free and some rules being enforced more effectively.

China also has a problem of conflicting interests in the way it administers tobacco control policy. It has given its State Tobacco Monopoly Administration responsibility to lead the implementation of the FCTC. However, this agency also has responsibility over the CNTC, which is the largest single manufacturer of tobacco products in the world (Hu, Mao, & Shi, 2010). There is genuine concern that the interests of CNTC sometimes take precedence over the interests of public health, so administration of tobacco control policy in China needs to be changed to give health interests priority.

As a country that has only recently begun to educate its population about the harms of smoking, China still has smoking embedded in aspects of its culture. It is common to have tobacco products offered as gifts to reinforce friendships and relationships (Pan & Hu, 2008). Similarly, when men meet, it is customary for everyone to offer cigarettes to signal respect and hospitality, providing a barrier to quitting (Zhang, Chan, et al., 2012). These normative influences are likely to gradually disappear as they have in countries that have taken tobacco control seriously for years, but while they persist, they are likely to keep some more socially cued smokers from quitting.

Tobacco use in India is very different to China. India has an estimated 120 million smokers, the second largest number after China. It has also ratified the FCTC and is beginning to put in place strong policies. In India, cigarettes comprise just 19% of tobacco consumption, while bidis (a mix of tobacco and other products wrapped in a leaf) account for 53% and are the main form of smoking among women, with most of these produced by hand (GATS, 2010). However, in most states the main form of tobacco use for women is smokeless, in a variety of forms, while overall smokeless use among men, while at similar rates to women, is lower than for smoked tobacco. Data from GATS India gathered in 2009–2010 estimated that more than one-third (35%) of adults in India use tobacco in some form or other. The prevalence of overall tobacco use is 48% for males and 20% for females. Prevalence of smoking is 24% and 3% for males and females, respectively. Prevalence of smoking and chewing tobacco varies widely between different states and is associated with sociocultural characteristics. Tobacco chewing is more common in the Central, Eastern, Western, and Northeastern states compared to the Northern and Southern states. Smoking of tobacco is relatively higher in the Northern states (except in Punjab where tobacco prevalence is one of the lowest because the Sikh religion prohibits tobacco consumption). As in China, India's rapid economic growth and increase in people's disposable incomes are expected to increase smoking consumption. Less is known about the early impact of the strengthened tobacco control initiatives in India; they are likely to have some positive effects, but difficulties in implementation and the largely unregulated cottage industry for much of the tobacco production are major challenges to any rapid progress.

Sociodemographic Patterns of Use

Historically, uptake of smoking occurred first among more advantaged groups, but they were the first to give up when informed of the health effects. In countries like the USA, smoking is now much more prevalent among disadvantaged groups, although there are some cultural differences. For example, Hispanics in the USA have lower smoking rates in spite of lower average socioeconomic status (SES) than other groups (Centers for Disease Control and Prevention, 2010; Siegel & Faigeles, 1996).

In most countries, smoking began as a predominantly male practice, only being taken up by women later, particularly in countries from Europe or European origin. In much of the developing world, rates of smoking among men are far higher than among women, reflecting greater sex-role differentiation in those cultures. In Asia, in particular, smoking has remained socially unacceptable for women and rates have typically remained low. In countries with strong tobacco control policies, rates among women have remained low, or even reduced, while in countries without strong policies, such as in Japan, they were increasing, until those countries began to take action. The increases, where they occurred, tended to be in the more affluent countries, or among the more affluent elite in less developed countries, and have been linked to the capacity of the tobacco industry to link their products to modernity and to the desirable aspects of Western lifestyles.

In developed countries where tobacco use has declined to around 20% or lower, the rates are much higher among the most disadvantaged sections of those societies, including the marginalized minority groups (e.g., American Indians, Australian aboriginals), people with mental illnesses (including other drug problems), and others who have fallen off the social ladder (e.g., the homeless) (Barbeau, Krieger, & Soobader, 2004). These pockets of high prevalence are going to be a major challenge for the future, especially as rates of smoking in these groups may not be declining as fast as in the broader community.

In Western countries, and increasingly in developing countries, smoking is linked to social disadvantage as the educated and the well-off get the message and quit, and also protect their children from becoming smokers. Smoking rates are very high among the dispossessed in rich societies, and where they exist, among their indigenous peoples. That said, there is increasing evidence that being poor or poorly educated is not directly related to tobacco use. The high use is among those who are disadvantaged in other ways, especially related to the negative experiences associated with disadvantaged positions in society or with impaired mental health. For example, we are finding that peasants (the poor with limited education) in some Asian countries are at least as willing and able to quit smoking as their more affluent urban cousins. In some countries, where tobacco use is more recent, use is also overall greater among more affluent urban dwellers, as this is the group that tends to be early adopters as they have the financial resources to afford it. Over time, the use of tobacco tends to spread down into the disadvantaged, who as a result of their disadvantage may get proportionately more immediate benefit from use, but over time tobacco use actually leads to a reduction in overall wellbeing.

The strong association of smoking with some forms of disadvantage means that tobacco control efforts should be seen as part of making a more equitable society. There is now compelling evidence that smoking increases financial stress (due to the cost) and exacerbates other causes of distress. Further, smoking makes a major contribution to the higher levels of ill health and premature mortality experienced by the dispossessed (Jha & Chaloupka, 1999).

Elements of a Comprehensive Approach to Tobacco Control

To effectively deal with a problem as complex as tobacco use requires an integrated and comprehensive approach as no single intervention will solve the problem. Solutions to the problems of tobacco use can range from influencing the harmfulness of the product through to influencing patterns of use. They need to attack one or more aspects of the chemistry of the products, the way it is marketed, psychological responses to use, aids to support cessation, and various aspects of the context of use, through to the motivations of various groups including tobacco companies which profit from trade in tobacco. Change can occur at various system levels: at the level of the person, their family (or friendship network), the community to which they belong, and the broader societal influences (both national and international). The relative importance of these factors is a function of where the locus of power exists for enacting changes to facilitate the desired behavior outcomes, i.e., the organizational level of the state (local through to national) that controls the key determinants of interest. Most of the environmental conditions that need to change to facilitate effective tobacco control (beyond what the person can do themselves) require action at societal (usually national, but sometimes state or provincial) or international levels. The main exception is the regulation of smoke-free places as in some countries local government have considerable power. In the USA, local governments led the move to smoke-free places and were important pioneers in setting the scene for larger-level jurisdictions to follow.

The critical issues to consider in controlling tobacco use are to what extent the environment can be modified to reduce cues to smoke tobacco and the extent to which individuals need assistance to enact desired changes. To the extent that tobacco use is socially determined, social change needs to be an important part of the solution. However, because of its addictive nature many individuals are going to need help to change, even if social conditions could be optimized for discouraging use. In this section, we consider both social and individual approaches to tobacco control.

Tobacco control is strongly grounded in science. It is only through epidemiology that we know how harmful smoking is. Science is also increasingly contributing to the development and evaluation strategies to control tobacco. Tobacco control researchers are leading the development of new research methods (or creative adoption of existing methods) (Borland & Cummings, 2010; IARC, 2008) that are providing a paradigm for understanding population-level behavior change that is being increasingly considered for other health behaviors. Examples of this include the adaptation of methods from marketing to evaluate mass communications and the International

Tobacco Control Policy Evaluation (ITC) project which is conducting parallel cohort studies in a range of countries to explore both:

- the impact of population interventions using other countries as controls (Fong, Hyland, et al., 2006; Thompson, Fong, et al., 2006) and
- cross-country differences that might reflect differential effects of policies either as a function of progress in tackling the problem or cultural differences (see the later section on denormalization).

Good science is built on and aids the development of good theory. Tobacco control has been conceptualized by some as a simple fight between good and evil, with responsible social forces working to remove an evil industry. While this may be a useful perspective for antismoking advocates to take, it is an unduly narrow conceptualization. More sophisticated models are needed. We have attempted to reconceptualize the problem using open-systems thinking (Borland, Young, et al., 2010b) – see Fig. 26.5. In most of the world's countries, it is useful to think of the current system as a tobacco use management system, with a regulatory core putting some constraints on the ability of the tobacco industry to market its products and some, typically poorly resourced, organizations providing information about the harms and supporting cessation. The way social forces act can be changed in two ways. First, by tilting the playing field toward one set of forces (e.g., supporting antismoking forces against the tobacco industry). This can be done by imposing constraints as to what the tobacco industry can do by way of laws (e.g., laws restricting tobacco advertising) and/or via the availability of resources (e.g., taxes on producers) or by helping the opposing forces (e.g., funding to antismoking groups). The second way is by changing the nature of the forces or institutions operating in the area, which changes what they are motivated to do. An example of this from the regulatory arm is the policy changes that led to governments moving from a model of regulating tobacco products like any other consumer product to one where the goal was changed to discourage its use. To change the nature of the tobacco industry would require either transforming tobacco companies into something other than profit-maximizing corporations, or finding a substitute for smoking that they could market more profitably (either of which would transform the landscape if it occurred). The set of societal forces created by the three kinds of forces within the system is the major determinant of the context in which individuals act, modulated by interpersonal social forces and the extent to which they have become dependent on tobacco or have otherwise integrated it into their lifestyle.

Systems analysis helps organize a range of major issues facing tobacco control. First, the current system is not structured to eliminate tobacco use, merely to manage it, either downward or at worst to reduce its growth. Until recently, very few people within tobacco control have called for an end to tobacco sales, and where they have, details as to how this could be achieved without unacceptably high levels of illicit trade have been conspicuously missing, making them aspirational statements more than plans (see special issue of Tobacco Control (2013) on Endgame issues) ("The Tobacco Endgames," May 2013).

Second, most of the costs of tobacco control are treated as externalities (costs that are not managed within the system), meaning there is no effective feedback mechanism for ensuring that tobacco control efforts are properly funded. Currently, only a very small proportion of the resources that most governments get from tobacco-specific taxes are returned to programs to support tobacco control, and overall levels of funding are far less than for many other public health and public safety issues, which are objectively much less destructive to health. Thus, while most public health problems represent a net cost to governments, tobacco is often a net source of revenue, even after accounting for the costs to governments of tobacco-related illness.

Third, continuing to allow tobacco companies to market their products to consumers while they are structured as for-profit corporations is

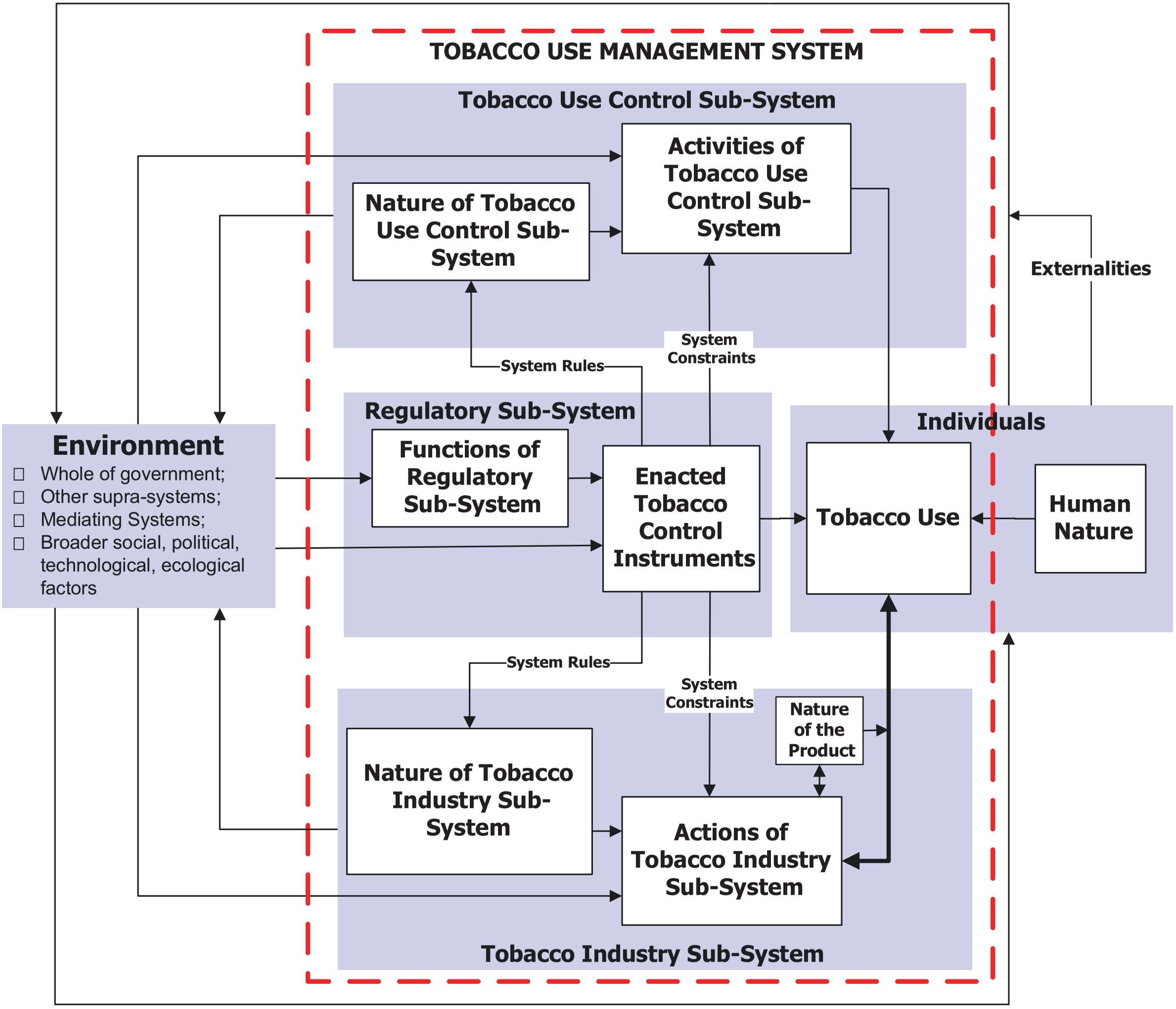


Fig. 26.5 A schematic diagram of the tobacco use management system (Adapted from Borland et al., 2010). This diagram shows how three conceptually different sets of institutional forces act on individuals. It does not show the normative influences of others acting as individuals

making resolution of the problem more difficult and it institutionalizes powerful forces within the system that have goals inconsistent with the system as a whole.

Fourth, the regulatory capacity of the system is limited, with most regulatory control still held by central government, meaning that the system is slow to respond to changing conditions. In the USA, from 2009, the Food and Drug Administration (FDA) has been given the power to regulate tobacco, so more concerted action is likely in the future, although early attempts to reform health warnings on packs have been thwarted by industry-led litigation leading to injunctions. Regulation in ways designed to reduce the level of a profit-making activity is bound to attract opposition from forces that profit. However, over time we might expect a more rational set of rules governing tobacco manufacture and sale.

Fifth, the current espoused goal of eliminating tobacco use precludes rational appraisal of harm-reduction strategies, something that should be intrinsic to any use management system. This is an important issue which is covered in more detail in the section "Harm Reduction and Product Regulation."

Finally, related to several of the above points, aspects of tobacco use have implications beyond the health system; thus attempts to change need to take into account a broad range of social forces, including the implications for other unrelated industries of regulating tobacco. In this regard, there would be considerable benefits if tobacco control forces were to join with other social movements for more socially responsible public policy, but unfortunately there is a tendency to treat tobacco as a completely separate issue.

While a systems approach is critical for analyzing the problem and testing the viability of potential solutions, it is not a useful framework for negotiating the needed change. Young, Borland, & Coghill (2010, 2012) have used a version of Actor Network Theory (ANT; a theory of the sociology of sociotechnical change) to organize the complex of individuals, organizations, facts, and arguments that together form the negotiated process that creates change in contested situations (see Fig. 26.6). ANT conceives of four broad sets of forces, usefully conceived of as two pairs that come together and interact in complex ways to determine outcomes. The original version of Latour (2005) was primarily concerned with the institutionalization of material things, while our adaptation is to ideas and policies with physical resources taking a more peripheral role. One pair has the possibilities for actions and the evidence and arguments used to support the various options, and related to this, the activities of organized interests who act to support and push particular positions. In a clearly contested issue like smoking, it can be useful to separate out the arguments and influence of pro- and antiforces. This pairing interacts with another, that covers public acceptance and support at one pole, and at the other, the responses of institutionalizing powers, be they scientific bodies to accept the nature of issues and problems or governments which legislate or regulate and control implementation and enforcement. Resolution of an issue requires that the institutionalizing responses are congruent with public desires and the absence of issues to generate sufficient opposition to potentially overturn or disrupt the operations of institutionalized responses.

The negotiated nature of social change is a key reason why solutions are often rationally flawed and some potentially powerful solutions are not achievable. The compromises necessary to get sufficient support for an innovation to be adopted often mean that the intellectual integrity of the innovation needs to be compromised. ANT considers the powers of various forces and of the frequent need to enact change through indirect paths. For example, in many countries early efforts to achieve smoke-free places used the systems of occupational health and safety. Although this provided the needed support, it meant nothing could be done about exposures outside workplaces. In time as workplace-oriented bans were seen to be beneficial, there was sufficient support to tackle the remaining areas as is now happening. Thus far, it has not proved possible to negotiate the regulatory changes required to properly tackle tobacco (although there are signs that this is changing). In the absence of sufficient support within government for strong action, other forces, such as community activism and litigation, have been

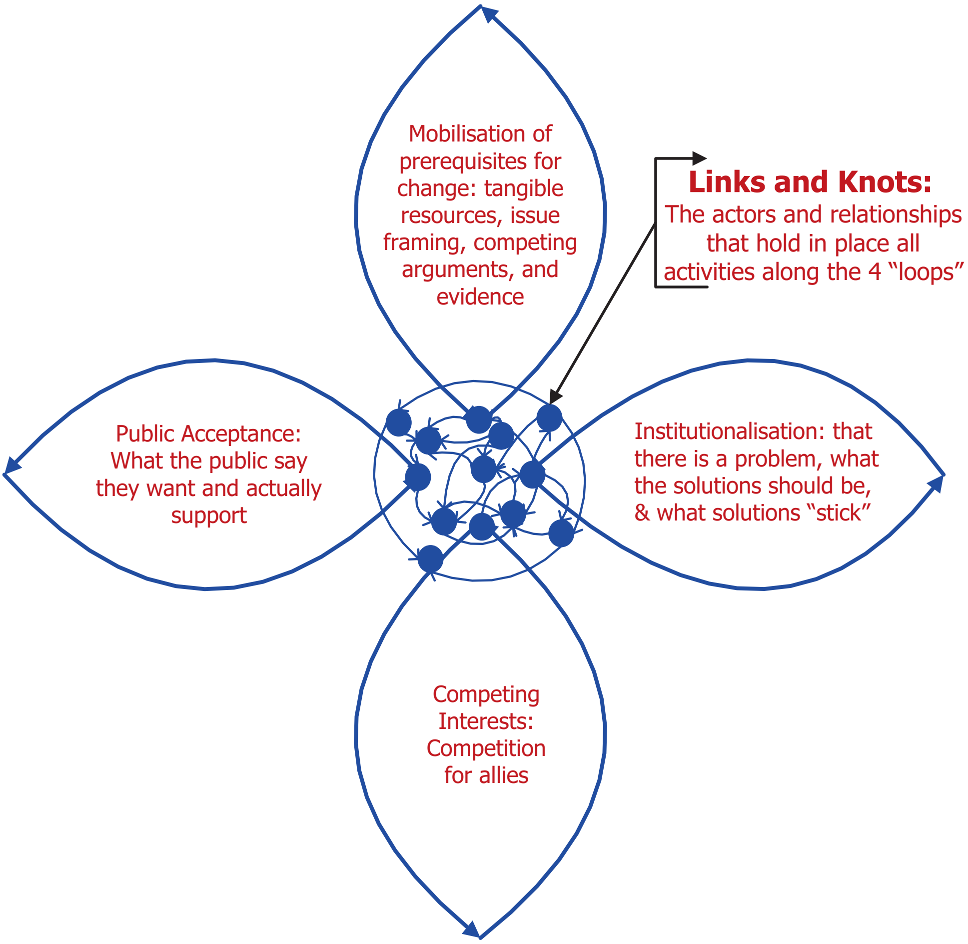


Fig. 26.6 The four kinds of interaction that influence the adoption and institutionalization of policy innovations (Adapted from Young, Borland, & Coghill, 2010)

successfully used to force government action, and at the same time they have changed the way society views tobacco and the tobacco problem.

Some lawyers argue that aggressively marketing tobacco might be technically illegal, given tobacco harms when used as intended and the appalling record of the industry in not unambiguously warning about those harms (Liberman & Clough, 2002). There have been a number of successful prosecutions of tobacco companies, primarily in the USA for failure to properly warn. However, the deep pockets of tobacco companies and the complexities of the cases make this a difficult strategy to implement. That said, none of this goes to the basic legitimacy of selling a product known to shorten the lives of as many as two-thirds of its long-term users, when used as intended (Pirie, Peto, et al., 2013). The failure to confront big tobacco may be motivated by a fear that successful litigation would result in the tobacco industry being made illegal overnight and the social dislocation that it could cause given the large numbers of tobacco addicts. The social problems that resulted from prohibition of alcohol in the USA are often given as an example of the inadvisability of prohibiting smoking.

As alternative solutions to the tobacco problem begin to gain acceptance as viable, it may be that litigation rather than legislation will be the tool that brings about the major changes to the industry many believe are needed. However, even

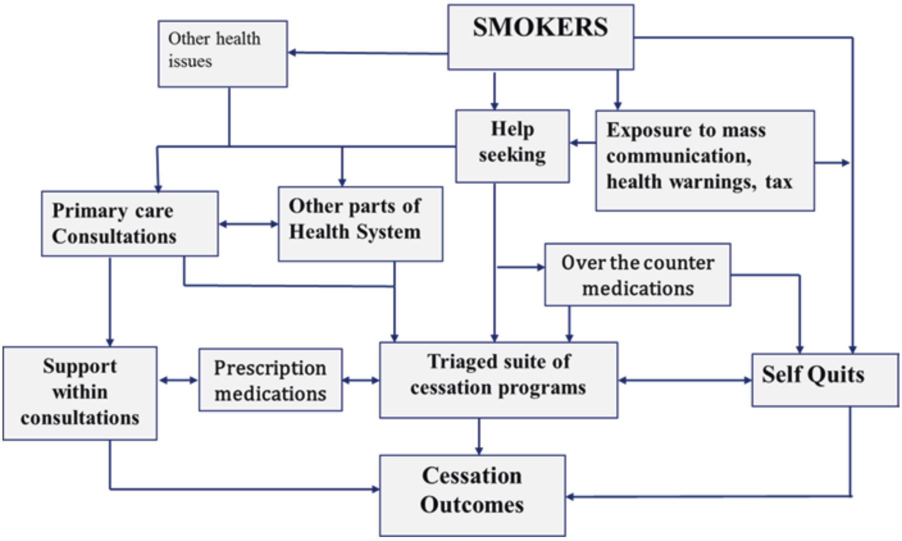


Fig. 26.7 A comprehensive smoking cessation system showing a pathway of self-quitting stimulated by population-level strategies, strategies that also stimulate activity to support quitting within the health-care system

if litigation forces action, systematic government action (regulation and/or legislation) will still be required to create a workable system.

Within this broader context there are a range of specific interventions that can occur to further tobacco control (see Fig. 26.7).The main ones are briefly discussed in the following subsections.

Informing the Public

Central to a rationality-based society is that people have adequate information to make decisions about products and activities that affect their lives. Strategies to achieve a better informed public range from provision of information by health authorities to mandated warning and product information (on packaging, at point of sale and on advertising, where it is allowed). Public information campaigns utilize the mass media, in both paid and unpaid form, and for young people, through education programs in schools. However, mere knowledge is not enough, people need to have an emotional engagement with the knowledge and understand that quitting smoking is a viable strategy for reducing their risk. People experiencing tobacco-induced diseases have this level of engagement, if they do not think action is too late, but we cannot wait until diseases occur to motivate quitting. This is why it is important to use vicarious learning techniques to generate this sense of need for action in those who are not at immediate risk of the problems. Graphic depictions of the harms is one way of doing this, sometimes using media to bring the cases of others to the attention of the at-risk population.

Health Warnings and Product Information on Packaging

There is now compelling evidence that warning labels on packaging improve knowledge and generate concerns about the harms of smoking, and through this, stimulate increased quitting (Borland, Wilson, et al., 2009, Borland, Yong, et al., 2009), although their net effect on cessation is probably small. Warnings with graphic photographs of smoking-related harms, first introduced in Canada in 2001, are the current state of the art in this area.

It is also now clear that strong warnings that lead to some degree of avoidance of warnings by smokers are effective. However, many psychologists believe that “scare tactics don’t work.” This belief is based on research which shows that punishment does not change behavior, but merely suppresses it, and the belief that such stimuli result in avoidance of the issue. There are a number of reasons why this belief turns out to be wrong. First, graphic communications are not punishment. They are better thought of as discriminative stimuli, as indicators about the harmfulness of the product than as noxious in themselves. As cues they act to remind the person that the behavior is dangerous, and this is what leads to increased action to desist. As long as the source of the concern persists, which it does for a genuinely risky behavior, the warning is likely to continue to have the effect of reminding us of the harmfulness of smoking. The issue of avoidance is somewhat different. There is a lot of evidence that avoidance leads to reduced engagement with an issue in experimental studies (Peters, Ruiter, & Kok, 2013), but these almost always entail isolated presentations of risk. However, avoidance is a temporary solution. Mandated warnings of risk remain present on the packs. It should also be noted that avoidance, when it does occur, is motivated by the evasiveness of the risk information and, so, is an expression of concern about the issue. On the occasions when the person avoids a graphic warning, they are unlikely to contemplate change; however, over time those who avoid most also tend to be confronted and think about the risks most (Borland, Yong, et al., 2009), and it is on these occasions when they fail to avoid that they are more likely to act. Finally, for young people and those not at risk from the behavior, graphic images do not appear to evoke fear, but disgust. The association of smoking with disgust may have a preventive value in combating images of smoking as attractive. Thus, prevention effects of graphic warnings among adolescents may function in very different ways to the ways they stimulate concern and thoughts of quitting among smokers.

Mass Media

The mass media is the main source of health information for many people, and even with the Internet, it remains the main source of unsolicited information. It is important for conveying new information and for reminding people about things they already know, but have either forgotten or are ignoring. This is why it is important to ensure that as much as possible of the scientific research on tobacco and its harms gets into the mass media. US research has shown a strong link between the number of media stories and quitting-related activity (Pierce & Gilpin, 2001). This can be done at very little expense as the media have a voracious appetite for news and human-interest stories. To maximize uptake it is important to frame the stories in ways that attract the reader's interest, often by including a personal angle. Getting stories into the media is likely to be less effective in countries where interests associated with the tobacco industry have influence over content.

Similarly, well-constructed advertisements about the harms of smoking, and possibly about the devious behavior of tobacco companies, raise the profile of the issue and make the issue more personally relevant, and thus encourage smokers to quit and sometimes motivate them to seek help. While advertising is expensive, it reaches large numbers, so it is actually quite a cheap form of intervention based on per person influenced.

The health effects ads appear to have their effects by essentially the same mechanisms as the way health warnings on packs work. Because TV ads are mini-films, they can convey a much more graphic and nuanced message than a picture with a small amount of accompanying text, but on the other hand, they may only be seen a few times, unlike the pictures on the packs which can be seen several times a day. Graphic mass media communications also contribute to discouraging youth from tobacco use. Part of the prevention effect seems to stem from disgust associated with linking the unattractive and disfiguring aspects of disease to smoking, rather than the anxiety about future harms to them that drives smokers.

To be effective, messages need to deliver on or be part of a larger campaign that makes the case that smoking is too harmful to continue (or to engage in) and that cessation or avoidance of it is the best solution. This requires gaining an affective engagement with the issue. Mere knowledge is not enough, and to achieve this affective engagement, as noted above, vicarious learning can be an important strategy (Hill & Dixon, 2010).

In the coming years, there is likely to be increased international coordination of efforts to get important tobacco stories into the media, and continuing pressure on governments to continue to warn against the harms. While most people have heard that tobacco is harmful, because it does not seem harmful, the level of harm is widely underestimated, and thus the need for action is similarly underestimated. This rationalizing or underestimation of risk is common to most addictions and often seen as indicative of the psychological processes associated with addiction. Keeping the issue before the public and making the harms emotionally salient will remain important strategies for discouraging use.

The mass media is also a good way to reach lower-SES smokers. Especially when the advertising is both designed to be seen as relevant and shown in programs they tend to view, it is at least as effective at influencing them as more advantaged smokers. Further, as they utilize mass media for health information more than other groups, they are more likely to be influenced here than from sources that one has to actively seek out. Having the issue of smoking prominent in the mass media can also motivate health professionals by making them both more aware of the issue and more aware that their clients have been similarly informed, and thus making them more likely to discuss smoking with their clients, something known to motivate quitting and/or be better prepared to respond to increased queries from smokers.

School-Based Programs

Programs targeted at preventing the uptake of tobacco use have generally not been shown to have marked long-term effects although they can slow the rate of uptake temporarily The more effective programs seem to incorporate information about the harms (i.e., reasons for not smoking), understanding of dependence/addiction, skills training (especially refusal skills), plus information countering the common misperception that more young people smoke than actually do (Buller, Borland, et al., 2003).

A key part of the problem is that in telling people not to do something there must be a mention of what not to do (Wegner, 1994). This generates interest in the behavior, which the preventive message needs to overcome before it can play a positive role. Thus prevention programs that do not adequately convey the reasons for avoiding the behavior can be counterproductive. There is evidence that the tobacco industry has exploited this dilemma in the way it has provided prevention programs in schools. On the face of it, these may appear to be admirable acceptance of responsibility. However, these programs notably deemphasize the health harms and focus on individual choices that smoking is not for children, but a choice some adults make. The limited evidence available suggests that these industry programs encourage some tobacco use by helping frame tobacco use as a legitimate (thus sensible) choice and a sign of adult independence (Landman, Ling, & Glantz, 2002). Whatever their reasons, the tobacco industry has no place in tobacco education. It is not reasonable to expect commercial tobacco interests to make the necessary, strong, unequivocal, negative statements about a product they profit from selling.

Many experts in the field believe that good public education plays a useful and probably necessary role. It is better to have the discussion in the classroom where the arguments against use can be presented, than out of class where they occur in the presence of the product and often no countervailing messages. However, unless accompanied by strong societal policies discouraging all harmful tobacco use, and thus primarily focusing on adults, it is unlikely to have much effect. Our experience in Australia, mirrored elsewhere where it has been studied, is that when you ask young people about what has influenced them, it is strong antismoking messages directed at encouraging adult smokers to quit. By contrast, they see messages directly focusing on youth as less effective for them (some think they could work for younger children). This may be because it treats tobacco as something no one should do, while youth-targeted ads run the risk of having a subtext of wait till you are an adult, something that acts as a magnet for many young people (Landman, Ling, & Glantz, 2002). Young people in modern societies, at least, are motivated to behave like adults and are resistant to the idea that there are some things open to adults that they should not do. This is consistent with research that finds that even the most effective school programs to prevent smoking tend to have modest impacts, and with the success in smoking prevention in countries like Australia which have for the most part focused communications on encouraging adults to quit, with school- and youth-oriented messages consistent with this, i.e., you should not smoke because it is not good for anybody, and as it is very addictive, you run a risk of not being able to stop if you take up the habit.

Other Media

The new social media (the integration of interactive elements of the Internet with mobile telephony) provide both huge challenges and opportunities for tobacco control. The threat comes from the potential of the industry to seed pro-smoking groups, given that such activities are hard to regulate. The opportunity is that it allows the potential for more genuinely interactive engagement with the issue and the opportunity of well-informed members of the community to become active partners in getting the messages out. The Internet will be most effective for those seeking information or help, but mass media will continue to play an important role for motivating people to seek information or help as people need to be sufficiently motivated before they will proactively seek things out. Also, because of interactive capacities, the Internet makes it easier to interact with the potential audience, to hear their views and understand the ways they frame the issue, and thus provides the capacity to respond appropriately, rather than expect the audience to adapt to the frame provided by experts speaking to them through the mass media.

Countering Tobacco Industry Marketing

Modern marketing is framed around the four Ps: Product, Promotion, Place, and Price. Tobacco control activities to date have tended to focus on promotion, and, through taxation, price, all of which we consider in this section, with product modifications reserved for the section "Harm Reduction" because it raises issues beyond product innovation as a marketing tool.

Many of the techniques that are now ubiquitous in mass marketing were first used, or first perfected, for selling tobacco, in particular the manufactured cigarette (Proctor, 2012). The tobacco industry continues to be a leader in the development of new marketing techniques, motivated, at least in part, by the constraints put on them from using established methods.

Restrictions on Promotion

Legislative bans, or other agreements, to eliminate tobacco advertising have been an important strategy since the 1970s. Bans on television often led the way. In many countries, bans now extend to all electronic media, newspapers and magazines, and billboards, and all forms of sponsorship by tobacco companies. Increasingly, advertising is also being eliminated at point of sale. Reviews of the impact of such laws indicate that when they are relatively comprehensive, they do reduce tobacco use, but if they are weak, tobacco companies can compensate by spending more on areas that are still allowed (Jha & Chaloupka, 1999). A number of countries, including early adopters France and Thailand, now require cigarettes to be kept under the counter to eliminate the promotional aspect of cigarette displays. There is evidence that this policy can reduce spontaneous purchases (Li, Borland, et al., 2013), so it is likely to have a small positive impact on cessation outcomes, although the likely small size will make finding direct links difficult. Display bans should restrict storage to cabinets where the contents are not clearly visible to the public when opened, as is the case of large cabinets behind the seller, a set-up which draws attention to the products inside when opened.

Tobacco promotion has not been eliminated. The essence of modern marketing is the brand, and tobacco products are all attractively branded. This results in smokers becoming unpaid brand promoters each time they publicly display the brand they are smoking. The closest any country has come is Australia. Since the end of 2012, all tobacco products sold in Australia are in plain, standardized packaging. Apart from the large colorful health warnings that are mandated on 75% of the front, 90% of the back and generic contents information on one side, the rest of the pack is a dull dark olive-brown color and the names and variant descriptor (where relevant) of the brand are only allowed in a standard font (see Fig. 26.7). In addition, all branding on cigarette sticks has been prohibited. This goes a long way to reduce the capacity of companies to use brand imagery, but while they can retain brand names (especially those with existing connotations due to past promotion), there will still be some capacity to promote brands. While for-profit companies can continue to compete against each other, there must be marketing potential in the brand names and whatever else they can use to add value to the basic products. If active promotion of tobacco products is to be eliminated, it may be necessary to stop for-profit tobacco companies from marketing their products directly to consumers. Banning sale of cigarettes for profit does not mean prohibition as not-for-profit mechanisms can be used to supply the demand (Borland, 2003), but in a way that does not degenerate into "the more you sell the more you make," something unacceptable for products as harmful as cigarettes. The nonprofit agencies (either arms of governments or through some other mechanism) could take control of the marketing of the products. Similar mechanisms have been used to control the sale of alcohol in various countries including North America and Scandinavia, although many of these have focused on controlling distribution without addressing marketing. Nevertheless, these strategies have been shown to reduce consumption compared to for-profit distribution and marketing. As modern marketing is at the core of product sales, and marketers largely control the distribution network, if marketing is controlled, most of the benefits of such an approach would be achieved.

A major promotional strategy still used by the tobacco industry is known as relationship marketing. One key aspect of relationship marketing is to position the desired activity as part of a broader lifestyle. This involves building and helping to sustain a lifestyle where the product, in this case cigarettes, is designed to fit – just one of the things you do and have. Linkages to brands are through colors and design elements, and/or through strategic product placement. The best-known example of this is color (Coombs, 2013). The brand Luck Strike packet design was a red bull's-eye on a green background. Research found that many women found the green color clashed with their clothes. Instead of changing the design, Edward Bernays, the father of public relations (and a nephew of Sigmund Freud), was consulted and decided to make green fashionable. The American Tobacco Company started promoting fashion events (e.g., balls, cocktail parties) using the same base green color in the design of the setting for the event and encouraged people to fit in. The green Lucky Strike pack acted as a complement to attempts to be fashionable and both green and Lucky Strike became fashionable for a time. As an aside, Bernays became embarrassed by his success in getting more women to smoke and became an antismoking activist in later life. The lesson here is clear, where the context happens to fit the product, there is less need for overt product advertising because the context itself and other people using the product in those contexts are powerful forms of promotion. It is extremely difficult if not impossible to impose legislative controls on such indirect promotion, especially if the events that are designed to promote the image (i.e., the desired fashion) are funded by legally independent third parties. In the future, plain packaging will make brand-specific relational marketing more difficult as all brands look very similar.

A remaining challenge, and one the FCTC convention of parties may develop a protocol on (an extension of the international laws), is cross-border advertising, which is occurring through satellite broadcasting and, increasingly important, the Internet, both to promote the products and to facilitate product sales.

Price and Taxation

Tobacco use is price sensitive, even though it is addictive. Increased prices (in real terms) increase cessation and reduce consumption

(Jha & Chaloupka, 1999). The best estimate of the elasticity of price is that a 10% increase in price reduces consumption by around 4% (IARC, 2011). That is, smoking is relatively inelastic, but nevertheless still somewhat sensitive to price. Moreover, its price elasticity may vary in different groups. Price appears to have a stronger effect on uptake than on consumption by existing regular users, at least in part because adolescents have less disposable income and perhaps because many of the young people are not addicted, or at least are less addicted than those who have smoked for longer. For existing smokers, reductions driven by price changes are due to some combination of cessation and reductions in consumption among continuing smokers. It should be noted that reduction in cigarettes per day does not necessarily translate into reduced consumption of nicotine (or of the accompanying tar and carbon monoxide) as each remaining cigarette could be smoked harder.

The onset effects of price increases are virtually instantaneous, making them easy to detect, but less is known about how long they are sustained if prices are kept constant in real terms.

Governments use tax on tobacco as an important source of revenue. In recent years, tobacco control advocates have pushed for tax increases as a means of controlling use. Tobacco taxes are one of the few popular taxes (even among smokers in countries where they understand how harmful it is and know they should quit). Countries with strong tobacco control policies have up to around 75% of the retail cost made up of taxes. High taxes can also have the effect of limiting tobacco companies' flexibility to use price as a marketing tool, as it creates an effective minimum price.

Price differentials between jurisdictions and high taxes do provide incentives for illicit trade, something that can have other social harms such as the institutionalization of crime and corruption, as well potentially providing access to cheaper (tax not paid) tobacco products. However, a range of other factors, particularly level of institutional corruption and quality of enforcement mechanism, are important in determining whether an illegal trade will develop and how extensive it is likely to be.

Price can lead to a reduction in tobacco use, but it can also result in changes in patterns of consumption if there are price differentials between tobacco products. For example in the UK in the last 20 years, the percentage of smokers using mainly hand-rolled tobacco (RYO) has more than doubled, particularly among women. This increase has been attributed to tax differential between factory-made (FM) and RYO cigarettes, and increased overall tax rates, coupled with easy access to duty-free rolling tobacco from continental Europe. This may have been further advanced by efforts by the tobacco industry to market it as a cool and natural choice. Similarly in Sweden, the move from smoked to smokeless tobacco use (especially among men) has been attributed to the lower cost of smokeless. That use is much less among women highlights the fact that cultural factors can diminish the motivational force of price.

High prices, while providing a greater incentive to the poor to quit, can cause problems for those unable to quit, because the costs of smoking can result in them skimping on essentials which can result in families going hungry, eating poor quality food, and/or being poorly clothed. In some countries there is evidence of this happening, while in other, more affluent countries, only the most economically disadvantaged seem to suffer in this way, and they are often able to access cheap illicit supplies. There can be no complete solution to the tobacco problem that does not attend to the needs of these groups, as smoking rates are particularly high among the most disadvantaged.

Place of Sale

Tobacco remains one of the most readily available consumer products on the market. Many countries have prohibited sales to minors, and a few, like France, limit its sale to specialist retailers; however, in most countries tobacco is still available in places where children buy sweets. Density of tobacco outlets is related to the prevalence of smoking in the area (Chuang, Cubbin, et al., 2005). Based on experience in restricting sale of other products, e.g., alcohol (Campbell, Hahn, et al., 2009), it is likely that reducing the number and type of outlets, and/or hours of purchase would reduce consumption.

Restrictions on Use: Smoke-Free Places

There has been major progress in many countries in the move to smoke-free environments. This has been motivated by the evidence on the harms of passive smoking, especially to nonsmokers. After implementation, we generally find high levels of compliance and increased support, including among smokers. The most difficult places to make smoke-free have been bars and gambling venues, two activities that are strongly associated with smoking. However, as Ireland demonstrated in 2004, totally smoke-free pubs (bars) are not only achievable but strongly supported by the community (Fong, Hyland, et al., 2006). As smoke-free policies are being implemented in countries with little history of public education about the harms (of both passive and active smoking), compliance has sometimes been a problem. In many cultures, it seems that people need to believe that a policy is in most people's interests before they comply.

Mandated smoke-free public places (including work places) lead to reduced cigarette consumption among continuing smokers and a small temporary increase in cessation (IARC, 2009). Smoke-free public places seem to have a small positive effect on people making their homes smoke-free, which, in turn, seem to be an aid to successful cessation. There is also some evidence that having smoke-free public places, particularly recreational venues like bars and clubs, inhibit uptake of smoking.

Supporting Cessation

So far this chapter has focused on environmental factors which can be influenced at a societal level, or at least at the level of lower-level jurisdictions within countries. However, these strategies can only get us so far, as we pointed out earlier. Many existing smokers remain unable to quit even in countries which have adopted most of the possible strategies to nudge their populations away from smoking. This section focuses on helping individuals who need or seek help to quit.

Cessation Aids

There is now overwhelming evidence (www.treatobacco.net) (Treatobacco.net) that a range of medications can be effective aids in smoking cessation when used for periods of around 6–12 weeks (Cahill, Stevens, et al., 2013). These medications, including nicotine itself (as nicotine replacement therapy, NRT), plus two other drugs Bupropion and Varenicline which work on different aspects of the brain's reward system, are all demonstrably effective. There is also some evidence that using medication for longer can at least delay relapse, but only during the period the drug is being used. Anecdotally, some ex-smokers continue to use NRT long term, but it is not clear whether this is necessary for preventing relapse or a choice due to presumably positive effects of use.

There is also evidence that a wide range of behavioral interventions from structured self-help manuals, through tailored self-help resources, through Quitlines to face-to-face individual or group programs, all help smokers to quit, with the success rates increasing with increased length up to several sessions (see a number of Cochrane reviews for the evidence: http://tobacco.cochrane.org/our-reviews, accessed April 28, 2014). Although limited in their ability to sustain nonsmoking, as discussed next, across the variety of modes of delivering cessation services, a common behavior change methodology has evolved over 40 years of research on smoking cessation that provides an important model for behavioral medicine in general (stated here in general terms – exemplified by how they apply to smoking cessation):

1. Reviewing reasons for the behavior change. This involves both enhancing an understanding of the cons of smoking and challenging the pros, which combine to influence the person's motivation to quit and, by challenging

the pros, is designed to reduce ambivalence about doing so.
2. Setting a concrete, specific plan for behavior change – This may involve decisions as to whether to use medications, professional guidance, through to choosing a quit date.
3. Acquiring any necessary resources, skills, and supports. For example, purchasing stop smoking medication, enrolling in a quit course, practicing relaxation skills, asking one's partner for support, and asking your smoking friends not to offer you cigarettes.
4. Identifying and developing concrete plans for addressing issues that may compromise success – identifying predictable temptations for relapse and making specific plans for avoiding or mitigating them. A useful strategy is to rehearse statements of the kind "If in a specific situation, use a particular strategy to deal with the problem" (e.g., "If I feel myself becoming stressed, I will take three long deep breaths, and leave the situation if I am still having problems.") These framing statements are known as Implementation Intentions (Gollwitzer, 1999; Gollwitzer & Sheeran, 2006) and is one promising way to improve the likelihood of appropriate actions being triggered when in problematic situations.
5. Encouraging sustained vigilance and efforts to maintain new behaviors. It is this last part that is most difficult. As in many other areas of behavioral medicine, the challenge is helping people sustain healthy behaviors.

More intensive advice-based programs are increasingly delivered via the telephone rather than face-to-face. There has also been an upsurge of use of automated advice programs, consisting of either or both tailored personalized advice on the Internet or short frequent advice messages to mobile phones. Both forms of automated intelligent programs have been shown to be effective. These are computer programs that tailor advice to the smoker based on their responses to relevant questions. They were first developed by Prochaska and associates in the early 1990s (Prochaska, DiClemente, et al., 1993) based around the Transtheoretical Model of Change, but have now expanded to be provided from other conceptual models (see www.QuitCoach.org.au for one example). More recently, interventions have been developed which send short pieces of advice via text and/or graphics to mobile phones. These are generally less tailored than those delivered via the Internet. In principle, the provision of detailed advice, coupled with the potential of providing regular prompts, and also of rapidly responding to relapse crises, should have additive effects, but while each has been shown to be effective in its own right, the evidence for additive effects is currently weak.

While both cognitive-behavioral interventions and pharmacotherapy help quitting and when combined their effects are greatest (Stead & Lancaster, 2012), all of the benefit appears to occur during the time the interventions are actually being provided, and there is little evidence of interventions having persistent effects beyond the point where they are being actively delivered (Hajek, Stead, et al., 2013). Evidence is also emerging that the factors that determine short-term success in quit attempts may be different from those that affect long-term maintenance, suggesting that different strategies may be needed to help some of those who survive the difficult early weeks to stay quit longer term. Clearly most ex-smokers already have what it takes, the challenge is to find signs of vulnerability and develop strategies to overcome them. Unfortunately, at present there are no demonstrably effective cognitive-behavioral *intervention* strategies that have been reliably shown to sustain maintenance of smoking cessation. As a result, some people have turned to a consideration of using clean forms of nicotine long term as an alternative approach to sustaining abstinence, particularly for those who find staying quit particularly difficult. We discuss this possibility in more detail in the later section "Harm Reduction and Product Regulation."

The Challenge of Getting Smokers to Quit

Earlier in the chapter, we pointed out how addictive smoking is and some of the challenges associated with successfully quitting. This section begins from that knowledge base and considers the kind of system we need to facilitate getting smokers to quit and to make the most use of effective cessation aids.

Uptake of help, particularly advice-based help, remains low, even when subsidized or free. This is probably due to a combination of beliefs that one “should be able to do it myself” and the deep ambivalence about change that characterizes tobacco use and other dependencies. It is also influenced by the way the services are provided. For example, contradicting talk about the importance of paying for a service in order to value it, free cessation assistance offered to members of a health plan, although less effective among participants, recruited sufficiently more participants to generate a greater net impact on overall numbers quitting (Curry, Grothaus, et al., 1998). Accessibility is important. In the UK, there is much greater use of face-to-face services as there is a well-organized and readily available network of services. However, in most other places, telephone-based Quitlines are generally preferred to face-to-face services, at least in part due to the convenience.

The effect of interventions is not just a matter of how effective they are when used, it is also a function of what proportion of smokers is prepared to use them in their quit attempts. As noted above, promotion of the issue in the media drives people to seek help, as does product-specific advertising. However, unless interventions are seen as desirable, the effects of promoting them will be limited. To maximize cessation requires both a population of smokers who are motivated to confront the challenge and universal access to systems that will maximize success, with such interventions being seen as desirable to use. This requires the complex mix of population strategies to support activity and aids to facilitate success.

While seeking support might seem sensible, the ambivalence that smokers feel, a belief that they should be able to just quit, coupled with a widespread distrust of both pharmaceuticals, and even more of counseling approaches, results in an over reliance on ineffective strategies and strong tendencies to avoid action as much as possible.

Ambivalence does not just affect the smoker, it affects those around them. Ambivalence toward health-enhancing change is not something most health-care providers feel comfortable dealing with. The current health-care system is focused on curing illness and generally expects its patients to be motivated to act in ways their advisers tell them will improve their health. Smokers’ ambivalence about being advised to quit is transmitted to health professionals, in part by negative reactions when they are not “ready” for the information. As a result, health professionals often avoid the issue of cessation unless it is central to the presenting problem, to both avoid feeling uncomfortable themselves and because of fears of making their patients feel uncomfortable. The tendency to avoid is further motivated by the reality that most health professionals lack the skills to help smokers and there are few systems in place for referral to sources that can assist. Recommendations by health professionals that smokers seek help are not enough to get most to act. Active referral where the person is directly put in touch with the service is needed. Active referral to Quitlines which offer a callback counseling scheme is feasible and is available in some places. It is acceptable to both smokers and health professionals and leads to more successful quitting (Borland, Balmford, et al., 2008).

Because smoking cessation involves a lifestyle change as well as overcoming a dependence, and treatments only support short- to medium-term behavior change, unless ex-smokers discover that they can cope and enjoy life at least as well as when they smoked (if not better), they remain at ongoing risk of relapse, even years after successfully quitting. For example, if ex-smokers continue to believe that smoking helps them cope with stress, they are more prone to relapse, especially when they are subject to high levels of stress (Dijkstra & Borland, 2003). Beliefs about emotional regulation appear to be the important ones, as beliefs about social and other functions of smoking do not appear to influence relapse.

This brief analysis suggests two major challenges: finding ways to confront or cut through ambivalence and that would encourage smokers to use the sort of help that will maximize their chances of success; and finding ways for health professionals to raise the issue with smokers that maximize the likelihood of action.

Smokers may come into contact with options for help in different ways (see Fig. 26.7). They may seek help directly from specialist cessation services (Quitlines and face-to-face services), perhaps motivated by strong and regularly presented antismoking messages; they may seek help from their own health-care provider who may provide it or refer them on; or they may be referred to help by other parts of the health-care system. Of these, the first is likely the main way when smoking cessation is widely promoted in the mass media and other community communication channels. However, the health-care system has obligations to do as much as it can to facilitate smoking cessation as well. We are still some way off providing all the encouragement and support many need to quit successfully. Unless we can find such strategies, we will need to consider substitution as the most attainable alternative, even though that may result in the persistence of addictive nicotine use. The upside is that there will be far fewer adverse health effects.

The Denormalization of Smoking

Smoking, being a socially embedded behavior, is subject to normative influences, which vary across cultures, and as a function of the way the society responds to the problem. In many countries today, smoking is no longer seen as socially desirable for any group in the community, and is widely accepted as being highly detrimental to health. However, in other countries it is still normative, as little effort has been put into educating the public.

Cultural differences may determine the extent to which subjective norms influence smokers' quitting behavior. In more individualistic cultures such as the USA and Australia, smokers may be more influenced by their own attitudes toward smoking than by antismoking norms, whereas in more collectivistic cultures such as in Asia, societal norms against smoking may play a greater role and somewhat different role (Hosking, Borland, et al., 2009). Religion is another cultural factor that can influence normative beliefs about smoking especially in countries where religion is central to the lives of people. Different religions or modes of their expression may lead to them influencing smoking in different ways (Yong, Hamman, et al., 2009), and they may vary in the extent to which they dominate broader societal norms (Yong, Borland, et al., 2012).

The process of changing what is normative in a social group is not something that can be simply imposed from outside. Normalization is an emergent property of the ways people think, talk, and act around a topic or activity. External agents can seed discussion with information and encourage people to challenge problematic practices, but unless the people accept the need for change, it will be resisted. Even within a society, laws that do not achieve community support are widely ignored or broken. This can be seen with some drugs that are currently illegal, such as marijuana, where in some places use is reported to be greater than for drugs like tobacco-delivered nicotine which is legally allowed.

Initially, attempts to challenge normative behaviors are often resisted, but at some point there can be a rapid transformation, and what was previously normative becomes unacceptable (Rogers, 2003). Attitudes to smoke-free policies tended to change in this way, with the change in attitudes further supported by the experience of complying with imposed bans on smoking in public places. As smokers found that they could readily comply and that they also often enjoyed the smoke-free environments, they not only complied but became supportive of the restrictions. In other words, discovering that compliance was not a major problem, then led to a virtuous cycle of increased support or, at the very least, reduced active opposition, and the new behavior patterns became rapidly normalized. Similarly, as smoking becomes denormalized it should be easier for smokers to quit, but this effect may be masked by the addictiveness of the product, meaning that the remaining smokers are more physiologically and psychologically addicted than those who have quit. If so, it would suggest that much of the quitting that occurs in relation to the reduced normativeness of smoking might be among those who were less biobehaviorally addicted.

It is notable that the progress in movement to smoke-free places has been much faster than the move away from active smoking. We think this is for two main reasons. First, societies are more active at solving problems where other people are affected (by passive smoking), than where the harm falls on the person engaging in the behavior. People are seen as having some rights to make their own choices and own mistakes as long as it does not adversely affect others. Second, we think it is partly because where people smoke is largely determined by social factors, which are relatively easy to change, while smoking is more determined by addiction and thus is more difficult to shift. Combined together, this explains why some countries have largely solved the problem of passive smoking, although it really only became an issue in the late 1980s following the publication in 1986 of the US Surgeon General's report concluding that passive smoking caused lung cancer and some other conditions. This can be contrasted with the situation with active smoking, where a similar level of scientific consensus as to its harms has been known since the early 1960s, yet it remains a big issue today. This shows that many of those addicted to smoking (via nicotine delivery) can alter their patterns of use to fit in with environmental constraints, but find it much harder to quit altogether.

Denormalization has played a central role in the decline in smoking driven by the knowledge of its harms. This can be seen by reconsidering Fig. 26.1 and noticing that the large decline in smoking in the USA started with the widespread publicity afforded by the conclusions of the 1964 US Surgeon General's report. However, the effects of knowledge do not have an instantaneous effect as do price changes, so the impact of knowledge has been hard to pick up in empirical studies that only covers a brief period. This is particularly the case now that almost everyone knows that smoking is harmful, and educational interventions are mainly reminding them of this and trying to get them to realize *how harmful* it is. That so many people continue to smoke in this denormalized climate is proof that denormalization and knowledge of themselves are not enough.

Harm Reduction and Product Regulation

The regulation of tobacco products brings us into the area of harm reduction. The main aim of tobacco product regulation is to reduce the harmfulness of the products, ideally at a population level, although most regulators tend to focus on harm to each exposed individual and tend to neglect the issue of the impacts on total population use. It is important to understand that a product that is somewhat less harmful, but used by many more people, could do more population-level harm although it does less harm, on average, to each of its users.

To understand the potential for harm reduction it is important to know the sources of harm. Although nicotine is the component of smoke that is responsible for its sustained use, it is other components that are causing the health harms. This separation of what is addictive from what is harmful raises the possibility of less harmful ways of delivering nicotine.

The tobacco industry has invested large amounts of money in attempting to develop cigarettes that are less toxic and/or carcinogenic (herein collectively referred to as toxic or toxins), while still being attractive to consumers. To date, they have failed. The first attempt was the introduction of filters. However, filters do not change the mix of chemicals much, they filter out nicotine at a similar rate to other toxins, and as smokers smoke primarily for the nicotine, they adjust and take in more of the filtered smoke, ending up with similar levels of nicotine along with the other harmful chemicals (Kozlowski & O'Connor, 2002). Filters have not provided any major reduction in cigarette harmfulness, but by giving the impression of reduced harm, may have helped allow the market to grow and thus they have been net counterproductive.

Before the evidence was in on the effects of filters, several governments set limits on the amount of tar, nicotine, and often carbon monoxide produced by cigarettes. This led to marketing opportunities to promote cigarettes which delivered lower levels of these chemicals. These were the so-called "Light" and "Mild" cigarettes. They were designed to taste less harsh and delivered lower levels of toxins when smoked by a machine with a fixed intake of smoke. The industry used filter ventilation, small holes in the paper surrounding the filter, to allow air to mix with the smoke. The industry knew what we now know, but see Kozlowski et al. (Kozlowski, Frecker, et al., 1980) who warned us at a time when we were not listening that smokers compensated for this dilution effect: they blocked some of the holes and took larger and deeper puffs. This is easier to do with the cooler, more diluted smoke, thus ending up with similar levels of inhaled toxins and the same levels of disease (including new kinds of cancer deeper in the lungs).

The FCTC mandates prohibiting the misleading use of the terms "mild" and "light" and recommends removing misleading yield measures from packaging where they had been mandated. These bans have had a limited impact (Yong, Borland, et al., 2011). Consumers experience the "lights" as slightly less harsh and interpret this reduced averseness as evidence of reduced harmfulness, helping to reduce concerns about the potential harms to them of smoking (Shiffman, Pillitteri, et al., 2001). The core problem has not been addressed, that of filter venting, and thus the problem remains.

It has become clear that there is no prospect of reducing the harmfulness of smoked tobacco to acceptable levels. The main problem is that the combustion creates new toxins, and filters have not proved selective enough to remove enough toxins to make a large difference. Currently, marketed cigarettes vary considerably in the levels of toxicants they produce (WHO, 2007). There is a moral imperative to force companies to clean up or stop producing the more toxic cigarettes, even if the net reduction in toxin load to smokers is modest. The importance of targeting harmfulness has been heightened recently with the 2014 US Surgeon General's report (U.S. Department of Health and Human Services, 2014) concluding that cigarettes may be causing more lung cancer. The most plausible culprit for this is filter venting, and thus the case for banning this engineering feature has become much stronger.

In contrast to smoked tobacco, smokeless tobacco products can be cleaned up to have low levels of toxins. As a result, some public health people and some tobacco companies have explored the potential of smokeless tobacco as a harm-reduction strategy. The Swedish experience has been important in fueling support for this strategy. Sweden's then government-owned tobacco monopoly was the first group to develop low-toxin forms of smokeless tobacco. The Swedish government allowed smokeless to be sold at a cheaper price than smoked, but until recently, allowed no health claims. In the 1970s, use of Swedish oral snuff ("snus" in Swedish) was a dying habit of old men. Use has recovered: there are now more snus users among Swedish men than smokers, among whom the smoking rate is low, indeed lower than for women where few took to snus. Epidemiological research indicates that levels of smoking-related disease are notably low in Swedish men and are largely comparable to nonsmokers for snus users. Expert panels have estimated that snus and products like it are at least 90% less harmful than cigarettes, perhaps more so (Levy, Mumford, et al., 2004; Royal College of Physicians, 2007).

One recent product development that has excited interest as a harm-reduction option is of vaporized nicotine products (VNPs). These create an aerosol containing nicotine when puffed on in a way analogous to smoking e-cigarettes (electronic cigarettes). These products vaporize nicotine in a solution of typically propylene glycol and/or glycerin using a battery-powered heater, which is switched on either manually or by starting to puff on a mouthpiece linked to the heated liquid. They are known by various names, including e-cigarettes (electronic cigarettes), and more recently, especially among those who want to differentiate them from smoking, other names such as personal vaporizers, with the behaviour called vaping. There are other similar devices being developed or in the early stages of dissemination that heat rather than burn tobacco to create the aerosol to be inhaled, and other devices that do not require heating, but release metered doses of an aerosol containing nicotine from a pressurized chamber each time the person puffs on the mouthpiece. Some VNPs look like cigarettes, but others look completely different to any smoked product. There are now a number of groups of ex-smokers who use and promote the use of VNPs as low-harm alternatives to smoking – so-called Vaper groups. The evidence to date is that VNPs are by far the most attractive alternative to smoking to date, and that they can help smokers to quit (Hartmann-Boyce et al., 2016); however, whether they are good enough to migrate most smokers away from smoking is less clear.

We know that a small percentage of ex-smokers continue to use NRT long term, and studies from Sweden show that some smokers have successfully quit by switching to smokeless tobacco, and more appear to be doing so using VNPs. Indeed, in the UK in 2013, VNPs were the most used form of drug for smoking cessation, even though they are not approved as medicines and cannot be promoted as cessation aids, and those using them were more likely to be successful than those using approved nicotine replacement products (West, Brown, & Beard, 2014).

There is currently a vigorous, and sometimes acrimonious, debate within the tobacco control community as to the appropriateness of a harm-reduction approach, rather than continuing to pursue an abolitionist agenda. Those opposed to a harm-reduction approach fall into two broad camps, those who see any form of addiction as bad and are concerned that harm-reduced products might lead to more people using nicotine-containing products. The second group is concerned about the workability of the approach and sees the possibility of just as many smokers and lots of other nicotine users, thus potentially leading to more harm (the extreme version of this concern). By contrast, those sympathetic to harm reduction (a group that includes the authors), see it as having a huge, as yet untested, potential to reduce or eliminate the most harmful form of nicotine dependence, that of smoking cigarettes, especially if it can be done in a way that minimizes the possible downsides. This means adding harm reduction onto the existing set of tobacco control strategies, not treating it as an alternative.

Taking a comprehensive population-approach perspective not only involves all of the strategies discussed above, it also requires consideration of characteristics of tobacco products that encourage and/or sustain use and the extent to which they are intrinsic to the product or are potentially removable or modifiable. Australia through its Plain Packaging legislation has already legislated to make cigarettes look less appealing, and Canada and Brazil have legislated to remove additives from tobacco, particularly flavors that make them more appealing to use, in part by tempering the naturally aversive taste of inhaled smoke. These actions should make cigarettes less attractive to novice users and should be encouraged more widely. In addition to the extent that suitable alternatives are available, it becomes much more feasible to reduce the nicotine in cigarettes, so that they become overall less satisfying and addictive. Having viable alternatives to cigarettes for delivering nicotine should mean less risk of a black market in unregulated products developing (i.e., the types of cigarettes available now). Making cigarettes less attractive and/or less addictive could thus help shift the balance toward VNPs, compensating for their current lower levels of psychologically attractiveness.

Based on all we know about addictive substances, the more potent the initial reaction to the use of the drug, the more likely it is for an addiction to develop; thus it is easier to quit current nicotine replacement products than it is for smokeless tobacco, which in turn is easier than quitting smoking (Fagerstrom & Eissenberg, 2012). If we apply this principle to VNPs, they are likely to fall in addictiveness between smokeless tobacco and cigarettes. However, technological advances in e-cigarettes are likely to result in them becoming closer to cigarettes in their capacity to deliver nicotine, and to the extent that the experience is similar to smoking should have increased potential to be acceptable substitutes for smoking. If a product was invented that was as good as smoking, then smoking would be likely to rapidly disappear as smokers do not want to die prematurely, and all other things being equal (e.g., price and availability), the problem of smoking would solve itself. Unfortunately, we are far from being in this situation at present, although we may be approaching the situation that if we were to tilt the playing field enough in favor of VNPs, we might be able to prohibit or heavily restrict cigarettes without it producing a societally unacceptably sized black market (Borland, 2013). We simply do not know where we are with current products, partly due to rapid product innovation and partly due to the paucity of good research.

It is extremely likely that if VNPs were allowed and encouraged as a cessation aid, it would increase the numbers of smokers successfully quitting even if VNPs prove no more effective as it is likely that some smokers who would not otherwise quit would use them to quit. This is likely, given the spontaneous enthusiasm some ex-smokers have shown, even to the extent of setting up Vapers clubs (as they are known) which encourage use and educate smokers on how to best use them to gain the greatest satisfaction, and thus be the best possible replacement for cigarettes.

It is likely that the more attractive the product, the greater the impact on existing smokers. However, it is also likely to be more attractive to nonsmokers, both ex-smokers who miss the experiences associated with smoking but have been able to forgo them in the face of the high risks and nonsmokers who would not otherwise have taken up smoking. That is, we are faced with the uncomfortable situation that the better the solution the greater the risks.

The evidence from Scandinavia is that the availability of snus there has led to more tobacco use, particularly among males, but snus has not been a gateway to smoking among those who would not otherwise have smoked (Foulds, Ramstrom, et al., 2003; Ramstrom & Foulds, 2006). There is increasing evidence that VNPs are attracting the interest of youth, and some unscrupulous companies are actively promoting these products to youth, but no evidence yet on whether there will be progression to smoking that would not otherwise have occurred.

We think it unlikely that use of VNPs or other low-harm nicotine products will lead to more regular smoking as youth are aware of the harms of smoking, but we acknowledge that it might lead to more experimentation with cigarettes, especially if they remain readily available. Unless it facilitates uptake of smoking, it will have a beneficial effect to the extent that it can get smokers to quit cigarettes.

At present VNPs are banned in some countries (either altogether or only if they contain nicotine), while they are allowed in others with regulators working to develop appropriate frameworks to minimize health and other risks. Thus we are facing a great natural experiment as to what contribution they can make and to what extent the fears of some will be realized. We would like to see governments that allow VNPs support extensive postimplementation research to help us most rapidly find out what their effects are on smoking, what uptake occurs among nonsmokers, and ultimately whether they are as low in harm as we would expect extrapolating from what we know about other similar products.

Conclusions and Challenges for the Future

Reducing the harm from use of a dependence-inducing substance that has been, and in many ways still is, deeply embedded in national cultures and economic activities is a complex and difficult task. No single strategy has had much potency of itself. The mix of strategies that has been used today has reduced the prevalence of cigarette use from over 40% or 50% to less than 15% of the population in the most successful countries – a remarkable public health accomplishment given its addictiveness and the need to change social, cultural, and economic climates which until recently had been supporting smoking. To make further progress is likely to require greater application of the existing known strategies as well as new strategies based on a more fundamental appraisal of the role of the tobacco industry and the marketing of tobacco products. It is becoming clear that more is required than environmental and associated policy changes leading to the denormalization of smoking, although this is an important part of the solution. We believe that there needs to be a renewed focus on biobehavioral factors. In this regard, dual-process models of psychological functioning may provide the best framework for understanding this complexity (Borland, 2014). Dual-process theories postulate two sets of factors within the individual to jointly determine behavior in conjunction with contextual (environmental) conditions. These two sets of factors are first, bottom-up, reactive, operational responding to environmental cues, and top-down, language-based, executive functions that act to arbitrate conflicts between operationally generated action tendencies and which can operate in relation to linguistically defined propositional goals and as such can apparently transcend the contingencies of the moment (Borland, 2014). Dual-process models are leading to the development of innovative new interventions based on principles of conditioning that may provide powerful new tools to modify complex resistant behavioral patterns like smoking (Wiers, Gladwin, et al., 2013). However, we need to be open to the possibility that the lure of mind-altering drugs like nicotine may be too strong to resist permanently. It may also require society to decide whether the ultimate goal of tobacco control should be the elimination of all nicotine use, or the less ambitious effective elimination of smoked tobacco as an addictive behavior and condoning the use by adults of low harm, but psychologically rewarding forms of nicotine.

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27

Promoting Physical Activity Behavior: Interventions and Mediators

Edward McAuley, Sean P. Mullen, and Jason Fanning

Introduction

The demographic landscape of the United States is undergoing a transformative shift. As a nation, we are becoming older (Goulding, Rogers, & Smith, 2003; Center for Disease Control and Prevention, 2015a), less active (Pleis & Lucas, 2009), and more overweight/obese (Center for Disease Control and Prevention, 2010). For example, the proportion of the population aged 65 years or older is projected to increase from 12.4% in 2000 to 19.6% in 2030 (Goulding, Rogers, & Smith, 2003; Center for Disease Control and Prevention, 2015b) with the number of adults aged 65 years or older estimated to increase from nearly 35 million in 2000 to approximately 71 million in 2030. The rapidity of this trend is even more pronounced in the segment of the population aged 80 years and older. Additionally, in spite of the well-documented benefits of regular physical activity (see below), participation rates have either remained stagnant at alarmingly low levels, or have declined. Most recent estimates suggest that 21% of adults aged 18 years and older engage in regular leisure-time activity at sufficient levels of physical activity to reach public health guidelines. As one might predict, there is a consistent decline in activity with age, with only 16% of those 65 and older being inactive (Behavioral Risk Factor Surveillance System, 2013). Paralleling these levels of inactivity, not surprisingly, are the national statistics associated for overweight and obesity. Obesity levels have steadily risen in adults 20 years and older from 19.5% in 1997 to 35% in 2011–2012 (Ogden, Carroll, et al., 2014; Center for Disease Control and Prevention, 2010), and these numbers are higher for Hispanic and African American adults. It is of considerable concern that these gradient increases are also demonstrated in children and adolescents (Ogden, Carroll, et al., 2014).

These issues are not unique to the United States and similar trends have been documented internationally. European populations report comparable activity rates as the United States with only 31% of the population reporting sufficient physical activity (Sjöström, Oja, et al., 2006). Regionally, 54.1% of men and 45.3% of women from Greece are physically active (Filippidis, Tzavara, et al., 2011). In Scotland, about two-thirds of the population is failing to meet the equivalency of CDC physical activity guidelines (Physical Activity Task Force, 2005). Australian data suggests that less than 30% of adults met physical activity recommendations in 2008 (Australian Bureau of Statistics, 2009). Inoue et al. (Inoue, Murase, et al., 2009) reported

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that only 21% of Japanese adults were sufficiently active.

The extent of objective physical activity data from low- to middle-income countries is less than from higher income countries, but several reports (Dugas, Harders, et al., 2010; World Health Organization, 2012) indicate that physical inactivity, especially in growing urban areas, is a problem in these countries and accounts for appreciable burden of noncommunicable disease. It is apparent, however, that among less developed countries walking (rather than moderate to vigorous physical activity) accounts for a much greater volume of exercise. This may be attributable to infrastructure and culture that supports walking as exercise and/or transportation (Bauman, Bull, et al., 2009).

Overall these health statistics paint a rather bleak picture for society at large. Advances in modern medicine, better living conditions, and environmental and worksite health improvements in developed countries all contribute to the population living to an unprecedented age. However, such increases in lifespan are accompanied by an increase in chronic health conditions such as cancer, stroke, and disability. Taken together these outcomes are likely to seriously jeopardize quality of life. Similarly, the health consequences of being overweight or obese in adults are equally deleterious. Obesity-related medical costs were estimated at $147 billion in 2008 (Finkelstein, Trogdon, et al., 2009), and this figure may increase by as much as $66 billion per year by 2030 (Wang, McPherson, et al., 2011). Obesity and overweight-related conditions in adults include heart disease, diabetes, cancer, arthritis, and a host of other conditions (Jensen, Ryan, et al., 2014). In children, obesity is associated with increases in cardiovascular risk factors, Type 2 diabetes (previously classified as an adult disease), and social discrimination (Pratt, Arteaga, & Loria, 2014; Surgeon General's Report, 2007).

It is well established in the scientific literature that physical activity plays an important role in the accrual of physical and psychological health benefits. Unfortunately, as noted earlier, participation rates across the lifespan are typically quite poor and appear to decline as we age. The present chapter provides an overview of the various approaches that have been adopted by behavioral scientists in an effort to increase adoption and maintenance of physical activity. These approaches range from center-based to home-based interventions and from media-based strategies to considerations relative to altering the built environment. We begin with a brief overview of the physical and health benefits that have been reliably associated with regular physical activity participation. We then provide an overview of the main findings derived from several different approaches to influencing physical activity and include detail on some exemplar studies. Where meta-analytic data are available, we report overall effect sizes determined across studies. We then provide a brief summary of what is known in terms of the theoretical mediators of physical activity intervention approaches reviewed and conclude by highlighting important targets for future research. Although we will not provide in-depth discussion of the topic, it is important to acknowledge a growing field of research concerned with the reduction of sitting behavior. Though clearly related to physical activity, sitting behavior is conceptually distinct, as it is independently associated with obesity, metabolic health, and mortality when controlling for physical-activity level (Matthews, George, et al., 2012). Over the last several years, researchers have identified long, unbroken bouts of sitting time, rather than total amount of sitting time, to be the most deleterious to health (Healy, Dunstan, et al., 2008). See Owen, Baumen, and Brown (2009), Van Uffelen et al. (2010), and Biswas et al. (2015) for reviews.

Physical and Psychological Benefits of Physical Activity Participation

Physical inactivity has consistently been identified as a modifiable risk factor for a host of chronic conditions including cardiovascular disease (CVD), diabetes, some cancers, disability, and compromised psychological health (Blair, Kohl III, et al., 1995; Keysor, 2003; McAuley &

Rudolph, 1995; U.S. Department of Health and Human Services, 2000; Taylor, Cable, et al., 2004a; Taylor, Brown, et al., 2004b; Warburton, Nicol, & Bredin, 2006). Indeed, CVD is the leading cause of death in the United States, where approximately 1 in 3 adults suffer from this disease (Rosamond, Flegal, et al., 2008). Numerous longitudinal, observational studies have provided convincing data that physical activity and fitness are associated with reductions in CVD and all-cause mortality (Blair, Kohl III, et al., 1989) and that this effect holds true for men (Myers, Kaykha, et al., 2004) and women (Hu, Willett, et al., 2004). Moreover, these associations appear to operate in a dose-response fashion, as those with lower activity and fitness levels have the greatest risk of premature death (Erikssen, Liestøl, et al., 1998).

Similar findings have been reported relative to physical activity as both a preventive behavior for type 2 diabetes and as a management modality for the disease (Warburton, Katzmarzyk, et al., 2007). For example, Williamson, Vinicor, and Bowman (2004) reviewed the scientific evidence from randomized controlled trials involving lifestyle intervention effects for the prevention of type 2 diabetes in high-risk individuals. Weight loss achieved through physical activity and dietary changes reduced incidence rates over a 4-year period by up to 60%. Similarly, reductions in mortality risk in those with diabetes can be brought about by relatively modest increases in physical activity (Gregg, Gerzoff, et al., 2003). Indeed, over 2.8 years, the Diabetes Prevention Program demonstrated that physical activity, and particularly weight loss achieved through physical activity, can yield a dramatic reduction in onset of type 2 diabetes (58%) (Diabetes Prevention Program Research Group, 2002).

The most consistent and well-documented associations between physical activity and cancer appear to be relative to breast cancer and colon cancer. Although the evidence has been identified as somewhat inconsistent (Ibrahim & Al-Homaidh, 2011), it has been reported that the risk reduction for breast cancer incidence ranges from 20 to 40% in favor of active versus sedentary women (Lee, 2003; Vainio, Kaaks, & Bianchini, 2002). However, whether physical activity is implicated in survival for those women with breast cancer has proven to be a contentious issue. A recent meta-analysis, Ibrahim and Al-Homaidh (2011) suggests that an inverse relationship exists between physical activity level and all-cause mortality. Specifically, prediagnosis physical activity was associated with reduced breast cancer mortality in women with a BMI <25 kg/m^2. In addition, intermediate-to-high levels of physical activity were associated with an 18% reduction in all-cause mortality. Moreover, participating in physical activity, at any level, was associated with a 30% reduction in mortality from breast cancer and 41% reduction in all-cause mortality. Wolin, Yan, Colditz, and Lee (2009) report the magnitude of risk reduction for colon cancer in a meta-analysis suggesting that being physically active affords a 24% reduction in risk and was similar for both men and women. Although it was not possible to determine the exact nature of the dose-response relationship, Wolin et al. (2009) previously reported that the equivalent of 5-6 h per week of brisk walking resulted in a 23% reduction in risk among women.

As well as having favorable and consistent effects on physical health, engaging in physical activity has been associated with a host of psychological benefits. These include reductions in anxiety (Herring, O'Connor, & Dishman, 2010; Petruzzello, Landers, et al., 1991) and depression (Phillips, Kiernan, & King, 2003; Ströhle, 2009) and enhancements in quality of life (QOL; McAuley & Morris, 2007; Rejeski & Mihalko, 2001) and cognitive function (Hillman, Erickson, & Kramer, 2008). For example, Petruzzello et al. (1991) reported that the overall effect of physical activity on anxiety was modest ($d = -.24$), and this effect was similar for both acute ($d = -.23$) and chronic activity ($d = -.25$). The effect is, however, moderated by a number of factors including exercise mode (aerobic activity, $d = -.26$; anaerobic activity, $d = -.06$). In a more recent meta-analysis, Herring et al. (2010) reported an overall change in patients with chronic illness receiving exercise as a primary treatment or as an adjuvant for nonanxiety related medical conditions. This effect was increased when exercise programs lasted up to 12 weeks, sessions were greater than 30 min in duration, and the reporting period for anxiety was greater than 1 week. Thus, the evidence suggests that the anxiolytic effects of physical activity, although modest, are quite consistent across healthy and diseased populations.

The physical activity and depression relationship has been reviewed quite extensively in meta-analytic and narrative review format. Although the consensus is that depression is reduced as a function of being physically active, this literature is plagued by methodological inconsistencies and lack of rigor (Lawlor & Hopker, 2001). However, in those studies employing true randomized designs there appears to be evidence to support the relationship (see (Phillips, Kiernan, & King, 2003), for a review). For example, randomized studies of clinically depressed patients suggest that exercise is as effective in reducing depressive symptoms, and possibly more so, than interventions such as medication, meditation, and psychotherapy (Babyak, Blumenthal, et al., 2000). As Phillips et al. (2003) state, the literature suggests that exercise may be a feasible, inexpensive, nonpharmacological option for the treatment of depression.

However, randomized trials examining aerobic exercise effects in those individuals who fall within the normal range for depressive symptoms have consistently failed to find any depression reduction effects of exercise interventions (Phillips, Kiernan, & King, 2003). A 6-month randomized trial compared the effects of aerobic (walking) and nonaerobic (stretching/toning/balance activities) on depressive symptoms in nondepressed older adults (Motl, Konopack, et al., 2005). Using latent growth analyses, they reported a small but significant decrease in symptoms at intervention end ($d = -.26$), a reduction that was maintained at 12-month ($d = -.18$) and 60-month ($d = -.29$) follow-up. This effect was not moderated by exercise condition. As previously noted, physical inactivity can lead to chronic disease, obesity, and disability, ultimately compromising QOL. It is therefore unsurprising that a considerable literature focuses on the physical activity and QOL relationship (see (McAuley & Morris, 2007; Netz, Wu, et al., 2005; Schuch, Vasconcelos-Moreno, & Fleck, 2011) for selected reviews). Although the construct of QOL has been defined and assessed in many ways, there does appear to be a consistent effect of physical activity on QOL. In a meta-analysis of the effects of physical activity on psychological well-being in older adults, Netz et al. (2005) reported an overall effect size of $d = .24$ with stronger effects for aerobic activity ($d = .29$) and moderate-intensity activity ($d = .34$). More recent examinations of this relationship have suggested that physical activity effects on more global indices of QOL (e.g., satisfaction with life) are indirect rather than direct (McAuley, Konopack, et al., 2006). In these models, physical activity is proposed to have a significant effect on more proximal physical activity outcomes such as self-efficacy (Bandura, 1986, 1997), which in turn has a direct effect on indicators of physical health status (e.g., function, disability) and mental health status (e.g., perceived stress, affect, self-esteem). These latter factors, often measured under the rubric of health-related quality of life, are proposed to be determinants of global QOL. Cross-sectional (White, Wójcicki, & McAuley, 2009) and longitudinal studies (McAuley, Morris, et al., 2007b; White, Wójcicki, & McAuley, 2012) have provided preliminary support for this pattern of relationships.

An intriguing and rapidly expanding literature focuses on the effects of physical activity and cardiovascular fitness on cognitive function (see Hillman, Erickson, & Kramer, 2008; Kramer, Erickson, & McAuley, 2008; McAuley, Kramer, & Colcombe, 2004; McAuley, Mullen, & Hillman, 2013a; Smith, Blumenthal, et al., 2010; Voss, Nagamatsu, et al., 2011 for reviews). This literature has focused primarily on older adults, given the well-established association between age and declines in cognitive processing. However, increasing attention is being paid to this association in children and adolescents (Davis & Cooper, 2011; Hillman, Pontifex, et al., 2014). Building on the findings from an extensive animal literature (e.g., (Cotman & Berchtold, 2002; van Praag, Shubert, et al., 2005), data from randomized controlled trials suggest that fitness-induced change, as a result of aerobic exercise interventions, is associated with improvements in executive function (e.g., planning, decision making, error correction, response inhibition). However, there is some debate as to the size of this effect with Colcombe and Kramer (2003) suggesting it to be moderate to large (g = .68), whereas Smith et al. (2010) report a much more modest effect (g = .12). However, it should be noted that the Smith meta-analysis included participants aged 18 years and above likely attenuating the strength of the effects reported by Colcombe and Kramer (2003), whose meta-analysis focused only on randomized controlled trials with older adults. Importantly, evidence suggests that fitness change brought about by aerobic exercise is associated with both brain structure and function (Colcombe, Kramer, et al., 2004; Kramer, Erickson, & Colcombe, 2006). Indeed, a recent study, Erickson et al. (2011) reported that a 12-month aerobic exercise intervention resulted in significant increases in the volume of the anterior hippocampus, leading to improvements in spatial working memory. Exercise training increased hippocampal volume by 2%, effectively reversing age-related loss in volume by 1–2 years. Such findings reflect a very exciting direction for exercise and well-being.

The mechanisms through which physical activity brings about these benefits are varied. For example, enhancement of domain-specific, physical activity-related self-perceptions have been implicated in improvements in quality of life and self-worth and reductions in functional limitations. Physiological benefits are believed to occur as a result of metabolic adaptations. Social benefits are enhanced through increased exposure to supportive social networks. Finally, mechanisms theorized to be at the heart of the physical activity effects on brain structure and function include increased blood-flow to the frontal cortex and up-regulation of neural growth factors (Churchill, Galvez, et al., 2002).

Taken collectively, there can be little doubt that the effects of regular physical activity on physical and psychological health are well established and our understanding of these relationships continues to grow. Unfortunately, as noted earlier, the proportion of the population meeting public health guidelines, no matter how modest, is declining or has stagnated at levels likely to have continuing serious implications for the health and well-being of the population and society. To this end, behavioral scientists have been testing an array of approaches designed to promote adoption and maintenance of physical activity. The remainder of this chapter is devoted to providing an overview of this literature.

Levels of Approach to Promoting Physical Activity

Most approaches to physical activity promotion have been conducted at the individual level, albeit in different ways. Until the turn of the millennium, the physical activity research tradition mainly involved evaluating the effectiveness of center-based interventions and features of the research setting were generally overlooked or recognized as barriers to future wide-spread dissemination. More recently, researchers have begun testing the feasibility of delivery within natural settings, such as the home and work, where features of the environment may facilitate physical activity adoption and maintenance. The most successful interventions are likely to be those that incorporate multiple levels of approach targeting individual, social, and environmental influences. The following section describes some of the advances in this area, and outlines the advantages and disadvantages of each application.

Center-Based Interventions

Much of the evidence for the efficacy of physical activity interventions has been based on behavioral interventions delivered within university and healthcare settings (for reviews, see Eakin, Glasgow, & Riley, 2000; Eden, Orleans, et al., 2002; Marcus, Williams, et al., 2006; Petrella & Lattanzio, 2002; Smith, 2004). We refer to all of these interventions as “center-based” approaches to physical activity promotion. These approaches have unique advantages, including the ability for participants to interact directly with highly trained healthcare professionals and to use specialized equipment. In addition, center-based approaches offer far greater levels of control over the intervention environments, affording more rigorous examination of specified hypotheses.

There is consistent evidence that interventions delivered within these structured environments have a positive effect on physical activity (Conn, Hafdahl, et al., 2008; Conn, Valentine, & Cooper, 2002). For example, Conn et al. (2002) applied meta-analytic procedures to examine the overall effect of 43 interventions (33,090 participants) on physical activity and to explore the moderating features of interventions that influenced effect sizes across the studies. The studies reviewed included symptomatic and asymptomatic adult samples, involved in center and home-based studies, and were limited to interventions that focused on aerobic exercise only. Conn et al. (2002) reported a modest overall effect (d = .26) of interventions for increasing physical activity and a greater effect for center-based interventions relative to home-based interventions (d = .47 vs. d =. 24). Several design features were associated with greater effect sizes including center- and group-based delivery (vs. home- and individual-based) and having a self-monitoring component (i.e., participants recorded their physical activity). In a separate meta-analysis of patient education programs for chronically ill adults, Conn and colleagues (2008) also found that effect sizes were larger for programs which featured self-monitoring components. Interestingly, their meta-analytic reviews have consistently shown that the presence or absence of cognitive modification strategies (e.g., reframing, goal-setting, decision balancing) and socially mediated strategies (e.g., modeling and support) had no moderating effect on physical activity behavior.

There is evidence to suggest that tapered intervention intensities at the end of a program can improve adherence to study protocols. An exemplar study involving a transition from center to home is the Lifestyle Interventions and Independence for Elders Pilot (LIFE-P) physical activity intervention (Fielding, Katula, et al., 2007). In the LIFE-P study, sedentary older adults were randomly assigned to an intervention condition (i.e., multicomponent center-based exercise training plus behavioral skills training) or to a health education control. The intervention condition was tapered from three sessions per week for the first 2 months, to two per week for the following 4 months, to one per week for the remaining 6 months. Participants in the intervention condition had significantly more change in self-reported physical activity from baseline to 6 and 12 months relative to participants in the control group. Also, participation in the center-based intervention for the last 6 months of the trial remained relatively high (49.8% of classes attended) given that the majority of exercises were conducted at home. Attendance rates were even higher among those who completed home-based physical activity logs (79.5% vs. 45.9%). However, it must be considered that the tapered schedule was combined with behavioral skills training leaving the possible independent contributions of each of these to future research. This intervention served as the foundation for a larger recently completed intervention of 1635 older adults with physical limitations which proved successful against major mobility disability and persistent mobility disability (Pahor, Guralnik, et al., 2014).

A recent trend has been to utilize interventions aimed at increasing physical activity while simultaneously improving other health behaviors (e.g., dietary behaviors, smoking cessation, stress management). For example, Toobert, Strycker, Glasgow, Barrera, and Angell, (2005) conducted a 6 month, multiple behavior change intervention with postmenopausal women with Type 2 diabetes, focusing on physical activity, eating patterns, stress management and social support. Participants were required to attend a 2 ½ day nonresidential retreat, followed by weekly 4-h meetings targeting each topic for 1 h. Participants were randomly assigned to either a Mediterranean Lifestyle Program (MLP) or a usual care (UC) condition. Throughout the course of the intervention, the MLP group exhibited a more favorable behavioral profile, including significantly more self-reported physical activity than the UC condition. However, in a 7-year follow-up study, Toobert, Strycker, Barrera, and Glasgow (2010) found that most of the lifestyle changes returned to pretreatment levels, including physical activity.

Center-based interventions are often expensive to maintain given the costs of equipment and personnel. Additionally, it takes substantial time to deliver these programs and to train intervention providers. There are also significant population-specific barriers that may emerge, especially for older adults, including lack of transportation to the site of the intervention (Schutzer & Graves, 2004). In fact, center-based interventions rarely involve representative samples, and this may be due to the fact that they fail to reach people outside of university environments through conventional recruitment procedures. Although there is evidence that center-based interventions are effective for increasing physical activity, at least in the short term (Marcus, Williams, et al., 2006), one particular problem is that participants often return to their preintervention physical activity levels when they are no longer receiving professional guidance. Intervention providers have taken many innovative approaches to bolster adherence to study protocols postintervention, including adding "booster strategies" (Müller-Riemenschneider, Reinhold, et al., 2008). In some studies, multiple forms of media (e.g., phone, Internet) have been used to deliver supplemental information to participants, whereas additional intervention sites (e.g., worksite, home) are also used to encourage lifestyle change within more natural environments. As we discuss later in this chapter, center-based approaches continue to be used, although integrative approaches and "booster" interventions may be more effective at facilitating long-term behavioral change.

Workplace Interventions

As behavioral scientists have come to realize, the workplace offers a unique environment in which to influence the health behaviors of large numbers of employees and their families. There are a number of reasons for this including the potential for significant reach across an extended period of time and the fact that worksite settings offer a variety of resources to encourage adoption and maintenance of physical activity. These can include corporate policy, multimedia interventions, activity-related signage, departmental teams, etc. (Pronk, 2009; Pronk & Kottke, 2009). Engaging individuals to be active in their work environment has proven to be a popular strategy for enhancing physical activity and several reviews of this literature exist (Conn, Hafdahl, et al., 2009; Engbers, van Poppel, et al., 2005; Matson-Koffman, Brownstein, et al., 2005; Proper, Koning, et al., 2003; Shephard, 1995).

Conn et al. (2009), summarizes the status of what we know about the success of workplace interventions in increasing physical activity in a recent meta-analysis in which they report a modest overall effect for worksite interventions employing an intervention and control group with post-test design (d = .21) which corresponded to a difference of 612 steps per day in favor of the intervention group over the control condition. Interestingly studies assessing fitness changes as a function of the intervention fared better with an overall effect size of d = .51. When transformed to maximal oxygen consumption this effect reflects a mean difference between groups of 3.5 mL/kg/min in favor of the intervention condition. However, it should be noted that there was considerable heterogeneity across studies. In addition, worksite physical activity interventions appeared to have effects on other work-related factors such as reduced absenteeism (d = .19), lower job stress (d = .33), and greater job satisfaction (d = .20).

Abraham and Graham-Rowe (2009) reached similar conclusions in a systematic review and random effects meta-analysis analyzing studies reporting workplace interventions between 1997 and 2007. They report the overall effect for fitness and physical activity changes as a function of such interventions to be modest (d = .20). However, the reviewers note that evidence points to more recent studies being more rigorously designed and in those studies which evaluate physical activity only interventions (as opposed to including other lifestyle change elements), the effect size for fitness change was *d* = .27. As Abraham and Graham-Rowe (2009) point out, the public health impact of such an effect, if applied across the population, could be considerable. Studies which targeted walking or step counting were more effective (*d* = .54*)* than interventions which targeted overall lifestyle changes (*d* = .14).

Like Abraham and Graham-Rowe (2009) and Conn et al. (2009), several recent systematic reviews have concluded that better designed studies of worksite physical activity promotion programs should be an important priority (Malik, Blake, & Suggs, 2014; To, Chen, et al., 2013). Still, over the last several years a number of exemplar studies have emerged that reflect a more rigorous approach to such interventions. For example, Dishman, DeJoy, Wilson, and Vandenberg (2009) evaluated the efficacy of the *Move to Improve* program; a systematic 12-week group-randomized intervention incorporating a social ecological approach to enhancing physical activity in 16 Home Depot Inc. worksites. The intervention specifically targeted organization action and goal-setting (both personal and team goals). The organizational action component consisted of endorsement and support from management, committees consisting of both management and employees to implement the intervention, group goals and incentives, and use of environmental signage as prompts to physical activity. The intervention was compared to a standard of care control group which received a health risk approval and monthly newsletters regarding the benefits of physical activity. The primary outcomes were physical activity assessed by questionnaire and daily steps assessed by pedometer.

The intervention resulted in approximate increases of 29, 24, and 50 min per week spent in moderate activity, vigorous activity, and time spent walking, respectively, compared to an approximate increase of 19 min in each for the control group. Intervention participants also increased their pedometer steps to greater than 9000 per day by week 5. Further analyses examined the extent to which participants met public health guidelines for physical activity. At baseline, about a quarter (24%) of control participants met recommended levels of activity as compared to 31% of the intervention condition. Whereas the control condition did not change across the 12-week period, over half (51%) of the intervention condition met the guidelines at study end. Thus, the *Move to Improve* intervention, combining organizational action and both individual and team goal-setting, appears to reflect an encouraging, well-designed, and efficacious intervention for promoting worksite physical activity participation.

Warren, Maley, Sugarwala, Wells, and Devine (2010) reported findings from *Small Steps are Easier Together,* a study designed to improve walking in women in rural worksites. The target population is of importance given that lower income, rural women are the least likely segment of the population to meet physical activity recommendations. The 10-week intervention incorporated local support from cooperative extension educators, locally determined behavior change strategies, goal-setting, online monitoring of walking progress, and e-mail support and feedback. Pedometer step counts were the primary outcome measure. Findings indicated significant increases in weekly steps for every week beyond baseline ranging from 24.9% to 45.8% increases; however, daily steps on average did not meet public health guidelines (M = 7342), although the average weekly increase represents approximately 90 added minutes of walking per week. Although smaller in scope than the Dishman et al. (2009) study, these findings attest further to the efficacy of more social ecological approaches to enhancing physical activity in worksites.

With few exceptions, the studies examining worksite intervention effects on physical activity have restricted the length on their interventions to 12 weeks or less (e.g., Chan, Ryan, & Tudor-Locke, 2004; Dishman, DeJoy, et al., 2009; Gilson, McKenna, et al., 2007) and there have been calls for implementing longer interventions to determine whether effects are maintained beyond the 10–12-week period (De Cocker, De Bourdeaudhuij, & Cardon, 2009; Malik, Blake,

& Suggs, 2014; To, Chen, et al., 2013; Warren, Maley, et al., 2010). De Cocker et al. (2009) conducted a 20-week quasi-experimental intervention with a social services company in Ghent, Belgium. Participants in the intervention worksite were provided with educational materials, a pedometer, e-mail information and tips on a weekly basis, social support via a worksite step competition, goals, and promotion of staircase use and walking circuits. The comparison worksite participated in baseline and follow-up assessments only. Physical activity, as the primary outcome was assessed by questionnaire and step counts.

Interestingly, in contrast to other studies in this area, De Cocker et al. (2009) reported an overall, nonsignificant ($p = .07$) decline in mean steps per day. However, there were significantly different decreases between conditions with the control worksite having a twofold greater decrease in daily steps (−1389) than did the intervention condition (−618). There was no significant change in self-reported physical activity overall, and the two conditions did not differ significantly. At first glance, one might consider that this intervention had the opposite effect of what had been intended. However, the findings need to be considered in the context of a seasonal effect whereby the intervention began at the end of summer (September) and concluded in winter (February). Therefore, one might argue that although the intervention failed to increase physical activity across the 20-week period, it potentially attenuated the greater declines that were exhibited by participants in the control condition.

It appears that the majority of interventions designed to improve physical activity behavior in worksite populations are moderately successful in the short term, but it remains to be determined whether these effects can be maintained. The methodological rigor of many of worksite physical activity studies has been criticized (Conn, Hafdahl, et al., 2009; Malik, Blake, & Suggs, 2014; To, Chen, et al., 2013), yet some studies, while continuing to embrace social ecological approaches, have strengthened the rigor of their designs (e.g., Dishman, DeJoy, et al., 2009). Using social ecological approaches to change physical activity behavior allows individual worksites to tailor the intervention to their site to maximize success. Unfortunately, this type of design does not lend itself well to identifying which strategies are the "active ingredients" for change. However, they do have the distinct advantage of including input and support from all constituents involved in the intervention.

Clearly, worksite interventions have numerous advantages which, if effectively harnessed could have considerable public health impact in the future. As Pronk and Kottke (2009) and others have noted, the workplace is an arena where the promotion of physical activity initiatives can be delivered to large numbers of people, on a repeated basis, over long periods of time. The literature is encouraging in that there appears to be a consistent effect of worksite interventions increasing physical activity and related outcomes. The effect appears stronger in well-controlled studies. Continued efforts are needed to refine interventions, integrate successful interventions into best practice approaches to health promotion, and, where possible, compare the efficacy and effectiveness of selected intervention components (Dishman, Oldenburg, et al., 1998).

The same properties that make the workplace appealing as a venue for physical activity intervention make it an important point of intervention for the reduction of sitting behavior. Unfortunately, technological advancements have made unbroken bouts of activity ubiquitous in the workplace (Healy, Dunstan, et al., 2008; Owen, Healy, et al., 2010): Some estimates indicate that many employees spend more than 75% of their time seated, and much of this is in bouts of at least 30 min (Evans, Fawole, et al., 2012). Healy and colleagues (2013) implemented a 4-week multicomponent intervention aimed at decreasing workplace sitting. The research team worked with those in the workplace to develop strategies to reduce sitting. At the environmental level, workstations were installed that allowed individuals to easily alternate between seated and standing positions. Finally, each participant underwent a 30-minute face-to-face consultation with health coaches to identify various behavior change strategies, and these were followed by weekly telephone calls. When compared with a control condition, those that received the intervention decreased the amount of time spent sitting by 2 h, and increased the time spent standing by 2 h. Additionally, the intervention condition had two more transitions from a seated to a standing position per hour, and one less hour per day of prolonged sitting time. These early findings are promising, but much like workplace interventions for improving physical activity, research using longer intervention periods is warranted.

Home-Based Interventions

Home-based interventions offer an alternative intervention approach to overcoming common barriers to center-based research such as having to travel to a facility or scheduling difficulties. Delivering intervention materials in-home provides the individual with a safe, convenient exercise environment. In a summary of home-based physical activity interventions for middle-aged and older adults, Atienza (2001) stated that those interventions that targeted moderate to vigorous physical activity improved physical functioning in normal and special populations (e.g., those with COPD, arthritis) alike. Unfortunately, at the time, few studies addressed the need to maintain physical activity postintervention. Additionally, poor adherence was common among trials yielding null effects, possibly due to the lack of researcher supervision. However, a few trials have maintained contact with participants, thereby increasing adherence, and yielding stronger effect sizes.

In one such study, King, Haskell, Taylor, Kraemer, and DeBusk (1991) maintained contact with participants in a home-based intervention via telephone calls during a 1-year randomized controlled trial. They compared high-intensity group-based training, high-intensity home-based training, low-intensity home-based training, and an assessment-only control. At month 6 and month 12, both home-based conditions reported significantly higher adherence rates than did the group-based condition (78.7% ± 33.9%, 75.1% ± 31.8%, and 52.6% ± 29.9% respectively). Cox, Burke, Gorely, Beilin, and Puddey (2003) used a two arm design comparing the effects of a center-based exercise program to a home-based program with adult Australian women. In the center-initiated arm, participants attended regular exercise sessions three times per week for 6 months followed by 12 months of home-based exercise. The second arm exercised at home for the duration of the 18-month program. At each time point, adherence rates were higher among participants in the center-based condition. More recently, McAuley and colleagues delivered a 6-month progressive exercise program targeting flexibility, strength, and balance designed to be delivered in the home (McAuley, Wójcicki, et al., 2012). Those randomized into the intervention condition received six exercise sessions delivered via digital video disks (i.e., digital versatile disc, DVD), and were encouraged to use each of the six sessions at least three times per week for 1 month. Those in the control condition received a commercial healthy aging DVD. Both groups received telephone support calls from the research staff with the same frequency and duration. Individuals that received the intervention reported higher levels of physical activity (Gothe, Wójcicki, et al., 2014) and improved physical function and quality of life (McAuley, Wójcicki, et al., 2013b) at the end of the 6-month intervention, and enhanced physical function was maintained after 6 months postintervention (Wójcicki, Fanning, et al., 2014a).

Clearly within the context of prescribed activity programs, home-based interventions appear effective. However, as Atienza (2001) noted, engaging individuals in physical activity postintervention remains an issue. In response, some investigators have chosen to focus on the accumulation of physical activity within daily life. These “lifestyle” interventions are similar to home-based interventions in that both seek to provide convenient physical activity that avoids common barriers; however, they are typically less structured than home-based interventions, encouraging participants to self-select activities that can be accumulated throughout the day (e.g., walking to the bus stop, using stairs rather than taking elevators). Behavioral and environmental cues, such as signage prompting stair use or educational sessions teaching behavioral skills, aid in incorporating these activities into daily life. For example, Opdenacker, Boen, Coorevits, and Delecluse (2008) conducted a 2-year study in which they randomly assigned older adult participants to a structured exercise intervention, a lifestyle intervention, or a standard care control group. Participants in the lifestyle group attended an educational session in which the research staff taught behavioral strategies, supplied participants with a pedometer, and information and brochures on various forms of exercise and active transportation. These individuals then met with an instructor, receiving a set of exercises tailored to their preferences. The staff maintained contact with "booster calls" once or twice each month. The structured exercise intervention met three times per week, completing 60–90 min of endurance, strength, flexibility, and balance training. After 1 year, participants in both groups increased physical activity significantly relative to control. However, only the lifestyle group maintained daily steps and active transportation after 2 years; the structured exercise group showed no differences in step counts compared to the control. By integrating physical activity into daily routines, participants were successful in maintaining an active lifestyle 1 year postintervention.

These comparative studies help to evaluate the efficacy of various interventions, allowing investigators to identify which are most effective in the initiation and maintenance of physical activity behavior. In a landmark 2-year study, Dunn et al. (1999) compared a typical structured (i.e., center-based) intervention to a lifestyle intervention. During the first 6 months, the structured group attended three to five sessions of exercise each week. For the remaining 18 months, participants met quarterly to participate in group activities. The lifestyle group was instructed to accumulate 30 min of moderate-intensity physical activity on most days of the week for the first 6 months. They also met weekly in a classroom format to learn behavioral skills (e.g., problem-solving) during this time, meeting monthly for the remaining 18 months. Both groups significantly increased energy expenditure at 2 years; however, the lifestyle group increased primarily in energy spent in moderate-intensity exercise, in contrast to the structured group which primarily increased energy spent in vigorous intensity exercise. The authors note that for those individuals whose perceived barriers to exercise might include lack of time, lack of access to facilities, or a dislike of vigorous activity, lifestyle interventions are more efficacious than more structured trials. Additionally, the lifestyle group was significantly more cost-effective, an important consideration often ignored in physical activity intervention studies.

Overall, the evidence suggests that home-based interventions are effective for increasing physical activity whether they are delivered as stand-alone interventions or in combination with other approaches. It should also be noted that home-delivered interventions have been found to be more cost-effective than structured exercise programs (e.g., Kahn, Ramsey, et al., 2002). However, further research efforts are needed to determine whether and how intervention effects might be maintained without professional guidance. The success of home-based programs may be due to participants feeling more comfortable at home, as well as providing a viable alternative to center-based approaches to promoting physical activity in certain populations. For instance, some individuals may have difficulty attending programs conducted at larger facilities due to functional limitations, whereas others may simply have a strong preference to exercise alone. Tailored information with constructive and motivational feedback also appears to facilitate adherence at home (Artinian, Fletcher, et al., 2010; Lustria, Cortese, et al., 2009).

Phone-Based and Print-Based Interventions

Telephones have been used both as a sole delivery method to promote physical activity and in conjunction with other methods, such as printed materials (e.g., newsletters) which are mailed to participants. Telephone contact has been used for well over two decades and found to be effective for increasing self-reported and objectively measured physical activity (Castro & King, 2002). There are unique advantages to these media-based methods, including overcoming barriers such as geographic distance and travel time for participants. Phone and mail-delivered interventions also increase time efficiency for intervention providers. Such methods may be applied as primary interventions alone or together, or delivered as separate "booster strategies" to supplement other interventions.

In Castro and King's (2002) review of telephone-assisted counseling interventions, they found consistent evidence that these approaches are more effective than standard care. They also appear to be equally effective for increasing physical activity in both healthy and special populations. Castro and King (2002) suggested that including a telephone-counseling component within other physical activity interventions may facilitate adherence. Indeed, Dishman and Buckworth's (1996) review of physical activity interventions suggested that involving some form of media-based delivery (i.e., print, telephone) was associated with greater effects on increasing physical activity than face-to-face interventions. In a review of tailored print interventions, 7 of 12 studies reported positive effects on physical activity 3–18 months postintervention (Short, James, et al., 2011). These effects may be a function of such approaches being perceived as more personalized, as Napolitano and Marcus (2002) reported that participants who received personalized and motivationally matched materials had greater levels of physical activity than participants who received more generic information.

There is also evidence to suggest that print and telephone interventions are effective methods for increasing physical activity without any additional supervised or structured intervention. Marcus and colleagues (2007) compared these two intervention methods in a 12-month randomized controlled trial. Participants receiving telephone calls (*M* duration = 13 min) and printed materials (i.e., feedback, manuals, and tip sheets) showed an increase in self-reported physical activity at 6 months relative to the control group. At 12 months, participants receiving printed materials reported significantly more minutes spent engaging in physical activity than those receiving phone calls. Additionally, the print-based group was three and five times more likely to achieve 150 min of physical activity at 6 and 12 months, respectively, relative to the control group. The telephone only condition reported identical levels of physical activity to the print condition at 6 months, but no differences from the control group at 12 months.

Interestingly, Humpel, Marshall, Iverson, Leslie, and Owen (2004) reported that printed materials with and without follow-up phone calls were equally effective at increasing self-reported walking behavior after 3 weeks, but a higher percentage of participants reported reading the brochures in the mail plus phone intervention. When used as a "booster strategy," telephone counseling and print-delivered materials may be even more effective. For example, following 2 months of weekly physical activity classes, sedentary, low-income women, were randomly assigned to receive physical activity telephone counseling plus printed newsletters, or newsletters only (Albright, Pruitt, et al., 2005). After 10 months, participants in the phone plus print condition showed significantly greater energy expenditure compared to the group who received newsletters only.

Although print and telephone approaches have been shown to be fairly consistent methods for increasing physical activity, there are some inconsistencies in reported effects of these interventions. For example, Greaney et al. (2008) randomly assigned older adults to either a combined phone and print-based intervention or a contact-control group. The intervention included a manual detailing exercise benefits, guidelines and safety, newsletters, a multipage report with individual and normative feedback based on assessments, and three coaching calls. After 12 months, no significant increase in self-reported physical activity was found. In a similar 12-month study, with diabetic and hypertensive patients, Eakin, Reeves, Winkler, Lawler, and Owen (2010) compared a telephone-counseling condition with "usual care" (i.e., primary care visits). Both groups received feedback on assessments by mail, but the telephone group also received counseling, a pedometer, and a workbook with information on physical activity and healthy eating. At 12 months, both groups increased self-reported physical activity and also fruit and vegetable intake but exhibited a declining trend at 18-month follow-up.

Eakin and colleagues (2010) suggested that telephone counseling may be most effective in changing behavior if it is the sole delivery method or if it is used as a follow-up treatment after a more intensive mode of intervention delivery. Alternatively, longer-lasting effects may have resulted from titrated person-to-person contact. In an evaluation of TeleWalk, a telephone-counseling program designed to increase walking behavior among older adults (Kolt, Oliver, et al., 2006), participants indicated that both the counselor and printed materials encouraged them to be physically active, and 14% wanted to be paired up with others of similar ability who lived within the same neighborhood. In other words, transitioning from less contact with professionals to more face-to-face contact with supportive community members may be necessary to maintain the positive effect of these programs.

An important trend in communication over the last decade has been the movement away from dedicated landline telephone use. According to CDC (Center for Disease Control and Prevention, 2014) data and PEW (Smith, 2015) estimates, between 43% and 46.5% of adults in the United States live in a wireless-only household (i.e., do not use landline telephones). Global cellular phone adoption is consistent with these trends and text messaging via short message service (SMS) is the most widely used feature on cell phones. These trends may offer an important advantage to those attempting to influence health behavior, as voice and individualized text content can be provided in any location, and indeed researchers have begun to test these features. Fanning, Mullen, and McAuley (2012) published a meta-analysis of the effects of mobile device-delivered interventions on physical activity. The majority of the studies included involved text messaging, and there was a significant moderate effect (g = .54 [95% CI = .17 to .91]) on physical activity outcomes, indicating that this is may be an effective method for influencing behavior. Note that intervention designs utilizing smartphone devices is discussed in the following section.

In summary, it appears phone and print-based interventions are effective for increasing physical activity behavior among adults, although further work is necessary to determine their long-term impact. Phone-based approaches are likely to be more cost-effective, particularly for large-scale interventions, compared to mailing printed materials or conducting onsite interventions (e.g., center, work), as printing and postage costs, and personnel fees grow exponentially with increases in sample size. However, there is the potential for nontailored, telephone and mailed materials to be perceived as impersonal (Napolitano & Marcus, 2002). As tailored interventions grow in popularity (see Short, James, et al., 2011) and coupled with the increasing capabilities of SMS via cellular phones, there is exciting potential for information to be highly individualized, delivered with increasing regularity, and to be accessible on-demand (e.g., Hurling, Catt, et al., 2007).

Computer and Internet-Based Interventions

In the last decade, advances in Internet technology have allowed users to interact with website content, to generate and share text and video, and to receive instantaneous customized feedback (Vandelanotte, Spathonis, et al., 2007). Additionally, Internet accessibility has increased dramatically. From 2000 to 2014, adult Internet access in the United States increased from 46% to 87% (Perrin & Duggan, 2015). Internet access continues to rise internationally as well, with approximately 40% of the global population having Internet access and use has increased by approximately one billion individuals since 2010 (Internet Live Stats, 2014). This trend has been driven in large part by increasing access to the web via mobile phones. In the United States, 63% of all mobile phone users access the Internet with their phone, and 34% of all Internet users access the Internet solely by their phone (Smith, 2015). Altogether, improvements in Internet accessibility should contribute to an extended reach of intervention content to nearly any location with larger, more representative samples.

Webb, Joseph, Yardley, and Michie (2010) conducted a meta-analysis, evaluating the success of Internet interventions for changing a host of health behaviors including physical activity. They reported a small positive mean effect for those studies specifically addressing physical activity ($d = 0.24$); however, there was substantial heterogeneity across studies. Additionally, they reported a small effect for those studies using theory to guide selection or development of behavioral techniques ($d = 0.19$) and a stronger effect for studies using theory to select participants ($d = 0.33$) across all health behaviors. Unfortunately, the authors failed to provide the corresponding effects for individual health behaviors such as physical activity. In a comprehensive review by Joseph et al. (2014), 44 out of 72 (61.1%) Internet-based interventions had positive effects on physical activity. The majority of these were theory-based (68%) but similar to the Webb et al. (2010) meta-analysis, there was considerable heterogeneity in study design (e.g., intervention durations lasted 2 weeks to 13 months). Consequently, it is difficult to determine the extent to which individual theories offer promise for guiding the design and implementation of Internet interventions for physical activity. Results of a systematic review conducted by Joseph and colleagues (2014) indicate that theory-based, Internet-delivered RCTs have become more common in recent years; however, they found that the use of behavioral theory did not lead to better outcomes in the included studies. The researchers posit that this may be due to the manner in which the studies target important theoretical constructs.

The ability to provide instantaneous, automatically generated and individualized feedback is one of the unique and appealing features of Internet interventions (Marcus, Ciccolo, & Sciamanna, 2009; Wanner, Martin-Diener, et al., 2009). Indeed, these tend to be more effective at increasing physical activity relative to nontailored interventions (De Vries, Kremers, et al., 2008; Ogilvie, Foster, et al., 2007). In a meta-analysis of computer-tailored interventions to promote health behavior change, Krebs, Prochaska, and Rossi (2010) found a modest effect ($d = 0.16$) for interventions that included physical activity outcomes, with 43% of participants adherent to physical activity recommendations at follow-up as compared to 34% who received nontailored interventions. It is, however, important to consider the content of the feedback. In a 3-month study, Slootmaker, Chinapaw, Schuit, Seidell, and Van Mechelen (2009) provided Dutch office-workers with an accelerometer and access to the study website where participants could upload activity data, plan and evaluate activity relative to their goals, and receive feedback customized to these goals. The intervention, however, was unsuccessful at increasing physical activity levels, and the authors noted that only a small proportion of the participants (39%) found the content of the feedback useful or appealing. Internet-delivered interventions are able to provide personalized content and feedback that previously required face-to-face interaction (Kroeze, Werkman, & Brug, 2006), thus creating a customized program to the participant, and reduced hours for research staff. However, these findings underscore the fact that creating content that is relevant to the individual is necessary to realize these benefits.

Internet interventions may be particularly useful for promoting physical activity in those individuals with physical or mental health concerns. Mailey et al. (2010) used a 10-week Internet intervention to increase physical activity in college students receiving mental health counseling. Participants in the intervention group were given access to a website providing information on the benefits of physical activity and strategies for maintaining physical activity behavior. Additionally, participants met with activity counselors on two occasions to set goals and outcome expectations and to assess progress and discuss barriers. The control group received usual care relative to mental health counseling. The researchers reported a significant effect for increased activity in the intervention group relative to control (*d* = 0.68 and *d* = 0.05 respectively). A process evaluation suggested that participants desired a higher level of interaction with the website, a preference that is line with recent recommendations to design more interactive, dynamic user interfaces (Glasgow, 2009). Finally, Motl, Dlugonski, Wojcicki, McAuley, and Mohr (2011) adapted the Internet intervention developed by Mailey et al. (2010) for individuals with relapse-remitting multiple sclerosis (MS). They found a significant increase in physical activity in the intervention group (*d* = 0.72) as compared with control (*d* = 0.04).

In recent years, some researchers have sought to incorporate relatively new technologies, including popular social media platforms, e.g., Facebook, Twitter (Cavallo, Tate, et al., 2012; Wójcicki, Grigsby-Toussaint, et al., 2014b), and smartphone-based applications (apps), in behavioral interventions. One particularly interesting feature of both technologies is their broad adoption and ubiquity within the daily lives of many individuals. For example, 1.4 billion individuals used Facebook on a monthly basis in 2014, and daily users numbered nearly 900 million (Facebook, 2015). Regarding Twitter, in 2015 monthly users numbered greater than 288 million, and roughly 500 million tweets are sent each day (Twitter, https:/twitter.com/). Similarly, smartphone apps have become a daily staple for many individuals. As of the third quarter of 2013, adults in the United States spent more than 30 h per month with their smartphone apps, an increase from 18 h per month in the fourth quarter of 2011 (Nielsen, 2014). Such broad reach may allow researchers to better disseminate evidence-based health interventions that include elements that would otherwise require a visit to the research center, such as one-on-one counseling (e.g., Alley, Jennings, et al., 2014), targeted and thematic group-based discussions (e.g., Wójcicki, Grigsby-Toussaint, et al., 2014b) and highly tailored instantaneous feedback (Glynn, Hayes, et al., 2014). Still, like any emerging trend, it is important that practitioners continue to evaluate the use of these platforms to determine which features are most effective. Conroy and colleagues (2014) underscored this point in their review of commercial physical activity smartphone apps that had received top consumer ratings. The authors found that evidence-based behavior change techniques were not common in these apps, and users may have to interact with multiple apps concurrently to initiate and maintain behavior change.

In addition to identifying effective features of emerging technologies, researchers have had difficulty designing, funding, conducting, and publishing research in the face of the rapid evolution of consumer technologies (Glasgow, Phillips, & Sanchez, 2014; Riley, Glasgow, et al., 2013). Some estimates indicate that this research cycle often takes 7 years to complete (Riley, Glasgow, et al., 2013). Accordingly, a study published in 2014 is likely to have been conceptualized the same year that the first iteration of the Apple iPhone was released. It has, therefore, been suggested that research methodologies adapt to allow for more rapid evaluation and publication (see Boudreaux, Waring, et al., 2014; Riley, Glasgow, et al., 2013). Doing so will provide essential data for behavioral scientists and practitioners who wish to replicate and refine activity-enhancing features.

Environmental Influences on Physical Activity

It is well-recognized that in order to reverse declining or consistently low physical activity rates, it is important to identify those correlates of activity that are most amenable to change. To this end, most interventions have relied upon underlying theoretical approaches that emphasize individual level change variables. There have been several important reviews of this literature with Humpel, Owen, and Leslie (2002) identifying 19 early studies examining the relationship between physical activity and five categories of subjective and objectively assessed environment. These early studies suggested that certain elements of facility accessibility (e.g., cycle paths, access to local parks), opportunities for being active (e.g., home equipment, local area opportunities for physical activity), safety (e.g., neighborhoods safe from crime), and aesthetics (e.g., enjoyable scenery) all had weak to modest associations with physical activity participation.

Wendel Vos, Droomers, Kremers, Brug, and Van Lenthe (2007) have made the case that identifying those environmental factors that facilitate and impede physical activity is necessary, if promoting physical activity at the local and national levels is an important public health goal. They systematically reviewed 47 studies conducted between 1989 and 2004 primarily in the United States and Australia. They used the ANGELO framework (Swinburn, Egger, & Raza, 1999) to group environmental influences along physical (i.e., what is available for physical activity), sociocultural (i.e., attitudes and beliefs of the community/society), economic (i.e., cost of health behavior), and political (i.e., the regulations and rules that influence physical activity) environments. Using a minimum of three records for each class of environment, evidence was considered "convincing" if more than half of the records for each environmental category reported a significant association in one direction and a "possible" association was reflected by 40–50% of the records reporting a significant association in the same direction. Further, they examined these associations from the perspective of general, moderate, and vigorous activity; a sedentary lifestyle; commuting activities; bicycling; and walking.

Their findings indicated that 75% of the records within the review reported no associations with physical activity suggesting that environmental characteristics are less important to physical activity than has been argued in the literature. Alternatively, it could be that the constructs were inappropriately defined and/or measured (Wendel Vos, Droomers, et al., 2007). No evidence was found for relationships between economic environment and physical activity. Relative to each of the classes of physical activity behavior, findings were mixed. For example, only social support (sociocultural environment) was positively associated with general physical activity whereas there was no evidence at all for any environmental category as a correlate of either a sedentary lifestyle or moderate activity. Relative to vigorous activity, there was convincing evidence for access to physical activity equipment and social support and possible support for the convenience of facilities. When vigorous and moderate activity were combined, there was convincing support for social support and having someone to exercise with and a possible association with recreation facility accessibility and the availability of trails for activity. This latter correlate was the only environmental factor associated with activity for transport and no reliable environmental correlates were identified for bicycling. Additionally, there was supportive evidence for social-environmental determinants (i.e., having someone to be active with and having social support) being associated walking. A possible association was reported between walking and the availability of sidewalks.

The consensus from reviews such as those summarized above is that the relationship between the built environment and physical activity is promising (Humpel, Owen, & Leslie, 2002) but that more evidence is needed to determine the efficacy of environmental influences in changing this complex behavior (Giles-Corti & King, 2009). Indeed, a number of authors have noted that, if environmental determinants are to be effective in engendering policy change, then it is incumbent on the scientific community to provide evidence based upon intervention studies (Humpel, Owen, & Leslie, 2002; Sallis, Owen, & Fotheringham, 2000). With that in mind, we now provide an overview of two interventions for enhancing physical activity by changing the environment.

Nicoll and Zimring (2009) adopted an innovative approach to improving stair climbing by designing an office building with "skip-stop" elevators. The California Department of Transportation building in Los Angeles is comprised of two vertical circulation cores; one core has main elevators for able-bodies users which stop at every third floor (skip-stop) and an American Disabilities Act compliant elevator which stops at every floor and is accessed by a security pass. The other core had six traditional elevators which stopped at every floor. In addition, the "skip-stop" core has an adjacent open and aesthetically pleasing staircase between floors. This intervention core was contrasted with the other building core where the elevator stopped at every floor with an enclosed fire exit stairwell. Stair use was assessed over a 24-week period using infrared monitors for the skip-stop stairs and access reports from card readers on the traditional enclosed stairs. The results showed a 33-fold greater use of stairs in the skip-stop core than in the traditional core. Although it may be difficult to generalize these findings, they certainly represent a promising architectural approach to modifying existing and building new structures that would encourage stair use in both industrial and residential buildings. As the authors note, current elevators can be reprogrammed, stairwells can be open access, and accommodations can be made for persons with disabilities to permit elevator access on any floor.

Whether retrofitting a neighborhood to provide more connectivity by building an urban greenway/trail has an impact on physical activity was recently investigated by Fitzhugh, Bassett Jr, and Evans (2010). In this quasi-experimental study, physical activity at the neighborhood and school level in a retrofitted intervention neighborhood was compared with two control neighborhoods matched on socioeconomic parameters. Direct observation of physical activity was conducted at baseline and then 14 months later after completion of an urban greenway/trail in the intervention neighborhood. Physical activity counts increased significantly in the experimental condition across the intervention period whereas the activity counts in the two control neighborhoods declined significantly across the same period. There were no significant changes in active transport to school activity across the period in either the intervention or control conditions. However, control neighborhoods at both baseline and postintervention had higher levels of active transport to school activity, and this was significant at follow-up. It is encouraging that once again, in a study that adopts more stringent methods and design, it appears that modifying the built environment can have positive effects on physical activity behavior.

In conclusion, there appears to be a wealth of cross-sectional data suggesting modest associations between the built environment and physical activity behavior. Also, aggregation of multiple small effects can lead to substantial public health gain (Jeffery, 1989). However, only a few rigorously designed, prospective studies of this relationship exist. Moreover, it is important to keep in mind that the built environment-physical activity relationship constitutes only one aspect of the social ecological model. Indeed such models are founded on the premise that behavior change emerges from influences at the individual, sociocultural, physical environment, and policy levels (Sallis, Cervero, et al., 2006). Thus, a focus solely on the built environment as a determinant of physical activity is as inconsistent with the ecological model as a focus exclusively on intraindividual factors (Satariano & McAuley, 2003).

Understanding Intervention Effects on Physical Activity: Key Constructs and Processes

Understanding why interventions do or do not influence physical activity behavior is crucial to effectively bringing successful interventions to scale. This can be achieved by effectively designing interventions that capitalize on known and consistent relationships with key theoretical processes and mediators. Unfortunately, much of the physical activity literature examining theoretical associations has been cross-sectional, and true tests of the intervention-mediator-physical activity effect have been scarce (Rhodes & Pfaeffli, 2010). Moreover, the focus of much of this literature has been on individual level factors (i.e., attitudes, expectations, intentions), although more recent endeavors have adopted multilevel approaches. Clearly, progress in understanding this complex health behavior will come from studying neither individual or environmental levels alone but from an integrated approach. In this section, we present a brief overview of factors that appear to underlie physical activity behavior change.

Individual Level Factors and Processes

Although there are a host of individual level correlates of physical activity, we have restricted our discussion to the role played by individual expectations, as they are perhaps the most often studied factor in this literature. One important type of expectations is self-efficacy, a central component of Bandura's (1986, 1997) social cognitive theory (SCT). Self-efficacy expectations reflect one's beliefs in his or her ability to successfully carry out a course of action (Bandura, 1997). Such perceptions influence the activities in which individuals choose to engage, the amount of effort they will invest in those activities, and the extent to which they will persist when they encounter barriers and/or failures. Self-efficacy has been consistently identified as a determinant of an array of health behaviors (Bandura, 1997) including physical activity with evidence to suggest that it is both an antecedent and a consequence of this health behavior (McAuley & Blissmer, 2000).

McAuley and his colleagues (2010; McAuley & Mihalko, 1998) have observed that in several interventions, self-efficacy has actually declined across the time course of the trial. Thus, baseline measures may be artificially inflated, possibly obscuring any mediating effect of self-efficacy on physical activity. They propose that inactive adults entering exercise interventions may not have the appropriate previous experiences to formulate accurate efficacy expectations and, therefore, overestimate their capabilities at baseline. Furthermore, as they become exposed to the intervention they recalibrate their personal efficacy. Additionally, they suggest that not all efficacy measures might be expected to have similar trajectories (McAuley, Mailey, et al., 2010). For example, measures which assess self-efficacy to overcome barriers or to adhere to exercise prescriptions over time may not fare as well as those measures which assess confidence to complete progressive gradations of specific tasks (e.g., walking further or longer). Indeed, Rhodes and Pfaeffli (2010) noted that of the SCT studies that they reviewed, only Blanchard et al. (2007) conducted mediator analyses and found a mediating effect for task-related self-efficacy but not barrier efficacy.

To examine whether trajectories of self-efficacy measures differentially changed across time, McAuley et al. (2010) examined four different efficacy measures across a 12-month exercise trial. Using latent growth curve and latent class analyses, they reported that baseline efficacy measures declined significantly after 3 weeks into the trial and then increased significantly at 6 months before declining to baseline levels at 12 months. These findings suggest that efficacy-boosting strategies may need to be planned at multiple time points of an exercise intervention. It may be especially important to teach self-regulatory strategies for boosting efficacy toward the end of a program as participants are facing the prospect of exercising on their own. In short, we need to rethink how and when we measure self-efficacy in physical activity interventions, if we are to effectively test whether or not it is a significant mediator of intervention effects on physical activity. Additionally, considering how self-efficacy may interact with other nonindividual-level factors may provide important information for the design of interventions and exercise programming.

Consistent evidence exists for the mediating role that self-efficacy has on long-term physical activity behavior (McAuley, Morris, et al., 2007b) and on outcomes associated with physical activity participation such as quality of life (Rejeski & Mihalko, 2001; White, Wójcicki, & McAuley, 2009) and functional limitations (McAuley, Morris, et al., 2007a). However, there needs to be further systematic attempts to determine whether self-efficacy and other SCT variables are influenced by interventions and in turn whether they influence physical activity. Again, to do so will require rigorous attention to matters of research design, and the timing and accuracy of the measurement of SCT and physical activity variables.

Perceived behavioral control (PBC) is another element of the expectations construct that has received attention in the physical activity domain. PBC is a component of the theory of planned behavior (Ajzen, 1991) and reflects the perceived ease or difficulty of adopting or engaging in a behavior. It is important to note here that many individuals have considered perceived behavioral control to be the conceptual equivalent of self-efficacy. This is erroneous given that believing a behavior to be easy or difficult (perceived behavioral control) is conceptually and theoretically distinct from beliefs in one's capabilities to successfully execute a behavior (self-efficacy). Indeed, in one of the few meta-analyses to test the utility of self-efficacy and perceived behavioral control in predicting intention and behavior, Armitage and Conner (2001) suggest that both play independent roles in predicting health behavior. Moreover, they note that self-efficacy and perceived behavioral control may differentially influence behavior depending upon the behavior under scrutiny. Especially pertinent to the concerns of this chapter, it is clear that control beliefs such as PBC and self-efficacy are particularly pertinent to challenging health behaviors such as physical activity, weight management, and smoking cessation, in contrast to behaviors that are generally viewed as requiring considerably less effort (e.g., a simple medication regimen).

In the context of individual processes that may influence physical activity, researchers have used the transtheoretical model (TTM; Prochaska & DiClemente, 1982) to understand how people move through various stages of change, typically from precontemplation through contemplation, preparation, action, and maintenance. Movement through the stages is posited to be influenced by decisional balance (i.e., weighing the pros and cons of being active), experiential (e.g., self-evaluation) and behavioral processes (e.g., reinforcement management), and self-efficacy. For example, Marcus et al. (2007) and Napolitano et al. (2008) found that behavioral processes mediated the effect of telephone and print-based interventions on physical activity, whereas self-efficacy and decisional balance had no effect. In a meta-analysis, Marshall and Biddle (2001) found that the most robust changes in TTM constructs occurred from the preparation to action stages as evidenced by increases in perceived pros ($d = .97$), decreases in perceived cons ($d = -.46$), and increases in use of processes of change ($d_{\text{range}} = .55–1.18$). Rhodes and Pfaeffli (2010) have noted in a recent review that 50% of the interventions studies using TTM constructs failed to find any effect of the intervention on physical activity. Of the four that did find an effect, half of them reported that TTM constructs did not mediate the relationship. As previously noted, Napolitano and her colleagues (2008) did find a true mediating effect of some TTM constructs between the intervention and behavior. Clearly, further research is warranted before definitive conclusions can be drawn as to the efficacy of TTM-based interventions for influencing physical activity and those constructs that would be expected to mediate such an effect.

Multilevel Approaches

Recognizing that individual level approaches to understanding health behavior change are insufficient, scientists have embraced social ecological models (Bronfenbrenner, 1979). These models are characterized as frameworks for understanding roles played by intrapersonal, interpersonal, organizational, community, and policy factors and the interactions among them in changing health behavior (Sallis, Owen, & Fisher, 2008). Sallis and his colleagues (2006) proposed an ecological model specifically for creating more physically active communities. Their model places interpersonal factors (i.e., demographics, biological, psychological, family) at the center and branches outward from more to less proximally influential factors such as the perceived environment, active living domains, behavioral settings (i.e., access, characteristics), and policy environment (i.e., health care policies, park policies, community zoning regulations).

Given the scope of such models, there have been few attempts at intervening at all levels, and many studies which claim to have taken a social ecological approach to understanding physical activity in adults have focused almost solely on elements of either the built or perceived environment (see an earlier section for examples). As noted earlier, these studies are predominantly cross-sectional and account for relatively modest amounts of variance in the physical activity behavior (Giles-Corti & King, 2009). For example, Haughton McNeill, Wyrwich, Brownson, Clark, and Kreuter (2006) used social cognitive theory (Bandura, 1986, 1997) and the social ecological model to make specific hypotheses relative to the potential mediators of the environment and physical activity relationship in a community sample of adults. Haughton McNeill et al. (2006) took the perspective that social and physical environmental factors would influence physical activity through the mediation of individual level factors. In addition, they proposed a direct relationship between the physical environment and physical activity.

Using structural equation modeling, they tested separate models for walking, moderate-intensity activity, and vigorous intensity activity. Although they found support for social and physical environments having indirect influences on all types of physical activity and for some elements of the physical environment having direct effects on physical activity, the most interesting findings were for self-efficacy. This individual-level correlate had the strongest association with physical activity and, of most interest, evidenced a positive gradient dose-response. That is, the association became stronger as the degree of physical activity became more challenging; supporting a fundamental theoretical tenet of social cognitive theory that self-efficacy has the greatest utility in challenging situations (Bandura, 1997). Although there are numerous strengths associated with this study, the cross-sectional nature of the design precludes causal statements. Nevertheless, Haughton McNeill et al. (2006) offer an interesting platform from which to potentially design interventions linking individual, social, and physical environmental influences on physical activity.

Although there are a significant number of published articles that espouse adoption of a social ecological model to understand physical activity, few interventions incorporate all of the individual, social, and physical environments that constitute such a model. Indeed, even the cross-sectional studies which have attempted to examine individual contributions of these environments have come to the conclusion that individual level variables, and in particular self-efficacy, are the strongest correlates of physical activity (Azar, Ball, et al., 2011; Ball & Crawford, 2006; Cleland, Ball, et al., 2010; Haughton McNeill, Wyrwich, et al., 2006). A number of considerations are important here. First, conducting interventions that manipulate, change, or seek to influence each of these environmental levels is a daunting task. Second, more efforts are needed that replicate or extend structural models such as that proposed by Haughton McNeill et al. (2006) to determine the reliability of those factors which may mediate overall social and physical environmental influences. Third, if factors such as self-efficacy are consistently found to mediate the effects of other factors, then interventions which manipulate efficacy with respect to more expansive social and physical environmental factors may serve to integrate social cognitive and social ecological models (Cleland, Ball, et al., 2010). Finally, Giles-Corti and King (2009) recommend that to optimize environments that promote physical activity, researchers from all disciplines need to "think outside of the square," and to adopt a systems theory approach to understanding how different components of the complex social ecological model of physical activity can influence and be influenced by other parts of this system.

Where to Next?

Numerous narrative, meta-analytic, and systematic reviews have come to similar conclusions relative to what we know about the benefits of a physically activity lifestyle and how to change this behavior. An array of intervention approaches has met with success in getting adults to adopt physical activity over the relatively short term of the intervention. However, much less is known about what constitutes the best intervention for maintaining this behavior. In large part, it has been argued that effective behavior change may best be brought about by targeting mediating variables (Baranowski, Anderson, & Carmack, 1998). Unfortunately, the extent to which these relationships have been tested, yet alone supported, is disappointingly low (Baranowski, Anderson, & Carmack, 1998; Lewis, Marcus, et al., 2002; Rhodes & Pfaeffli, 2010). As Rhodes and Pfaeffli (2010) note, we live in a world that has socially and environmentally ingrained a physically inactive lifestyle into our existence. This recognition points to the importance of social ecological approaches that address multiple layers and channels of influence on physical activity. These may ultimately stand the best chance of changing the behavior of large numbers of people over continued periods of time (Sallis, Owen, & Fisher, 2008). It is recognized that this may be both costly and difficult to implement. However, the escalating physical, mental, economic, and societal costs of inactivity and sedentary behavior are problems of such magnitude that multidimensional approaches to sustained physical activity may be not only what is required for population-level effectiveness, but also the most cost-effective.

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28

Behavioral Management of Obesity: Enduring Models, Applications to Diabetes Prevention and Management, and Global Dissemination

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Despite countless promises from the popular media of "miracle cures" for obesity, the prevalence of obesity continues its relentless increase in both developed and developing nations (Ng, Fleming, et al., 2014). In the USA, the rapid increase in the prevalence and incidence of obesity was initially noted in the 1980s (Flegal, Carroll, et al., 1998). The prevalence of obesity had increased from 14.5% to 22.5% over the course of about 15 years (Flegal, Carroll, et al., 1998). As early as 1992, attention was being given to the number of children who were overweight or obese. An article in *Science* included obesity with issues such as teenage suicide, pregnancy of unwed mothers, and declines in college aptitude test scores as one of the pressing conditions facing children in the USA (Fuchs & Reklis, 1992). By the early turn of this century, considerable attention was being given to the obesity epidemic not only in adults but also in children (Robinson, 2000). To demonstrate the early consequences of excess fat mass, studies demonstrated that obese children were suffering from hyperlipidemia and hypertension (Freedman, Dietz, et al., 1999), at increased risk for type 2 diabetes (Pinhas-Hamiel, Dolan, et al., 1996), and developing atherosclerotic lesions (Berenson, Srinivasan, et al., 1998). Currently, 69% of adults and 31.8% of children in the USA are classified as overweight or obese (Ogden, Carroll, et al., 2014). Globally, it is estimated that 671 million individuals are obese (Ng, Fleming, et al., 2014). Not only is this a substantial increase compared to 30 years ago, the increase has accelerated in the last decade (Stevens, Singh, et al., 2012).

The obesity epidemic has occurred relatively recently, but the issue of weight loss has been

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discussed for a much longer period. Cases of individuals engaged in weight loss have been dated back to at least the fourth century A.D. (Lacey, 1982). For example, in the Middle Ages, several cases of religious women were reported to have existed on very little food over extended time periods only by virtue of spiritual power (Bell, 1985; Halmi, 1982; Hammond, 1879; Lacey, 1982). However, many of these early instances may more closely resemble eating disorders. In terms of the behavioral management of weight, William Banting developed a diet to promote weight loss in 1863 (Banting, 1863). Diets had been developed before this to address health concerns including diabetes, but Banting was among the first to develop a diet strategy that resembles the dieting of today. In the 1800s, obesity was neither a focus of medicine nor an area of scientific inquiry. It was almost 100 years later when the first behavioral studies were conducted to address obesity (Ferster, Nurnberger, & Levitt, 1962; Stuart, 1967). Studies on the "self-control of overeating" described behavioral principles (e.g., stimulus control, shaping) that are still used in obesity management today (e.g., to promote changes in diet and physical activity). In 1973, a conference on obesity was held at the National Institutes of Health in order for obesity experts to discuss "the need for heightened research on psychological, physiological, and biochemical determinants of this important health derangement" (Leavitt, 1973).

Though behavioral strategies showed promise in reducing weight, their use has not led to long-term weight maintenance (Laddu, Dow, et al., 2011). In fact, the promise of behavior modification has always been that inappropriate lifestyle behaviors could be self-controlled after patients receive training in the use of these techniques. If behavioral techniques are successful, they should be self-reinforcing because they would lead to weight loss and a sense of self-control (Foreyt, Goodrick, & Gotto, 1981). Patients who undergo behavioral training do lose weight, typically around 8% after 6 months of intervention but do not ordinarily continue weight loss following treatment. Despite the theoretical underpinnings of behavioral theory, the state of behavioral obesity treatment in the 1970s was summarized as follows:

> *Although behavior therapy has advanced the treatment of obesity, its results are still of limited clinical significance. Weight losses have been modest and the variability in results large and unexplained. Even long-term maintenance of weight loss which, it was originally hoped, would be of particular benefit of the behavioral approach, has not yet been established.* (Stunkard, 1978)

Sadly, this statement still reflects the state of behavioral weight management in most cases. However, several behavioral treatments recently have been and are being studied that suggest the long-term maintenance of clinically significant weight loss is possible (Diabetes Prevention Program Research Group, Wadden, et al., 2009; Look AHEAD Research Group, 2014a). The Diabetes Prevention Program (DPP) and Look AHEAD are models of behavioral programs that focus on lifestyle change and provide important answers on how best to treat this intractable and punishing condition.

Behavioral Treatments for Obesity

Although many necessary components (e.g., diet and physical activity-related behaviors) to treat obesity have been identified, behavior modification remains the bedrock of weight control programs (Foreyt & Pendleton, 2000). In its guide to selecting treatments for obesity, the National Institutes of Health recommends behavior modification for all individuals receiving treatment for overweight and obesity (National Institutes of Health, 2000). Changes in diet and physical activity remain the ultimate goals, but it is the behavioral strategies used that can help patients to overcome barriers that are associated with making these changes. Even in the case of bariatric surgery, behavioral management is needed to promote the lifestyle changes that are necessary for short- and long-term weight control. Behavior modification strategies with the most success take a lifestyle change approach aimed at helping patients adhere to healthy diets and sensible physical activity regimens.

The DPP and Look AHEAD studies had similar lifestyle interventions for overweight and obese adults that incorporated a tailored problem-solving approach that includes self-monitoring, goal setting, contracting, problem solving, stimulus control, cognitive restructuring, stress management, and social support (Poston & Foreyt, 2000). The goal of DPP was to determine the role of lifestyle intervention and medication in the prevention of type 2 diabetes (Diabetes Prevention Program Research Group, 2002). Along with the complementary objective of 150 min per week of moderate physical activity, the principal objective of the DPP lifestyle intervention was to assist participants at risk for diabetes in achieving and maintaining a weight loss of at least 7% (Diabetes Prevention Program Research Group, 2002). In order to achieve this objective, the lifestyle intervention of the DPP program included a comprehensive array of behavioral techniques, individual case management by "lifestyle coaches" who also delivered the intervention, frequent contact with participants throughout the duration of the study, and ongoing intervention which started with a 16-session initial core curriculum and continued with personalized maintenance sessions (Diabetes Prevention Program Research Group, 2002). Moreover, this array was flexibly tailored within sites to individual needs and across sites to site-specific cultural or regional factors.

The Look AHEAD study adapted the DPP lifestyle protocol to participants who have already been diagnosed with type 2 diabetes. It differed, however, in several ways. During the first year, the Look AHEAD treatment was provided primarily in a group rather than in an individual setting, and the use of liquid meal replacements was encouraged (Look AHEAD Research Group, Wadden, et al., 2006). The Look AHEAD study examined the impact of intentional weight loss as it relates to reduced cardiovascular morbidity and mortality (Look AHEAD Research Group, Wadden, et al., 2006). Specifically, the principal goal of the Look AHEAD study was to determine the combined effects of deaths from cardiovascular diseases, nonfatal heart attacks, nonfatal strokes, or hospitalization for chest pains during the study period of 13.5 years (Look AHEAD Research Group, Wadden, et al., 2006). Participants were randomized to either a diabetes support and education (DSE) or an intensive lifestyle intervention (ILI) condition. The DSE condition received three 1-h group meetings per year focusing on diet, physical activity, and social support (Wesche-Thobaben, 2011). Information was provided, but behavioral strategies to promote adherence were not taught. Participants in the ILI condition were encouraged to achieve a sustained weight loss of 10% of initial weight and to increase moderately intense physical activity to at least 175 min per week (Look AHEAD Research Group, Wadden, et al., 2006).

The ILI, however, utilized meal replacements as a form of portion control (Look AHEAD Research Group, Wadden, et al., 2006). Participants were given a daily calorie goal which varied (1200–1800 calories a day) depending on the individual's calorie needs (Look AHEAD Research Group, Wadden, et al., 2006). During the initial phase of treatment, participants were encouraged to replace two meals a day with a liquid shake (meal replacement) and one snack with a bar, as well as increase intake of fruits and vegetables. After month 7, calorie goals were adjusted based on weight loss during the first 6 months and individuals' future weight loss goal. A gradual shift of replacing one meal and one snack a day with a shake or bar and increasing consumption of low-energy-dense foods was encouraged.

The intervention included gradually increasing physical activity to a specific number of minutes per week, engaging in at least 10,000 steps daily, and incorporating exercise into daily lifestyle (Look AHEAD Research Group et al., 2006). Specifically, during the first 6 months of the intervention, participants were encouraged to increase activity to 125 min per week by week 16 and to 175 min per week by week 26. For the remainder of the study, participants were encouraged to engage in at least 175 min of exercise per week.

Behavioral Strategies

The following sections detail the behavioral strategies common to DPP, Look AHEAD, and most other state-of-the-art weight loss programs, including commercial applications such as Weight Watchers.

Self-Monitoring Self-monitoring is an essential component of behavioral weight loss treatments (Berkel, Poston, et al., 2005) and involves raising self-awareness through observing and recording behaviors (Kanfer, 1970). Participants in the Look AHEAD study used various self-monitoring techniques. Specifically, participants recorded their daily food intake and monitored their physical activity by totaling calories consumed and recording minutes of activity and step count, respectively. Additionally, at each weekly meeting, participants' weights were recorded in order to provide feedback about their progress and increase motivation. All of the self-monitoring methods used in Look AHEAD were strongly correlated with one another, with self-reported physical activity being the strongest correlate of weight loss at the end of the first year (Wadden, West, et al., 2009). Additionally, increased self-monitoring was related to greater treatment attendance. These findings provide clear support for the importance of self-monitoring. Even though reporting of behavioral changes may not have been accurate, self-monitoring, especially of physical activity, was still associated with weight loss. A clear example of the importance of the act of self-monitoring and not necessarily the correctness of the information recorded was demonstrated with food records. Specifically, participants who engaged in self-monitoring to a greater degree by keeping more detail on their food record at screening lost more weight at year 1 than individuals who were less detailed (Tsai, Fabricatore, et al., 2014).

In general, at the outset of treatment, self-monitoring involves observing and recording behaviors without requiring individuals to change diet or physical activity habits. Other variables that may be recorded include the time of day a food is eaten, the type of exercise completed, and the emotional state of the patient before, during, and/or after those activities. This feedback process is a significant aspect of intervention. Several studies have demonstrated a correlation between self-monitoring of food intake and one's weight with long-term weight loss and maintenance (Epstein, Valoski, et al., 1995; Williamson, Anton, et al., 2010; Israel, Guile, et al., 1994; Wing, Tate, et al., 2006).

Self-monitoring involves three processes that influence behavior change. First, self-monitoring records serve as a guide as they provide important information to individualize treatment. For example, records provide insight to patterns of behavior which can then be targeted as part of the intervention. The second process is one of increasing awareness. Even if individuals overestimate or underestimate their behaviors, the act is still effective because it is a persistent reminder of weight-related goals (Lichtman, Pisarska, et al., 1992; Trabulsi & Schoeller, 2001). A third process is that self-monitoring, especially if carried out before food is eaten, can help to break up chains of almost automatic eating that may have developed such as in eating snacks.

Goal Setting A goal-based approach for weight loss was used in both the Look AHEAD and DPP programs (Diabetes Prevention Program Research Group, Knowler, et al., 2009; Look AHEAD Research Group, Wadden, et al., 2007). Specifically, both programs used a tailored approach by identifying strategies that would be most appropriate for the specific situations of their participants.

All aspects of the Look AHEAD study included goal setting (i.e., individualized action plans); participants set goals for overall weight loss, caloric intake, and physical activity. In order to achieve the larger goals of the program, participants established small, measurable, and achievable goals at the beginning of treatment. For example, the physical activity goal during the first month was to walk for 50 min a week with the amount of minutes gradually increasing over time. Additionally, in the Look AHEAD study, it was important to establish differing goals toward a similar outcome in order to lessen the monotony of constantly working toward the same goal. This also allowed participants to choose goals that were most meaningful to them.

Goal setting is necessary as a base for effectively promoting weight loss by reinforcing small changes. Setting small, measurable, and attainable goals also is intended to increase motivation and foster a sense of accomplishment through creating a positive momentum for future change when such goals are achieved. This momentum is important especially as many individuals try multiple times to lose weight and may feel that future attempts are unlikely to be successful. Setting realistic and effective goals is also intended to aid in treatment adherence. Additionally, encouraging changes that can easily be incorporated throughout a "regular" day is of great importance for adherence and promoting sustainability. For example, in the Look AHEAD study, participants were provided with exercises that could be incorporated into their daily routine, such as taking the stairs instead of the elevator, walking to a colleague's office instead of sending an email, and parking at the back of the parking lot instead of in the spot closest to their destination.

Focusing on lifestyle changes incorporated into a daily or weekly ritual may increase awareness of improvements in health and thus lessen the focus on unrealistic goals and increase motivation and treatment adherence. Regarding weight loss efforts, it may be helpful to focus on improvements in health, energy, and fitness that are frequently observed with an initial modest weight loss of 5–10%, which also is a realistic goal to achieve. For example, a weight loss of 5% or 10% is associated with reductions in triglycerides, blood glucose, and hemoglobin A1c (HbA1c, a measure of average blood glucose over the previous 2–3 months) and improvements in one's sense of well-being and self-esteem (Jensen, Ryan, et al., 2014). This may also lead to increasing functional and recreational activities, such as being better able to play with one's children, walking up a flight of stairs without being out of breath, or being able to tie one's shoes with less difficulty.

Contracting Contracting defines expectations and responsibilities as they relate to treatment (Foreyt, 2005). In Look AHEAD, contracts were used in combination with goal setting to enhance motivation to achieve short-term behavioral changes and ultimately successfully adhere to treatment. Contracting involves selecting and writing down realistic behavioral goals to perform between sessions and signing a document to finalize the agreement. In other cultures, this may be viewed differently, but in the USA, contracts emphasize explicit, tangible features that support change. Such goals may include limiting eating out to one less meal a week or walking for 10 extra minutes a day. In order for this strategy to be successful, it is important to understand the responsibilities and explicitly discuss what is required.

Problem Solving As with contracting, problem solving also is important for effective achievement of goals. Once realistic goals have been set, problem solving introduces methods of identifying potential barriers that may hinder achievement of these goals and brainstorming possible solutions to overcome these obstacles. In turn, this may also increase confidence in achieving goals and self-efficacy to effectively face potential problems. Problem solving is a continuous process that involves monitoring toward goals, determining the effectiveness of implemented solutions, and identifying new solutions when appropriate.

Problem solving has been shown to be an integral aspect of weight loss and maintenance efforts (Perri et al., 2001). For example, attrition is a common problem in obesity treatment. Individuals do not return for their next appointment for many different reasons, such as weight gain or not meeting a goal. Thus, it is important to acknowledge early in the intervention that setbacks are a normal part of the treatment process and to develop a plan which can be implemented when setbacks arise.

Stimulus Control Stimulus control, another important component of weight management used to facilitate behavior change, includes techniques of manipulating cues in the environment. Specifically, stimulus control is intended to alter and manage environmental cues that may trigger adaptive or maladaptive patterns of exercise and eating. For example, making unhealthy snacks unavailable may assist in decreasing caloric intake, and making a gym bag readily available may increase the likelihood of engaging in physical activity. Another technique of stimulus control involves controlling the setting in which eating occurs. Eating at the kitchen table only and preparing one's plate before sitting down, as opposed to serving foods placed at the center of the table, are examples of methods used to create a setting that promotes healthier behaviors. Anecdotally, people report fewer thoughts and urges for food as they narrow the cues associated with them. Overall, making healthy lifestyle changes to the immediate environment is a significant aspect of successful weight management.

Complete or partial meal replacements serve as another method of stimulus control by providing exact portions and decreasing exposure to certain foods that may trigger overeating. Meal replacements also have been shown to be a safe and effective strategy for weight loss and long-term weight maintenance (Flechtner-Mors, Boehm, et al., 2010; Flechtner-Mors, Ditschuneit, et al., 2000; Heymsfield, van Mierlo, et al., 2003). The ILI group of the Look AHEAD trial successfully incorporated meal replacements by initially replacing one to two meals per day with portion-controlled, vitamin- and mineral-fortified low-energy meals (Look AHEAD Research Group, Wadden, et al., 2006).

Cognitive Restructuring Another barrier to weight loss is dysfunctional thinking patterns, such as beliefs that losing weight will resolve problems in various aspects of one's life. Cognitive restructuring identifies these patterns and manages thoughts through restructuring them to a more beneficial nature (Fabricatore, 2007; Wadden & Foster, 2000). Cognitive restructuring strategies, such as personal affirmations, are commonly used to deal with setbacks regarding weight loss. Setbacks are common triggers for dysfunctional thinking patterns (Fabricatore, 2007). Dysfunctional thinking patterns may cause one either to view a setback as a reason to abandon efforts or deny the significance of the setback. In either case, these types of thoughts may impede long-term weight loss. To overcome this barrier, cognitive restructuring assists in recognizing thoughts that are rather extreme and helps manage unrealistic expectations about weight loss.

Stress Management For some individuals, successfully engaging in behavior change may be hindered due to stress (Foreyt, 2005). This may be due to negative lifestyle changes adding to their level of stress. Individuals with high levels of stress may need support and psychological resources in order to make meaningful changes in their lives. Since physical activity reduces stress reactivity and aids in weight loss and management, it can be used as a strategy for managing stressful life situations. Additional stress management methods include progressive muscle relaxation and meditation. Progressive relaxation assists in maintaining lower levels of stress during weight loss and maintenance and meditation increases feelings of self-control. Also, meditation may act as an effective goal since it is a relatively easy strategy for patients to incorporate in their daily lives, and like aerobic exercise, meditation appears to be habit-forming for some individuals. Overall, managing stress aids in the transition toward a healthier lifestyle and also increases the likelihood of maintaining these changes.

Social Support Weight loss and long-term weight maintenance efforts can greatly benefit from social support (Foreyt & Pendleton, 2000). Social support provides many benefits including role modeling, assisting with problem solving, and serving as an emotional outlet for issues that may be experienced during weight loss treatments. Individuals can often feel that weight loss changes are daunting; however, the support of other important individuals can make these changes less difficult and demanding. Lack of social support may lead individuals to fall back into old unhealthy habits in the long-term.

In the Look AHEAD study, during the initial phase of the intervention, participants attended weekly sessions, either as a group or individually. The group sessions were designed to increase social support by encouraging participants to create a close bond with other program participants. This also promoted a sense of accountability for reaching weight loss goals. Additionally, techniques such as motivational interviewing were utilized in order to support the relationship between participants and research staff. Participants were also encouraged to seek social support from family members, friends, and any other individuals with similar goals. For example, in order to stay on track with physical activity goals, participants were encouraged to recruit walking partners from their family and social environment.

Maintenance of Weight Loss Despite successful initial weight loss, most individuals receiving behavioral treatment remain overweight, and many regain some or all of their lost weight. This progression of weight regain was shown in Look AHEAD participants (Look AHEAD Research Group, Wing, et al., 2013); however, it was much slower than what is found in other studies. Additionally, participants in the ILI condition demonstrated significant weight loss compared to the DSE condition at every annual assessment including at 9.6 years (6% mean weight loss compared to 3.5%) (Look AHEAD Research Group, Wing, et al., 2013). Overall, Look AHEAD demonstrated that long-term weight loss is achievable with a treatment that has a high enough intensity and appropriate behavioral supports.

Incorporating Behavioral Strategies into Intervention Behavioral change strategies play a prominent role in the treatment of obesity as they are essential in assisting with making lifestyle changes. When written in a way that each behavioral strategy is discussed independently (as done in this chapter), it may seem that they are also used independently; however, behavioral strategies are meant to be used in combination with each other. For example, raising self-awareness regarding caloric intake and physical activity behaviors is essential to weight loss and maintenance efforts, and it should be followed by setting goals for gradual change in order to promote behavior change. Specifically, making gradual changes, such as steadily reducing calories and increasing physical activity, may result in losing weight at a safe rate and relatively easily. Furthermore, social support and scrutiny may support these gradual changes and ultimately long-term weight maintenance as long as individuals believe that they are under scrutiny (Berkel, Poston, et al., 2005; Jeffery, Drewnowski, et al., 2000). Finally, problem solving may be important as individuals regain weight or slowly begin to return to pretreatment behaviors (Foreyt, 2005). Individuals will almost certainly struggle to maintain the behavioral changes they have made. Problem-solving strategies to prevent relapse can include engaging in different ways of dealing with certain situations such as holidays, social interactions, the influence of friends and family members, and one's thoughts.

Key Issues for Success and Dissemination

Individual Differences Several factors can impact treatment outcomes and should be taken into account. For example, individuals with reduced income may be more averse to changing their eating habits if this results in an increased monthly food bill. They also may have less access to safe locations to engage in physical activity. Low-income individuals may be limited in their access to health care and preventative care. The impact and association of the socioeconomic environment of the individual with diabetes and its effects on health and depression have only briefly been addressed (Gary-Webb, Baptiste-Roberts, et al., 2011). Considering the ill health effects and stress that comes with living in lower socioeconomic environments, it is important to determine what these effects have on preexisting conditions such as obesity and diabetes. Look AHEAD participants living in areas of higher poverty, as compared to those living in areas of lower poverty, had significantly lower scores for overall physical and mental health as well as more limitations physically, emotionally, and socially. These findings help further illustrate the negative effects and overall poorer health status that can result from living under lower socioeconomic status (SES) conditions and demonstrate the importance of SES being taken into consideration when designing and evaluating weight management programs. The effect that SES conditions may have on weight management still requires further investigation, but evidence suggest that lower SES may be related to increases in weight (Gary-Webb, Baptiste-Roberts, et al., 2011). Although research is lacking in ways to better reach low-income individuals (Harvey & Ogden, 2014), strategies to address this issue have been developed. For example, telecommunication technology may assist with these individuals by increasing the possibility of dissemination and allowing for significant tailoring to take place (Costa, Fitzgerald, et al., 2009; Griffiths, Blignault, & Yellowlees, 2006; Noh, Cho, et al., 2010). As more and more people have cell phones (Duggan & Smith, 2013), delivering interventions through this method is promising. However, the overall effectiveness of these programs to date is limited (Harvey & Ogden, 2014).

Cultural differences are also important factors that can impact weight loss attempts, and evidence suggests that ethnic minorities are underrepresented in many trials which can affect the interpretability of findings to these groups (Mount, Davis, et al., 2012). For example, in Look AHEAD, African-Americans were found to have higher adverse levels of blood pressure, heart rate, serum creatinine, and other blood markers which excluded them from being enrolled in the study (Mount, Davis, et al., 2012). Based on these findings, it may be important to modify trial eligibility in future studies to ensure greater proportions of often excluded and underrepresented populations (Mount, Davis, et al., 2012).

Genetics The roles of genetic factors in obesity have often been noted (Frayling, Timpson, et al., 2007; Herbert, Gerry, et al., 2006; Loos, Lindgren, et al., 2008; Sabatti, Service, et al., 2009; Scuteri, Sanna, et al., 2007; Speliotes, Willer, et al., 2010; Thorleifsson, Walters, et al., 2009; Willer, Speliotes, et al., 2009), but the mechanisms and processes linking genes and obesity remain unclear. Gene regions associated with higher risks for obesity, as determined from previous gene-wide association studies (GWAS), were compared to dietary intake, as measured through food-frequency questionnaires, from subjects in Look AHEAD. The study found that certain obesity risk genes were associated with various dietary patterns and habits including more eating episodes per day; eating more servings from dairy groups and products; more servings from the meat, eggs, nuts, and beans group; and lower energy use from consumed proteins. These findings suggest a genetic component may affect eating patterns as well as the type of food consumption among overweight patients with type 2 diabetes. These findings provide important information on how genes interact with health behaviors and have implications for providing a more individualized approach to weight loss (McCaffery, Papandonatos, et al., 2012).

Adherence In Look AHEAD, adherence to treatment recommendations predicted weight loss outcomes at 1 year (Wadden, West, et al., 2009). Although adherence to meal replacement recommendations and attendance at treatment sessions were significant predictors of weight loss, adherence to the recommendations for physical activity was the strongest predictor of weight loss at year 1 (Wadden, West, et al., 2009). Participants with the highest levels of self-reported physical activity lost 11.9% of their initial weight compared with 4.4% for those with the lowest physical activity. Although the study design did not allow for conclusions to be made regarding the reasons for weight loss, physical activity appears to play a critical role (Johnston, 2012).

The strongest determinant of achieving significant weight loss at 4 years in Look AHEAD was initial weight loss in year 1 (Wadden, Neiberg, et al., 2011). The oldest participants lost significantly more weight at year 4 than the youngest participants. Likewise, those who were older attended more treatment sessions, had more contacts with treatment staff, and self-reported greater behavioral adherence to the intervention. It was suggested that the older participants (age 65–74 years) may simply have more time to devote to the lifestyle intervention or that motivation to improve health may be higher in this age group. Overall, these findings are encouraging given that older adults are at increased risk in terms of both morbidity and mortality (Johnston, 2012).

Intensity and Duration of Treatment Treatment intensity may provide an effective strategy for weight management through continued contact with the intervention (Foreyt, Goodrick, et al., 1981). In the Look AHEAD trial, the intervention was intensive with participants attending weekly meetings, three group meetings and one individual meeting monthly, for the first 6 months of the intervention (Look AHEAD Research Group, Wadden, et al., 2006). Even though contact was reduced over time, long-term contact with participants also likely played an important role. In many cases, strong relationships were built between participants and study staff creating a supportive environment for long-term behavioral change. Based on these observations, it appears important to find ways to have high levels of intensity at the beginning of treatment and also to include a plan for contact over an extended period of time as this was done in both Look AHEAD and DPP. Engaging social supports may be one way to promote this in a "real-world" setting. For example, peer support has been shown to improve self-management of diabetes in multiple international settings (Fisher, Boothroyd, et al., 2012).

Primary Outcomes

The Look AHEAD intervention ended after 9.6 years due to a lack of significant results and supporting data for the study's primary outcome which was a significant decrease in cardiovascular morbidity and mortality between the ILI and DSE (Look AHEAD Research Group, Wing, et al., 2013). Even though weight loss was significantly greater in the ILI than the DSE group at every annual assessment, the primary outcome of lower rates of cardiovascular morbidity and mortality in the ILI group was unsupported. Specifically, the ILI focusing on weight loss did not significantly reduce the rate of CVD and death in overweight or obese adults with type 2 diabetes. However, many other benefits were experienced in the ILI compared to the DSE group. Most importantly, Look AHEAD demonstrated that long-term weight loss and maintenance is achievable through a lifestyle change intervention. Indeed, Look AHEAD is the largest, most comprehensive, and most successful randomized study of weight loss and maintenance to date (Perri, 2014).

In addition to its impacts on weight loss itself, the ILI intervention led to initial improvements in symptoms of sleep apnea (Foster, Borradaile, et al., 2009), cardiorespiratory fitness (Jakicic, Jaramillo, et al., 2009), physical functioning (Foy, Lewis, et al., 2011), body image (Stewart, Bachand, et al., 2011), and health-related quality of life (HRQOL) (Williamson, Rejeski, et al., 2009). The following is a brief description of some of the additional outcomes associated with the Look AHEAD intervention.

Additional Outcomes

Maintenance of Weight Loss Without follow-up care, obese individuals usually regain much of their initial weight loss within a year following treatment, and a return to baseline weight is often observed within 3–5 years (Perri, 2014). At year 1, participants in the Look AHEAD study who received the ILI achieved greater weight loss, losing 8.6% of their initial body weight compared to 0.7% for participants in the DSE (Wadden, West, et al., 2009).

Over time, participants regained some of their initial weight loss; however, on average, participants who received the behavioral lifestyle intervention maintained 4.7% weight loss at both 4 and 8 years compared to 1.1% and 2.1% for participants in the DSE, respectively (Look AHEAD Research Group, 2014a; Wadden, Neiberg, et al., 2011). Participants in the ILI had a 6.0% weight loss compared to a 3.5% weight loss in the DSE at 9.6 years (Look AHEAD Research Group, Wing, et al., 2013).

Reductions in Cardiovascular Risk Factors Improvements in weight loss were accompanied by reductions in measures of cardiovascular risk factors including fasting glucose and blood pressure as well as a decrease in the number of medicines used to treat their diabetes, blood pressure, and cholesterol compared to participants in the DSE at 1 year

(Look AHEAD Research Group, Pi-Sunyer, et al., 2007). Indicators of cardiovascular health such as cardiovascular fitness (Jakicic, Jaramillo, et al., 2009), resting heart rate (HR), an HR range, HR at 2 min following exercise, and heart rate recovery during exercise were also found to be improved in the ILI group versus the DSE group (Ribisl, Gaussoin, et al., 2012).

Severe Obesity Rates of severe obesity continue to increase, while the prevalence of overweight and mild obesity may have stabilized in recent years (Flegal, Carroll, et al., 2012). This subgroup has primarily been excluded from clinical weight loss trials due to comorbid conditions. Severe obesity is associated with higher mortality rates compared with overweight and moderately obese populations. Severe obesity not only puts individuals at risk for developing diabetes and other cardiovascular diseases, but once an individual develops type 2 diabetes, life expectancy may be significantly shortened. Since extreme categories of obesity comprise the most rapidly growing and high-risk segment of the overweight population (Flegal, Carroll, et al., 2012), effective methods for treatment are needed. Participants in the ILI condition who were severely obese (class III obesity, BMI ≥ 40) were compared to participants in overweight (BMI, 25 to <30), class I obese (BMI, 30 to <35), or class II (BMI, 35 to <40) obese categories. At year 1, severely obese ILI participants showed comparable weight losses in terms of percent weight loss to class I and class II obese participants. All obese participants showed significantly greater weight loss compared to the overweight participants. All BMI groups (i.e., overweight, classes I, II, III obesity) showed improvements in fitness, physical activity, cholesterol, risk factors for cardiovascular disease, and diabetes indicators. Treatment session attendance did not differ among weight categories. That is, far from being "too severe to treat with mere behavioral approaches," the severely obese benefitted in a manner parallel to those with less pronounced overweight. Although bariatric surgery is often recommended for the very severely obese, this treatment option is limited in scope. Although effective, this procedure is performed on less than 1% of the severely obese population each year. The Look AHEAD findings suggest that the behavioral treatment of obesity may be an effective treatment option for some of the severely obese population, a population that is typically presented with limited options for weight loss (Unick, Beavers, et al., 2011).

Nephropathy Overweight and obese individuals with type 2 diabetes are at increased risk for renal dysfunction which also puts these individuals at risk for cardiovascular mortality (Afkarian, Sachs, et al., 2013; Fox, Matsushita, et al., 2012). Renal dysfunction is an example of a microvascular complication resulting from poor control of blood glucose levels (Fowler, 2008). Improvement in glucose control is associated with improvement in microvascular complications resulting from type 2 diabetes. Individuals who participated in the ILI had a 31% lower risk of occurrence of very-high-risk chronic kidney disease (Look AHEAD Research Group, 2014b). Improvements in weight, HbA1c, and blood pressure were found to be associated with the decreased risk of kidney disease in these individuals. Because chronic kidney disease is a risk factor for cardiovascular-related death, reduction in one's risk of chronic kidney disease may ultimately lead to reduced mortality (Afkarian, Sachs, et al., 2013; Fox, Matsushita, et al., 2012). While the ILI was not found to reduce the rate of CVD and death after 10 years, it is possible that the beneficial effects of the ILI will take longer to appear (Look AHEAD Research Group, 2014b).

Markers of CVD Risk Cardiovascular disease is the largest single cause of death in the world (World Health Organization, 2012). Adipose tissue dysfunctions have been found to play a large role in the development of many of the metabolic abnormalities (Xu, Barnes, et al., 2003). Adiponectin is a marker of adipose health and often found in large quantities in circulation; however, adiponectin is often found in decreased amounts in obese individuals. Participants in the ILI condition demonstrated improvements in adiponectin levels by

11.9% and HDL cholesterol levels of 9.7% compared with changes in DSE which were 0.2% and 1.3%, respectively (Belalcazar, Lang, et al., 2012). When adjusting for demographic information and medical history, adiponectin changes were found to remain significantly associated with HDL-C change. Overall, these increased levels of adiponectin suggest that lower instances of cardiovascular events may be expected for individuals in the ILI condition (Belalcazar, Lang, et al., 2012).

Mobility and Bone Health As people age, they begin to experience issues such as joint pain and stiffness and decreased mobility. Obesity in older adults exacerbates these problems (Magliano, 2008). Participation in the Look AHEAD ILI that encouraged physical activity and weight loss resulted in a 48% reduction in mobility-related disability when compared with the DSE group. Improvements in weight and fitness mediated the effect of lifestyle intervention on slowing the loss of mobility (Villareal, Chode, et al., 2011). Improvements in the mobility and physical functioning of individuals with knee pain in the ILI group have also been reported (Foy, Lewis, et al., 2011).

Because decreased bone mineral density is associated with increased risk of fracture which is a common risk for older adults, the impact of weight loss on bone mineral density also was examined (Schwartz, Johnson, et al., 2012). Despite improvements in fitness, the weight loss achieved at year 1 by participants in the ILI condition was associated with greater bone loss at the hip and femoral neck than those in the DSE group. However, changes in bone mineral density at the lumbar spine and the whole body did not differ between the two groups. While there was a modest decrease in bone mineral density in the hipbone of subjects, further research will need to determine if this decrease was associated with increased risk for hip fractures (Schwartz, Johnson, et al., 2012).

Diabetes Remission Diabetes is often considered an irreversible condition; however, results from the Look AHEAD trial suggest that a lifestyle intervention can be effective to help overweight and obese participants achieve partial or complete remission of their type 2 diabetes, defined as meeting criteria of prediabetes or nondiabetic level of glycemia (i.e., fasting plasma glucose <126 mg/dl and HbA1c < 6.5% with no antihyperglycemic medication) and sustain these improvements long-term (Gregg, Chen, et al., 2012). Remission rates were higher among participants who had diabetes for a shorter amount of time, did not require insulin therapy, and had lower levels of blood sugar when they entered the study. In addition, greater weight loss and improvements in physical activity were associated with likelihood of achieving partial or complete remission (Gregg, Chen, et al., 2012).

Quality of Life Health-related quality of life (HRQOL) is a self-reported measure of a person's perceived mental and physical health (Gandek, Sinclair, et al., 2004; McHorney, 1999; Centers for Disease Control and Prevention, 2000; Selim, Rogers, et al., 2009). Participants in the ILI condition demonstrated significant improvements in HRQOL compared to those in the DSE (Williamson, Rejeski, et al., 2009). Additionally, within the ILI group, individuals with the lowest scores for HRQOL at the beginning of the study demonstrated the greatest improvements. Improved physical fitness, weight loss, and reduced physical symptoms partially contributed to the improvements in HRQOL. Much of the research on changes in HRQOL and lifestyle changes related to weight loss has yielded conflicting findings. Look AHEAD addressed some of the shortcomings of previous studies and, therefore, adds clarity to the subject (Williamson, Rejeski, et al., 2009).

Depression Depression and weight management have often been an issue when treating overweight and obese patients. In past studies, some participants suffering from depression have demonstrated further or intensified mood disorders following weight loss (Campos, 2005; Keys, Brozek, & Henschel, 1950; Rubin, Knowler, et al., 2005). The Look AHEAD study sought to further examine these factors and determine if moderate weight loss in depressed subjects led to higher symptoms of depression and thoughts of suicide and whether initial symptoms of depression would limit weight loss after 1 year (Faulconbridge, Wadden, et al., 2012). ILI participants were found to have lost more weight and have lower depression scores compared to DSE participants. Additionally, within the ILI group, there were no significant differences in total weight loss for participants who did and did not demonstrate depressive symptomatology. These findings suggested that intentional weight loss did not worsen mild or moderate symptoms of depression but, in fact, lowered levels of depression in overweight/obese subjects with type 2 diabetes (Faulconbridge, Wadden, et al., 2012).

Extending Related Behavioral Interventions to Global Settings

The Look AHEAD intervention was conducted in the USA. The earlier pioneering work of DPP has been extended globally. DPP has gained significant support from studies focusing on diabetes prevention in Finland, China, Japan, and India with all of these showing a reduction in type 2 diabetes incidence ranging between 42% and 58% (Knowler, Barrett-Connor, et al., 2002; Tuomilehto, Lindstrom, et al., 2001; Kosaka, Noda, & Kuzuya, 2005; Pan, Yang, et al., 1997; Ramachandran, Snehalatha, et al., 2006), with generally good maintenance for up to 20 years (Li, Zhang, et al., 2008). Moreover, in preventing or postponing type 2 diabetes, the behavioral interventions have been shown to be more cost-effective than treatment with drugs such as metformin (Herman, Hoerger, et al., 2005; Ramachandran, Snehalatha, et al., 2007).

After the efficacy studies had demonstrated that lifestyle change was effective in diabetes prevention, the next step was to test whether the findings could be replicated in more "real-world" community settings and in different countries. This has taken place in two phases, starting first with implementation and dissemination studies in high-income countries (HIC) and then, followed more recently by implementation trials in low- and middle-income countries (LMIC).

DPP Translation in High-Income Countries

Both the DPP (Knowler, Barrett-Connor, et al., 2002) and the Finnish Diabetes Prevention Study (Tuomilehto, Lindstrom, et al., 2001) achieved risk reduction of 58% through a program that was intensive and conducted in research settings with special resources. For example, the Finnish study included a median number of 20 individual counseling sessions with a clinical dietitian who had high expertise on type 2 diabetes, offered a free access to gym, had a substantial number of the participants on a very-low-caloric diet, and extended over 6 years, with a median length of 4 years (Lindstrom, Ilanne-Parikka, et al., 2006). Furthermore, all participants in both studies already had impaired glucose tolerance and so were at a high risk for type 2 diabetes. Such interventions are not replicable in real-world community settings, clarifying a need for testing a less intensive and more feasible intervention.

Remarkably, the first wave of implementation studies showed similar outcomes as those of the DPP with more feasible, acceptable, and cost-effective delivery systems (Absetz, Oldenburg, et al., 2009; Ali, Echouffo-Tcheugui, & Williamson, 2012). Here we detail two of these, the GOAL program in Finland (Absetz, Valve, et al., 2007), which tested the real-world implementation of the Finnish Diabetes Prevention Study (Tuomilehto, Lindstrom, et al., 2001), and the Greater Green Triangle Diabetes Prevention Program (GGT DPP) (Laatikainen, Dunbar, et al., 2007), a study that replicated the findings of the GOAL program in Australia. Both programs were successfully scaled up after initial evaluations and are continuing to be refined in their respective countries (Oldenburg, Absetz, et al., 2011).

In contrast to the research settings of the Finnish DPS and DPP, the GOAL and the GGT DPP were designed for the primary health-care setting, where participants could be routinely identified with the FINDRISC screening tool (Lindstrom & Tuomilehto, 2003). Health-care professionals such as dietitians and primary care nurses were identified to deliver the intervention in small groups, with a short, 3-day training for group facilitation. In Finland, the project had formed partnerships with municipal health-care centers, which implemented the program as one of their preventive care practices, while in Australia the GGT DPP project hired allied health professionals to deliver the intervention in GP practices partnering with the project.

Both the GOAL and GGT DPP included five sessions held fortnightly and one booster session at 8 months (Absetz, Valve, et al., 2007; Laatikainen, Dunbar, et al., 2007). The underlying behavior change model adopted was the health action process approach (the HAPA-model, Schwarzer & Fuchs, 1996), and the main behavior change techniques included risk appraisal, self-monitoring, goal setting, action planning and planning of coping with barriers, regular monitoring and evaluation of progress, and feedback directed toward revising individual objectives and plans for action and coping. Each GOAL session was planned to last for 2 h, while in the GGT DPP, session length was reduced to 90 min. Sessions were scheduled for weekdays (Mon–Thu) either late in the afternoon or early in the evening to fit into work schedules of both participants and health-care personnel.

Effectiveness of the GOAL program in Finland and the GGT DPP in Australia was documented in implementation studies involving over 350 participants in Finland and almost 300 in Australia (Absetz, Valve, et al., 2007; Laatikainen, Dunbar, et al., 2007). Both programs were implemented largely as planned with majority of participants and group facilitators satisfied with the programs (Oldenburg, Absetz, et al., 2011). High participant satisfaction was also reflected in the rather high retention rates throughout both programs (Oldenburg, Absetz, et al., 2011). The main source of dissatisfaction by participants as well as facilitators was the relatively short duration of the program and difficulty in handling separate worksheets instead of workbooks, both factors that were raised in the facilitator training and could be effectively dealt with later in the long-term implementation and up-scaling of the program.

The primary objective of both programs was to achieve a reduction in type 2 diabetes risk via attainment of five secondary objectives defined by the Finnish DPS (Tuomilehto, Lindstrom, et al., 2001) and entailing nutrition (total fat ≤30E%, saturated fat ≤10E%, fiber ≥15 g/1000 kcal), physical activity (≥30 min/day moderate), and weight loss (≥5%). By 12 months, 20% of the GOAL participants achieved at least four of these five key outcomes, results that were comparable to the original trial. Physical activity and weight loss goals were achieved significantly less frequently than in the original trial, 65% vs. 86% and 12% vs. 43%, respectively (Absetz, Valve, et al., 2007). Three-year follow-up of the GOAL indicated continued statistically significant risk reduction in weight (−1.0 +/−5.6 kg), BMI (−0.5 +/−2.1 kg/m^2), and serum total cholesterol (−0.4 +/−1.1 mmol/l) (Absetz, Oldenburg, et al., 2009). Twelve-month results of the GGT DPP included reductions in weight of 2.52 kg, waist circumference by 4.17 cm, fasting glucose of 0.14 mmol/l, plasma glucose 2 h after oral glucose challenge by 0.58 mmol/l (0.36–0.79), total cholesterol by 0.29 mmol/l, low-density lipoprotein cholesterol by 0.25 mmol/l, triglycerides by 0.15 mmol/l, and diastolic blood pressure by 2.14 mmHg (Laatikainen, Dunbar, et al., 2007).

For both the GOAL and GGT DPP, analyses on the psychosocial processes of lifestyle change confirmed the general applicability of the behavior change model used in the interventions (Laatikainen, Philpot, et al., 2012; Renner, Hankonen, et al., 2012), as well as its applicability across socioeconomic strata (Hankonen, Absetz, et al., 2009).

Long-Term Implementation and Up-Scaling

For scale-up and maintenance, the GOAL program has undergone some key refinements following the initial real-world implementation trial. Specific modifications have included an inaugural session to give an overview of the program and timetable; one follow-up session to extend support up to 18 months; increased participatory and activating exercises; strengthening facilitators' training program with components on group facilitation; increased user-friendliness of the participant workbook; community-based activities in collaboration with local NGOs, e.g., healthy cooking and physical activity; and a peer support group program that has evolved as a spin-off for participants who have graduated from the GOAL program. Additionally, the training of group leaders has increased: initially, it consisted of 2 days prior to first group session plus 1 day during the program. Currently, 3 days prior to program plus 1 day annually provide adequate opportunity to build skills and self-efficacy in the program delivery and group facilitation and to share experiences with other facilitators.

The GGT DPP was translated and scaled up in the State of Victoria in Australia as the Life! Program (Dunbar, Hernan, et al., 2012; Janus, Best, et al., 2012). Multiple strategies were introduced for reaching the target population such as social marketing and incentives for GP practices and Life! Facilitators. The intervention is now offered either as a face-to-face program with one individual and five group sessions or as a telehealth coaching program with six one-on-one calls. The group sessions are also open to a partner or a friend. Facilitators' training program includes one orientation day, a self-learning period, and a 2-day workshop on session contents and facilitation skills (Reddy, Vaughan, & Dunbar, 2010). Facilitator training program is complemented with online training modules and there is a quality control system in place. Participants also have access to online supports.

DPP Translation in Low- and Middle-Income Countries

Only two of the first-wave efficacy trials were conducted in LMICs, i.e., the Da-Qing study in China (Pan, Yang, et al., 1997) and the Indian Diabetes Prevention Program (IDPP) (Ramachandran, Snehalatha, et al., 2007). The Da-Qing study included a 6-year active intervention with three lifestyle counseling arms targeting either diet or exercise only or both diet and exercise. It was delivered at community facilities in small groups of high-risk individuals identified with IGT. The study is exceptional in showing long-term effects for up to two decades: a 43% lower diabetes incidence 14 years after the 6-year active intervention had ceased. Remarkably, there was little difference in weight change between the intervention and control conditions during the active intervention. Furthermore, the three intervention arms were equally effective in risk reduction both in short- and long-term (Li, Zhang, et al., 2008). As with the other efficacy trials (Knowler, Barrett-Connor, et al., 2002; Tuomilehto, Lindstrom, et al., 2001), the IDPP tested a relatively intensive intervention comprised of individualized advice by a health provider on healthy diet and regular physical activity with monthly telephone calls to maintain motivation. The study was conducted in an urban, mainly middle-class population with persistent IGT. It achieved a 30% reduction in type 2 diabetes incidence. However, the IDPP would be difficult to "scale up" to community or national level as such, it being not feasible to provide one-on-one advice to the >20 million people with IGT in India (International Diabetes Federation, 2013). As over two-thirds of India's population lives in rural areas, strategies that are less dependent on health-care providers and health-care services are needed for broad diabetes prevention.

The limited scalability of the findings from the efficacy trials has been carefully identified in a systematic review of 30 published implementation trials of diabetes prevention programs that have utilized lifestyle interventions derived from either US DPP or Finnish DPS (Aziz, Absetz, et al., 2015). However, none of these were conducted in LMICs. The HICs represented – mainly the USA but also many Western European countries, as well as Australia and Canada – differ from LMICs in terms of their health systems, culture, traditions, and lifestyle behaviors. Further, HICs share many enabling features for disease prevention that developing countries still lack. Thus, extension of the DPP to LMICs requires considerations of the circumstances, health systems, and cultures of those settings.

The Kerala Diabetes Prevention Program (KDPP) (Sathish, Williams, et al., 2013) in India is one of the first studies to test the feasibility and effectiveness of a culturally adapted model for diabetes prevention in a LMIC. We will describe the translation of the KDPP from the GOAL and the GGT DPP as a case example to illustrate key factors in adaptation across cultures and extension into LMICs. Before describing the program in Kerala, the following sections review considerations that guided translation from the HICs to the LMIC setting.

Health on the Public Agenda Although people in the HICs are often said to live in a so-called obesogenic environment, there are also many contextual factors that actually support healthy lifestyle and lifestyle interventions. From the 1980s onwards, health has become an important consideration in many policies, with countries such as Australia, Canada and Finland in the lead (WHO, 1986; 2012). Public and private healthcare organizations and non-governmental organizations support prevention and control of noncommunicable diseases (NCDs). Employers and their organizations increasingly recognize the need for worksite programs and policies to promote occupational health (Sparling, 2010). Furthermore, although people in HICs live in a highly motorized environment, they also often have efficient public transportation, good access to roads that are safe for walking and bicycling, as well as recreational sports facilities.

On the other hand, however, LMICs are increasingly adopting the obesogenic features of modernization, but without the counterbalancing health promoting elements. The main public health emphasis is still largely on communicable diseases, maternal and child health services, and malnutrition, as is reflected, e.g., in the United Nations' Eight Millennium Development Goals for 2015, none of which are directly related to noncommunicable diseases. In LMICs, the informal employment sector is large. Bitran (2014) estimated that in Southern and Southeast Asia, only one-third of the workforce is employed in the formal sector. Hence, with an abundance of cheap, uninsured workforce whose illness costs do not fall on the employers, there are often no incentives for NCD prevention in occupational settings. Furthermore, population awareness of prevention of noncommunicable diseases also tends to be low (Daivadanam, Absetz, et al., 2013).

Research Tradition and Infrastructures for Prevention HICs enjoy a number of resources for prevention not present in LMICs. These include:

- Financial support
- Infrastructure for program implementation and delivery, such as health-care personnel with adequate education
- Research base concerning the factors that influence the development of type 2 diabetes and its prevention

Individualistic Models of Behavior Change Many of the major diabetes prevention programs are based on behavior change models and techniques and a long tradition of behavioral scientific research that has evolved almost exclusively in the Western World. This research tradition has emphasized the individuals' role as an active decision-maker, with psychosocial constructs such as outcome expectations, self-efficacy (Bandura, 2004), and individual goals and self-regulation (Carver, 2004) for lifestyle change identified as primary determinants of behavior change. Strategies for behavior change draw largely from cognitive-behavioral therapeutic tradition such as self-monitoring, goal setting, and creation of specific action plans as some of the most effective behavior change techniques (Lara, Evans, et al., 2014; Michie, Abraham, et al., 2009). As noted earlier in the chapter, for example, the GOAL program and the GGT DPP were each based on the health action process approach (Schwarzer & Fuchs, 1996) with its emphases on risk perception, outcome expectations, self-efficacy, intention to change, and individual actions and coping. However, the relevance of these theories and the applicability and effectiveness of the techniques in more collectivist cultures have not been well tested. Moreover, key contextual factors of a more collective nature such as household decision-making, household efficacy, and perceived household cooperation and response in relation to a change in behavior are not often factored into the intervention process or the program (Daivadanam, Wahlstrom, et al., 2014).

Strategies for Extending Diabetes Prevention to the LMICs Translation and planning of the KDPP intervention were done following the phased approach for designing complex interventions (Campbell, Fitzpatrick, et al., 2000) starting from (1) a comprehensive needs assessment including policy and research reviews and a qualitative interview study, and proceeding through (2) program translation and modeling to (3) exploratory pilot and (4) a definitive RCT, with (5) long-term implementation as the final goal and hence reflected in the entire process. The next sections describe progress to date, through the pilot study and revisions of the program for the RCT that is currently underway.

Needs Assessment: Relevance of the Problem In contrast to the long history of policies, research, and programs in NCD prevention that led to GOAL and GGT DPP, the needs assessment for the KDPP (Daivadanam, Absetz, et al., 2013) showed that, although India currently has the second largest number of people with type 2 diabetes, over 60 million, prevention of the disease still does not emerge high on the national agenda. The history of NCD prevention policy is relatively recent, and the impact still largely unevaluated. It was not until 2010 that recommendations for diet and physical activity were published as part of the National Program for Prevention and Control of Diabetes, Cardiovascular Diseases and Stroke (NPDCS). Epidemiological research revealed a very high prevalence of clinical and anthropometric risk factors for metabolic syndrome and type 2 diabetes. While modernization is increasing these risk factors in the whole of India, Kerala is by far the most advanced in this transition. The changes are largely attributable to diet and sedentary lifestyle. This is most common among women, who also have a higher prevalence of type 2 diabetes. Furthermore, sedentariness related to all aspects of life (work, leisure, and commuting) is not only an urban phenomenon but applies to rural India, too (Daivadanam, Absetz, et al., 2013).

Needs Assessment: Target Behaviors The GOAL and the GGT DPP as well as earlier diabetes prevention studies focused on moderate weight loss, increased intake of fiber, reduced total and saturated fat, and increased in physical activity (Absetz, Valve, et al., 2007; Laatikainen, Dunbar, et al., 2007). In addition to these, reduction in carbohydrates with high glycemic index such as refined rice and sugar containing foods and beverages, as well as improved sleep and reduction of smoking (among males), emerged as important targets.

Research on psychosocial determinants has been very limited in India. Still, the needs assessment review and qualitative research (Daivadanam, Absetz, et al., 2013) pointed at low awareness of personal risk and risk factors as well as low self-efficacy for and outcome expectations of prevention in general and behavior change in particular and hence supported the applicability of the health action process approach, the theoretical model behind the GOAL and the GGT DPP. However, the needs assessment also revealed a high dependence on family and cultural norms in decision-making related to lifestyle in India. Findings from the qualitative research especially suggested that application of the behavior change model would need further adjustment from a purely individualistic into a more collectivist and family-oriented focus. These observations were mirrored in other NCD interventions in India which suggested that risk reduction requires multilevel strategies including awareness raising, community empowerment, and individual and family empowerment (Balagopal, Kamalamma, et al., 2008; Daivadanam, Wahlstrom, et al., 2013, 2014; Krishnan, Ekowati, et al., 2011; Kumar, Sarma, & Thankappan, 2012; Mohan, Shanthirani, et al., 2006; Murukutla, Turk, et al., 2012; Ramachandran, Arun, et al., 2010).

Intervention Aims The KDPP adopted the same risk reduction objectives as earlier studies but without evidence-based benchmark for similarly precise nutritional, physical activity, and weight loss objectives. Additionally, broader secondary objectives for the KDPP included:

1. To increase motivation in type 2 diabetes prevention among participants and their families and communities by
   (a) Raising awareness of type 2 diabetes risk and potential for lifestyle in preventing the disease
   (b) Increasing outcome expectations for and self-efficacy in prevention with lifestyle change
2. To strengthen individual and community skills and capability to healthy lifestyle changes with the support and help of KDPP peer group, families, and community at large
3. To increase opportunities for healthy lifestyle changes with the support and help of KDPP peer group, families, and community at large

Program Translation and Modeling Participants for the KDPP were identified from electoral wards and their diabetes risk tested with home screening using an Indian Diabetes Risk Score. The main mode of program delivery was small group meetings held in a community locality such as reading room, a local school, or participant's home that was accessible to all participants. Although participation was based on risk status, the participants were encouraged to bring family members along to the group meetings. Based on a tradition of peer-led community groups in India and findings from peer-led interventions including the US National Diabetes Prevention Program (Albright & Gregg, 2013), plans included recruiting and training peer leaders specifically for the KDPP.

The KDPP program was designed as a 12-month program to commence with an inaugural small group meeting to introduce the program and nominate peer leaders from within the group, followed by four fortnightly and subsequent monthly small group sessions of 60–90 min each until the end of the program. To meet the participants' needs for information, the program was designed to contain a half-day diabetes education session delivered in larger groups by a specially nominated KDPP expert panel and a possibility for the groups to use the expert panel also later during the program. The decision to extend the program to 1 year was due to several reasons. First, finding a suitable time for sessions was not easy and Sunday appeared to be the only free day of the week. However, there are many festivities, family gatherings, and other events to compete over participants' time so sessions could not be too frequent. Due to time constraints, 90 min was the maximum participants could be expected to spend at the sessions. The program contained a broader range of behaviors than in the GOAL and the GGT DPP. Although the official literacy rate in Kerala is very high, almost 90%, many people have had only a few years of formal education and may not have used their skills for many decades. Hence, many of the exercises in the program were expected to take longer time to complete. Finally, a common point of criticism from participants in the GOAL and GGT DPP had been that those programs should have lasted longer than they did.

Behavior Change Techniques The behavior change techniques of self-monitoring, goal setting, action and coping planning, etc. described earlier in this chapter that were common to Look AHEAD and DPP translations in developed countries also formed the basis of the KDPP behavior change model. Instead of focusing on individual control, the issues related to unhealthy lifestyles and the identification of healthier options were to be addressed collectively. For example, assessing risks and reappraising outcomes were to include consideration of the implications for families. Setting lifestyle goals took place with participants' family members and others living in the same household. By emphasizing collective problem solving and collective ways to pursue healthier lifestyles and to support one another, it was expected that not only individuals' but also families' self-efficacy would be enhanced.

In addition to its emphasis on the family, the KDPP explicitly included community empowerment as a key program objective. Strategies for community empowerment included identification of key community leaders and other influential citizens who act as local resource persons for the KDPP groups and the peer leaders, identification and partnering with key stakeholder organizations in the local communities, and supporting their roles in creating social norms and planning and developing local environments, events, or programs together with the KDPP groups to enable more healthy lifestyles to all the community members.

Flexible Program Content In the GOAL and the GGT DPP, all groups followed the same structured program with predefined exercises. In the KDPP, by contrast, all the groups tackled diet and physical activity, but the specific contents of the group sessions were flexible and depended on the specific needs of each group. Suggested contents for diet covered, e.g., portion size, identifying cooking substitutions to reduce fat, increasing fruit and vegetable consumption, and decreasing sugar intake, while contents for physical activity included, e.g., finding enjoyable activities for individuals and groups, incorporating those activities into daily routines, and avoiding injuries and accidents. Tobacco control and cessation, reducing alcohol consumption, and sleep were to be dealt with based on the participants' needs and interest. The KDPP also included handbook and workbooks for the participants and a manual for the facilitators and peer leaders.

Exploratory Study An exploratory study of the KDPP was conducted with two groups to test (1) participant identification with home screening and mobile clinic testing, (2) delivery of small group sessions from inaugural meeting through session four, (3) delivery and contents of diabetes education session, and (4) peer leader selection process. This pilot highlighted some important challenges. While overall participation was moderate, male participation was a problem not only due to work constraints but also due to the belief that disease prevention activities were more appropriate for women. Although our expectations for illiteracy had been higher than the official 10%, in practice participants frequently were unable to read and write the local language (Malayalam). Many participants were familiar with type 2 diabetes through family members or relatives who already had the disease. However, this led to two things that compromised their motivation in self-care: first, many were fatalistic about getting the disease themselves, and second, they expressed that management of their significant other's disease was their first priority, not prevention of their own disease. Finally, although peer leader identification proved to be unproblematic, a major area of improvement was to find strategies to build the peer leaders' and the group members' confidence in their ability to manage sessions and benefit from them in the absence of the professional KDPP intervention team.

Modification of the KDPP from Exploratory Study Challenges identified in the exploratory pilot study led to development of a staged approach to program rollout and implementation. In the resulting plan, the first 2 months of the intervention focused on recruitment and retention with strategies highlighting the relevance and benefits of the program to participants and their families, as well as to the peer leaders. This initial phase also sought to raise awareness and support for the KDPP objectives from the communities. The community leaders of each electoral ward identified the local resource persons (LRP) to support the peer leaders and the groups. Also, an additional diabetes education session was introduced to address management of type 2 diabetes, as this had been the major concern for the pilot participants, and to link it to prevention of the disease.

The next 3 months focused on building peer leader skills and self-efficacy. The skills were targeted to enable and strengthen peer support among participants, to raise awareness of existing healthy habits and ways to improve them, as well as to build self-efficacy among participants and their families. Peer leader training in phase two included 2 days focusing on further skill building and sharing perceived benefits, positive experiences, and solutions to problems. The KDPP intervention team kept in frequent contact with the peer leaders, providing them with ongoing support both directly and via the LRPs.

The final 6 months of the 12-month program emphasized ways to maintain and expand the changes toward healthier habits with the peer support and help of extracurricular activities such as kitchen gardening, yoga training, walking groups, etc. At this point, the groups sought to disseminate messages into their communities and develop further plans to activate their communities in diabetes prevention and a healthier lifestyle. In a workshop organized by the KDPP, peer leaders and LRPs shared ideas to develop their plans and identify community organizations with which they could partner in putting the ideas into practice.

A randomized controlled evaluation of KDPP with a 2-year follow-up is currently underway (Sathish, Williams, et al., 2013). The findings, so far, indicate that the program has been very successful in engaging those for whom it is intended. This includes recruitment rates of 75% among eligible individuals and a retention rate at the 1-year assessment of over 90%. Additional indicators of successful implementation and engagement include high participation rates – almost half of the participants attended 75% or more of the intervention sessions over 1 year – and very positive feedback from participants as well as local community and health leaders. There are also early indications that many of the activities undertaken by the peer support groups have been further implemented and have "spread" to the broader communities in which the program participants live. These early findings strongly suggest that the Kerala Diabetes Program and delivery model that have been developed for India are well accepted, adopted, and more widely implemented by people with high risk of diabetes and their communities.

Conclusions

A solid foundation for the management of obesity has been laid with behavioral change strategies playing a prominent role. Knowledge about *nutritional* approaches to weight management will continue to evolve, but these *behavioral* strategies will remain the foundation for assisting patients to make lifestyle changes to adopt healthy eating. This has been exemplified through the DPP and Look AHEAD studies. For example, not only is Look AHEAD the largest and longest randomized controlled trial for weight loss (Perri, 2014), it has demonstrated that through intensive intervention, the elusive goal of long-term weight loss is possible. Although the differences in weight loss between the ILI and DSE conditions declined over time and the trial found no significant differences in cardiovascular endpoints (Look AHEAD Research Group, Wing, et al., 2013), significant improvements were initially demonstrated across multiple areas of health including quality of life (Williamson, Rejeski, et al., 2009), mobility (Foy, Lewis, et al., 2011; Schwartz, Johnson, et al., 2012), and sleep apnea (Foster, Borradaile, et al., 2009). Notably a significant proportion of individuals experienced partial remission of their diabetes (Gregg, Chen, et al., 2012).

In the USA, dissemination of these approaches of the DPP – centered on behavior change strategies for lifestyle change – has been vigorous with appreciable successes (Albright & Gregg, 2013). The efforts to extend them globally have shown success in developed countries, through the GOAL program in Finland (Absetz, Valve, et al., 2007) and the Greater Green Triangle Diabetes Prevention Program in Australia (Laatikainen, Dunbar, et al., 2007). The Kerala Diabetes Prevention Program (Sathish, Williams, et al., 2013) has moved the dissemination efforts to low- and middle-income settings. It shows still the general applicability of the basic model and of behavior change but, stimulated by the cultural setting of India, also expands emphases on family and community.

The broad sweep of this work reveals an impressive progression of understanding and application in behavioral medicine. Without requiring change in some highly inferential personality characteristics as had long been assumed, the initial work of Stuart showed that focusing on specific eating behaviors could alter body weight (Stuart, 1967). Throughout the last third of the twentieth century, behavioral medicine researchers refined the set of behavioral change strategies useful in initiating and maintaining weight loss (Foreyt & Pendleton, 2000; Jeffery, Drewnowski, et al., 2000; Stunkard, 1978; Wadden & Foster, 2000; Wing, Tate, et al., 2006). The twenty-first century has brought reports of the remarkable application of these approaches to major public health problems – diabetes prevention and management (Diabetes Prevention Program Research Group, 2002; Look AHEAD Research Group, Wadden, et al., 2006; Look AHEAD Research Group, Pi-Sunyer, et al., 2007; Look AHEAD Research Group, Wing, et al., 2013; Look AHEAD Research Group, 2014a; Tuomilehto, Lindstrom, et al., 2001). Dissemination is in progress in the USA and other upper-income countries (Albright & Gregg, 2013; Absetz, Valve, et al., 2007; Laatikainen, Dunbar, et al., 2007) and, now, with promising results in low- and middle-income settings (Sathish, Williams, et al., 2013).

Among the many lessons from this field, three stand out. First is a model of cultural adaptation. Consider for a moment the extent to which diet and obesity are culturally influenced and, then, how much one might expect key approaches to weight loss to vary tremendously across different groups, cultures, and countries. From that perspective, the general applicability of the basic behavior change strategies for weight management across very different settings – Australia, Finland, the USA, China, and India – is remarkable. To be sure, those principles needed to be tailored to the specific conditions in each of those settings, such as with the increased emphasis on family and community in the Kerala DPP, but still the fabric seems fairly generalizable. This reflects a model of standardization by function rather than by specific protocol or details of interventions (Aro, Smith & Dekker, 2008; Hawe, Shiell & Riley, 2004). In the present case, goal setting is an important feature of weight management programs. How those goals are set, for example, with individuals or, as in India, with families, may vary from setting to setting, but key functions, like goal setting, seem to have quite robust generality.

A second key lesson is the importance of ongoing contact or support. The Da-Qing program continued contact every 3 months throughout its course (Pan, Li, et al., 1997). Look AHEAD provided monthly contact and varied programs throughout the years it was implemented (Look AHEAD Research Group, 2014a). The idea that we can teach individuals skills with which they can autonomously manage their weight for the rest of their lives is not supported by data. Rather, sustained weight loss – like all behaviors – appears to require sustained reinforcement through ongoing contact and support. This appears also to be true of diabetes self-management. In a meta-analysis, duration of intervention was the best predictor of success of self-management programs in improving metabolic control (Norris, Lau, et al., 2002).

The third lesson emerging is the importance of context. Reflecting the importance of ongoing contact to support sustained weight loss, research also points to the importance of families and community contexts for sustained health behaviors. In this regard, the emphasis on these contexts for individuals' diabetes prevention in the Kerala DPP is noteworthy and may provide useful models for other countries in the coming years.

The needs of the 2.1 billion individuals worldwide who are overweight or obese (Ng, Fleming, et al., 2014) remain a daunting challenge. The research reviewed here shows, however, that real benefits are attainable through well-established behavioral change strategies. What is critical appears to be continued innovation in ways to adapt and disseminate those behavior change strategies with different groups, countries, and cultures, along with supportive policies to create food and community environments conducive to long-term healthy diet, physical activity, and body weight (Brownell, Kersh, et al., 2010; Gearhardt, Bragg, et al., 2012).

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29

Preventing Violence and Injury

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Introduction

Traumatic injuries are among the leading threats to global health, causing more than five million deaths annually (World Health Organization [WHO], 2008). Injuries result in more deaths than all other causes combined for people aged 5–44 years and contribute significantly to premature life lost and years lived with disability for all countries, all regions of the world, and all age groups (Peek-Asa & Hyder, 2008). Injury deaths are caused by many factors including unintentional mechanisms such as road traffic crashes, drowning, falls, and fires as well as intentional mechanisms such as homicide and suicide. Injuries disproportionately affect the young, and eight of the 15 leading causes of death for people aged 15–29 are related to injuries (Peden, McGee, & Sharma, 2002), with road traffic crashes, self-inflicted injuries, and interpersonal violence in the top 5 (Krug, Sharma, & Lozano, 2000; Krug, Dahlberg, et al., 2002; Peden, McGee, & Sharma, 2002; Peden, McGee, & Krug, 2002).

Deaths from violence and injury are merely the tip of the iceberg – for each death, thousands of nonfatal injuries require medical treatment, many of which lead to long-term disability. The disability-adjusted life year lost, or DALY, was introduced by the World Bank and World Health Organization as a measure of disease burden (World Bank, 1993). The DALY combines the loss of healthy life from premature mortality and the estimated years of disability from nonfatal disease, thus integrating the burden of mortality and morbidity (Murray, Vos, et al., 2012). Injuries are estimated to account for more than 11% of all DALYs (Murray, Vos, et al., 2012). Road traffic crashes account for 27% of all injury-related disability-adjusted life years lost, followed by self-inflicted injuries, falls, and interpersonal violence (Murray, Vos, et al., 2012).

Injuries place a severe physical, emotional, and financial burden on individual victims, their families, and our society. To prevent injuries and their negative consequences, many intervention strategies have been used to effectively change individual behaviors and/or policies or to improve technologies and the environment. There is strong evidence of the effectiveness of these

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preventive interventions, including use of seat belts to prevent traffic injuries, bicycle helmets to prevent bike-related injuries, residential smoke detectors and the implementation of fire safety education programs to improve home safety, home visitation of new parents to prevent mistreatment of children, and tenant-based rental assistance programs to prevent youths from witnessing or becoming victims of crime. Widespread implementation of such interventions could save thousands of lives annually.

When designing interventions, it is essential to take into account the fact that injuries are inextricably linked to behavior at the individual, community, and societal levels. Although injury types and associated risk factors are highly varied, individuals who exhibit risky behavior are likely to be at increased risk for all types of injury, and this link has been identified across many cultures and countries (Begg & Gulliver, 2008; Dong, Peek-Asa, et al., 2011; Yi, Poudel, et al., 2010). Factors associated with communities and larger society, such as safety-related norms and cultural practices, also play a critical role in injury incidence as these factors influence the likelihood that safety-related policies are implemented and enforced and/or the types of environmental approaches that are utilized. Thus, examining multiple levels of influence on behavior is critical in the estimation of the burden of injury and in the design and implementation of effective prevention and intervention programs.

Despite the fact that many intervention strategies have been successfully used in violence and injury prevention and control, injury prevention research continues to remain an understudied area in behavioral medicine, partially due to disproportionate distribution of research funding in the area of violence and injury compared to other health problems. For example, in the United States, injuries account for 31% of years of potential life lost before age 65, more than cancer and heart disease combined (Runyan, Hargarten, et al., 2010). However, federal research support is lower for injury than either of these other research topics. Furthermore, many injury prevention strategies, for example, those to reduce road traffic crashes, occur across multiple governmental sectors and outside of the healthcare field. Because the field is so multidisciplinary, coordinated research and preventive measures require multisectoral collaborations. Despite these challenges, the field of injury and violence prevention has advanced tremendously in the past decade.

This chapter will describe the global burden of injuries, provide a context for multilevel behavioral approaches to violence and injury prevention, and provide four examples that illustrate the intervention programs and strategies utilized to target changes at the individual, family, community, and policy levels to prevent violence and injury. These four examples target increasing seat belt use, smoke detector installation, bicycle helmet use, and preventing intimate partner violence.

Global Distribution of Violence and Injury

According to newly published results from the Global Burden of Disease Study, injury mortality increased to 10.7% from 1990 to 2013 (GBD 2013 Mortality and Causes of Death Collaborators, 2015). During this same period, road injuries increased to 15% and rose from the tenth leading cause of death to the fifth leading cause worldwide. Self-harm, interpersonal violence, and falls all rose in their ranking, while drowning and fire and heat had a lower rank in 2013 than 1990. Globally, injuries are disproportionately distributed in low- and middle-income countries compared with high-income countries. Of the more than five million injury deaths each year, more than 85% occur in low- and middle-income countries (Peden, McGee, & Sharma, 2002). The highest injury mortality rates for men are in Africa, followed by Europe, Southeast Asia, and the Americas, all with an injury mortality rate exceeding 100 per 100,000 population (Peden, McGee, & Krug, 2002). Injury mortality rates for males in the Eastern Mediterranean and Western Pacific are lower, about 87 per 100,000 population. Regional patterns of injury mortality differ somewhat for women. Although African women also have the highest rates, 75.1 per 100,000 population, women in the Americas have the lowest rate, with 29.4 per 100,000 population. Women in the regions of Southeast Asia, Western Pacific, Eastern Mediterranean, and Europe all have rates exceeding 45 per 100,000 population.

These mortality trends illustrate a common pattern found throughout the world: men have higher rates of injury mortality than women. Worldwide, injury mortality rates for men exceed those among women for road traffic crashes, interpersonal violence, self-inflicted violence, drowning, falls, and poisoning. This difference is most marked for road traffic crashes and interpersonal violence, for which men have mortality rates that exceed women's by more than a factor of three. Fire-related deaths are an exception, with women experiencing a slightly higher mortality rate than men. Although a great deal of research has confirmed the gender differential, little research has examined causal reasons. The most frequent reason cited for higher injuries among men and boys is increased risk-taking behavior (Hu & Baker, 2009).

Another uniform trend of injuries globally is the age distribution: injuries disproportionately affect the young. Nearly 50% of the world's injury deaths occur among those aged 15–44, and another 20% occur among those under 15. As with gender, the age trend also has important behavioral implications that present a paradox: compared to the elderly, young people are far more resilient and more likely to survive a traumatic event, yet the majority of injury deaths do not occur among the elderly (although the elderly do have high mortality rates). Thus, the resilience of the young to injury is somehow offset by the frequency or severity of the exposure.

Injury types have different distributions by region. As measured through DALYs, Southeast Asia alone accounts for 34% of the burden of traffic crash injuries. The Western Pacific Rim accounts for another 24%. These regions are characterized with large populations and rapid industrialization (Stevenson, Yu, et al., 2008). However, increases in vehicle production, ownership, and miles traveled have not been accompanied by effective programs to improve safety behavior. Many countries in these regions do not have a sound motor vehicle safety culture that integrates the promotion of individual safety (such as seat belt use and consumer preference for cars with strong safety records), safety-promoting policies (such as enactment and enforcement of drunk driving laws), and coordinated efforts to incorporate safety into road and vehicle design. This paradox of miles traveled vs. road traffic-related DALYs can largely be explained by the effects of safety behaviors implemented at the individual, community, and societal levels (Graham, 1993). Regional road traffic-related DALYs are strongly correlated with income level, with low- and middle-income countries experiencing DALYs lost up to five times greater than high-income countries within the same region, which suggests that availability of resources for infrastructure development is critical (WHO, 2002).

Regional patterns of interpersonal violence and self-inflicted harm show similar correlations by income, with 95% of interpersonal violence and 86% of self-inflicted harm DALYs lost in low- and middle-income countries. More than a third of interpersonal violence DALYs are lost in the Americas and another 23% in Africa. Regional patterns for self-inflicted DALYs are quite different: the Western Pacific Region accounts for only 11% of DALYs lost for interpersonal violence but 38% of self-inflicted harm. Similarly, Southeast Asia accounts for 14% of DALYs lost for interpersonal violence but 26% for suicide (WHO, 2002).

Compared with road traffic crashes, less is known about the larger cultural influences and behaviors that impact violence and self-harm, although these cultural contexts are critical factors in prevention (WHO, 2002). After the World Health Organization released the first global report on violence and health in 2002, attention to violence prevention as a global priority has gained considerable attention (WHO, 2002). The WHO report prioritizes primary prevention and identifies strategies to reduce violence at the individual level, including social development and treatment programs; the relationship level, including family therapy programs; the community level, including coordinated community interventions and public education campaigns; and the societal level, including legislative and policy changes. There is a critical need to grow the evidence base to help identify successful and cost-effective programs and to identify the most effective strategies to translate proven approaches across cultures.

Research to compare global trends of injury mortality rates, DALYs lost, and regional comparisons by age, gender, and injury type has only been available for approximately the last 10 years. Several types of injuries stand out as having distinct regional patterns. Mortality from poisoning was markedly higher in low- and middle-income countries within Europe than any other region or income level. Poisoning-related DALYs lost were high in low- and middle-income countries in Africa as well as in India. DALYs lost from drowning are concentrated in low- and middle-income countries in Africa as well as in India and China. These surveillance efforts, however, represent a very important step in recognizing the burden of injury and, ultimately, in identifying effective prevention and intervention steps. Increased attention to injury research and program development will help identify the causes driving these trends and methods to reduce the injury burden.

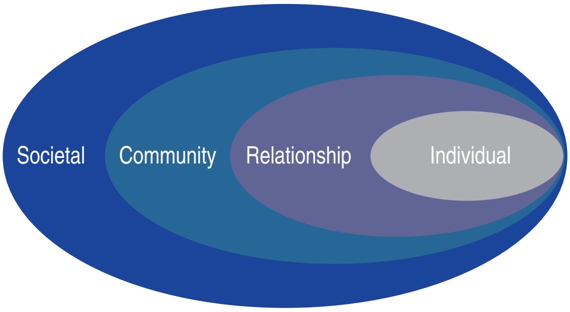
Application of Theory to Violence and Injury Intervention

The Socioecological Model: A Framework for Violence and Injury Prevention

The Socioecological Model is a framework which suggests that there are multiple levels of influence on specific health and health-related behaviors (Centers for Disease Control and Prevention [CDC], 2009). While individuals are responsible for instituting and maintaining specific health behaviors necessary to reduce the risk of violence and injury and improve health, individual behavior is determined to a large extent by the physical and social environment (e.g., road condition, home safety devices, community norms and values, and policies). Efforts to prevent injuries and violence are more likely to be successful when we work within multiple spheres of influence at the same time. The four-level Socioecological Model displayed here includes the interplay between individual, relationship, community, and societal factors that put individuals at risk of injuries and violence (CDC, 2009). The model can assist in better understanding the determinants of behaviors leading to injuries and violence (Dahlberg & Krug, 2002). This knowledge is useful when designing, implementing, and evaluating violence and injury prevention interventions (Fig. 29.1).

Individual Level The first level of the Socioecological Model identifies biological and personal factors that increase or decrease the risk of injuries and/or violence (CDC, 2009). Some of these factors include age, education, income, substance use, history of abuse, and the practice of safety behaviors. Prevention strategies at this level are often designed to promote attitudes, beliefs, and behaviors that will ultimately prevent violence and injury. Interventions for individual-level influences are often designed to target an individual's social and cognitive skills and behavior and include approaches such as counseling, therapy, and educational training sessions.

Fig. 29.1 Socioecological Model



Examples of such programs include an education program for school children to increase their knowledge on bicycle safety and sexual assault prevention programs for college students aimed at increasing awareness and reducing rape supportive attitudes and behaviors (Nagel, Hankenhof, et al., 2003; Vladutiu, Martin, & Macy, 2011).

Relationship Level The second level examines how close relationships with family, friends, partners, and peers increase or decrease the risk of injuries and/or violence. Violence prevention strategies at this level may include mentoring and peer programs designed to reduce conflicts, foster problem-solving skills, and promote healthy relationships. A recent intervention that targeted skill building found that couples who improved their healthy relationship and conflict management skills had reductions in intimate partner violence (Cleary & Gottman, 2012). Injury prevention strategies may include parent-focused programs to increase the supervision of children, peer programs to reduce behaviors that lead to injury (e.g., drinking and driving), and healthcare provider discussions with their patients on injury prevention. A study of children presenting in the emergency department found that 39% of parents who received counseling from a primary care physician reported making at least one positive change in their environment to make it safer for children at a 2-week follow-up (Claudius & Nager, 2005). Several randomized trials that focused on the critical role of parents in the driving experience of their children, including the *Checkpoints Program* and *Steering Teens Safe*, have demonstrated success in improving parent-teen driving safety communication and consequently improved safe driving attitudes and behaviors of the teen drivers (Beck, Hartos, & Simons-Morton, 2006; Hartos, Eitel, & Simons-Morton, 2002; Ramirez, Yang, et al., 2013.; Simons-Morton, Hartos, et al., 2005; Yang, Campo, et al., 2013).

Community Level The third level explores the settings, such as schools, workplaces, and neighborhoods, in which social relationships occur and seek to identify the characteristics of these settings that are associated with injuries and/or violence. Prevention strategies at this level are typically designed to impact the climate, processes, and policies in a given system. For example, establishment of sexual harassment or violence policies in the workplace can send a message that these behaviors are not tolerated, and there are consequences for those who engage in these behaviors (American Academy of Pediatrics Committee on Pediatric Workforce & Pletcher, 2006; Feda, Gerberich, et al., 2010). Another example of a community-level intervention is installing free smoke alarms or offering discounted smoke alarms for resident homes to reduce fire-related injuries and deaths (DiGuiseppi & Higgins, 2001; Yang, Peek-Asa, et al., 2008).

Societal Level The fourth level looks at the broad societal factors that help create a climate in which risk behaviors that lead to injuries and violence are discouraged. These factors include social and cultural norms, including the safety culture. Other large societal factors include the health, economic, educational, and social policies that reduce economic or social inequalities between groups in society (CDC, 2009). One example for societal level influences is to determine societal norms that accept violence and identify strategies for changing those norms. Such interventions often involve collaborations of multiple partners to change laws and policies. Seat belt laws and bicycle helmet laws are two examples of societal level strategies that have been found to increase injury prevention behavior (Karkhaneh, Kalenga, et al., 2006; Nichols, Tippetts, et al., 2014). Further, high visibility enforcement, law upgrades, and higher fine levels have been associated with highest levels of seat belt use (Nichols, Tippetts, et al., 2014).

An example of the application of the Socioecological Model lies in the promotion of smoke alarms in low-income neighborhoods. The socioecological approach can be used to increase the knowledge, skills, and self-efficacy to install and maintain smoke alarms, which can reduce the risk of fire-related injury and death. Door-to-door education about the importance of smoke alarms could be implemented at the individual level. Family-centered programs could be used to teach parents about the importance of smoke alarms and help them set up a fire escape plan with their family. At the community level, smoke alarm giveaway programs through fire departments, and at the societal level, policies that require smoke alarms in all homes will increase the proportion of homes with functioning alarms.

Each of the four levels in the Socioecological Model can be considered a point of influence. Violence and injury prevention interventions should include a continuum of activities that address multiple levels of the Socioecological Model. These activities should be culturally appropriate and specifically tailored to fit the target population's needs. This multifaceted and tailored approach is much more effective at sustaining prevention efforts over time than any intervention that only focuses on a single sphere of influence.

Types of Prevention Interventions

Prevention is a strategy or approach that reduces the likelihood of risk of onset, delays the onset of adverse health problems, or reduces the harm resulting from conditions or behaviors. Violence and injury prevention approaches can be classified into three types based on the time that a violence and injury prevention program occurs: primary, secondary, and tertiary prevention.

Primary prevention is an approach that aims to prevent the injury or violent event from occurring in the first place. Some examples of primary prevention include setting the thermostat on the hot water heater to below 120 F and always testing the water temperature before letting a child get into a bathtub to prevent burns for children; placing a nonskid mat in the bathtub or shower and/or participating in an leg strength exercise program to prevent falls for older adults; and media campaigns in the community to promote nonviolence in relationships. Primary prevention strategies also include educational sessions or mass media campaigns to raise awareness or increase knowledge as well as government and state requirements including those designed to prevent industrial injuries and policies mandating safety features in cars that reduce crash risk or policies that restrict access to workplaces by non-employees.

Secondary prevention is an approach used to reduce the severity of injury during an injury event. For example, secondary prevention strategies for motor vehicle crashes are those that reduce the level of energy in the crash, but do not prevent the crash itself. Some examples of secondary prevention include seat belts, air bags, and helmets. Among secondary strategies are also educational sessions to teach children about the proper use of a bicycle helmet, free residential smoke alarm installing programs to cue evacuation behaviors of residents in the event of a fire, youth sports traumatic brain injury legislation mandating removal from play following actual or suspected concussions and permission to return to play by a licensed healthcare professional, and training of teachers to identify boys who need individualized counseling on conflict management. These activities can either reduce the severity of injury or interrupt the development of subsequent injury or violence.

Tertiary prevention is an approach that takes place after an injury or violent event occurs. The goal is to lessen the long-term effects of the event and optimize full recovery. Tertiary prevention programs aim to improve the quality of life for the injured by limiting complications and disabilities, reducing the severity and progression of injuries, and providing rehabilitation to restore self-sufficiency. Some examples of tertiary prevention include one-on-one counseling for victims of domestic violence, shelter programs for battered women, prescribed physical and cognitive rest for youth with sports-related concussions, and comprehensive trauma systems designed to effectively care for trauma victims. Unlike primary and secondary prevention, tertiary prevention may involve actual treatment for the injuries including medical treatment and rehabilitation after car crashes, fires, and incidents of violence.

Though the distribution varies based on the country and injury or violence topic, a combination of primary, secondary, and tertiary prevention strategies should be used to address incidents of violence and injury. Each type of prevention involves different strategies and, often, different target populations. A growing emphasis has been placed on primary prevention because these strategies have the greatest impact (Krug, Dahlberg, et al., 2002). Interventions can also be divided into groups based on the population that is targeted. They can be classified as being universal, selected, or indicated. *Universal* interventions are designed to favorably shift risk and/or protective factors across a whole population. Examples include mass media campaigns or policies regarding seat belt use, helmet use, and smoke alarm installation and use. *Selected* interventions are those that are aimed at people who have been identified in some way as being at heightened risk for injury and/or violence victimization or perpetration. More specific examples include smoke alarm giveaway programs in low-income areas with high fire mortality rates and intimate partner violence prevention programs for women who live in countries or communities where violence is considered somewhat culturally accepted. *Indicated* intervention approaches are aimed at those who are already experiencing symptoms of a condition. Some examples of indicated interventions include policies restricting gun ownership in individuals who have been convicted of domestic violence and bicycle helmet giveaway programs for children who go to the emergency room after a bicycle accident. In general, universal and selected interventions are more likely to be aligned with primary prevention, while indicated interventions are often forms of secondary or tertiary prevention. Each of these approaches should be considered when determining the best injury or violence prevention design.

Haddon's Matrix

Haddon's Matrix, developed by William Haddon, is a conceptual model that systematically portrays an injury or violence issue in temporal and epidemiological components with the goal of identifying prevention countermeasures (Haddon, 1970; Runyan, 1998). According to this framework, injuries occur with a certain time sequence, and the occurrence of an injury involves the epidemiology triangle (host, agent, and environment) (Fig. 29.2). Thus, the framework combines a temporal dimension similar in some respect to distinctions among types of prevention, with the kind of distinctions among sources of influence of the Socioecological Model. Combining the two axes of the Haddon Matrix framework, one can evaluate the relative importance of different factors and design interventions.

	Personal Factors	**Vector or Agent Factors**	**Physical Environment Factors**	**Social Environment Factors**
Pre-Event	Driver's experience, training or visual acuity	Speed of travel, Vehicle characteristics (lighting, braking, handling)	Road type, quality and markings	Safety-enhancing social norms/ cultural practice
Event	Use of seat belts, Driving impairment (e.g., drunk driving)	Safety devices, Crash protective design	Crash protective roadside objects	Enforced seatbelt and drunk-driving laws
Post-Event	First aid skill, Physical resilience	Ease of access, Fire risk	Rescue facilities, Access to trauma care	Programs of preparedness for EMS responders

Adapted from WHO, 2006.

Fig. 29.2 Example of Haddon's Matrix in crash-related injury prevention (Adapted from WHO, 2006)

There are three steps in using Haddon's Matrix (1970; Runyan, 1998). The first is to use community data to determine the injury problem. Step two is to brainstorm potential ideas for interventions and fill them into the cells of Haddon's Matrix. Within the second step, one should start assessing the contributing factors or characteristics from the perspective of (1) personal factors, (2) the agent of energy, (3) the physical environment, and (4) the social environment. Then, one should examine which factors are related to these time phases: (A) pre-event, (B) event, and (C) post-event.

In the case of a car crash, some examples of personal factors that could be targeted to prevent a crash (pre-event) include the driver's experience, training, and vision. Pre-event agent factors could include speed of travel and vehicle load characteristics. Physical environment factors in the pre-event phase include road type, quality, and markings; social environment factors include safety-enhanced norms or practices. These factors should be identified for each stage in the matrix, until it is completely filled out. It is important to remember that prevention can be focused on any of the cells of the matrix.

Once the matrix is completely filled out, the third and final step in using Haddon's Matrix is to make decisions about the best intervention options. In general, many post-event factors could be target of tertiary prevention, while the pre-event and event factors are more likely to be changed using primary or secondary prevention strategies. When comparing to the Socioecological Model, personal factors are consistent with the individual-level determinants, while the agent and environmental factors are often connected with the community and societal level determinants. For example, interventions can address the host/pre-event cell (e.g., teaching teens about dangers of drinking and driving) or the agent/pre-event cell (e.g., improvements in vehicle safety such as antilock brakes). Interventions can also be implemented to change the physical environment by reducing the risk of injury pre-event or post-event (e.g., building roundabouts or circular intersections to prevent crashes or improving ambulance service systems to reduce paramedic response time). Changes can also be made in the social environment (e.g., changing social norms around driving safety or training responders for emergency preparedness). Many factors should be considered during this step, including evidence on the effectiveness of certain strategies, known characteristics of the culture and population, the setting, and the budget. Nonetheless, the use of the Haddon Matrix and careful consideration of other theoretical approaches will increase the chance of intervention success.

Four Examples Applying Principles and Concepts of Behavioral Medicine to Violence and Injury Prevention

The following sections will describe interventions that were designed to increase seat belt use, smoke detector installation, and bicycle helmet use and reduce intimate partner violence. These four sections highlight injuries that are prevalent, produce immense burden, and have theory-based interventions with evidence of success. These examples will depict the importance of multilevel interventions and illustrate how the behavioral medicine concept can be used to prevent injuries and violence.

Example 1: Seat Belt Use

Road Traffic Deaths and Injuries

Road traffic injuries are among the most rapidly increasing causes of global mortality, estimated to become the third leading cause of death worldwide by the year 2020 (WHO, 2004). Low-income countries account for nearly 85% of this burden, but many high- and middle-income countries also have exceedingly high mortality rates, with motor vehicle crashes representing the largest cause of death among adolescents and young adults (WHO, 2004). An estimated 20–50 million individuals are injured in road crashes each year, accounting for an estimated 38.4 billion, or 2.6%, of all DALYs. The toll of these deaths and injuries, including the physical and psychological burden on individuals, families, and communities as well as medical and quality of life costs, is staggering.

A large proportion of road crash victims in low- and middle-income countries are vulnerable road users such as pedestrians and bicyclists (WHO, 2004). However, increasing industrialization accompanied by increased use of personal vehicles has led to an increase in the proportion of victims who are vehicle occupants. One of the most effective methods of reducing injury during a crash (secondary prevention) is the seat belt.

Studies have overwhelmingly supported the effectiveness of seat belts, which reduce fatalities and severe injuries by more than 50% (Campbell, 1987; Evans & Frick, 1986; Rivara, Koepsell, et al., 2000). The automobile seat belt was first implemented in the early 1950s in both the United States and in Sweden, yet even today, over half a decade later, we have not attained the prevention potential of the seat belt due to low and varied use of seat belts by occupants. Creating a culture of seat belt use has turned out to be a complex interplay of multiple behavioral approaches at the individual, family, social, and political levels.

Efforts to Increase the Wearing of Seat Belts Through Policy

The first step in achieving the potential prevention effect of the seat belt was mandating that they are available in cars, which in Haddon's Matrix is a pre-event agent change that is tantamount to behavioral change at the policy and industry level. In the 1950s, seat belts were first introduced in the United States as an option for consumers, and consumers bore the cost of installation. Strong efforts of medical and advocacy communities that promoted information about the growing toll of motor vehicle crash deaths and the effectiveness of seat belts led to new safety standards, introduced in 1968, that required seat belts to be installed in all occupant positions. Although advocates at that time believed that mandated seat belt availability would lead to a high proportion of use, only about 11% of occupants actually wore their seat belt (Peterson, Tilman, et al., 1999). Other countries have been much slower to regulate seat belt installation in cars. For example, China did not require seat belts to be in the back seat of cars until late 2004 (Routley, Ozanne-Smith, et al., 2008).

In order to increase seat belt use, many countries and localities have implemented policies that require seat belt use. In 1970, the state of Victoria, Australia, passed the first law worldwide making seat belt wearing compulsory for drivers and front-seat passengers (Trinca & Dooley, 1977). The implementation of this law led to an estimated 33% decrease in motor vehicle occupant deaths and injuries. The United States introduced its first seat belt legislation in 1984, when the state of New York required all front-seat and child back seat occupants to be belted (Peterson, Tilman, et al., 1999). Since that time, all 50 states have implemented some type of seat belt use law, but these first laws were "secondary," which allowed ticketing for seat belt non-use only when the vehicle was stopped for a reason not related to the seat belt. These secondary laws in the United States were found to increase seat belt use to about 63%. Currently, 16 states in the United States have only secondary seat belt enforcement laws, and one state has neither a primary or secondary seat belt law for adults (Governors Highway Safety Association [GHSA], 2015).

Implementation of primary laws, which allow police to pull over a car for the sole reason of non-seat belt use, increased seat belt use to approximately 78% (Peterson, Tilman, et al., 1999). Currently, 33 states in the United States have primary seat belt laws for at least the driver and front-seat passengers (GHSA, 2015). In the United Kingdom, front-seat belt usage rose from 37% to 95% after introduction of the seat belt law, which also resulted in the reduction of hospital admissions due to road traffic injuries by 35% (Rutherford, 1985). Primary laws are more effective than secondary laws because they are more easily enforced; one study showed a seat belt use rate of 9 percentage points higher in states with primary laws than those with secondary laws (Nichols, Tippetts, et al., 2014). Enforcement and monetary fine amounts are also essential elements of policy success (Nichols, Tippetts, et al., 2014). However, even with primary laws, the potential prevention effect of the seat belt was far from attained.

Efforts to Increase the Wearing of Seat Belts Through Policy Enforcement

Although policies requiring seat belt use are an essential part of increasing use, policies are largely ineffective without enforcement. Qatar, for example, introduced a front seat passenger seat belt law accompanied with strong enforcement on January 1, 2002, which led to increased safety belt usage among patients hospitalized from a road traffic crash from 8% in 2001 to 67% in 2004. The overall rate of hospital admissions due to road traffic injuries was decreased by 17.7% (Bener, Al Humoud, et al., 2007). Enforcement was identified as a critical element of this law's success.

The absence of enforcement leads to lackluster impact. One study in Russia, for example, found that only 15–20% of the Russian population used seat belts despite a national law requiring their use (Akhmadeeva, Andreeva, et al., 2008). Despite laws in Greece and Italy, seat belt wearing was below 60% (Routley, Ozanne-Smith, et al., 2008). Policies are complicated because they often do not apply to all drivers. In Nigeria, for example, a primary law for drivers led to seat belt use of 31.7%; however, the use among front-seat and rear seat passengers, neither of whom were covered by the law, was 10.3% and 0.4%, respectively (Sangowawa, Alagh, et al., 2010). Pakistan also only requires seat belt use for drivers, with exceptions for some types of vehicles, drivers, and roads. Here too, seat belt use is very low, averaging 20% (Klair & Arfan, 2014). Laws in different countries vary considerably in their requirements, exclusions, enforcement, and penalties (Weiss, Sirin, et al., 2006). In addition, local and state/provincial laws often vary within countries. With the complexities of these policies, it is not surprising that policies alone do not garner the desired level of behavior change.

Research throughout the world demonstrates that policies must be enhanced with larger social efforts to change behavior – a critical step in creating a seat belt culture. In Turkey, seat belt use was observed to be as high as 70% among drivers on inner-city roadways (WHO, 2004), which is attributed to their primary law for drivers. A separate study found that 52.1% of adults were belted, but in the same vehicles only 29.4% of children were belted and the same percentage of children were found sitting on the lap of an adult (Porter, Lajunin, et al., 2010). These findings suggest that occupants are motivated to wear their seat belts in order to obey the law, but the motivation to protect occupants from death or injury if the car crashes seems missing (since the most vulnerable occupants were not protected).

Efforts to Increase the Wearing of Seat Belts Through Educational Campaigns

Evaluations of coordinated approaches to increasing seat belt use have found higher use and more significant decreases in crash fatalities and injuries. A multifaceted intervention in Guanzhou, China, augmented existing legislation with police officer training to increase enforcement and social marketing and health education campaigns to raise public awareness (Stevenson, Yu, et al., 2008). A 12% increase in seat belt use was observed. Social campaigns alone, however, have not shown substantial effects in the absence of enforcement. An intensive campaign to increase seat belt use in Greece, conducted in the absence of increased law enforcement, resulted in gains of less than 6% (Petridou, Trichopoulos, et al., 1999). Studies in the United States have also confirmed that availability, policy, and enforcement, augmented with social marketing campaigns are an effective approach, leading to a strong recommendation in the Guide to Community Preventive Services (Shults, Nichols, et al., 2004).

Finally, studies show that multifaceted efforts must be persistent. China enacted a seat belt law for drivers in 2004, with local and provincial laws following. Seat belt wearing observed in two cities was nearly 50% for drivers, less than 10% for front-seat passengers and less than 1% for rear seat passengers. Only 1 year following the implementation of the laws, seat belt use decreased significantly and continued on this trend for several more years (Routley, Ozanne-Smith, et al., 2008). The authors attributed these declines to reduced efforts for enforcement and public education.

Despite variation in cultures on individual, social, and political behavior, the research available worldwide consistently identifies that a coordinated, multifaceted, and persistent approach is needed to create a seat belt wearing culture. Though much research has shown great impact on societal level changes like seat belt mandates for car manufacturers or laws mandating use, these changes alone do not necessarily lead to individual behavior change. To increase seat belt use, all socioecological levels must be addressed, including the family. Studies have shown that risk behavior, and seat belt use in particular, does have familial patterns (Habib, Hamdan, et al., 2010). Familial patterns, along with cultural differences and norms, should be considered when designing interventions. Although global progress over the last 50 years has included increased seat belt availability, implementation of seat belt legislation and enforcement in many countries, and recognition that public education and social norms campaigns are critical, seat belt use rates throughout the world vary markedly. Great promise in the future lies in our ability to evaluate and translate successful approaches, with the focus of efforts housed in the low- and middle-income countries with the highest motor vehicle occupant fatality and injury rates.

Example 2: Smoke Detector Installation

Fire-Related Injuries and Deaths

Fires are a leading cause of unintentional injury deaths worldwide. It is estimated that fires cause about 1% of the global burden of disease and 300,000 deaths per year (Murray & Lopez, 1996). In just 1 year's time, residential fires caused 491 deaths and 14,100 nonfatal injuries in the United Kingdom. In the United States, a total of 3240 civilian deaths and 15,925 injuries resulted from fires (Karter, 2014). Fire death rates are far higher in low-income countries. Though deaths and injuries resulting from fires have decreased in the last 25 years, home fires still cause 85% of all fire deaths in the United States (Karter, 2014). Injuries and deaths caused by fires remain a global public health and safety concern today, because of the immense impact on health, the environment, and society as a whole.

Globally, children and adults under the age of 44 account for the highest proportion of deaths from fires. Socioeconomic status is also associated with a disproportionate burden of fire-related consequences; as in many countries, the poorest groups are less likely to practice safety behaviors and more likely to suffer from fire-related injuries and deaths (CDC, 2010; Flynn, 2010; Istre, McCoy, et al., 2001; Mock, Rissa, et al., 2002). Furthermore, low socioeconomic status is also associated with many personal risk behaviors and home characteristics. Some of these include cigarette smoking, alcohol intoxication, nonfunctioning smoke alarms in homes, homes located in rural areas, and older housing (Mallonee, Istre, et al., 1996; Peek-Asa, Allareddy, et al., 2005; Runyan, Johnson, et al., 2005). Each of these behaviors and home characteristics are found to be associated with increased risk of fire-related injuries and deaths in many countries (Leistikow, Martin, & Milano, 2000; Netherlands Institute for Safety Nibra, 2009).

Most fire deaths occur at night while victims are sleeping. The cause of death is likely to be inhalation of smoke and toxic gases rather than burns. This may be partially explained by the fact that vapors from the fire are inhaled before the sleeping occupant is aware of the fire (Ahrens, 2001; Hall, 2001). A working smoke alarm is one of the most effective and least expensive ways to help prevent and reduce fire-related deaths and injuries, because they detect fires before they become dangerous and provide sufficient warning to occupants so that they can escape safely from the building. Smoke alarms ensure a high level of protection and safety in a residence. Results from existing research show that functional smoke alarms minimize property damage, prevent injuries, and reduce the risk of dying in a fire by 50% and the risk of having a reportable fire by 75% (Marshall, Runyan, et al., 1998; Runyan, Bangdiwala, et al., 1992).

Like other injury prevention interventions, resident fire safety can in theory be advanced by educational, engineering, or legislative strategies. Several resident fire safety intervention programs have focused on promoting smoke alarm ownership, improving smoke alarm functionality, or both. Strategies include local ordinances requiring alarms, smoke alarm giveaway programs, counseling by physicians and other health professionals, and reminders to test alarms and replace batteries (DiGuiseppi & Higgins, 2001). These interventions consider the strategies influencing both individual level determinants (e.g., education campaign or counseling) and environmental level factors (e.g., providing or installing free alarms) in the Socioecological Model. Through randomized or nonrandomized trials, these intervention strategies have been shown to increase smoke alarm ownership and function. Among these strategies, installation and maintenance of smoke detectors in households have been shown to be one of the most effective ways to prevent deaths and injuries from fires.

Increasing Smoke Alarm Ownership and Functioning

Two commonly used intervention strategies include programs that provide free smoke alarms and programs that install them within homes, and often these two steps are combined. Results from several smoke alarm giveaway community trials show a modestly greater effect on smoke alarm ownership and functioning alarms than did education alone (DiGuiseppi, Slater, et al., 1999; DiGuiseppi & Higgins, 2001; Mallonee, Istre, et al., 1996). Several large-scale fire safety projects have utilized this strategy. The “Let’s Get Alarmed!” program (DiGuiseppi, Slater, et al., 1999) distributed 20,050 smoke alarms to households in the inner-city London area. Individuals in low-income areas or areas with material deprivation were successfully targeted. Other smoke alarm community trial giveaways have been able to more successfully track smoke alarm outcomes. The “Oklahoma Smoke Alarm Project” in the United States found that during the 6 years following the project, the fire-related injury rate decreased by 81% among the target population, compared to a 7% decrease in the rest of Oklahoma City (Mallonee, 2000). A community-based installation program in Dallas, Texas, found house fire-related deaths and injuries to be reduced 68% in program homes about 5 years after installation, compared to non-program homes (Istre, McCoy, et al., 2014). However, rates declined after the sixth year, probably due to alarms losing their functionality. One randomized controlled trial in the United Kingdom (Ginnelly, Sculpher, et al., 2005) found that over 1 year later, the prevalence of functioning smoke alarms was about the same in the intervention and control groups, suggesting that giving away free smoke alarms may not automatically increase an individual’s awareness of the benefits of having a working alarm, or the skills and knowledge required to install and maintain smoke alarms (DiGuiseppi & Higgins, 2001).

Existing evidence indicates a substantially greater effect on smoke alarm functionality when free alarms were actually installed compared to just providing vouchers for free alarms (DiGuiseppi & Higgins, 2001). An additional analysis showed both types to be cost-effective, but installation programs fared better on a cost-benefit analysis (Liu, Mack, & Diekman, 2012). One program in the United States tested the difference in outcomes by having two separate groups – one that received free direct installation of fire alarms and the other which received free vouchers (Harvey, Aitken, et al., 2004). Upon follow-up, almost 90% of households in the installation group had working alarms, compared to just 65% of the voucher group. One large reason for this is that 47% of households in the voucher group never redeemed their voucher. Similarly, results from a randomized trial involving free smoke alarm installation in rural homes in Iowa in the United States showed that approximately 99% of the study homes had at least one functioning alarm (Yang, Peek-Asa, et al., 2008). While several programs that solely utilize either home or school-based smoke alarm education did not show strong beneficial effects on smoke alarm ownership or alarm functioning, interventions that used multifaceted mass media and community-based injury prevention approaches have demonstrated success in smoke alarm functionality (Ta, Frattaroli, et al., 2006).

For example, one intervention paired smoke alarm installation with in-home education on escape planning. At follow-up, participants had significantly increased their fire safety knowledge and practices, and 97% of homes had functioning alarms on each level of the house (Duchossois, Nance, et al., 2009). Canvassing programs that include free smoke alarm installation demonstrate higher rates of working smoke alarms 1 year later, compared with programs that did not install alarms or only installed for participants who requested it (DiGuiseppi & Higgins, 2001).

Findings and Regulations That Influence Behavioral Interventions

Despite the immense impact of smoke alarms on fire safety, several studies have indicated high rates of nonfunctioning alarms in homes, with estimates ranging from 20% to 50%. Common reasons for alarm nonfunctioning include alarm removal, missing batteries, and the batteries being disconnected. False (nuisance) alarms often lead residents to deliberately disable smoke alarms, often as result of the alarm going off because of cooking fumes or steam and making noise continuously when powered (Netherlands Institute for Safety Nibra, 2009). To ensure smoke alarm functionality, the National Fire Protection Association in the United States has authorized standards and codes on how smoke alarms should be installed in homes. The codes require that a smoke alarm be placed on each level of a house (including the basement). In the USA, smoke alarms have been required in all new buildings since 1998. In rental properties, landlords are responsible for installing working alarms, and tenants are responsible for their upkeep. The codes require that alarms be installed according to the manufacturer's directions and recommend that alarms are not installed near kitchens, bathrooms, garages, or workshops.

Smoke alarms with ionizing sensors are especially prone to false (nuisance) alarms because they are more sensitive than photoelectric alarms at detecting small particles produced by hot and flaming fires, including particles created through cooking (Mueller, Sidman, et al., 2008). Since false (nuisance) alarms are the most common reason that residents disable smoke alarms, such actions can result in a nonfunctioning smoke alarm, which puts a household at an increased risk of fire-related injuries and deaths (Yang, Peek-Asa, et al., 2008). Therefore, photoelectric alarms, which are less likely to have nuisance alarms, have better long-term function near kitchens. Because alarm type and location can have such an impact on the alarm's effectiveness, these considerations should be kept in mind when designing interventions aimed at smoke alarm installation (Rowland, DiGuiseppi, et al., 2002; Yang, Jones, et al., 2011). It is essential to address the long-term maintenance of smoke alarms, so greater emphasis should be given to the continued functionality of alarms (Peek-Asa, Yang, et al., 2010; Peek-Asa, Yang, et al., 2011).

Because many fire deaths occur during sleeping hours, it is essential that alarm warning systems are effective at waking a variety of populations from deep sleep in order to increase the chance of survival. Research has shown that young children and older adults have a more difficult time being awakened by a smoke alarm than do other age groups. It is important to consider the pitch and frequency of the tones that these age groups are awakened by (Manchester, Meklenburg, et al., 2009). Similarly, individuals with hearing problems may need alternative smoke alarms to best receive warning of a fire.

Smoke alarm regulations also have an impact on the scope of behavioral interventions to reduce fire-related injuries and deaths. Denmark, Finland, Japan, Norway, and Sweden have adopted legislation requiring all homes to be equipped with smoke alarms, while many others require all new homes to have smoke alarms (Manchester, Meklenburg, et al., 2009). Other countries including Australia, the United States, and Canada do not have nationwide legislation but rather have provisions that territories/states/provinces can adopt. Even local provisions may be unrealistic in other nations, due to the fact that smoke alarms are unaffordable to the general population (Hendrie, Miller, et al., 2004). In many of these countries, it is essential to identify alternative methods to protect a home and its residents from fire-related injuries and deaths. Several research studies detail the most effective smoke alarm arrangements for residences. However, this "ideal" is not applicable to all countries. Differences in cooking methods, housing style, economic climate, and source of heating are just a few considerations that are important in determining the best fire prevention intervention.

Example 3: Bicycle Helmet Use

Bicycle Injuries

Injuries to bicyclists are a global public health problem with detrimental effects on the health and well-being of individuals both in higher-income countries where the prevalence of recreational bicycling is high and in low- and middle-income countries where bicycling is one of the predominant modes of transport. Furthermore, in recent years, injuries to young bicyclists have emerged as a particular concern in higher-income countries, such as in the United States, (USA) because of the popularity of bicycling as means of recreation and exercise among young people – especially children and the costs associated with these injuries (Hamann, Peek-Asa, et al., 2013). Nearly three-fourths of children aged 5–14 in the United States have ridden a bicycle in the past month (Dellinger & Kresnow, 2010). In the United Kingdom (UK), children aged 11–16 had an average annual cycling mileage that was higher than any other age group (Gill, 2005). Although the age of riders may vary, the risk of injuries remains a threat to all bicyclists.

Head injuries are among the most severe injuries to bicyclists, comprising one-third of emergency department visits and two-thirds of bicycling deaths (Rowe, Rowe, & Bota, 1995; Sacks, Holmgreen, et al., 1991). However, most of these injuries are largely preventable. Bicycle helmets provide physical protection for the face and head by partially absorbing the force of blunt trauma and dissipating energy so that the head alone does not sustain the total force of a blow. Research findings have revealed that helmet use substantially reduces both the likelihood and severity of head injury, with the risk of head injury reduced by 63–88% (Thompson, Rivara, & Thompson, 2000). Bicycle helmets provide nearly equal protection for crashes involving motor vehicles and crashes from all other causes, with a reduced risk of head injury at 69% and 68%, respectively (Thompson, Rivara, & Thompson, 2000).

Despite the vast degree of protective effects afforded by bicycle helmets, relatively few children and young people wear them. Observational studies from high-income countries estimate the proportion of child bicyclists who wear helmets to be relatively low, with examples from Sweden (33%), the United Kingdom (14%), France (22%), and the United States (13–65%) (Dellinger & Kresnow, 2010; Inwood, Whitley, & Sexton, 2005; Nolen, Ekman, & Lindqvist, 2005; Richard, Thélot, & Beck, 2013). In Turkey, a middle-income country, child bicycle helmet use is estimated at 4% (Secginli, Cosansu, & Nahcivan, 2014), and helmet use in other middle- and low-income countries is not likely to exceed this proportion.

To effectively promote bicycle helmet use among children, a number of intervention programs have been designed and implemented that utilize a behavioral approach. These approaches are often informed by social and behavioral theories emphasizing multilevel interventions. The behavioral medicine bike helmet interventions are all event-level factors in the Haddon Matrix, as helmets do not prevent accidents necessarily but can reduce the number and severity of injuries that result. They range from educational programs, promotional campaigns, and community incentives, to state and local laws requiring that bicyclists wear helmets. These interventions have been implemented across many countries, been carried out in different settings, and employed multiple strategies (Royal, Kendrick, & Coleman, 2007). The examples provided below illustrate how intervention strategies may effectively modify the behavior of an individual by incorporating educational campaigns, community incentive programs, and legislative initiatives.

Efforts to Increase the Wearing of Bicycle Helmets Through Legislation

The Socioecological Model posits that mandating bicycle helmet wearing may be an effective societal level approach in increasing the behavior of helmet use because efforts to increase the use of bicycle helmets through legislation affect virtually the entire population, in contrast to interventions that only reach individuals who choose to participate. Many countries, including the USA, have taken this approach to promote bicycle helmet use. In the United States, the first bicycle helmet law was passed in California in 1986 and became effective in 1987. This law was amended in 1994 to cover everyone under age 18. In Australia, the Royal Australian College of Surgeons played a leading role in initiating both a statewide campaign to promote the use of approved safety helmets and also in introducing a compulsory safety helmet law in Victoria, Australia. Following their efforts, bicycle helmets then became mandatory nationwide (Grande, 2007). Since then, many other countries including Canada, the Czech Republic, Finland, Iceland, New Zealand, and Sweden have passed bicycle helmet laws, in at least one jurisdiction, for either minors only or for all riders. Spain requires helmets on interurban routes. To date, in the USA, 21 states and the District of Columbia have statewide mandatory helmet laws, either for children under 18 or for all ages, and 37 states have mandatory helmet laws for varying age groups in some jurisdictions. Surveys from the United States, Canada, and France indicate support for helmet use legislation (Parkin, Degroot, et al., 2014; Richard, Thélot, & Beck, 2013).

Reports demonstrate an increase in bicycle helmet use following enacted helmet laws (Karkhaneh, Kalenga, et al., 2006). One study conducted in the United States found that laws have increased the average helmet use probabilities by 18.4% (Rodgers, 2002). Further, a systematic review of the scientific evidence on the effectiveness of bicycle helmet legislation in various countries suggests that helmet use increased significantly – between 45% and 84% – after passing helmet laws (Gilchrist, Schieber, et al., 2000). The effects of helmet laws have crossed several countries and cultures, as they have been shown to increase helmet use in Australia, New Zealand, and Canada (Hagel, Rizkallah, et al., 2006; Povey, Firth, & Graham, 1999; Vulcan, Cameron, & Watson, 1992). Considering its international success, mandatory helmet legislation is recognized as an effective strategy in increasing bicycle helmet use.

While increased bicycle helmet use is often systematically related to the presence of state helmet laws, there remains a debate on whether helmet laws help reduce head injuries. Some researchers conclude that bicycle helmet legislation appears to be effective in increasing helmet use and decreasing head injury rates among intervention groups (Karkhaneh, Rowe, et al., 2013; Macpherson & Spinks, 2007). However, others have found that although enforced helmet laws increased helmet use by 40% or more, they did not produce an obvious decrease in the percentage of head injuries (Robinson, 2006). Some opponents contend that bicycle helmet laws may not reduce the rate of injuries but rather reduce injuries by reducing overall cycling. Along these lines, data from New Zealand and Western Australia indicate that reductions in numbers of injuries are less than reductions in cycling (Erke & Elvik, 2007).

Promoting Bicycle Helmet Wearing by Children Using Nonlegislative Interventions

Bicycle helmet interventions often include a variety of components. Some of these are education campaigns, distribution of free helmets, and/or a provision of subsidized or discounted helmets, since bicycle helmet wearing is not currently enforced in every country. The theoretical assumptions that underline these nonlegislative, community-based intervention approaches are that a change in an individuals' knowledge of and/or attitudes toward bicycle helmet use and increases in that individuals' perceived benefits and/or reductions in the perceived barriers of bicycle helmet use will increase use. In addition, the provision of free or subsidized helmets may serve as cues to action for bicycle helmet use.

Nonlegislative bicycle helmet interventions have been utilized in many settings and with a variety of program components and have been shown to be an effective prevention strategy for head injuries caused by bicycle crashes or falls. Results from a recently published meta-analysis show that nonlegislative interventions led to more than double the bicycle helmet use among children and young people compared to control groups. The effect was greater in community-based studies and in those providing free helmets, compared to interventions that were in school settings or provided subsidized helmets (Royal, Kendrick, & Coleman, 2007). Several studies on community-wide education campaigns focusing on bicycle helmet use by school-aged children found that helmet use increased significantly, with increases varying from less than 5% to over 10%, after a campaign and/or distribution of educational material. Additional research has found an increase in bicycle helmet use after a program for children admitted to the emergency department for treatment. Children who directly received a free helmet (vs. a voucher or verbal counseling) had greatest chance of helmet use at follow-up (Wu & Oakes, 2005).

Global Implications of Helmet Use as a Behavioral Intervention

Behavioral interventions that focus on increasing bicycle helmet wearing vary across the globe. Because of this, it is important to consider many factors when designing an intervention to increase the use of bicycle helmets. First, it is essential that the specific helmet types used have been shown to be effective in reducing the risk of head injury. There are contrasting results in the literature in relation to the effect of helmets on the rate and severity of head injuries, and through the use of research-based effectiveness criteria, the most successful types of helmets can be identified. Only helmets that have been proven to reduce injury risk should be used in interventions.

Second, many individuals may have little or no access to bicycle helmets because of helmet cost and lack of availability to consumers. In this case, helmets must be provided for free or at a greatly reduced price as an important first step of head injury prevention. Because research has shown that providing helmets is not sufficient to ensure their success in reducing head injuries, additional components that promote fitting a bicycle helmet properly and wearing a bicycle helmet consistently need to be included in the intervention.

Third, it should be recognized that legislation/policy surrounding bicycle helmet use can have a significant impact on injury prevention programs. However, such legislation or policies are not easily enacted or changed. Even if policies do exist, if they are not enforced, bicycle helmets may still not be used regularly. Thus, enacting bicycle helmet laws alone may not be adequate for ensuring their protective effect on head injuries.

Last, it is important to consider the knowledge and attitudes surrounding bicycle helmet use in the context of culture and population. Studies looking at cross-cultural helmet practices have shown that bicycle helmet use varies from 39.2% to 1.9% among all of the countries studied (Klein, Thompson, et al., 2005). Because openness to wearing helmets, as well as resistance to them, will be so different from one culture to another, ideal program components would likely vary based on the country at hand. Considering cultural and population factors in designing an intervention to improve bicycle helmet knowledge, attitudes and behaviors will undoubtedly contribute to the program's success.

Example 4: Preventing Intimate Partner Violence

An Emerging Global Public Health Priority: Preventing Intimate Partner Violence

Worldwide, UNICEF and the WHO report that a quarter to three quarters of women around the world experience some form of violence from an intimate partner over their lifetime (The Commonwealth Fund, 1999; WHO, 2005a, 2005b). Despite this high prevalence, intimate partner violence is heavily underreported, with barriers to reporting that include societal stigma of being a victim, fear of retaliation by the perpetrator, fear of lost income, and fear of isolation from family.

In addition to its high prevalence and global pervasiveness, intimate partner violence is gaining attention as a public health priority because of the deleterious effects on its victims, their families, and society. Over half of women who are victims experience mental health effects, including depression, anxiety disorder, symptoms of post-traumatic stress disorder, and suicide attempts (Coker, Sanderson, & Dong, 2004). In addition to physical trauma from the violence itself, victims are also at risk for physical conditions, such as gastrointestinal disorders, chronic pain syndromes, hypertension, and cardiovascular disease. Intimate partner violence has been linked to alcohol, tobacco, and drug use. It has also been linked to increased exposure to HIV, other STIs, pregnancy complications, and adverse pregnancy outcomes such as premature labor and low infant birth weight (WHO, 2013). Negative effects on families include a high co-occurrence with family and child violence, chaotic and disordered familial relations, and the potential for generational patterns of perpetration and victimization (Fishback & Herbert, 1997). From a societal standpoint, the United Nations recognized in its Millennium Declaration of September 2000 that violence against women is a major threat to social and economic development (WHO, 2005a).

Steps toward preventing IPV first involve change at the social and political levels to develop a strong intolerance for violence and second to make assault against an intimate partner an unacceptable and illegal act. This level of behavior change has taken a long time in many countries, but creating attitudes of intolerance toward violence are being adapted more readily as global attention to family violence increases.

Developing a Strong Intolerance for Violence

The root causes of intimate partner violence are broad and complex, as is the development of effective intervention and prevention programs. Attitudes regarding partner violence are influenced by individual, familial, and societal norms. Social acceptability of violence against women is a complex construct: although many cultures include some level of intimate partner violence as acceptable, every culture has a threshold at which the frequency, intensity, or severity is unacceptable (Go, Johnson, et al., 2003). This diversity in social norms complicates a uniform approach to reducing violence in intimate relationships. Qualitative research in a low-income community in Chennai, India, found that both partners reported that husbands regularly beat wives in most marital relationships. However, violence was intensified by familial financial and work-related stress, societal gender norms, and strict gender role expectations (Go, Johnson, et al., 2003). In sub-Saharan Africa, a survey found that women were more likely to justify IPV than men. Common situations where it was perceived to be more justified included neglecting the children and going out without telling the husband (Uthman, Lawoko, & Moradi, 2009).

Because social definitions of unacceptable violence vary considerably, comparable measures of the frequency of violence against women are difficult to define. The World Health Organization has published a multi-country study on the prevalence and risk factors for IPV (WHO, 2005b). Research to identify the prevalence of IPV is an important first step in changing social norms; before the problem can be reduced, it must first be recognized. Thus, surveys from around the world that rigorously define and measure the prevalence of IPV are critical in helping identify the health burden before intervention strategies are developed to change the notion that violence against women is unacceptable.

Legal strategies to respond to intimate partner violence exist in most countries, but little evidence exists to suggest that these approaches reduce the prevalence or severity of IPV. In most countries, murder of an intimate partner is considered unacceptable, and such acts have severe legal and social penalties. However, most countries also have some situations in which partner homicide is condoned. Dowry deaths or honor murders, although officially illegal, receive lax judicial penalties due to the social acceptability of the act. Many countries also have specific legal penalties for nonfatal domestic violence. For example, the United States usually requires mandatory Batterer Education Programs as part of the sentence of a domestic violence conviction. However, growing evidence suggests that these programs have poor compliance and little effect on recidivism (Babcock, Green, & Robie, 2004; Hilton & Harris, 2009). Individual behavioral strategies that focus on the dynamics of the couple have been more promising in reducing intimate partner violence than those implemented through the court system (O'Leary & Smith Slep, 2011; Woodin & O'Leary, 2010).

Multilevel Behavioral Strategies to Change the Cycle of IPV

Growing evidence suggests that the most effective approach to reducing the burden of intimate partner violence lies with prevention (pre-event factors in Haddon Matrix) rather than treatment (post-event factors). The World Health Organization identified the public health approach as an effective means to reduce intimate partner violence and encouraged efforts to focus on primary prevention (WHO, 2005a). Changing the cycle of IPV will require multilevel behavioral strategies at the societal, community, relationship, and individual levels, with efforts focused on both prevention and intervention.

Prevention will be most effective at the community and societal levels, focused on increasing national commitment and changing social norms regarding IPV (Salazar, Valladares, et al., 2009; Vanderende, Yount, et al., 2012). Two studies of attitudes of acceptance toward IPV, one conducted among European Union countries and one conducted with 17 countries in sub-Saharan Africa, found that accepting attitudes toward IPV, long tied to higher prevalence, were independently influenced by socioeconomic indicators at the individual, neighborhood, and country levels (Gracia & Herrero, 2006; Uthman, Moradi, & Lawoko, 2009). The European Union study also found high levels of victim blaming across participating countries (Gracia & Herrero, 2006).

IPV may be effectively reduced through social programs and infrastructure improvements that have little to do with the violence itself, such as increased access to education, generally increasing levels of income and financial stability, and promotion of gender equality. Individual risk factors that increase the risk of intimate partner violence victimization and perpetration include young age, illiteracy, low educational levels, lack of financial means, lack of social networks, drug and alcohol use, and poor communication skills (WHO, 2005b). Program strategies that address these risk factors may be promising prevention approaches. Long-term gender equality is also seen ecologically as a method to reduce IPV prevalence (WHO, 2005a). One study in Ethiopia focused on gender equitable norms in young men and found self-reported reductions in violence toward their partners (Pulerwitz, Hughes, et al., 2015). Ironically, however, another study found efforts to promote gender equality to be linked to increased prevalence of IPV (Uthman, Lawoko, & Moradi, 2009) possibly because women become empowered and report more incidents. Given the high public health burden of IPV, increased attention from global organizations such as the World Health Organization, World Bank, and UNICEF is highly appropriate. The World Health Organization has outlined country-level goals to address domestic violence, and these call for a coordinated multisector approach that addresses the violence directly and integrates with programs that increase social infrastructure with tangential gains in violence reduction (WHO, 2005a).

Conclusion

Injuries cause significant physical and psychological trauma as well as substantial costs to individuals, families, communities, and societies. Historically, the investment in injury prevention has not been commensurate with its burden (Bonnie, Fulco, & Liverman, 1999; Runyan, Hargarten, et al., 2010), and many countries are just beginning to identify violence and injury prevention as a public health priority. Despite the historic lack of priority, violence and injury prevention is increasingly recognized an important aspect of public health (Krug, Sharma, & Lozano, 2002; Peden, McGee, & Sharma, 2002; WHO, 2002). Thus, the future is likely to bring many new and innovative methods to reduce the burden of injuries. A socioecological approach is a useful framework to work within when designing, implementing, and evaluating violence and injury prevention interventions. Factors that can influence the risk of injuries and violence can be broken down into four spheres: individual, relationship, community, and society. The use of the model can aid in the identification of behavioral determinants leading to injuries and violence (Dahlberg & Krug, 2002). Because the behavior of an individual has a reciprocal impact on the environment at multiple levels, when violence and injury prevention interventions focus on changes within multiple spheres of influence simultaneously, an impact on health outcomes may be larger than that seen by single-level approaches. These interventions may also be more cost-effective because of the greater ability to influence behavior change.

As this chapter noted, a large number of interventions have successfully incorporated environmental changes and targeted influence at the societal level, which seems to have the most impact. Interestingly, legal approaches show strong results in reducing the three unintentional injuries discussed in the prior sections – those from fires, automobile crashes, and bicycle crashes. However, legal approaches have not been shown to have much of an impact on intimate partner violence, an intentional injury. This may be because IPV is deeply ingrained in sex roles and cultural practices and may be more resistant to change without transformation of social norms. The fact that such social roles and cultural factors may be resistant to change does not invalidate the importance of community and societal-level interventions. Indeed, interventions and campaigns at these levels are likely to be of especially great importance in changing cultural practices, social roles, and other broad, foundational determinants of IPV as well as other injury-related behaviors and health behaviors in general.

Environmental strategies may have the most impact alone, but the person-environment interaction must not be ignored. Policies or environmental changes without information, regulation, and enforcement will not necessarily lead to individual behavior change. Furthermore, these strategies require behavior change at the higher levels of the Socioecological Model, such as changes in policy-maker knowledge and attitudes that lead to policy implementation. Thus, it is essential that violence and injury prevention interventions target multiple levels of influence to maximize impact on reduction of injuries.

Applying a socioecological approach to designing a multilevel violence and injury prevention intervention will remain a challenge. First, a Socioecological Model doesn’t necessarily provide information as to which determinants may be the most important nor does it lay out specific constructs that could be addressed in a violence and injury intervention. In order to use a socioecological approach to design an injury prevention program, one also needs to use other social behavioral theories and models to address factors at each level.

Second, when evaluating the effect of multilevel comprehensive interventions, one cannot easily determine which target level activity caused the greatest change in behavior. Because it is difficult to examine the effectiveness of each point of influence, it might require a reliance on the effect as a whole. Nonetheless, because most of these interventions are usually used with populations providing large numbers of observations, it often allows for multilevel, multivariate analyses. Continued research with different intervention components can lend information on the effect of specific intervention components as well as a combination of multilevel influences.

Lastly, multilevel interventions are often very complex and require the cooperation of many groups as well as time and resources. It can be especially difficult to make changes on the policy level. Thus, without strong relationships among a variety of groups and organizations dedicated to a common cause, multilevel interventions are unlikely to reach their full potential.

Injury prevention continues to be a major global public health concern but is still an underappreciated area within behavioral medicine. Due to the variety of problems it encompasses and immense burden on individuals, communities, and society as a whole, there is a great need to expand awareness to health professionals. As the body of research and recognition in the field grows, so too does the need for more sophisticated intervention approaches. By applying the Socioecological Model involving several levels of an individual's environment, behavior change undoubtedly becomes more likely. Without this multilevel approach, interventions aimed at behavior change, as well as a reduction in global violence and injury, may have little impact.

Research and dissemination of proven practices in injury prevention offer strong potential for improved health and well-being, and perhaps one of the most promising elements is increased attention to safety behavior. At the individual level, improved efforts to create safe behavior as a social norm have been very promising in areas such as driving safety and violence prevention. At the societal level, research to better understand how to improve the safety culture – i.e., to ensure that safety is a priority in important decision-making processes, is badly needed. A concerted effort to develop an evidence base on how to implement strong policies, for example, could help standardize and make more effective existing safety policies. The area of injury prevention is an exciting frontier for behavioral medicine.

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30 Ongoing Behavioral Management of Common Chronic Illnesses

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> *"Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick."*
>
> Sontag, 1979, p. 3

Introduction

Teaching medical students about medical care for patients with chronic illnesses tends to lead to confusion, bewilderment, and anger in at least a few of them. Most medical students have images of their future professional lives as young physicians, dressed in white coats that flutter while running through empty hallways late at night – heading for the emergency room where they will perform heroic, complex medical miracles, after which the patient will go home the next morning, completely recovered. To many of them, it comes as quite a shock to learn about the "epidemiological transition": the shift from "cure" to "care" and the shift from acute illness to chronic disease (Harper & Armelagos, 2010). These changes in the focus of medical care have many implications for all involved: patients, their partners, physicians, other healthcare professionals, society, and psychologists who teach medical students or provide clinical care for patients with chronic somatic disorders in a behavioral medicine setting.

In this chapter we will outline some of the implications of this epidemiological transition for medical care and for behavioral medicine and specifically review and discuss the following:

- The characterization of "chronic illness" and its implications for the contributions that medical care and behavioral medicine offer to the well-being of patients with those illnesses
- Some theoretical models that are instrumental and important for providing medical and behavioral medicine care to persons with chronic physical illness
- Self-management of chronic illness
- The empirical literature on the ongoing behavioral management of six major chronic somatic illnesses, namely, asthma, COPD, cancer, cardiovascular disorders (in particular, heart failure), diabetes mellitus, and rheumatoid arthritis

The chapter will conclude with some suggestions that may help strengthen research on ongoing behavioral management of patients with chronic illnesses.

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Chronic Illness

The word "chronic" comes from the Greek "chronos," meaning "time"; in Greek, "chronikos" means "during a long period of time." The element of time, therefore, is a core concept in most descriptions of chronic illness. There is no generally accepted definition of "chronic illness." Verbrugge and Patrick provide a definition of "chronic conditions" that encompasses the core elements of most other descriptions of the concept:

> long-term diseases, injuries with long sequelae, and enduring structural, sensory, and communication abnormalities. They are physical or mental (cognitive and emotional) in nature, and their onset time ranges from before birth to late in life. Their defining aspect is duration. Once they are past certain symptomatic or diagnostic thresholds, chronic conditions are essentially permanent features for the rest of life. Medical and personal regimens can sometimes control but can rarely cure them. (Verbrugge & Patrick, 1995. p. 173)

"Most people reading this chapter will probably die of a chronic disease" – this is how Burish and Bradley (1983, p. 3) start the introduction to their book on coping with chronic disease. Some 30 years later, this statement is more true than ever. Public health researchers predict that by 2020, the chronic illness conditions of cancer, ischemic heart disease (including cerebrovascular disease), and chronic obstructive pulmonary disease (COPD) will make up the top of the list of diseases causing morbidity (Lopez, Mathers, et al., 2006).

Two myths deserve attention in the context of chronic (somatic) disorders. First, it is too simplistic to assume that medical care has contributed greatly to the increased longevity in industrialized societies. Bunker (2001) debunks this myth by demonstrating how "age-adjusted death rates were reported to be greater in countries with greater numbers of doctors, and presumably with more medical care […] death rates for diseases amenable to treatment were reported to be greatest in areas with the most medical care resources" (p. 1260). Behavioral scientists who claim that behavioral interventions for high-risk health behavior produce meaningful gains in life expectancy create myths as well: "with about a quarter of the population smoking, the population as a whole would gain about one and a half years if every smoker quit" (Bunker, 2001, p. 1262). Rose's "prevention paradox" seems to be valid here as well (John, 2011): "Population strategies which focus on reducing the risk of those already at low or moderate risk will often be more effective than strategies which focus on "high risk" individuals at improving population health" (John, p. 250). Morbidity and mortality are part and parcel of the "condition humaine" (Murray & Lopez, 1997).

Theoretical Models Regarding Behavioral Medicine Interventions in Chronic Illness

Various models have been developed, and tested, regarding medical and behavioral medicine management of people with chronic physical illnesses. Two models in particular stand out as they have been instrumental in the development of theoretical and empirical work: (1) the Common Sense Model, and (2) the Chronic Care Model.

In the *Common Sense Model*, the central tenet pertains to the making sense of physical sensations by people and the consequent steps in this process of sense making (Leventhal, Brissette, & Leventhal, 2003). When a person perceives a physical sensation, the person is assumed to be motivated to minimize the health-related risks and reduce the health threats in a fashion that is consistent with the representations s/he has about an illness. People form representations of an illness based on their knowledge of an illness, its representation in media (TV, Newspapers, Movies etc.), and encounters with the medical system. It is irrelevant whether these representations, or illness perceptions, are medically "correct" (assuming one could define what "correct" is). What *is* relevant is that these perceptions guide the response of patients to illnesses and, thereby, their self-management and outcome (see Fig. 30.1). Systematic reviews and meta-analyses

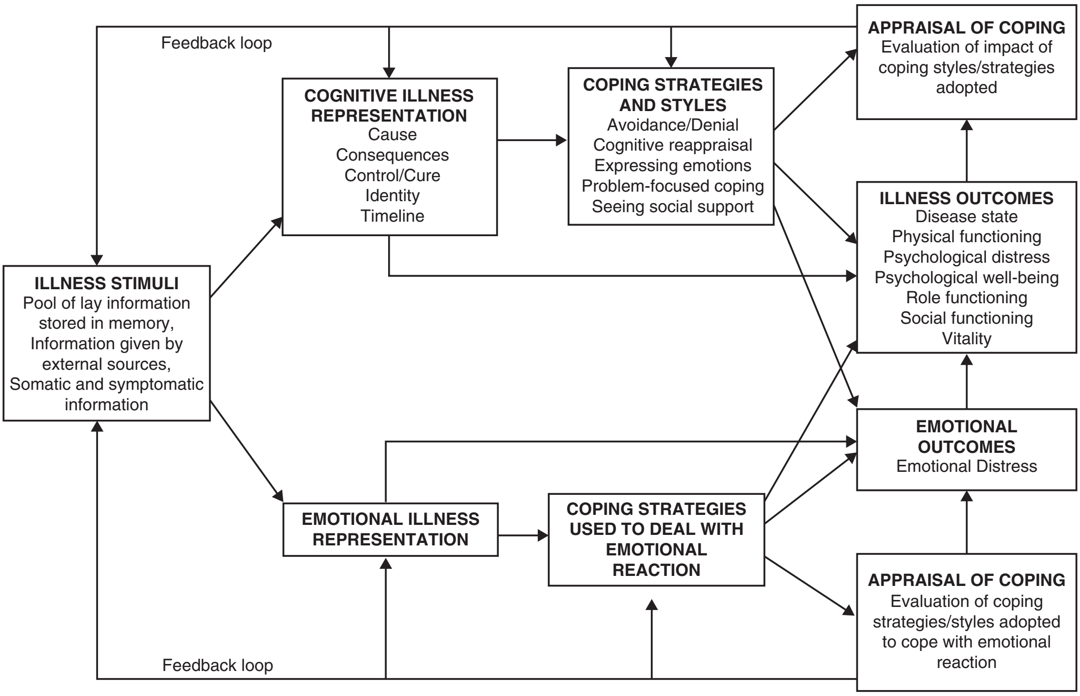

Fig. 30.1 The common sense model (From Hagger & Orbell, 2003)

of empirical work employing the Common Sense Model show how illness perceptions are powerful predictors of outcome in patients with chronic illnesses (Hagger & Orbell, 2003; Kaptein, Scharloo, et al., 2003). At least as important is the evidence about the effectiveness of interventions in the context of the Common Sense Model. If illness perceptions determine outcome, then changing illness perceptions should lead to changes (i.e., improvements) in self-management and, therefore, in outcome. A number of intervention studies do support this statement. For example, Jansen, Heijmans, Rijken, and Kaptein (2011) describe an intervention program and its initial encouraging results in patients with end-stage renal disease and their partners, based on the Common Sense Model. Skinner et al. (2011) report the positive effects of a self-management intervention in patients with diabetes, where the intervention lead to improvements in illness perceptions, which in turn were associated with positive changes in clinical characteristics.

As demonstrated in Fig. 30.1, contextual factors are not explicitly integrated into the Common Sense Model. These issues *are* part of the second model, the *Chronic Care Model* (Fisher, Brownson, et al., 2007; www.improving-chroniccare.org).

Here, self-management – a core concept in the Common Sense Model – is embedded into a social context and characteristics of the health system. The elements “community, resources, and policies” and “health systems, organization of healthcare” pertain to organizational characteristics of care delivery, where “practitioners have relationships to larger health care organizations and community resources that can support and enhance high quality chronic illness care” (Wagner, 2010, p. S637). Primary care (or family medicine, general practice) is conducive in achieving these conditions. Also, these organizational structures have implications for the education of healthcare professionals (e.g., Bodenheimer, Lorig, et al., 2002).

As Wagner and colleagues have noted, self-management interventions “generally emphasize the patient’s crucial role in maintaining health and function and the importance of setting goals, establishing action plans, identifying barriers, and solving problems to overcome barriers” (Wagner, Austin, et al., 2001, p. 74). These authors also importantly point out that “with a few exceptions, the tested interventions do not include long-term support for patient self-management or efforts to engage the primary care team” (Wagner, Austin, et al., 2001, p. 74). Other elements in the Chronic Care Model outlined in Fig. 30.2, such as delivery system designs, decision support, and clinical information systems, are aspects which help achieve productive interactions and improved outcomes.

A systematic literature review of applications of the Chronic Care Model in various chronic physical illnesses leads to modest optimism (Minkman, Ahaus, & Huijsman, 2007): “some evidence has been found that implementing interventions based on the Chronic Care Model improves performance (of the health care system and its professionals)” (p. 96). In their meta-analysis of interventions to improve care for chronic illnesses, Tsai, Morton, Mangione, and Keeler (2005) review 112 studies on asthma, congestive heart failure, depression, and diabetes in the context of the Chronic Care Model. They conclude that “… interventions that contain 1 or more elements of the Chronic Care Model can improve outcomes and processes for several chronic illnesses of interest to managed care organizations” (p. 487). Additional information on theoretical models and their application to the (self-) management of patients with chronic physical illnesses is provided by Newman and colleagues (Newman, Steed, & Mulligan, 2009).

The Common Sense Model and the Chronic Care Model – and related models, cf. Newman, Steed, and Mulligan, (2009) – point at the increasingly central position of the patient in modern medical care for people with chronic illnesses. Figure 30.3 illustrates this evolution.

The concepts of “self-management” and “disease management” at the top right-hand corner of Fig. 30.3 roughly reflect the Common Sense Model and the Chronic Care Model, respectively.

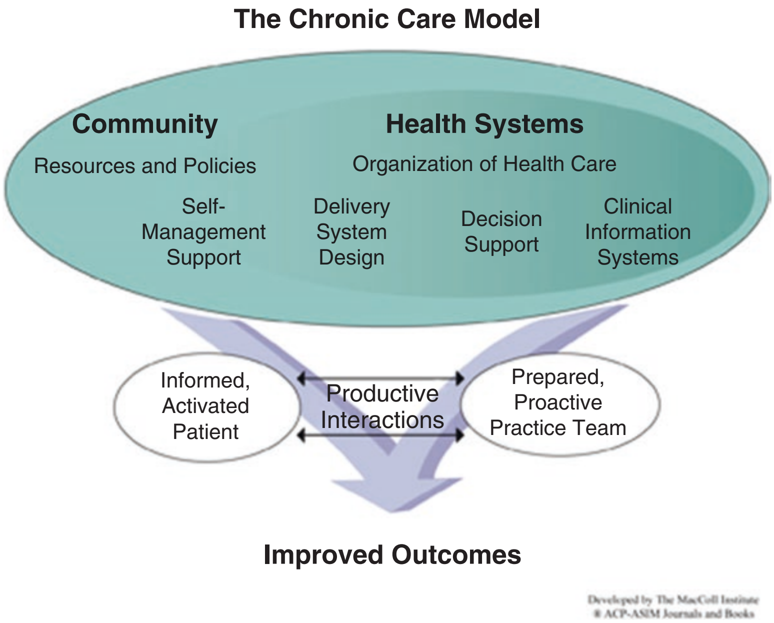

Fig. 30.2 The Chronic Care Model (Fisher, Brownson, et al., 2007)

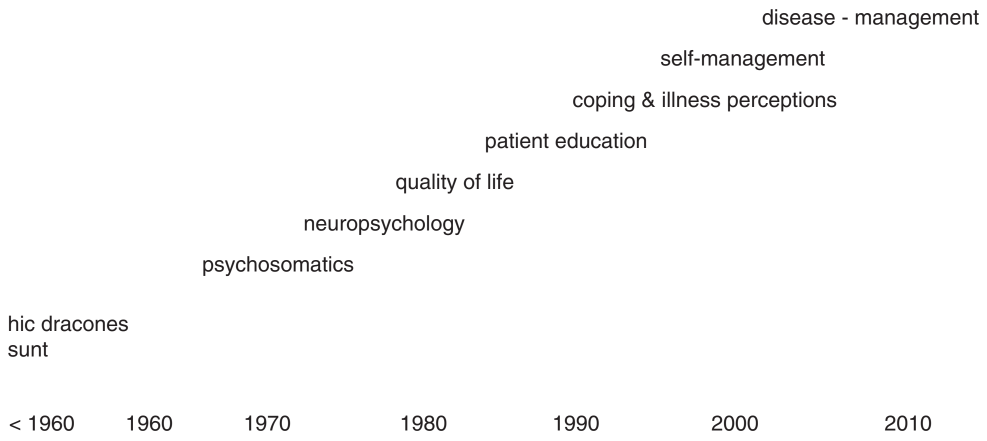

Fig. 30.3 Power to the patient: the increasing involvement of patients in medical care (Kaptein, Scharloo, et al., 2009)

Some 60 years ago, patients were quite often perceived as merely passive recipients of and in medical care. At best, their responses to illness were examined and conceptualized in the context of psychopathology, which it was thought contributed to the somatic disorder. Increasingly, patients have become more active partners in their interactions with healthcare professionals. Disease management is the most recent concept in this evolution. It is defined as “an approach to patient care that emphasizes coordinated, comprehensive care along the continuum of disease and across health care delivery systems – patient counseling and education, coordination, and standardization are key components” (Peytremann – Brideveaux, Staeger, et al., 2008, p. 434).

Self-management is a key component in the management of chronic illness. We might estimate that an “average” patient will have direct face-to-face contact with a health professional in the healthcare system about 1 hour per year, which means that during the other 8759 h of the year, the patient must manage his or her illness without healthcare providers. Self-management is defined by Barlow and colleagues as:

> … the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one’s condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. (Barlow, Wright, et al., 2002, p. 178)

Self-management skills are diverse and include such behaviors as gathering information, managing medication, symptoms and psychological consequences, adjusting lifestyle, mobilizing and drawing on social support, and communicating effectively (Barlow, Wright, et al., 2002).

In this part of the chapter, we have outlined some key theoretical concepts and models that have been employed in the chronic illness field. We now move on to self-management interventions and applications, focusing on ongoing efforts from healthcare providers and patients to continue self-management behavior in the long term.

Behavioral Management of Common Chronic Illnesses

As suggested in Fig. 30.2, self-management and disease management imply that patients with chronic physical illnesses are encouraged and empowered to self-manage their medical condition, in collaboration with people in their social environment, healthcare providers, and society.

Our focus in the current chapter is on *ongoing* behavioral management and its effect on various outcome measures. We will explore this in the context of six specific chronic illnesses, selected due to their high prevalence and the availability of a fairly substantive body of knowledge on the effects of self-management in patients with these illnesses: asthma; chronic obstructive pulmonary disease (COPD); cancer; cardiovascular disease, in particular heart failure; diabetes mellitus; and rheumatoid arthritis. Research was selected for inclusion here based on its empirical and theoretical contributions.

Asthma

Behavioral medicine management for patients with asthma aims at controlling and reducing the effects of the illness in the daily lives of patients. School absenteeism, absence from work, limitations of daily activities, hospitalization, and even death are consequences of asthma. Via managing medication, based on adequate symptom perception, quality medical care, and adjusting one's lifestyle, most patients are able to limit the impact of asthma in their daily lives (Kaptein & Creer, 2004). Cochrane reviews (e.g., Gibson, Powell, et al., 2002; McLean, Chandler, et al., 2010) and systematic reviews (e.g., Bravata, Gienger, et al., 2009) provide empirical support for this statement. The area of self-management in asthma is relatively well developed. Empirical studies on the effects of ongoing support for behavioral management of asthma are discussed below.

The promotion of self-management throughout the illness trajectory is nowadays considered one of the cornerstones of asthma treatment (BTS, 2008; GINA, 2010; NHLBI, 2007). Emphasizing the long-term character of care for patients with asthma, practitioners are advised to review patients' asthma control and to reinforce knowledge and self-management skills at every opportunity (NHLBI, 2007). A Cochrane review showed that for adult patients with asthma, the combination of regular review of asthma control by a healthcare provider with the promotion of self-monitoring of symptoms and/or of peak expiratory volume (PEF) and the use of a personalized written action plan for exacerbations was more beneficial than either of these initiatives alone (Gibson, Powell, et al., 2002). These combined interventions were associated with a reduction in hospitalizations, ER and unscheduled doctor visits, days lost from work due to asthma, episodes of nocturnal asthma, and improvement in quality of life. Although the evidence regarding the effectiveness of these interventions is quite consistent, recent surveys indicate many GPs do not yet appear to incorporate them on a regular basis (Boulet, Devlin, & O'Donnell, 2011).

School-based educational programs for children are an alternative route to provide asthma education. The advantage of these programs is that they provide education to children in a setting in which they are accustomed to receiving instruction and emphasize teaching children how to manage asthma rather than relying on parents to do so (Coffman, Cabana, & Yelin, 2009). Typically these programs are efficacious in improving knowledge, self-efficacy in managing asthma, and self-management behaviors. The effects of these educational programs for children with asthma on health outcomes, however, are mixed (Coffman, Cabana, & Yelin, 2009).

Bruzzese and colleagues (2011) present results from an intensive school-based program, targeting not only urban adolescents but also their medical care providers. Three group educational sessions about asthma were organized. In addition, students received individual coaching sessions once a week for 5 weeks, in which skills for asthma management were taught and reinforced. Students were coached in overcoming barriers to optimal self-management and were encouraged to visit their healthcare provider for evaluation and treatment (health educators offered to accompany students to the medical visit). Students' medical care providers were informed that their patients, participating in the program, would be referred to them and received instructions on how to complete a personalized action plan together with their patient. Participants were followed for 12 months. Every 2 months health outcomes (daily/nocturnal symptoms, school absenteeism, days with activity restrictions, and quality of life) were reviewed. In addition, self-management, medication adherence, use of the written action plan, and urgent healthcare use were assessed at 6 and 12 months. Results after 1 year following the intervention showed that this comprehensive approach had led to an increase in steps taken by the students to prevent asthma symptoms and higher self-efficacy to control asthma. Students in the intervention arm used their personalized action plan more frequently. Nocturnal symptoms, asthma-related school absenteeism, and days with activity restrictions were also consistently lower in the experimental condition. Finally, there was a significant reduction in healthcare use, while the number of acute medical visits, emergency department visits, and hospitalizations were all lower for students in the experimental condition. The authors themselves acknowledge the self-report nature of major outcome measures as a study limitation.

Community health programs have been developed to intervene in the living environment for patients with asthma. Repeated home visits provide the opportunity to tailor the intervention to the specific conditions of each patient and to monitor progress. Usually, the interventions focus on patient education regarding asthma triggers and ways to decrease or avoid triggers. Additionally, patients are often provided with tools or resources to decrease the impact of triggers (e.g., mattress or pillow encasements, vacuums, air filters, rodent traps, or high-quality door mats). A review of the outcomes of community health worker-delivered home-based interventions showed positive effects of these interventions on asthma symptoms, daily activity limitations, and emergency care use (Postma, Karr, & Kieckhefer, 2009). Changes in preventive (asthma trigger reduction) behaviors, hypothesized to mediate the effects of the intervention, were observed although this was largely dependent on the provision of resources as part of the intervention. Combining community health interventions with traditional clinic-based asthma education may yield a long-term added effect on symptoms and trigger prevention actions (such as vacuuming the child's bedroom, washing sheets, and avoiding indoor smoking (Krieger, Takaro, et al., 2009)).

Interventions that offer remote support to patients with asthma have been introduced over the last decade. McLean and coworkers performed an extensive review study on the effects of tele-healthcare for asthma patients (McLean, Chandler, et al., 2010). Tele-healthcare interventions were defined as those programs that enable remote delivery of patient-centered care (e.g., by telephone, text message, video, Internet), facilitate timely access to health advice and medications, prompt self-monitoring and medication compliance, and educate patients on trigger avoidance. Twenty-one randomized controlled studies were identified that compared tele-healthcare interventions with care as usual. The authors concluded that, on average, there were no clinically meaningful differences between the control group and the experimental condition with regard to quality of life and emergency visits over 12 months. However, it appears that for patients with poorly controlled asthma, tele-healthcare interventions reduce the risk of hospitalization and, as a consequence, have a beneficial effect on healthcare costs. Additionally, tele-healthcare interventions enable healthcare providers to review more patients in the same time span than during face-to-face consultations. There was no evidence that the delivery of remote healthcare increased chances of adverse events.

One example of a successful tele-healthcare intervention was performed by van der Meer and colleagues (van der Meer, Bakker, et al., 2009). In this study an Internet-based self-management program for patients with asthma was compared to usual care. In addition to the usual physician care, patients in the experimental condition monitored their asthma symptoms weekly by completing an online questionnaire. Patients received feedback with advice on how to adjust their medication (increase or decrease). This feedback was generated automatically according to a predefined algorithm and treatment plan.

During the study, patients were provided with asthma specific information and had the opportunity to contact a respiratory nurse specialist online. Additionally, patients were provided with two group-based self-management education sessions, aiming to increase knowledge, skills, and self-efficacy. After 1 year, patients in the internet group showed greater improvement in self-reported quality of life and asthma control than patients in the control group. Also, patients in the online group had experienced an increase in symptom-free days and showed a modest improvement in lung function. In sum, weekly online self-monitoring and subsequent treatment adjustment appears to be an efficient long-term intervention to improve asthma control, particularly for patients who report difficulty in controlling their asthma (van der Meer, Bakker, et al., 2009). Similar results were reported by Krishna, Francisco, Balas, König, Graff, and Madsen (2003).

Estes discusses the Chronic Care Model with “asthma as an exemplar” (Estes, 2011) –illustrating the potential relevance of the model for asthma. Fisher et al. (2009) report on the effects of ongoing support of self-management behaviors in a predominantly African American population, where mothers of children with asthma were encouraged to adopt an action plan about self-management by “asthma coaches.” These coaches aimed at providing the mothers with a regular visit to encourage them to adhere to the action plan. Rates of hospitalization were reduced significantly in the children with asthma in this condition of the randomized controlled study.

In summary, empirical evidence suggests there are positive outcomes of ongoing behavioral support to improve self-management in patients with asthma.

Chronic Obstructive Pulmonary Disease (COPD)

Chronic obstructive pulmonary disease (COPD) represents a major chronic illness in western societies, with developing countries picking up rapidly. COPD will be the third leading cause of death in the next decade (Lopez, Mathers, et al., 2006). The irreversible destruction of lung tissue, caused mainly by smoking tobacco, is associated with high levels of restrictions in daily activities, psychological problems (depression, anxiety), social isolation, high rates of use of healthcare services, forced retirement, and increased levels of mortality. Pharmacological treatment is helpful in reducing breathlessness, cough, and fatigue. However, progress in pharmacological management of patients with COPD is underwhelming. Behavioral interventions focus on pulmonary rehabilitation, self-management, smoking cessation and support, and disease management (for systematic review, Cochrane review, and meta-analysis, see Adams, Smith, et al., 2007; Effing, Monninkhof, et al., 2007; Peytremann – Brideveaux, Staeger, et al., 2008). The Cochrane review on self-management education in COPD concludes that “it is likely that self-management education is associated with no indications for detrimental effects in other outcome parameters. This would in itself already be enough reason for recommending self-management education in COPD. However, because of heterogeneity in interventions, study populations, follow-up time, and outcome measures, data are still insufficient to formulate clear recommendations regarding the form and contents of self-management education programmes in COPD.” (Effing, Monninkhof, et al., 2007, p. 2). The systematic review and meta-analysis conclude that “COPD disease-management programs modestly improved exercise capacity, health-related quality of life, and hospital admissions, but not all-cause mortality” (Peytremann – Brideveaux, Staeger, et al., 2008, p. 433).

As is the case in so many studies in so many medical conditions, there is a dearth of studies where *ongoing* interventions of self-management support are part of the experimental design, assessment, and outcome. Two early and two recent studies are worth briefly reviewing here. Güell et al. (2000) examined the short- and long-term effects of an ongoing pulmonary rehabilitation (PR) program in COPD patients. In a controlled design, 30 patients received PR care as usual, while 30 additional patients received PR care plus ongoing self-management support. This support consisted of 3 months with outpatient breathing retraining and physiotherapy, 3 months of daily supervised exercise, and 6 months of weekly supervised breathing exercises which included relaxation techniques and "educational sessions." On outcome measures such as dyspnea perception, fatigue, and emotional functioning, self-reported improvements were observed in the self-management group compared to the control group, even after a 2-year follow-up. Improvements were also found on the 6-min walk test.

Case management comprised the content of ongoing support in a study where a clinical nurse specialist and a social worker were part of an experimental condition in a controlled study design (Poole, Chase, et al., 2001). Both professionals saw the patients in their homes on a regular basis for a year. The patients (n = 16) were encouraged to discuss any problem they had with managing their illness, and they were provided with a problem plan and received education about how to self-manage exacerbations. Family members were encouraged to become involved with the intervention components. Weekly telephone calls and home visits every month were part of the ongoing interventions and support. The control group received care as usual, i.e., without case management. The support intervention led to a reduction in the number of bed days, while in both conditions the number of hospital admissions was reduced.

Adams et al. (2007) reviewed the use of the Chronic Care Model (CCM) in COPD prevention and management and concluded that "… patients with COPD who received interventions with 2 or more CCM components had lower rates of hospitalizations and emergency/unscheduled visits and a shorter length of stay compared with control groups" (p. 551). Two studies published following this review provide further evidence for this conclusion. In a study by Lawlor et al. (2009), long-term follow-up education, telephone support, and rapid future access to respiratory outpatient clinics led to significant reductions in emergency department visits and hospital admissions. In a qualitative Australian study, community nurses who provided ongoing behavioral medicine support to COPD patients reported changes in their views on their contribution to the care for the patients: "… this included a shift from a fatalistic, prescriptive, biomedical approach to a primary health care approach characterized by empathy, consultation, facilitation and a holistic focus" (Robinson, Courtney-Pratt, et al., 2008, p. 371).

In a recent review of behavioral interventions in COPD, we concluded that COPD is no longer an orphan disease with regard to self-management interventions (Fischer, Scharloo, et al., 2007; Kaptein, Scharloo, et al., 2009; Scharloo, Fischer, et al., 2012). Given the increasing amount of research examining the effects of ongoing self-management support in COPD, our cautious optimism seems to be upheld. Yet more rigorous research is required to further identify and elucidate the effective characteristics and aspects of self-management support. In this way we may be able to design more effective interventions to improve quality of life in people with COPD.

Cancer

Given the high incidence and prevalence of cancer, and the relatively long research tradition regarding behavioral interventions in this area (with or without ongoing support and intervention), there exists a relatively substantial body of empirical studies which has examined ongoing support and interventions. McCorkle et al. (2011) recently employed the Chronic Care Model as a guiding principle to review 16 studies on self-management, enabling and empowering patients to live with cancer as a chronic illness. Below we briefly discuss three of these 16 studies, in which the design encompassed ongoing (elements of) self-management interventions.

Bakitas et al. (2009) examined the effects of a nurse-led intervention on quality of life, symptom intensity, mood, and resource use in patients with advanced cancer. In a randomized controlled trial format, advance practice nurses ran four weekly educational sessions with monthly follow-up until death or study completion. The content of the intervention was "*e*ducate, *n*urture, *a*dvise, *b*efore *l*ife *e*nds [ENABLE]," and this led to significant improvements in quality of life and mood compared to the care as usual condition.

Miaskowski et al. (2004) examined the effects of the PRO-SELF Pain Control Program on pain intensity and quality of analgesic prescription in a randomized clinical trial design in patients with bone metastases. Specially trained oncology nurses delivered the intervention: pain was discussed from various perspectives (i.e., knowledge, self-management, medication, communicating with health providers). The nurses contacted patients in the experimental group by phone, and pain and its management were reviewed. Home visits were also part of the program. In the control group, patient received phone calls from the research nurses as well, but not home visits. Results showed significant health gains on self-reported pain levels and adequacy of pain medication prescription in the intervention group compared to the control group.

While the Miaskowski et al. study focused on individual patients in individual sessions, a study by Northouse, Kershaw, Mood, and Schafenacker (2005) had the dyad patient – family caregiver as the unit of intervention. Patients with breast cancer and their family caregiver were randomized in the experimental FOCUS condition or in the care as usual condition. FOCUS is the acronym for the elements of the program: *f*amily involvement, *o*ptimistic attitude, *c*oping effectiveness, *u*ncertainty reduction, and *s*ymptom management. The intervention comprised of three home visits by a trained nurse, spaced 1 month apart, with a booster phase 6 months later, two prearranged follow-up phone calls to both the patient and family caregiver. Results showed improvements in psychological outcomes, in patients and their family caregivers in the FOCUS compared to the control condition, and these positive results remained apparent after 3 months but not 6 months.

A UK review on cancer follow-up (Davies & Batehup, 2011) is also worth mentioning, not because it focuses on self-management per se, but because it adds the perspective of health service research. The review focuses on cancer survivors ("someone who is living with or beyond cancer," p. 143) and follow-up medical care. The authors conclude that their review highlights "… a shift towards patient empowerment via individualized and group education programmes amid an increasing survivors' ability to better manage their condition and the effects of treatment, allowing for self-referral or rapid access to health services when needed. The role of specialist nurses as key facilitators of supportive aftercare is emphasized, as is the move towards technology-based aftercare in the form of telephone or web-based services" (p. 142).

Cardiovascular Disorders: Heart Failure

An exhaustive review of ongoing support and intervention in the area of cardiovascular disease would merit a separate chapter in itself. Therefore, we have selected one diagnostic category within the class of cardiovascular disorders, associated with a major burden of disease and many self-management skills, namely, heart failure.

In a systematic review of randomized controlled studies, Jovicic, Holroyd–Leduc, and Straus (2006) examined six studies on self-management interventions and health outcomes in patients with heart failure. A later review by Yehle and Plake (2010) identified 12 studies, nine of which are randomized controlled trials. Two conclusions can be drawn from these reviews: (1) self-management in patients with heart failure leads to reductions in all-cause hospital readmissions and heart failure readmissions, and (2) self-management in these patients improves self-efficacy, which may be associated with positive outcomes on clinical variables. In intervention studies in which self-efficacy is the central dependent outcome variable, the reviewers found no dose-response effect, even following long-term interventions with ongoing support of self-management.

Jaarsma et al.'s (1999) study involved heart failure patients who received intensive, systematic, and planned education from a study nurse. Visits started in the hospital and continued in the home 3 and 6 months following discharge. Patients also received telephone calls in their homes, and during these calls and the visits self-management behavior was discussed and encouraged. Generic self-care behavior and heart failure-specific self-care behavior improved in the intervention group compared to the care as usual group. Use of healthcare resources was not different across the groups.

Krumholz et al. (2002) employed a similar randomized design of education and support intervention in patients with heart failure. An experienced cardiac nurse provided the patients with educational lessons and material. Telemonitoring was used by the nurse who phoned patients once a week for 4 weeks, then biweekly for 8 weeks, and monthly for the total intervention period of 1 year. Patients in the care as usual condition did not receive the calls. The study found that patients in the intervention group showed improvements in clinical outcomes, such as reductions in healthcare costs and hospital readmission and increased survival.

As with ongoing support for self-management behaviors in other chronic illnesses, internet-based interventions have been applied in patients with heart failure. One such application is System Providing Patients Access to Records Online (SPPARO), which was developed by Ross, Moore, Earnest, Wittevrongel, and Lin (2004). SPPARO is specialized software that consists of a patient-accessible web-based electronic medical record, an educational guide, and a message system for communication between the patient and hospital staff. Access to medical records may educate, engage, empower, and assist patients in the self-management of cardiovascular diseases. The authors conducted a randomized controlled trial in 107 patients with heart failure to assess SPPARO. Patients in the intervention (n = 54) and control group (n = 53) received questionnaires on health status, patient satisfaction, and self-reported compliance at baseline, 6 months, and 12 months. Use of SPPARO was highest during the first 3 months after enrolment and then gradually declined. The intervention group sent more messages to the practice than the control group. There was a trend toward self-efficacy improvement and patient satisfaction with doctor-patient communication in the intervention group. The authors conclude that patient access to medical records may offer modest benefits. However, only a small sample size was used, which limited the power to detect effects of the intervention.

Diabetes Mellitus

As emphasized by Fisher, Thorpe, DeVellis, and DeVellis (2007), living with diabetes mellitus is a lifelong situation patients must face and cope with. At the same time, they may feel somewhat comforted by the fact that support for ongoing self-management of this prevalent chronic physical illness seems to be one of the most developed. The relatively high prevalence of the illness and the major role of the patient him/herself in managing the daily tasks of monitoring and managing blood glucose levels may have contributed to this situation. In addition, patient organizations in the diabetes area were relatively quick in understanding the great importance of helping patients manage their illness themselves. Given this situation, it is not surprising that excellent systematic reviews, meta-analyses, and Cochrane reviews are available to allow conclusions to be drawn about the current state of knowledge regarding ongoing self-management support for people with diabetes.

A 2009 Cochrane review by Deakin and colleagues (2009) of group-based training for self-management in patients with diabetes mellitus type 2 concluded rather spectacularly that “Adults with type 2 diabetes who have participated in group-based training programmes show improved diabetes control (fasting blood glucose and glycated haemoglobin) and knowledge of diabetes in the short (four to six months) and longer-term (12 to 14 months) whilst also having a reduced need for diabetes medication. There is also some evidence that group-based education programmes may reduce blood pressure and body weight, and increase self-empowerment, quality of life, self-management skills and treatment satisfaction” (p. 2).

In her 2008 review of the effects of community-based peer support groups, ongoing home support via telephone, and eHealth, Clark concludes that

"… evidence supports the effectiveness of self-management education in individuals with diabetes, particularly in the short term … however, reviews have demonstrated sharp declines in benefits only a few months after interventions ended … overall, self-management education is most likely to be successful when it is part of a comprehensive and coordinated approach to diabetes care" (Clark, 2008, pp. 118–119).

Davis, O'Toole, Brownson, Llanos, and Fisher (2007) explored the contributions of community health workers (CHWs) on diabetes self-management. The authors collected data from logs completed by CHWs which described mode, place, type, duration, and focus of individual contact between the type 2 diabetes patient and the CHW. Data from semi-structured interviews with patients (n = 47, purposeful sample) were also used in the analysis. The CHWs logged 1859 individual contacts, in which they reported using the telephone 82% of the time, while face-to-face contact was used in 15% of the contacts. Most contacts were initiated by the CHWs (89%), and the median time of the contact was approximately 6 min. CHWs reported providing assistance (38% of the time) and teaching or practicing a skill (29% of the time) as the main focus of these individual contacts. The interviews with patients revealed that community health workers were monitoring the status of the patients and encouraging self-management through ongoing follow-up and support.

The authors conclude that community health workers make important contributions in teaching skills, helping with problem solving, motivation, and ongoing follow-up and support. CHWs were perceived by the patients as more accessible and helpful in explaining how to carry out self-management and more attentive than health professionals, family, and friends.

However, results should be treated cautiously given that the study involved a small and purposeful sample of type 2 diabetes patients, limiting its external validity.

Gambling and Long (2006) explored patients' perceptions of movement through the transtheoretical stages of change model (TTM) within a diabetes tele-care intervention. Case study data (n = 25) were drawn from a wider randomized controlled trial in which the effectiveness of proactive call center-based treatment support for patients with type 2 diabetes was explored. Twenty-five patients participated in in-depth post-trial semi-structured interviews. Patients were categorized in four groups based on their pre- and post-HbA1c results: good controllers that remained good (n = 7), poor controllers who remained poor (n = 6), poor controllers who became good (n = 10), and good controllers who became poor (n = 2). The "good to good" patients were all at the maintenance stage (having changed behavior for over 6 months) and only tweaked their management approach practices. The "poor to poor" group was at the pre-contemplation stage (no intention to take action within the next 6 months) and either did not apply advice provided, did not apply it long enough, or were unsuccessful in their attempts. The "poor to good" group tended to display strong experiential processes in terms of consciousness and dramatic relief. In this group, the tele-care workers became the first or major point of advice and support. The "good to poor" group only consisted of two patients who made some behavioral changes but did not fully understand the implications of poor control and/or did not make changes consistently. It is clear that each group had different processes over time and in different ways.

Qualitative studies may help shed light on patients' views regarding self-management. Danish researchers explored diabetes patients' views about their experiences with managing their illness, following self-management training. The results are important in the context of this chapter: patients said they needed specific support in the daily responsibility of managing diet, exercise, medication, and blood glucose monitoring (Rosenbek Minet, Lønvig, et al., 2011). In a similar vein, a study by van Bastelaar, Pouwer, Cuijpers, Riper, and Snoek (2011) identified symptoms of depression and diabetes-specific distress as barriers to adequate self-management. A web-based cognitive behavioral intervention was developed to address these issues.

Increasingly, nurses and physicians acknowledge the great relevance and importance of (ongoing) self-management in patients with diabetes (Dancer & Courtney, 2010, for nurse practitioners; Yu & Beresford, 2010, for (family) physicians). Both papers underline the point made by Fisher, Brownson, O'Toole, Shetty, Anwuri, and Glasgow (2005), "beyond the self in self-management" (p. 1524): contextual factors are at least as important as patient-related variables in encouraging and maintaining self-management behavior in patients with diabetes (or for any chronic illness, for that matter). This focus on contextual factors also minimizes the likelihood of blaming the patient, as their life worlds are revealed in greater depth.

Rheumatic Illnesses

The benefits of short-term programs promoting exercise, physical activity, and self-management regarding rheumatoid arthritis (RA) outcomes have been consistently demonstrated (Hurkmans, van der Giesen, et al., 2009; Iversen, Hammond, & Betteridge, 2010). However, as in other chronic illnesses, studies on the effectiveness of approaches to provide ongoing follow-up and support for promoting sustained disease management are scarce.

Three main areas have been investigated in the research to date, namely, interactive online environments for peer group support, community-deliverable exercise programs, and consolidation after rehabilitation.

Interactive Online Environments for Peer Group Support

One small qualitative study on the effect of participating in an online support group (van Uden-Kraan, Drossaert, et al., 2008) found positive empowering outcomes experienced by the participants, such as being better informed, feeling confident in their relationship with physicians, treatment and social environment, acceptance of the disease, optimism and control, self-esteem and social well-being, and collective action. Respondents (10 breast cancer, 11 fibromyalgia, and 11 arthritis) were highly active users, mostly female (*n* = 30), relatively young (43 years), with a mean disease duration of 2 years. The study was replicated in a larger sample (*n* = 528, 23% arthritis) with the same results, and no significant differences were observed between the diagnostic groups with regard to empowering outcomes (van Uden – Kraan, Drossaert, et al., 2009). The authors suggest that online support groups are a useful resource for patients and that healthcare providers should thus acquaint their patients with the existence of these groups. However, their studies also revealed that online support groups for arthritis are the least active when compared to the other diagnostic groups.

Community-Deliverable Exercise Programs

Arthritis-appropriate interventions identified by the Centers for Disease Control and Prevention (CDC) for use in public health settings in the USA include three physical activity and three self-management interventions (Brady, Jernick, et al., 2009). Of these the Arthritis Foundation Aquatic Program (AFAP, www.arthritis.org/aquatic-program.php), the Arthritis Foundation Exercise Program (AFEP/PACE, www.arthritis.org/af-exercise-program.php), and the Project Enhance Fitness (www.projectenhance.org) can be offered on an ongoing basis. The Arthritis Foundation offers practical help (training for instructors, implementation guidelines, marketing, connection to other programs, educational resources) for lay people from a community wanting to start a group.

With respect to other countries, ongoing exercise programs for patients with arthritis are generally offered through websites from (local) Arthritis Foundation offices (e.g., the UK, Australia, New Zealand, Germany) or patient alliances (e.g., UK, Netherlands). A recent meta-analysis suggests that (short-term) community deliverable exercise significantly improves pain and physical function in arthritis and other rheumatic diseases (Kelley, Kelley, et al., 2011).

Consolidation After Rehabilitation

Based on the trans-theoretical model of behavioral change, the Community Rehabilitation Network (CRN, Hong Kong) developed a three-phase self-management service which places more emphasis on the process of self-help and support services to assist patients with RA (Siu & Chui, 2004).

In the orientation (pre-contemplation) phase of the program (2–4 weeks duration), patients are provided with disease-related information and information on community resources. Patients are encouraged to (re-)mobilize their peer and social support network and alleviate their sense of helplessness in facing the disease, and readiness for developing effective ways of coping with illness is promoted. In the intervention (contemplation) phase (2–3 months duration), patients are encouraged to participate in three standardized intervention programs, including a stress management group, a self-management course, and a water exercise class. In the consolidation phase (6 months), patients are assisted to habituate self-management behavior and are stimulated to maintain a supportive social network. The services provided in this stage include regular reunion meetings and volunteer training programs to equip participants with further knowledge in disease management and available community resources as well as communication and peer counseling skills training to prepare them to conduct home and hospital visits to peers. In addition to the program elements, informal activities are organized throughout the three phases to help expand social support among participants and provide mutual support. Activities include social and recreational activities such as camping and outings, hospital visit/home visit by groups of two or three volunteers in the company of a staff member, and visits to centers offering consultations, educational talks and seminars, and community resources.

Compared to the control group (patients who declined after the orientation phase of the program), the 29 patients in the treatment group (self-) reported significantly greater improvement at the end of the consolidation phase. They improved significantly in self-efficacy, exercise behavior, and cognitive symptom management and made less use of community services for tangible help and more use of education service/support groups for health problems and of organized exercise programs. Their communication with their physician also improved. However, the study did not find significant differences in change scores for health outcomes such as pain and physical discomfort, energy and fatigue, self-rated health, and healthcare utilization between the intervention and the control groups.

For the treatment group, it was noted that more changes occurred in the consolidation phase, when the CRN adopted a facilitator role rather than an interventionist role, suggesting that the development of social networks plays an important part not only in sustaining the effects from the initial program but also in producing further improvements.

Discussion

There are a number of key themes that arise from the selective review we have presented in this chapter concerning ongoing behavioral intervention and support in patients with six major chronic physical illnesses. Self-management is associated with positive outcomes in patients with chronic physical illness. Self-management impacts on two major categories of outcome: it reduces use of healthcare services in some illnesses, and it improves quality of life in virtually all patients (see Newman, Steed, Mulligan, 2009, and the systematic reviews described in our chapter). In some cases, self-management may be as effective as some medical treatments. Much of the research (but not all) is guided by theoretical models on self-management, behavioral interventions, healthcare services, and medicine. Humanistic motives seem to be important in these scientific efforts, as are issues regarding financial costs of healthcare.

It is surprising that the “acute care model” still dominates not only medical care but self-management research and practice as well. Self-management research tends to employ the classic randomized trial, in which patients are allocated randomly to an intervention or a control condition. The control condition is generally care as usual, while the intervention is generally a 6-week self-management program.

Studies typically assess changes in a number of outcomes in both groups after a relatively short period of time and based on the results conclude that the patients in the intervention groups do better in some of these outcome measures. However, these improvements are not always maintained, nor frequently followed for longer periods of time. Some research indicates that 1 year later, patients are back to baseline levels of outcome measures. We are surprised that researchers (ourselves included) adopt an episodic care model in patients with lifelong illnesses, assessing the effects of intervention efforts after only 3-month "follow-up" (at best). Studies where effects of interventions in self-management behavior are assessed after much longer, and perhaps more relevant, periods are scarce. Researchers understand immediately why this is: research grants usually run for no longer than 3 or 4 years. Within this context, even a 1-year follow-up is difficult in such a limited period of research time. In addition, patients move to other cities, get bored by our ongoing self-management support effort, or die. Additionally, we know surprisingly little about patients' wishes regarding ongoing self-management support (cf., Devitt, Hatton, et al., 2010; Mann, & Gooberman – Hill, 2011; Tiemensma, Kaptein, et al., 2011). Healthcare providers may become annoyed by requests from researchers for filling out questionnaires and selecting and including patients in studies – although there are exceptions (e.g., Khunti, Gray, et al., 2012).

However, the research does suggest that the Chronic Care Model, and other theoretical models about human health and illness behavior, seem to be helpful in designing research about ongoing support in self-management of chronically ill persons. This is valuable for future research. Nurse practitioners, research nurses, and specialized nurses are a group of professionals who are providing much of the self-management training and material. Perhaps surprisingly, physiotherapists are conspicuously absent in studies on delivering self-management guidance and skills. Physicians also do not seem to spend enough time and care regarding discussing self-management with their patients, perhaps due to the time scarcity in healthcare organizations. Ironically, the same might be said for psychologists. Expert patients do not yet appear to represent a major category of trainers. This option deserves further study, in our opinion (cf., the Chronic Disease Self-Management Program, e.g., Ghorob, Vivas, et al., 2011; Ritter, Lee, & Lorig, 2011; Willis, Robinson, et al., 2011). In male veteran patients with diabetes, for instance, a reciprocal peer support program produced positive outcomes on biomedical outcome measures and self-reported diabetes social support (cf., Fisher, Boothroyd, et al., 2012). Web-based interventions are increasingly being employed in self-management interventions, and these are naturally appealing as methods to be used in this context: they can, once developed, be employed easily, cheaply, and at a time and place chosen by and convenient for the patient. Interventions available via the Internet allow patients more autonomy in deciding how to apply these interventions.

Within the field of behavioral medicine, a topic that is receiving increasing attention is "translational behavioral medicine," i.e., the translation and application of evidence-based, effective interventions from the behavioral medicine domain to patients. The Society of Behavioral Medicine launched a journal devoted to this topic recently. As we have seen in this chapter, scientists working in a behavioral medicine setting do achieve quite acceptable successes in motivating patients with chronic somatic illness to use available, effective, ongoing support systems. This use does impact on major outcomes, for most patients, most of the time. However, patients, healthcare providers, (commercial) companies that pay for and/or reimburse health services, and the society at large do not appear to be wholeheartedly convinced about this effectiveness. It cannot be overstated: incorporating self-management and ongoing self-management support should be part and parcel of regular care for patients with chronic illness (cf., Greenhalgh, 2009). However, while researchers may be confident that their research-based interventions lead to positive outcomes, it is another matter to convince clinicians to incorporate these findings as regular components of (medical) care (see for instance the paper by Hack et al. (2011), on facilitating the implementation of empirically valid interventions in psychosocial oncology and supportive care). The area of translational behavioral medicine research clearly deserves great attention in future research and clinical applications. Incorporating standards for self-management education into guidelines used by healthcare providers is another more structural way of trying to improve the quality of medical care (cf., Funnel et al., 2011, for diabetes).

The research we have reviewed in this chapter supports the statement that self-management is a crucial part of quality medical care. Whether self-management interventions are suggested, offered, and assessed soon after the contact between patient and healthcare provider, or 3, 6, 12, or 24 months later, is somewhat irrelevant. Patients with the conditions that were discussed in this chapter – asthma, COPD, cancer, cardiovascular disorders, diabetes mellitus, and (rheumatoid) arthritis – will have to self-manage their condition for the rest of their lives. Self-management and ongoing support for self-management, therefore, should be part and parcel of regular medical care.

Figure 30.4 below (in Fisher et al., *Diabetes Educator* 2007, 33 (Suppl 6), pp. 216S–224S, p. 221S) ties in the Chronic Care Model that we discussed before (p. 8) and the Common Sense Model (p. 886, this chapter) with self-management behaviors. The figure underlines the importance of the connections between the models that are discernable in the figure, and the three levels of variables, indicated in the left-hand side of the figure (cf., Battersby, von Korff, et al., 2010).

The model has implications for medical education as well. We need to educate and teach our physicians-in-training the skills to incorporate self-management techniques in healthcare, enabling them to know how to, for example, support the ongoing self-management of a 76-year old woman with rheumatoid arthritis – and probably more than one comorbid condition. Journals in medical education do pay attention to this issue (e.g., Bowen, Provost, et al., 2010; Holman, 2004). It is important to align medical education with the changes in patterns of morbidity in the next decades.

Disease	Behavioral objectives	Outcomes	Overall objective
Asthma	Symptom perception, symptom control, incorporating asthma in social and psychological life	Reduction of healthcare use, absenteeism from school/work, better QOL	Adapt and self-manage
COPD	Maintain physical activities, maintain social relations	Reductions in depression and anxiety, healthcare use, mortality	Adapt and self-manage
Cancer	Management of cancer treatment and its consequences	Improvement of QOL	Adapt and self-manage
Cardiovascular diseases	Management of physical, psychological, and social consequences of illness and its management	Improved survival, improved QOL	Adapt and self-manage
Diabetes mellitus	Adjust eating behavior, physical activities	Reduction of complications	Adapt and self-manage
Rheumatoid arthritis	Manage consequences of illness in daily life	Reductions in limitations in daily activities	Adapt and self-manage

Schematic representation of behavioral objectives, outcomes, and overall objective in six chronic somatic disorders
QOL quality of life

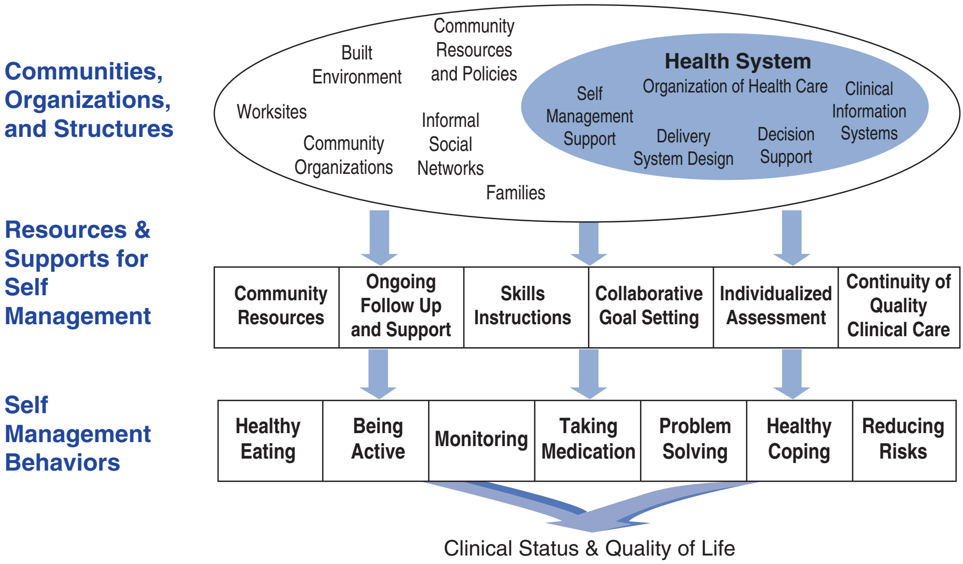

Fig. 30.4 Trilevel model of self-management and chronic care

Wagner, an important contributor to the thinking regarding chronic care management, quite rightly emphasizes the role of academic primary care in this context (Wagner, 2010). In line with our finding about nurses playing a central role in providing ongoing self-management support, Wagner maintains that "increasingly, nurses, medical assistants, or others on a practice team receive training in counseling strategies (e.g., motivational interviewing), and interact regularly with chronically ill patients at visits or by telephone" (p. S637).

Our review of studies on ongoing self-management support is limited – somewhat paradoxically – by the relative success of self-management in people with chronic illness: the number of studies in this area makes it virtually impossible to really adopt a helicopter view of the area. By focusing on review papers, meta-analyses, and Cochrane reviews, we have attempted to deal with this limitation. This research area would be improved with longer follow-up periods, and those providing research funds should also consider the implications of this for grant durations. Patients themselves, and their partners, may beneficially be more fully involved in the design and delivery of self-management intervention studies.

"The only important indicators of health and wellness are behavioral" – this exciting, albeit somewhat provocative, quote summarizes a major paper by Kaplan: "Behavior as the central outcome in health care" (1990). Given our review of self-management in six chronic somatic disorders, it should be evident that self-management has disease-specific elements, in addition to elements that appear to be valid for all chronic somatic disorders. In the table we present a rough sketch of behavioral objectives of self-management for the six illnesses and the associated behavioral outcomes (cf. Kaplan, 1990). A recent position paper in the *British Medical Journal* examined the concept "health." Rather than adopting the 1948 WHO definition, the author group took a bold step. They defined health as "the ability to adapt and to self manage" (p. 236, Huber et al., 2011). We think this author group is absolutely right – our chapter hopes to contribute to this viewpoint on health, illness, and quality of life. Therefore, in the table, the ultimate outcome measure is labeled "the ability to adapt and to self-manage."

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31

The Evolution of HIV Prevention Interventions and Chronic Disease Management

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Introduction

The Joint United Nations Programme on HIV/AIDS estimates that 2.6 million new infections and 1.8 million AIDS deaths occurred in 2009, and almost 33.3 million adults and children worldwide are currently living with HIV or AIDS, with the great majority of them in low- and middle-income countries (UNAIDS, 2010). Fortunately, the advent of antiretroviral therapy in 1996 has led to drastic positive changes to both the state of HIV prevention and the lives of people living with HIV. Since then, the mortality rate from AIDS has decreased, and the infection has transformed from a fatal illness to a chronic, more manageable one. Meanwhile, 30 years into the HIV epidemic, HIV prevention interventions throughout the world have varied tremendously in both the theories that guide them and the contexts in which they are delivered. Our main aims in this chapter are to (1) selectively review approaches to preventing HIV infection and (2) discuss issues surrounding chronic disease management of HIV.

In the development of HIV prevention interventions, an important consideration is the distinction between primary prevention (for uninfected individuals) and secondary prevention (for HIV-infected individuals). Primary prevention aims to help persons avoid contracting HIV. Primary prevention interventions can be undertaken at the individual, couple, community, and social-policy or structural level; it can also involve the promotion of HIV testing and counseling for HIV-negative persons who engage in high-risk behaviors. Secondary prevention aims to reduce adverse consequences for persons living with HIV as well as to reduce transmission to uninfected persons. Within secondary prevention, the most significant advancement has been made with antiretroviral therapy (ART) for HIV infection and associated medication adherence. ART works to suppress replication of the virus resulting in improved immune functioning, health, and reduced viral load for people living with HIV. However, the potential maximum benefits of ART will not be realized if people fail to adhere to their medications.

Patient- vs. Disease-Centered Approach

Altogether, with proper adherence to ART, the lives of people living with HIV can potentially be long and productive. Thus, secondary prevention efforts would benefit most when interventions are

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not only disease-centered but also patient-centered. That is, prevention for positives must recognize the many and intertwined aspects affecting disease management, including medication adherence, comorbid conditions, quality of life, and HIV stigma. Further, given the fact that these factors operate at multiple levels and multiple domains of an HIV-positive person's risk environment, prevention interventions are most likely to succeed when they shift the focus outside the individual. Interventions that target not only one's individual psychology but also the structural factors in one's environment are those most likely to achieve long-lasting behavior change.

Historically, HIV prevention interventions have been driven by a number of theories of behavior change. Recently, new biomedical models approaches have emerged that can be paired with behavior change models, including "treatment as prevention" (also known as "seek and treat"), pre-exposure prophylaxis, and male circumcision. Additionally, the HIV risk environment has been targeted as a means to achieve optimal HIV risk reduction among populations at risk for HIV.

HIV Prevention Approaches

Interventions based on theory result in greater behavior change (DiClemente & Peterson, 1994). However, standardization of theory-based interventions may not be optimal in achieving reductions in HIV cases given variations in HIV prevalence and incidence worldwide. Risk populations also vary widely by geographic region. Because of this, HIV prevention interventions must be tailored to account for local conditions and needs. The diverse HIV epidemics around the globe may be due to the infectiousness of the virus itself, the stage of the epidemic (generalized vs. concentrated), or the effectiveness of interventions that have been deployed. Different cultures, risk groups, and social drivers suggest that effective interventions may require different theoretical approaches. One way to organize our thinking about HIV prevention intervention that has gained increasing attention is the risk environment model, which asserts that four types of environmental influences – physical, social, economic, and policy – interact at the micro- and macro-levels to explain HIV transmission in at-risk populations. The micro-risk environment focuses on personal decisions and the influence of community-level norms and practices, while the macro-risk environment encompasses structural factors, such as laws, military actions, economic conditions, and wider cultural beliefs (Rhodes & Simic, 2005). Table 31.1 summarizes the HIV risk environment as it applies to HIV prevention interventions. Table 31.1 also lists behavioral theories that have been incorporated into the intervention examples that have addressed various levels of the risk environment. With the HIV epidemic evolving in magnitude and diversity, the development and implementation of interventions that integrate theoretical frameworks, biomedical models, and the risk environment of targeted populations will offer substantial benefits to efforts to reduce HIV transmission worldwide.

Global HIV prevention efforts have focused on various risk populations, including men who have sex with men (MSM), female sex workers (FSW) and their clients, high-risk heterosexual women, injection drug users (IDU), and transgendered individuals. HIV prevention efforts have scored successes and faced challenges, because each geographic region has a different presentation of the HIV epidemic with different populations that are most at risk.

Theories and Models Used in HIV Prevention Interventions

Behavior Change Theories and Models

A number of theoretical models of HIV-related behavior change have been either adapted or used in entirety to reduce sexual- or drug-related risk behaviors (or both) in various high-risk populations. Some of these models and theories are (1) the Health Belief Model; (2) Transtheoretical Model – Stages of Change; (3) Theory of Reasoned Action; (4) Social Cognitive Theory;

Table 31.1 The HIV risk environment model applied to HIV prevention interventions

Risk environment	Micro-environmental			Macro-environmental		
	Content	Theory	Example	Content	Theory	Example
Physical	• Homelessness • Prisons/Incarceration • Sex work locations • Drug use locations	None	**The Iran Prison Organization's** HIV prevention package for IDU prisoners; MMT programs constitute a main component; other services inc. NSPs and HIV education.	• Drug trafficking and distribution routes • Deportation • Geographical shifts in population	None	**The Living with HIV/AIDS project in Portugal** provides home care, treatment, psychosocial, rehab and legal support for migrants living with HIV and their families.
Social	• Relationship and network dynamics • Peer norms • Physical/sexual violence • Community attitudes • Local policing practices • Sexual orientation	Diffusion of Innovation Theory	**NIMH Project Accept in Africa**, designed to change community norms by (1) making VCT more available in community; (2) engaging community through outreach; and (3) providing post-test support.	• Stigma and discrimination • Exposure to war, conflict, or disasters • Ethnic or racial disparities • Gender inequalities • Social and cultural norms	None	**New York State (US) Human Rights Law** Bans discrimination against individuals with HIV/AIDS or those perceived to be infected with HIV; Office of AIDS Discrimination Issues handles complaints of HIV-related discrimination.
Economic	• Cost of condoms, syringes, medication • Few income generation and employment opportunities • Survival sex work • Cost of health care	None	**Intervention with Microfinance for AIDS and Gender Equity (IMAGE)** Group based microfinance and a gender and HIV education curriculum South African women.	• Scarcity of health service revenue and spending • Employment practices • Economic development	None	**CDC Funding ($359 million annually, FY2012-FY2016) for health department funding**: A new approach that better matches prevention dollars to HIV burden in affected areas focusing on high-impact interventions.
Political	Ensuring widespread coverage of: • HIV/STI testing and counseling • Antiretroviral therapy • Housing assistance for drug users, abused women, etc. • Sterile needles and syringes • Drug treatment • Male and female condoms	None	**HIV testing and linkage to care in US** Goal of 2010 National HIV/AIDS Strategy over the next 5 years is to increase percentage of newly diagnosed people linked to care within 3 months from 65% to 85%.	Laws and policies governing: • Protection of human and health rights • Sex work • Possession of drugs • Syringe access and exchange • Free highly active antiretroviral therapy coverage • Drug treatment	None	**100% Condom Use Campaign in Thailand** Condom use-only policy that requires all sex workers to use condoms with every customer; enlisted the aid of health authorities, governors, police, sex workers, and owners and managers of sex establishments.

Content for the risk environment model adapted from Strathdee, Hallett, et al., (2010) and Rhodes & Simic (2005)
MMT methadone maintenance treatment, *VCT* voluntary counseling and testing

(5) AIDS Risk Reduction Model; (6) Social Networks, Social Influence, and Peer Norms Theory; (7) Diffusion of Innovation Theory; and (8) Theory of Gender and Power. In the below section, we highlight these theories beginning with those focused more on individual factors followed by those focused on social and environmental factors.

Health Belief Model

The Health Belief Model is used to facilitate behavior change through attitudes and beliefs about the behavior (Rosenstock, Strecher, & Becker, 1994). Based on this model, individuals will change their behavior if (1) they regard themselves as susceptible to the condition, (2) they believe the health condition to have potentially serious consequences, (3) they believe that a course of action available to them would be beneficial in reducing either their susceptibility to or the severity of the condition, and (4) they believe that the anticipated barriers to (or costs of) taking the action are outweighed by its benefits (Rosenstock, Strecher, & Becker, 1994). Additional components of the model are (1) cues to action, a component that has not been systematically examined and refers to physical symptoms of a health condition or environmental factors that motivate individuals to change their behavior; (2) diverse demographic, socio-psychological and structural variables that may affect the individual's perceptions and indirectly influence the behavior; and (3) self-efficacy, introduced by Bandura, referring to the belief that one is able to execute the behavior required to produce the desired outcome (Rosenstock, Strecher, & Becker, 1994). Limitations of the Health Belief Model are that often only selected components are used to guide HIV prevention interventions and it does not incorporate the influence of social norms and peer influences on an individual's decision regarding their behaviors. Nonetheless, the model has been used in primary prevention of HIV through increasing condom use and in secondary prevention through early treatment of HIV.

Transtheoretical Model: Stages of Change

The Transtheoretical Model is organized around five distinctive stages through which individuals go through in making behavior changes: (1) *pre-contemplation*, with no intention to change behavior in the foreseeable future; (2) *contemplation*, giving serious consideration to changing behavior by weighing the pros and cons; (3) *preparation*, when individuals are ready to take action and are seriously planning to change their behavior; (4) *action*, when individuals initiate overt changes in their behavior and their efforts to change are visible to others; and (5) *maintenance*, a time of continued behavior change while preventing potential relapses (Prochaska, Redding, et al., 1994). Applied to HIV prevention in the form of condom use behavior: (1) *pre-contemplation* is not considering using condoms; (2) *contemplation*, recognizing the need to use condoms; (3) *preparation*, thinking about using condoms in the near future; (4) *action*, using condoms consistently for a short period; and (5) *maintenance*, using condoms consistently for a long period.

An important consideration in the application of this model to interventions is the identification of intervention methods linked with each stage. According to the theory, if a given intervention is mismatched to an individual's stage of readiness for change, it is likely to be ineffective (Prochaska, Redding, et al., 1994). Effective HIV prevention interventions are those that have been mapped onto an individual or population's readiness or stage of change. Individuals may pass through all stages but do not necessarily move in a linear manner. For example, in an HIV behavioral intervention for US women at risk for or infected with HIV, stage-tailored intervention print materials based on role model stories were used to model and encourage women's movement from their current stages to the next stage in terms of safe sex practices (Cabral, Cotton, et al., 2004). These stories incorporated a brief narrative about a woman's successful movement from an earlier to a later stage, the processes of change she used that contributed to her successful movement between stages, the stage of change achieved through this process, and her current stage of change related to HIV risk behaviors (Cabral, Cotton, et al., 2004). Most women reached by this intervention were at early stages of change for condom use, and behavior change overall was a gradual process (Cabral, Cotton, et al., 2004). In another HIV/STD prevention program for adolescents, individual counseling sessions were tailored to each participant based on their stage of readiness and influencing factors (i.e., cognitive, emotional, and behavioral activities and processes that people engage in when attempting to change behavior). With regard to disease prevention (i.e., condom use only or postponing sexual activity), those starting in pre-contemplation/contemplation were more likely to move forward to later stages than those in action/maintenance (Hacker, Brown, et al., 2005). Thus, the intervention was more successful at moving teens forward from lower stages of change than helping teens stay in action and maintenance (Hacker, Brown, et al., 2005).

Theory of Reasoned Action

The Theory of Reasoned Action has been applied to HIV prevention interventions targeting a number of at-risk populations including women, FSWs, MSM, and IDUs, frequently focusing on the promotion of condom use. The central premise of the Theory of Reasoned Action is that individuals make behavioral decisions on the basis of a reasoned consideration of the available information. Behavioral intentions reflect the extent to which an individual is motivated to perform the behavior or the individual's willingness to perform it (Fishbein & Ajzen, 2010). An individual's behavioral intentions are influenced by two conceptually distinguishable factors: (1) *attitude*, which reflects how favorably or unfavorably a person feels toward performing the behavior and which is shaped by an individual's beliefs regarding the behavior's outcomes and the evaluation of consequences of potential outcomes, and (2) *subjective norm*, which refers to the extent of perceived social pressure to perform the behavior and which is shaped by an individual's beliefs regarding other people's views of a behavior and the individual's willingness to conform to those views (Terry, Gallois, & McCamish, 1993). A limitation of the Theory of Reasoned Action is its inability, due to its individualistic approach, to consider the role of structural and environmental issues.

Social Cognitive Theory

Social Cognitive Theory asserts that providing information alone will not change behavior; rather, sustained behavior change requires that the person possess the skills needed to engage in the behavior and the ability to use these skills consistently and under difficult circumstances. In a reciprocal causation model, the following elements in Social Cognitive Theory operate as interacting determinants: (1) personal determinants in the form of cognitive, affective, and biological factors, (2) behavior, and (3) environmental influences (Bandura, 1986, 1994). This theory identifies four components for successful implementation: (1) information or knowledge, (2) mastery of self-protective skills and self-efficacy for implementing the skills, (3) social competency skills acquired through rehearsal and practice, and (4) social support for precautionary changes. Social Cognitive Theory is the most frequently used model for HIV behavioral interventions.

AIDS Risk Reduction Model

The AIDS Risk Reduction Model (Catania, Kegeles, & Coates, 1990) incorporates several variables from other behavior change theories, including the Health Belief Model and Social Cognitive Theory to provide a framework for explaining and predicting behavior change efforts of individuals specifically in relationship to the sexual transmission of HIV/AIDS. The AIDS Risk Reduction Model consists of three stages of behavior change: (1) labeling of high-risk behaviors as problematic, (2) making a commitment to changing high-risk behaviors, and (3) seeking and enacting solutions directed at reducing high-risk activities. Movement from stage to stage is expected to be dependent on achieving the goals of prior stages. In addition, several other internal and external motivators may play important roles in maintaining adequate motivation over time. These include (1) knowledge of the risks associated with various sexual practices, (2) perceptions of susceptibility to contracting HIV, (3) perceived costs and benefits associated with reducing high-risk sexual behaviors, (4) self-efficacy beliefs, (5) emotional states, and (6) social factors, including verbal communication skills, reference group norms, help-seeking processes, and social support (Catania, Kegeles, & Coates, 1990). HIV prevention interventions that have been guided by the AIDS Risk Reduction Model often address the reduction of sexual risk behaviors. With minor modifications, the AIDS Risk Reduction Model can be applied to interventions that target reductions in other HIV risk behaviors (e.g., substance abuse, needle sharing) (Catania, Kegeles, & Coates, 1990).

Diffusion of Innovation Theory

Diffusion of Innovation Theory has been used as the rationale for many community-level interventions in the context of HIV prevention. Diffusion of Innovation Theory refers to a process by which an innovation is communicated among members of a social system (Rogers, 2000). An innovation is an idea, practice, or object perceived as new by an individual or other unit of adoption (e.g., an organization). The characteristics of an innovation, as perceived by members of a system, determine the rate at which the innovation is adopted. Five attributes of innovations are (1) *relative advantage*, the degree to which a new idea is perceived as superior to the idea that it replaces; (2) *compatibility*, the degree to which a new idea is perceived as consistent with the existing values, experiences, and needs of potential adopters; (3) *complexity*, defined as the degree to which an innovation is perceived as difficult to understand; (4) *trialability*, the degree to which an innovation may be experimented with on a limited basis; and (5) *observability*, the degree to which the results of an innovation are visible to others (Rogers, 2000).

This model focuses on social networks and utilizes opinion leaders as agents of change. Opinion leaders are trusted, credible, and well-liked people in the community who are recruited and trained to conduct HIV prevention outreach. The Diffusion of Innovation Theory has been applied to HIV interventions in populations at increased risk for HIV through high-risk sexual behaviors. The goal is to diffuse innovative approaches to reducing sexual risk behaviors and increasing use of safer sex strategies. This is accomplished through enlisting a sufficient number of opinion leaders in at-risk communities to support and endorse changes in risk behavior. Although the Diffusion of Innovation Theory provides a framework for conceptualizing how changes in a population's behavior and norms can be achieved by opinion leaders, it does not directly address what opinion leaders should say to influence others to make changes in sexual risk behaviors that are not directly observable (NIMH Collaborative HIV/STD Prevention Trial Group, 2007).

Theory of Gender and Power

The Theory of Gender and Power has been used primarily in prevention interventions that target at-risk women. This theory's conceptual framework incorporates the social influences that compromise disadvantaged women's health and autonomy. The theory distinguishes three primary structures: division of labor, division of power, and the structure of cathexis (Connell, 1987). The sexual division of labor refers to the unequal allocation to women and men of certain occupations, such as "unpaid nurturing work," e.g., child care, housework, and caring for the sick and elderly; this often results in an economic imbalance in which women have to rely on men financially. Applied to HIV prevention, women who are unemployed have a high-demand and low-control work environment, and limited or no health insurance are at increased risk for HIV acquisition (Wingood & DiClemente, 2000). “Division of power” recognizes the power imbalances in heterosexual relationships that contribute to men’s authority, control, and coercion over women. Within this structure, women at increased risk for HIV are those with histories of sexual or physical abuse, low self-assertiveness and self-efficacy, and limited perceived control in their relationships (Wingood & DiClemente, 2000). “Cathexis” refers to society’s approved gender roles and its expectations for appropriate sexual behavior. It has been noted that the Theory of Gender and Power, in isolation, implies an intervention with unstructured discussion among the participants about gender and power issues and about how women cope with these issues in their daily lives (St Lawrence, Wilson, et al., 2001).

Biomedical Interventions

Emerging biomedical approaches include medical interventions to block infection, decrease infectiousness, or reduce the risk for HIV infection. Current interventions under investigation or proven to be efficacious are antiretroviral drugs used to reduce infectiousness in HIV-positive individuals or as pre-exposure prophylaxis, male circumcision, microbicides, and HIV vaccines.

Oral Antiretroviral Prevention

Antiretroviral HIV prophylaxis has been very effective in preventing mother-to-child transmission, with widespread use beginning in the 1990s. The use of short-course zidovudine and, subsequently, single-dose nevirapine for pregnant, HIV-infected women has been proven to reduce mother-to-child transmission in non-breastfeeding populations by two-thirds. Since then, several other regimens have been assessed in non-breastfeeding and breastfeeding populations (Padian, Buve, et al., 2008). Currently, there is great hope that this strategy will prove effective against other routes of transmission (Garcia-Lerma, Paxton, et al., 2010). Antiretroviral therapy has been explored as an HIV prevention measure in three domains: (1) reducing infectiousness among HIV-positive persons, (2) preventing infection in high-risk HIV-seronegative populations through pre-exposure prophylaxis (PrEP), and (3) preventing infection among HIV-negative persons through post-exposure prophylaxis (PEP) after occupational or nonoccupational exposure to HIV-infected blood or fluids (Kelesidis & Landovitz, 2011). PrEP uses ART in anticipation of HIV exposure from known or unknown sources with the aim of preventing HIV acquisition or, at least, altering the natural course of infection to attenuate disease progression, reduce morbidity, and/or decrease infectiousness (Kelesidis & Landovitz, 2011). PrEP is a promising prevention strategy consisting of oral administration of continuous (daily) ARV medication by HIV-negative individuals before potential exposure and throughout periods of risk (Garcia-Lerma, Paxton, et al., 2010).

An advantage of PrEP is that it can be used independently of sexual practices and other risk behaviors (Padian, Buve, et al., 2008). Medical prophylaxis is standard for the prevention of many other infections such as malaria, but it is experimental for HIV. Multiple lines of evidence including animal data, human clinical trials, and mathematical models suggest that PrEP might be effective in preventing HIV among high-risk populations (Abbas, 2011; Garcia-Lerma, Paxton, et al., 2010; Kelesidis & Landovitz, 2011). Candidates for use as an oral PrEP agent have largely been selected from drugs that are currently approved for treatment of HIV infection. The characteristics that make for an effective PrEP drug overlap with those for treatment drugs-good tolerability and safety, low pill burden, once-daily dosing, long half-life, high potency, and a good resistance profile (i.e., the HIV virus does not rapidly develop resistance to the drug or broad cross-resistance with other drugs) (Garcia-Lerma, Paxton, et al., 2010). PrEP has been proven effective among MSM, and the US Centers for Disease Control and Prevention (CDC) have issued interim guidance on its use in this population (Centers for Disease

Control and Prevention, 2011c; Grant, Lama, et al., 2010). Other recent studies have shown PrEP to be effective among heterosexual men and women, although important questions remain about which heterosexuals would benefit most (Centers for Disease Control and Prevention, 2011b). And in 2012, the US Food and Drug Administration approved Truvada for PrEP, a drug originally marketed as treatment for people who were already infected with the virus (US Food and Drug Administration, 2012). Truvada is the first drug approved to reduce the risk of HIV infection in uninfected individuals who are at high risk of HIV infection and who may engage in sexual activity with HIV-infected partners. Truvada, taken daily, is to be used for PrEP in combination with safer sex practices to reduce the risk of sexually-acquired HIV infection in adults at high risk.

Male Circumcision

Male circumcision has been shown to be efficacious in preventing female-to-male transmission of HIV infection (Auvert, Taljaard, et al., 2005; Bailey, Moses, et al., 2007; Templeton, 2010). The mechanisms by which male circumcision reduces HIV infection risk have been explored by researchers. The inner surface of the foreskin has a high concentration of HIV target cells. It is lightly keratinized and susceptible to microscopic tears, is exposed to vaginal secretions during sexual intercourse, and provides a moist environment that might sustain the viability of pathogens. Thus, an intact foreskin may facilitate survival and entry of the HIV virus, so that removing the foreskin reduces the risk of HIV infection (Padian, Buve, et al., 2008). Male circumcision also reduces the risk of genital ulcer disease, which has been shown to increase the risk of HIV infection (Padian, Buve, et al., 2008).

The protection benefit of circumcision for male-to-female transmission (the male partner being already HIV positive) has been debated (de Bruyn, Shiboski, et al., 2011; Padian, McCoy, Karim, et al., 2011). Observational studies have suggested lower male-to-female transmission of HIV from circumcised men who were HIV infected (de Bruyn, Shiboski, et al., 2011); whereas randomized controlled trials have shown either that circumcision had no effect on HIV transmission from HIV-infected men with higher CD4 counts or that circumcision reduced male-to-female transmission by up to 46% (de Bruyn, Shiboski, et al., 2011; Padian, McCoy, Karim, et al., 2011). Nonetheless, after three clinical trials demonstrated a strong effect of male circumcision in reducing HIV acquisition, the World Health Organization (WHO) and UNAIDS held a consultation in March 2007, which recommended that circumcision be recognized as an effective intervention for prevention of heterosexual HIV acquisition in men (Padian, Buve, et al., 2008). It also recommended that countries with generalized heterosexual epidemics and low rates of male circumcision be the focus for scaling up of this intervention, within the context of ensuring universal access to comprehensive HIV prevention, treatment, care, and support (de Bruyn, Shiboski, et al., 2011; Padian, Buve, et al., 2008). Implementation of male circumcision as a biomedical intervention in countries has been variable and confounded by human resource constraints, funding shortfalls, ineffective communication strategies, and lack of support from political and traditional leaders (de Bruyn, Shiboski, et al., 2011; Padian, McCoy, Karim, et al., 2011).

Microbicides

Microbicides are chemical agents in the form of creams, gels, and suppositories, applied topically within the vagina or rectum before sexual intercourse in order to prevent HIV and sexually transmitted infections (STIs) (Weber, Desai, et al., 2005). Microbicides were initially conceived as a female-controlled method (vaginal application) to prevent transmission via heterosexual intercourse; however, safe and effective antimicrobial compounds could also serve as important prevention methods for MSM (rectal application) (Padian, Buve, et al., 2008). The majority of microbicide candidates currently under testing are formulated with ARV drugs. The first vaginal microbicide to be studied was nonoxynol-9, an anionic surfactant initially developed in the 1960s as a contraceptive spermicide with lubricant properties, and latterly used extensively to coat latex condoms (Weber, Desai, et al., 2005). In the 1980s, observational data for nonoxynol-9 gel against HIV/STIs were encouraging. However, in randomized trials in the 1990s, this gel was ineffective in preventing HIV and other STIs (Padian, Buve, et al., 2008). These trials were followed by studies to assess other non-HIV-specific agents, such as vaginal defense enhancers, entry inhibitors, and fusion inhibitors; several of these products have been assessed, with disappointing results (Padian, Buve, et al., 2008). There is hope, however, that better results will be achieved with agents that specifically inhibit HIV and are based on the same ARV drug platforms that have been used successfully for HIV treatment regimens. These ARV drug platforms have shown quite remarkable efficacy in explant tissue and animal infection models.

Unlike their predecessors, these newer-generation products do not have to be applied at the time of sex (Microbicide Trials Network, 2011). Researchers are exploring their daily use as a gel and other formulations, such as a ring, that in theory could be inserted once a month, for example (Microbicide Trials Network, 2011). Tenofovir, a nucleotide analogue reverse transcriptase inhibitor used in HIV/AIDS therapy, represents the most advanced candidate within this category (Hladik & Doncel, 2010). A 1% vaginal gel formulation of tenofovir, delivered into the vaginal vault up to 12 h before and within 12 h after intercourse, reduced HIV acquisition by nearly 40% overall in the recently completed CAPRISA 004 Phase IIb HIV prevention trial, which involved 889 South African women (Hladik & Doncel, 2010; Abdool Karim, et al., 2010).

Tenofovir now represents the first vaginal microbicide proven to be safe and efficacious in the primary prevention of HIV in women. Several other clinical trials are underway investigating anti-HIV microbicides based on non-nucleoside reverse transcriptase inhibitors such as dapivirine. Specifically, the ASPIRE study was recently launched to test the effectiveness and extended safety of a drug-infused vaginal ring for preventing HIV infection in uninfected women in five African countries (Department of Health and Human Services, 2012). Also known as MTN 020, the study aims to determine whether the HIV antiretroviral drug dapivirine can safely and effectively prevent HIV infection when continuously released in the vagina from a silicone ring replaced once every 4 weeks. Significantly, the ASPIRE study is the first effectiveness trial of a vaginal ring for HIV prevention and of a product that contains an antiretroviral other than tenofovir or tenofovir combined with the antiretroviral emtricitabine (Truvada) (Microbicide Trials Network, 2012). Other classes of microbicide candidate involve specific entry inhibitors, including gp120 blockers, gp41 blockers, and CCR5 antagonists, integrase inhibitors, protease inhibitors, and a combination of active ingredients (Hladik & Doncel, 2010; Microbicide Trials Network, 2011). Although the commercial availability of microbicides is likely to be several years away, strategies for regulatory approval and successful product launch should be initiated to address the cultural and educational issues that will be essential to ensure that they be used correctly and in accordance with other prevention strategies (Nuttall, 2010). To date, most microbicide research has focused on vaginal microbicides used for the prevention of HIV in women. Yet receptive anal intercourse is common among MSM, and there is increasing evidence that heterosexual women in both the developed and low- and middle-income countries also practice receptive anal intercourse. Because of the prevalence of this practice, current studies are evaluating the safety of vaginal microbicides when used in the rectum, as well as exploring candidate microbicides formulated specifically for rectal use (Microbicide Trials Network, 2011).

Vaccines

Strategies for vaccine development include innate, cell-mediated, or antibody-mediated resistance to infection, or all three (Padian, McCoy, Karim, et al., 2011). The pursuit of a safe and effective HIV vaccine has met with disappointment over the past three decades, with the termination of studies showing neither protection from HIV nor alteration in viral replication in vaccine recipients (Munier, Andersen, & Kelleher, 2011; Padian, McCoy, Karim, et al., 2011). More recently, there has been renewed optimism about potential HIV vaccines, resulting from the trial of the Thai RV144 (ALVAC and AIDSVAX) vaccine administered to men and women aged 18–30 in Thailand, which revealed a 26.4% efficacy in the intention-to-treat analysis and 31.2% in the modified intention-to-treat analysis. Vaccination with ALVAC and AIDSVAX modestly reduced the risk of HIV infection but did not affect the viral load or CD4 T-cell counts in participants who were subsequently infected with HIV (Munier, Andersen, & Kelleher, 2011; Rerks-Ngarm, Pitisuttithum, et al., 2009). Research is ongoing to elucidate the underlying mechanisms of these modestly successful compounds (Munier, Andersen, & Kelleher, 2011).

A successful HIV vaccine would ideally be safe, affordable, tolerated by recipients, and elicit an effective and long-lasting immune response comprising both neutralizing antibodies (Nabs) and cytotoxic T-lymphocytes (CTL) that recognize diverse strains of the virus and protect at sites of possible infection (Munier, Andersen, & Kelleher, 2011). It is believed that Nabs would function to prevent infection at mucosal surfaces, whereas CTL would control the spread and amplification of any virus that avoids initial neutralization (Munier, Andersen, & Kelleher, 2011). A successful HIV vaccine might thus have two separate effects, one prophylactic and the other therapeutic, slowing or preventing disease progression and reducing viral load and CD4 cell-count decline in those whose infection is not prevented (Munier, Andersen, & Kelleher, 2011). Both effects would reduce transmission and lead to improved control of the HIV epidemic.

Integrating Behavioral and Biomedical Approaches: Treatment as Prevention

Thirty years after the start of the HIV epidemic, scientists are examining the benefits of integrating behavioral and biomedical approaches in HIV prevention. Given that antiretroviral therapy (ART) works in reducing infectiousness of HIV-positive persons, HIV treatment has received attention as a potentially high-impacting prevention strategy. The utility of treatment as prevention in reducing HIV transmission rates has been supported with mathematical modeling and recently with findings from the HIV Treatment for Prevention Trial (HPTN) 052 (Cohen, Chen, et al., 2011). This trial showed a 96% reduction in HIV transmission within discordant couples. In theory, treatment as prevention can be successful in curbing the epidemic when high-risk individuals engage in frequent testing and if found to be HIV-positive, are linked to care and receive early treatment. Further, the “seek and treat” approach argues that a reduction in a community’s viral load may be achieved when masses, ideally every individual, are tested. The effectiveness and feasibility of this approach is currently being tested in the United States in the Test, Link to Care Plus Treat or TLC-plus HPTN 065 study among MSM in Washington, D.C., and New York City (El-Sadr & Branson, 2010).

Individuals infected with HIV must be found, tested, and linked to care in order for seek and treat to achieve maximum outcomes in curbing the epidemic. Therefore, access to hard-to-reach and hidden populations is crucial. There are a number of approaches to finding difficult populations including the use of respondent-driven sampling (RDS) and outreach programs. RDS is a relatively new and arguably most promising sampling approach that involves a mix of snowball sampling and mathematical modeling that weighs the sample to compensate for nonrandomness. The expanded HIV testing component of HPTN 065 involves social mobilization with targeted testing messages, as well as implementation of a universal offer of HIV testing in emergency departments and hospital inpatient admissions. However, even when individuals are adequately found and tested, treatment as prevention will fail when some key factors are not recognized. These include intervention adherence, treatment of sexually transmitted coinfections, and risk compensation.

Intervention Adherence

Issues surrounding adherence are receiving more attention with advances in biomedical technologies for HIV prevention. Findings from studies of HIV-serodiscordant couples suggest near zero HIV transmission when infected partners have undetectable blood plasma viral loads (Quinn, Wawer, et al., 2000). Further, in the absence of co-occurring STI, ART can result in undetectable virus in the genital tract. Thus, with proper adherence, HIV treatment can be an effective prevention tool. Strict adherence is also demanded for the success of other biomedical prevention technologies, including pre-exposure prophylaxis (PrEP) and vaginal gel microbicides.

Different prevention strategies require varying degrees of adherence. For example, male circumcision requires one decision (to obtain the intervention or not), whereas other methods like oral antiretroviral drugs for HIV-negative individuals require daily decisions. Just as with reduced infectiousness among HIV-positive individuals on ART, reduced infectability is only achieved and sustained among HIV-negative individuals on PrEP given optimal adherence. The same is true for microbicidal methods. Whereas HIV transmission was reduced by 39% overall in the CAPRISA 004 trial, a 54% reduction was observed among high adherers (>80%). In sum, adherence is demanded for the success of biomedical prevention methods. Consequently, it has become more important for behavioral and biological scientists who engage in HIV prevention research to use their respective tools and skills to work together toward common goals (Padian, Buve, et al., 2008).

Sexually Transmitted Coinfections

Reduced infectiousness among HIV-positive individuals can only be achieved with proper adherence to antiretroviral medications, as well as the treatment of co-occurring STI. Sexually transmitted coinfection makes HIV-positive people much more infectious than their blood viral load indicates. The inflammatory process involved in STI increases the concentration of CD4 (immune) cells in the genital tract, including concentration of those cells already infected with HIV. STIs like trichomoniasis and bacterial vaginosis can also cause genital bleeding, heightening the risk of sexual transmission and mother-to-child intrapartum transmission. An important question however is whether STI treatment to prevent HIV transmission should target the HIV-negative or HIV-positive individual, as both are potentially rendered more vulnerable to becoming infected and infecting someone else, respectively, when they are dually infected.

Whereas there is strong biological plausibility and different studies and meta-analysis have confirmed the association between STI and HIV infection (Johnson & Lewis, 2008), results from intervention research have not been entirely clear on whether there is a causal association. For example, research among dually infected individuals has shown that suppression therapy of herpes simplex virus (HSV) reduces plasma, seminal, and genital HIV viral load (Baeten, Strick, et al., 2008; Zuckerman, Lucchetti, et al., 2009). However, such findings have not been matched by the results of several randomized control trials. One trial that included women who were HIV negative and HSV positive at baseline who received suppressive treatment with acyclovir did not show evidence of decreased HIV incidence (Watson-Jones, Weiss, et al., 2008). Another trial involving over 3000 HIV-serodiscordant couples where the HIV-infected partner was coinfected with HSV also revealed a similar null finding (Lingappa, Kahle, et al., 2009). Interpreting these trials has been challenging however, as each involves complex issues surrounding adherence, statistical power, population, and/or intervention content and implementation. Treatment of sexually transmitted coinfection is still regarded as an important area for HIV prevention.

Risk Compensation

Risk compensation has been a growing concern with the advent of ART (Baggaley, Powers, & Boily, 2011) and other preventive innovations

(Hagel & Meeuwisse, 2004). Risk compensation related to HIV essentially involves an individual's perception that receiving HIV treatment or another preventive intervention (e.g., male circumcision, PrEP) renders HIV transmission less likely, and therefore the individual "compensates" by engaging in higher-risk behavior. The notion of reduced risk is so powerful that studies have shown that the mere promise of expanded access to treatment or to PrEP is associated with significant increases in risk behavior among MSM (Stolte, Dukers, et al., 2004), IDUs (Tun, Celentano, et al., 2003), and heterosexuals (Grémy & Beltzer, 2004). HIV-positive individuals on ART do not appear to be more likely to engage in unprotected sex than individuals not on ART. There is however consistent meta-analytic evidence that individuals have more unsafe sex than persons if they believe that having an undetectable viral load protects against HIV transmission (Crepaz, Hart, & Marks, 2004). Consequently, perceptions of risk must be addressed in antiretroviral counseling.

Adherence

As important as adherence is across all of prevention and disease management, it takes on particular importance with HIV. Only with strict medication adherence does HIV become a chronic not fatal disease. A window of 85–95% adherence is typically demanded in order to achieve viral suppression and thereby reduced infectiousness, with at least 95% adherence to reduce early mortality (Lima et al., 2009). Strict initial adherence is argued to be especially important, as poor initial adherence can lead to failure of first-line medication regimens and drug resistance. However, attention to the Necessity-Concerns Framework is critical in promoting initial adherence, since patients' views and perceptions of the necessity for ART, even before they begin treatment, may determine whether they maintain adherence over the long term (Horne, Cooper, et al., 2007). In a study that applied the utility of the Necessity-Concerns Framework to patients' perceptions of ART in relation to treatment uptake and adherence, perceived necessity of ART was initially high among those accepting ART (Horne, Cooper, et al., 2007). Variation in perceived necessity of ART at this early stage predicted high adherence 12 months later; however, strong concerns predicted low adherence (Horne, Cooper, et al., 2007). Nonadherence can potentially lead to spread of a drug-resistant virus, resulting in a public health disaster. Some have used this argument to justify withholding treatment to populations at risk for nonadherence, including individuals in sub-Saharan Africa. However, research to date has demonstrated that this concern is largely unfounded. The evidence suggests that sub-Saharan Africans are no more likely to be nonadherent than North Americans and that the reverse may actually be true (Mills, Nachega, et al., 2006). Although different populations and settings may experience different barriers to adherence, many of the important barriers to adherence are consistent across developed and developing nations.

Generally, barriers to adherence can be patient related (e.g., self-efficacy), medication related, (e.g., regimen complexity), schedule related (e.g., a chaotic daily schedule), and social related (e.g., poor social support). A systematic review of the literature showed that consistent barriers across multiple settings include fear of disclosure, concomitant substance use, forgetfulness, suspicions surrounding treatment, a lack of understanding of treatment benefits, complicated regiments, poor quality of life, work, and family responsibilities, and access to medication (Mills, Nachega, et al., 2006). The last is of greatest concern in developing settings.

Chronic Disease Management

As people who are living with HIV are now living longer with proper ART adherence, researchers have focused more attention on chronic disease management among people living with HIV. Research on this issue has shown that approaches to HIV care have shifted from tertiary/specialist care to primary care, which was the approach largely employed at the beginning of the epidemic (Chu & Selwyn, 2011; Northfelt, Hayward, & Shapiro, 1988). Whereas opportunistic infections were of the most significant concern for HIV-positive patients, causes of death have now shifted to end-stage liver and kidney disease, as well as other non-HIV-related malignancies (Hooshyar, Hanson, et al., 2007; Lewden, May, et al., 2008; Palella, Baker, et al., 2006). Thus, HIV care in ambulatory settings has focused on the prevention of common diseases. The HIV-patient population has also evolved since the advent of ART. Aging-related issues have received growing attention in the HIV literature, as most of the people living with HIV are of middle and older age. In fact, 75% of the population living with HIV in the United States are at least 40 years old (CDC, 2007). There is increasing importance to address the needs of aging HIV-positive patients, including financial strain and social isolation (Pitts, Grierson, & Misson, 2005). Living with chronic HIV requires the ability and responsibility of long-term, day-to-day care.

With chronic illness, as opposed to acute illness, the patient is the primary caregiver (Holman & Lorig, 1997). The World Health Organization includes self-management as a best practice to improve clinical care and outcomes for chronic diseases (World Health Organization, 2001). A review of the literature on chronic disease self-management to highlight HIV-specific challenges showed that there are common elements or tasks in chronic disease self-management that fit within the categories of physical health, psychological functioning, and social relationships (Swendeman, Ingram, & Rotheram-Borus, 2009). Self-management programs should include treatment adherence, but this must be nested within a variety of other skillsets, including cognitive techniques for side effect and symptom management, working with healthcare providers, understanding laboratory tests, managing fatigue, and healthy eating and exercise (Gifford & Groessl, 2002). In the section below, we review some of the major factors affecting chronic disease management, including (1) comorbid conditions, (2) quality of life, and (3) stigma.

Quality of Life

As the course of the HIV epidemic has changed with ART, so have the challenges that affect the health-related quality of life of people living with HIV. Health-related quality of life refers to how well one functions and one's perceptions of one's own well-being in physical, mental, and social domains of life (CDC, 2011a). Understanding health-related quality of life among people living with HIV is important as it helps to determine the burden of chronic disease, changes in health over time, and treatment effectiveness.

Research suggests that compared to the general population, people living with HIV have worse health-related quality of life. However, this depends on disease stage and quality of life domain (Imam, Flora, et al., 2012). Individuals who have HIV and are asymptomatic report physical functioning similar to the general population, whereas not surprisingly those who are symptomatic or have AIDS report worse physical functioning (Hays, Cunningham, et al., 2000). In comparison, individuals living with HIV/AIDS regardless of symptoms seem to experience worse emotional functioning or mental health compared to the general population. Further, emotional well-being appears to be worse for people at all stages of HIV than for individuals who have other chronic diseases (e.g., diabetes, multiple sclerosis, end-stage renal disease) but better than individuals with clinical depression (Hays, Cunningham, et al., 2000).

A number of demographic, psychological, and social factors are associated with better health-related quality of life. This includes being employed, higher income, better social support, spirituality/religiousness, engaging in active and positive coping, and physical activity/exercise (Hays, Cunningham, et al., 2000; Remor, Fuster, et al., 2012). From a stress-coping perspective, individuals who utilize adaptive and active coping strategies appear to experience better quality of life than individuals who use maladaptive or passive coping strategies. This body of knowledge has helped lead to the development of interventions aimed to improve quality of life among individuals living with HIV (Brown & Vanable, 2011).

One type of intervention to improve quality of life has focused on exercise. Exercise training improves and maintains health and has been considered an important adjuvant therapy for HIV-positive patients (American College of Sports Medicine, 2006; Stringer, 1999). There has been a focus on improving both physical strength and endurance concurrently. A review of randomized controlled trials testing the efficacy of this concurrent training on health-related quality of life showed that it is safe and may be beneficial for medically stable adults living with HIV (Gomes Neto, Ogalha, et al., 2013). Thus, concurrent training may be an important intervention in the care of people living with HIV.

Other approaches focus on targeting psychological factors and mental or spiritual health (e.g., Brown, Hanson, et al., 2013). One particular intervention that appears to be more comprehensive and efficacious in improving quality of life, as well as HIV outcomes like viral load, uses Cognitive Behavioral Stress Management (CBSM). CBSM interventions directly focus on reducing stress and teaching cognitive coping skills and also indirectly impact perceived environmental control and self-efficacy, thereby also influencing positive social support. CBSM interventions provide relaxation skills training, social skills training, instruction in self-monitoring of environmental stressors, and teaches cognitive restructuring techniques. There is evidence among different populations affected by HIV (e.g., HIV-positive gay men) that CBSM can positively influence a number of outcomes, including reducing sexual risk behavior (Coates, McKusick, et al., 1989), depressed mood (Kelly, Murphy, et al., 1993), and CD4 count (Antoni, Baggett, et al., 1991).

Acknowledging the value of health-related quality of life among people living with HIV means recognizing the significance of mental health. HIV/AIDS is one of the most biologically "strong" diseases with which we deal, yet the roles of emotions and mental health are also substantial. Mental disorders (e.g., depression, bipolar disorder, schizophrenia) make individuals more vulnerable to behaviors that transmit HIV and interfere with HIV treatment adherence (Vlassova, Angelino, & Treisman, 2009). While ART works to improve immune functioning and overall physical health, improving mental well-being should also be a primary goal in prevention for HIV-positive individuals. As others have previously stated, there is "no health without mental health" (Prince, Patel, et al., 2007). Also, improved mental health is associated with other healthy outcomes, including a lower likelihood of substance use, reduced sexual risk behavior, and improved adherence to care and treatment (Sikkema, Watt, et al., 2010). Ultimately then, better mental health among HIV-positive individuals may lead to a reduction in HIV transmission. Secondary prevention efforts must include mental health treatment.

Comorbid Conditions

The most common comorbid conditions with HIV are substance use disorders and depression (Bing, Burnam, et al., 2001). People who receive treatment for substance use are more likely to be HIV-infected than the general population (Woods, Lindan, et al., 2000). Further, data from a large, nationally representative US sample revealed that both substance use and HIV increase the likelihood of having major depression (Hasin, Goodwin, et al., 2005). Depression among people living with HIV is relatively common and may result from multiple stressors including reduced social support, social isolation, and increased exposure to violence (Kokkevi & Stefanis, 1995).

The co-occurrence of HIV and comorbid conditions is associated with reduced self-care, including poor HIV medication adherence and high-risk behavior. For example, in a study of individuals living with HIV who also had an alcohol use disorder, lower self-efficacy was associated with poor medication adherence, which in turn affected viral load (Parsons, Rosof, & Mustanski, 2008). In another study of gay and bisexual men at an outpatient substance abuse treatment, the co-occurrence of HIV and psychiatric diagnoses, including major depressive disorder and social phobia, were associated with an increased likelihood of STIs (Shoptaw, Peck, et al., 2003). A meta-analysis has also shown that depression is related to accelerated immune system decline and mortality in people living with HIV (Herbert & Cohen, 1993), and a study done with HIV-positive persons from a community health center showed that this relationship exists even beyond the effects of ART nonadherence (Safren, Otto, et al., 2001). A body of research has also shown that poor health conditions co-occur and interact synergistically to contribute to higher-risk behavior and ultimately HIV transmission.

Substance abuse, violence, and AIDS have been understood to co-occur in what has been labeled a syndemic or the co-occurrence of two or more epidemics that interact and synergistically contribute to excess burden of disease in a population (Singer, 1996; Singer & Clair, 2003). Since initially proposed and modeled, researchers have used syndemic theory to examine HIV risk in high-risk and vulnerable populations, including urban ethnic minorities, MSM, and women in resource poor settings (González-Guarda, Florom-Smith, & Thomas, 2011; Parsons, Grov, & Golub, 2012; Pitpitan, Kalichman, et al., 2013; Stall, Mills, et al., 2003). This research has shown that individuals who experience multiple comorbid conditions, including but not limited to depression, history of childhood abuse, history of intimate partner violence, and substance use, are more likely to engage in high sexual risk behavior. A consistent finding is that the relationship is linear, such that individuals who report more psychosocial conditions report higher-risk behavior, and in some samples a higher likelihood of being or becoming HIV infected. Indeed, people are less likely to effectively engage in self-care and self-protection when they are dealing with a number of difficult conditions in their lives. This suggests that HIV interventions must be multifaceted to treat the whole person, not solely the disease.

To address this gap in current interventions, a sexual risk and stress reduction intervention was recently developed and tested for HIV-positive African-American MSM with childhood sexual abuse histories (Williams, Glover, et al., 2013). Compared to a general health promotion intervention, the stress-focused intervention was more efficacious in decreasing unprotected anal insertive sex and reducing depression symptoms (Williams, Glover, et al., 2013). This was observed for MSM with histories of both high and low childhood sexual abuse severity. In another culturally specific HIV risk reduction intervention for Hispanic women (SEPA [Salud/Health, Educación/Education, Promoción/Promotion, Autocuidado/Self-care]), there were five sessions covering STI and HIV prevention, communication, condom negotiation and condom use, and violence prevention (Peragallo, Gonzalez-Guarda, et al., 2012). SEPA was efficacious in decreasing STI incidence, improving condom use, decreasing substance abuse and intimate partner violence, and improving communication with partner (Peragallo, Gonzalez-Guarda, et al., 2012). These select interventions demonstrate that addressing comorbidities or syndemic problems can successfully improve multiple health outcomes.

Stigma

Perhaps nothing is more embedded into the multiple facets of the lives of people living with HIV than stigma. The social stigma attached to HIV is the process of being labeled, stereotyped, devalued, and discriminated against as a function of being HIV positive (Goffman, 1963; Link & Phelan, 2001). The underlying processes surrounding stigma are complex as stigma is socially constructed and is tied to concerns for power and dominance (Parker & Aggleton, 2003). Generally speaking, fear of contagion and negative, morally driven, and value-based assumptions about people who have HIV and its transmission helps to account for the severe stigma attached to the disease (Jones & French, 1984). People living with HIV encounter a great deal of prejudice and discrimination at multiple levels and domains of life.

At an institutional level, people living with HIV are affected by their government's laws and policies about or related to HIV. For example, HIV-positive individuals were denied access to care and treatment under the presidency of Thabo

Mbeki, and the United States currently denies federal funding for syringe exchange programs, which have shown to be instrumental in reducing HIV risk among injecting drug users. At an interpersonal level, people living with HIV often experience discrimination from employers and co-workers, are refused access to medication and health facilities, and are isolated by friends and family. Finally, at an individual level, many people living with HIV personally endorse or internalize the negative beliefs and feelings about being HIV positive, which can result in self-isolation from social supports and healthcare. Consequently, HIV stigma is associated with poor mental health, social and physical isolation, reduced access to care and treatment, higher transmission risk behavior, poor medication adherence, and overall poor quality of life. Worsening the situation is the fact that social stigmas are also attached to virtually all of the frequent comborbid conditions with HIV, including drug abuse, violence victimization, and mental health.

Despite its pervasiveness and the negative outcomes associated with HIV stigma, researchers have done relatively little to acknowledge it in HIV treatment and prevention efforts. This neglect has much to do with inconsistent definitions and relatedly an absence of good measurement tools. In an effort to provide direction to HIV researchers, Earnshaw & Chaudoir (2009) put forth an HIV stigma mechanism model that outlined how HIV stigma can operate from the perspective of the target and the perpetrator. That is, from the perspective of the person who is doing the devaluing and discrimination and of the person who is being devalued and discriminated against. Using this approach, HIV-positive individuals can experience stigma in three ways. One is anticipated stigma, or the extent to which an individual expects to be evaluated and treated negatively as a function of their HIV status. The second is enacted stigma, or the extent to which the individual believes they have experienced prejudice and discrimination from others. Third, as previously mentioned, is internalized stigma, or the extent to which the individual herself or himself endorses the negative beliefs, attitudes, and feelings toward people with HIV.

HIV stigma would be ideally tackled with community and political involvement to institute protections for and reduce prejudice and discrimination toward HIV-positive persons. This can include but is not limited to collective action efforts and public education about HIV and its transmission with the aim of reducing or eliminating the social stigma attached to HIV. HIV prevention interventions may also intervene at one or more of these stigma mechanisms. For example, prevention programs might incorporate strategies to reduce anticipated or internalized stigma among people living with HIV. A review of HIV stigma reduction interventions showed that a number of strategies exist for targeting stigma at its multiple levels (Heijnders & Van Der Meij, 2006). At the individual level, different counseling approaches may help to decrease perceived stigma. These include counseling to reduce emotional distress following an HIV test (Simpson, Johnstone, et al., 1998), selective disclosure of HIV status (Kaleeba, Kalibala, et al., 1997), and cognitive therapy to help reduce internalized stigma (Chan, Kong, et al., 2005; Corrigan & Calabrese, 2005). Self-help, advocacy, and support groups also appear to help reduce stigma at the individual level (Lyon & Woodward, 2003). At the interpersonal level, intervention strategies include educating family, community members, and healthcare providers to help eradicate negative attitudes and beliefs among persons potentially providing care to individuals with HIV (Kidd & Clay, 2003). Both the Memory Book Project in Uganda and the Yale Program for HIV-affected children and families are examples of projects aimed at helping individuals come to terms with stigma, secrecy, disclosure, and loss (Gewirtz & Gossart-Walker, 2000). Finally, at the institutional level, programs to reduce stigma target organizations like the workplace. For example, some projects have targeted instances of discrimination, like mandatory testing of applicants (Busza & Schunter, 2001; POLICY Project, 2003). Other strategies include advocacy and protest (Corrigan & Penn, 1999).

Global Review of Risk Environment Integration into HIV Prevention Interventions

The preceding pages have reviewed theoretical, practical, and disease-specific issues in preventing and managing HIV/AIDS. This has included recognition of the frequent connection between these, as in secondary prevention of AIDS among HIV+ individuals, and the importance of treatment of AIDS to prevent HIV transmission. Thus, HIV/AIDS illustrates a continuum from primary prevention through chronic disease management, as opposed to a view of these as distinct categories. This final section reviews global efforts in these areas, illustrating as noted above how theories and general knowledge about the disease, its prevention, and management need to be tailored to the circumstances in different regions and among different populations. In the interest of economy, we have emphasized prevention, but, as will be seen, many of the prevention efforts reviewed carry over and include elements of treatment and management. This review is selective, not comprehensive. Our examples will highlight strategies used in each setting, with an emphasis on how theories may have been appropriately or inappropriately applied. We conclude with guidance for future intervention efforts that utilize combination HIV prevention methods.

The United States

The Centers for Disease Control and Prevention estimate that more than one million people in the United States are living with HIV (Centers for Disease Control and Prevention, 2008). HIV disproportionately affects certain population groups: MSM, African-Americans, and Latinos. MSM account for more than half of all new HIV infections in the United States, and they are the only risk group in which new HIV infections have been increasing steadily since the early 1990s (Centers for Disease Control and Prevention, 2010; Prejean, Song, et al., 2011). During the period 2006–2009, African-Americans and Latinos consistently had rates of new HIV infection that were 7–8 and three times the rate for whites, respectively (Prejean, Song, et al., 2011). Moreover, in 2009, the rate of new infections among African-American and Latina women were 15 and four times that of white women, respectively (Prejean, Song, et al., 2011). The course of the HIV epidemic in the United States has also been fueled by drug use. The National Institute on Drug Abuse estimates that 25% of all infections are drug related (National Institute on Drug Abuse, 2011).

Numerous evidence-based HIV prevention interventions have been rigorously evaluated in these at-risk populations and have shown significant effects in reducing sex- or drug-related risk behaviors, reducing the rate of new HIV/STI infections, or increasing HIV-protective behaviors. For this region, we present select examples of theory-driven risk reduction interventions, most of which are recommended by the CDC as best-evidence interventions and proven to be efficacious in the populations that are most at risk.

Men Who Have Sex with Men

Tailored for black MSM, *Many Men Many Voices (3MV)* is a group-level intervention guided by Social Cognitive Theory (defined in the section on behavioral theories), Behavioral Skills Acquisition Model, and Transtheoretical Model of Behavior Change and the Decisional Balance Model. The Behavioral Skills Acquisition Model emphasizes effective characteristics for risk reduction counseling (e.g., assessing a person's knowledge of risk behaviors and risk reduction strategies; ensuring an individual's accurate perception of personal degree of risk, building confidence; ensuring commitment and intention to change; developing strategies to reinforce change; incorporating positive attitudes and effective listening skills with participants) (Kelly, 1995). The Transtheoretical Model of Behavior Change focuses on emotional, cognitive, and behavioral factors that influence an individual's decision to change behavior. Stages of Change, as described in the Stages of Change Theory section, is a concept central to the Transtheoretical Model of Behavior Change (Prochaska, Redding, et al., 1994). The Decisional Balance Model suggests that cognitive and motivational factors influence a person's perceptions about making decisions. Decisional balance assumes that behavior change occurs when an individual perceives change as a gain rather than a loss (Janis & Mann, 1977).

The *3MV* intervention addresses behavioral determinants and the micro-social environment (e.g., cultural, social, and religious norms, identity of black MSM, degree of connectedness to the black and gay communities, racism, homophobia). A unique component of *3MV* is the development of menus of behavior change options for HIV/STI prevention rather than a singular emphasis on condom use that is common in other HIV prevention interventions for MSM (Wilton, 2009). Some of these behavior change options include helping participants recognize how racism and homophobia are related to sexual and substance use risk behaviors, identifying the power and control dynamics that exist in their relationships, and enhancing participants' intentions to change their own risky behaviors (Wilton, 2009). This intervention was shown to be efficacious among a sample of 338 black MSM of HIV negative or unknown HIV serostatus in New York City. Specifically, participants randomly assigned to the *3MV* intervention reported significantly greater reductions in unprotected anal intercourse with casual male partners and number of male sex partners, consistent condom use during receptive anal intercourse with casual male partners, and increases in HIV testing (Wilton, 2009).

For HIV-positive MSM, the *Seropositive Urban Men's Intervention Trial* (*SUMIT*) used enhanced peer-led intervention to reduce sexual risk behaviors. The *SUMIT* intervention is guided by the Theory of Planned Behavior, Social Cognitive Theory, and Information-Motivation-Behavioral Skills Model without consideration of the risk environment (Wolitski, Parsons, et al., 2005). It is led by HIV-positive gay or bisexual peer facilitators. Structured group activities focus on sexual and romantic relationships, HIV/STI transmission, drug and alcohol use, assumptions about the HIV status of sex partners, disclosure of HIV status, and mental health (Wolitski, Parsons, et al., 2005). Compared with the standard intervention, fewer men assigned to the enhanced intervention reported unprotected receptive anal intercourse with a HIV-negative or serostatus-unknown partner at 3 months; however, there were no other significant differences in transmission risk or serostatus disclosure at 3 or 6 months (Wolitski, Gomez, & Parsons 2005).

Finally, a theory-based, psychosocial intervention for HIV-positive MSM, known as the *EDGE* study, was developed to reduce sexual risk behaviors in the context of ongoing drug use, a unique feature in HIV prevention research. The *EDGE* intervention study used a clinical approach, combining motivational interviewing with elements from Social Cognitive Theory and the Theory of Reasoned Action (Mausbach, Semple, et al., 2007). Motivational interviewing is a client-centered, process-oriented counseling approach that incorporates feedback on current behavior, emphasizes readiness for change and personal responsibility for change, delineates alternative strategies for changing behaviors, and promotes counselor empathy and support. To a certain degree, the macro-social environment (e.g., peer and social norms) was addressed in the course of the intervention sessions. Participants in the EDGE intervention demonstrated a significantly greater percentage of protected sex acts at 12 months post-baseline, as well as a greater increase in self-efficacy for condom use over time (Mausbach, Semple, et al., 2007).

Ethnic Minorities

To address the significant impact of HIV among Latinas, the *Women's Health Promotion (WHP) program* has been used for Spanish-speaking, heterosexual, HIV-negative women (Raj, Amaro, et al., 2001). WHP utilizes tenets of the Social Cognitive Theory, the Theory of Reasoned Action, and the Health Belief Model to reduce risky sexual behavior among a community-based sample of Latinas in Boston. In addition to HIV/STD education, condom practice, and negotiation skills, *WHP* included participant-suggested sessions that addressed aspects of the women's micro-social environment such as intimate partner violence, oppression, social justice, and non-HIV-related partner communication, as well as comprehensive health issues (e.g., mental health, depression, cervical cancer, diabetes, nutrition). Facilitators used psychoeducational strategies through lectures, group discussion, skill-building games, and role playing exercises (Raj, Amaro, et al., 2001). Women in the *WHP* intervention group demonstrated a substantial increase in condom use at the 3-month follow-up evaluation in comparison to women in the control group, who received only HIV prevention material and referrals (Amaro, Raj, et al., 2002). To date, the *WHP* remains the only program on the CDC Best Evidence list that is solely for adult Latinas and is culturally and linguistically tailored to their needs. Although it integrates some components from the micro-social environment, there was lack of evidence of improvements in those components in the 15-month post-intervention follow-up.

The *Eban* HIV/STD risk reduction intervention demonstrates the willingness of couples, specifically African-American HIV-serodiscordant couples, to participate in HIV prevention interventions. *Eban* integrates components of Social Cognitive Theory, such as historical and cultural beliefs about family and community preservation, and an Afrocentric paradigm into a relationship-oriented ecological framework (El-Bassel, Jemmott, et al., 2010). This intervention, facilitated by male and female African-Americans, included four sessions with individual couples and four sessions with groups of couples. Individual couple sessions were designed to address interpersonal factors associated with sexual risk reduction, including communication, problem solving, monogamy, and negotiation skills, while group sessions addressed community-level factors, including (1) increasing positive peer norms for condom use by emphasizing the threat of HIV to African-American communities, (2) reducing the stigma associated with being African-American couples affected by HIV, and (3) increasing social support for HIV risk reduction (El-Bassel, Jemmott, et al., 2010). *Eban* was conducted in four major US cities: Atlanta, Los Angeles, New York, and Philadelphia, and it reported significant reductions in HIV/STD risk behaviors among African-American HIV-serodiscordant couples (El-Bassel, Jemmott, et al., 2010).

Finally, the *SHIELD* program is a peer network-oriented HIV prevention intervention based on Social Identity Theory and peer outreach that was implemented for predominantly African-American HIV-positive and HIV-negative drug users (Latkin, Sherman, & Knowlton, 2003). Participants were asked to make public commitments to increase their own health behaviors and to promote HIV prevention within their social networks and community contacts. The intervention included multiple sessions for training and skill building that involved goal setting, role plays, demonstrations, and group discussions. To present HIV risk within a broader community context, the intervention emphasized the interrelatedness of HIV risk among individuals, their risk partners, and their community. The *SHIELD* intervention showed that by emphasizing pro-social roles and social identity and incorporating peer outreach strategies, interventionists could reduce HIV risk in low-income, drug-using communities (Latkin, Sherman, & Knowlton, 2003).

Western and Central Europe

In Western Europe, MSM were the most commonly diagnosed risk group through 1998. After that year, persons with heterosexual contact have been diagnosed more commonly (Sullivan, Hamouda, et al., 2009). Importantly, however, in Western Europe, MSM remain the group most at risk of acquiring HIV (Sullivan, Hamouda, et al., 2009). In France, for example, MSM accounted in 2009 for more than half the men newly diagnosed with HIV, yet they represented only 1.6% of the country's population (UNAIDS, 2010). In 2007, 3160 new HIV diagnoses were reported among MSM in the United Kingdom, the most ever among that group up to that point (UNAIDS, 2010). Few behavioral HIV prevention interventions have been rigorously evaluated for MSM in Europe; the paucity of studies demonstrates the need for prevention efforts in this area (Berg, 2009).

One of the few interventions designed for MSM with a prior STI diagnosis was conducted in a sexual health clinic in London, England, and drew upon the Transtheoretical Model of Behavioral Change, the Model of Relapse Prevention that focuses on the maintenance phase of the habit change process, and elements from Social Learning Theory (Imrie, Stephenson, et al., 2001). This cognitive behavioral intervention consisted of a one-day cognitive behavioral workshop in addition to a standard, 20-min, one-on-one counseling session through motivational interviewing techniques about sexual risk behaviors. Although this intervention was acceptable to participants and feasible to deliver, it did not succeed in reducing the risk of acquiring a new STI in MSM (Imrie, Stephenson, et al., 2001).

Similar findings were observed for community-based, peer-led interventions modeled after successful opinion leader interventions in the United States (Elford, Sherr, et al., 2002; Flowers, Hart, et al., 2002). For example, *The Gay Men's Task Force* (*GMTF*) intervention was an interagency collaboration in Scotland consisting of three elements, all independently shown elsewhere to be effective in promoting gay men's sexual health but combined here for the first time (Flowers, Hart, et al., 2002). These elements included (1) peer-led sexual health promotion conducted on the commercial gay scene, (2) gay-specific genitourinary medicine services in both hospital and gay community settings, and (3) a free phone "hotline" providing sexual health information and details of local sexual health services (Flowers, Hart, et al., 2002). The *GMTF* intervention did not produce community-wide changes in sexual risk behaviors, but there was higher uptake of hepatitis B vaccination and HIV testing (Flowers, Hart, et al., 2002). The ineffectiveness of the program's intervention for sexual risk behaviors contrasted starkly with the results of North American studies that had shown that peer education was effective for HIV prevention among MSM (Elford, Sherr, et al., 2002; Flowers, Hart, et al., 2002). This suggests that a model of peer education shown to be effective in one country may not be directly transferable to another and may need to be modified according to the risk environment in the target country.

Eastern Europe and Central Asia

In Eastern Europe and Central Asia, the number of people living with HIV has almost tripled since 2000 and reached an estimated 1.4 million in 2009 compared with 760,000 in 2001. The Russian Federation and Ukraine account for almost 90% of newly reported HIV diagnoses (UNAIDS, 2010). Since the early 2000s, there has been a rapid rise in HIV infections among people who inject drugs, causing HIV infection rates in this region to surge. The epidemic is concentrated among IDUs, sex workers and their clients, and, to a much lesser extent, MSM (UNAIDS, 2010). The availability and content of HIV prevention interventions for IDUs have been affected by the region's macro-political environment.

The response in many countries in the region has been heavily influenced by the legacy of the former Soviet Union, with its emphasis on the medical discipline of "narcology" (a subspecialty of psychiatry) to tackle drug dependence and harms. The Russian Federation, the largest country in the region, prohibits the provision of opioid substitution therapy (OST). Similarly, IDUs in Ukraine have traditionally been stigmatized, had no access to treatment, and had little access to prevention. However, in the last few years (and due in part to two large Global Fund grants administered by nongovernmental organizations), Ukraine has made significant improvements in the provision of harm reduction and HIV treatment for IDUs. By mid-2007, 645 needle and syringe programs (NSP) sites had reached more than 120,000 people, and by 2009, Ukraine was one of only seven countries in the world with more than 1000 of these sites (Mathers, Degenhardt, et al., 2010). Additionally, the government recently amended national policies to permit methadone maintenance treatment (MMT).

Although NSPs have been implemented in nearly all countries in the region, overall levels of coverage for the region are low, largely because of low levels of needle-syringe provision in

Russia; although there and in other countries, IDUs can purchase needles in pharmacies. And even though most countries have implemented OST programs, the scale of programs is very limited, with one person receiving OST for every 100 IDUs (Mathers, Degenhardt, et al., 2010). The most significant challenge in the region for IDUs is national policies, particularly in the Russian Federation, that oppose proven, effective, and cost-effective interventions to reduce HIV transmission and acquisition.

South and Southeast Asia

In Asia, an estimated 4.9 million people were living with HIV in 2009, and 360,000 were newly infected (UNAIDS, 2010). However, most national HIV epidemics appear to have stabilized, and no country in the region has a generalized epidemic. Asia's HIV epidemic remains concentrated largely among IDUs and FSWs and their clients (UNAIDS, 2010). HIV prevention interventions for IDUs and FSWs in the region have focused largely on the macro-political risk environment without the guidance of behavioral theories.

In 2008, according to the Reference Group to the United Nations on HIV and Injecting Drug Use, of the estimated 15.9 million (11.0–21.2 million) IDUs globally, 3.9 million (3.5–5.6 million) or 25% live in South, East, and Southeast Asia (Mathers, Degenhardt, et al., 2008). In China, where IDUs account for the largest number of HIV infections, MMT, NSPs, and drug addiction, treatment facilities have been at the forefront of HIV prevention (Chu & Levy, 2005; Li, He, et al., 2009; Qian, Schumacher, et al., 2006). In 2004, a National Task Force comprising the Ministry of Health, Ministry of Public Security, and State Food and Drug Administration was set up in accord with new national guidelines for methadone treatment and NSPs (Chu & Levy, 2005). Methadone treatment for IDUs was initiated as a first-stage pilot program in select provinces. After a 12-month follow-up of IDUs in eight MMT clinics, drug injection rate, drug injection frequency, and needle sharing rate had dramatically declined. By the end of 2007, over 500 officially recorded MMT clinics were available for 40% of heroin abusers, and by 2010, coverage was expected to increase to 70% (Li, He, et al., 2009). NSPs have also produced decreases in needle sharing and HIV infection rates. By the end of 2007, NSPs served at least 30% of officially registered IDUs, and by 2010, coverage was expected to increase to 50% of IDUs (Li, He, et al., 2009). The Chinese government has also actively sought to collaborate with neighboring countries to prevent drug smuggling across borders, discourage new users through anti-drug education campaigns, treat current users through various drug detoxification programs, and encourage community outreach programs to facilitate detoxification, rehabilitation, and harm reduction (Chu & Levy, 2005; Li, He, et al., 2009; Qian, Schumacher, et al., 2006).

For FSWs in the region, the most ambitious and innovative HIV prevention intervention has been the 100% Condom Use Program launched in 1989 in Thailand. The goal of the 100% Condom Use Program was to promote universal use of condoms in commercial sex venues to prevent HIV transmission (Rojanapithayakorn, 2006). Public health officials, brothel owners, local police, and FSWs collaborated at provincial and local levels to implement the program. FSWs were screened for STIs weekly or semi-weekly at government STD clinics, treated, and provided with a box of 100 free condoms. Compliance was checked by tracing male STI patients back to the brothels where they presumably were infected. Health workers could then follow up with visits to the brothels, providing additional information and condoms. The cooperation of law enforcement was also sought; potential sanctions for failing to comply with the program included the threat of closure of the sex establishment (Ainsworth, Beyrer, & Soucat, 2003). The program has increased the use of condoms in sex work from 14% early 1989 to over 90% since 1992, and the number of men presenting to government clinics for STI treatment dropped by 90% from 1989 to 1995 (Ainsworth, Beyrer, & Soucat, 2003; Kilmarx, Palanuvej, et al., 1999). Moreover, the number of FSWs has declined by 25% since 1989 (Kilmarx, Palanuvej, et al., 1999). Thailand is the only country in this region in which HIV prevalence is close to 1%, and its epidemic appears to be stable overall (UNAIDS, 2010). Since its introduction in 1989, this program has also been successfully implemented in Cambodia, the Philippines, Vietnam, China, Myanmar, Mongolia, and Laos, with variations in program components between countries (e.g., formation of FSWs' self-help groups, peer education, issuance of membership cards by local authorities) (Rojanapithayakorn, 2006).

Middle East and North Africa

An estimated 460,000 people were living with HIV in the Middle East and North Africa at the end of 2009, up from 180,000 in 2001 (UNAIDS, 2010). The number of people newly infected has also increased over the last decade; there were 75,000 people newly infected in 2009, more than twice the number in 2001 (UNAIDS, 2010). The general pattern in different countries in the Middle East and North Africa points toward an HIV epidemic heavily concentrated among IDUs and among prisoners who are also IDUs, with heterogeneity between countries dependent on the relative role of each of these high-risk groups (Abu-Raddad, Hilmi, et al., 2010; McFarland, Abu-Raddad, et al., 2010).

Interventions for IDUs and IDU prisoners in the region have centered around the macro-political risk environment but without the use of theories and biomedical models. Although drug use via injection has been identified in every country in the region, only 35% of countries have implemented NSPs and even fewer (13%) have implemented OSTs (Mathers, Degenhardt, et al., 2010). In many African countries, laws prohibiting opioids for treatment of pain have created a barrier to prescribing OST, although some promising changes have recently occurred, for example, in Morocco, where the use of MMT has recently been approved (Mathers, Degenhardt, et al., 2010). Regarding NSPs, evidence has been gathered in Tehran, Iran, that access to an NSP may reduce needle- and syringe-sharing practices among community-based IDUs (Zamani, Farnia, et al., 2010).

For IDU prisoners, the political response toward harm reduction programs has been gradual and limited to Iran, where the largest number of people who inject drugs reside (UNAIDS, 2010). Iran, like many countries, began with a supply reduction policy that criminalized any type of drug use, in any quantity (Razzaghi, Nassirimanesh, et al., 2006). Efforts in the early 1990s resulted in policy changes, and although supply reduction approaches continued, the revised policy allowed the Iran Prison Organization (IPO) to adopt harm reduction policies and implement comprehensive HIV prevention interventions for IDU prisoners in many provinces throughout the country (Farnia, Ebrahimi, et al., 2010). The IPO's main activities include drug treatment and prevention programs that encompass MMT, pilot NSPs, education, and epidemiological surveillance (Eshrati, Asl, et al., 2008; Razzaghi, Nassirimanesh, et al., 2006). Iran is the only country in the Middle East or North Africa that has introduced MMT for opioid-dependent prisoners (Farnia, Ebrahimi, et al., 2010). There are currently 142 clinics across the country's 30 provinces that provide MMT to male and female opioid-using prisoners, and most of the large correctional facilities in the 30 provinces have established MMT programs (Farnia, Ebrahimi, et al., 2010). The Iran Prison Organization's HIV prevention package, with MMT programs constituting a main component, is an exceptional model for other countries in the region (Farnia, Ebrahimi, et al., 2010). It is perceived as effective in reducing illicit drug injection in a prison setting as well as for preventing the transmission of blood-borne infections, including HIV, among prisoners (Farnia, Ebrahimi, et al., 2010).

Sub-Saharan Africa

Sub-Saharan Africa still bears an inordinate share of the global HIV burden. Although the rate of new HIV infections has decreased, the total number of people living with HIV continues to rise, with a 2009 estimate of 22.5 million, 68% of the global total (UNAIDS, 2010). Women represent the majority of those infected and the majority of those dying. Heterosexual sex is the main mode of transmission in the region (Kilmarx, 2009). The key risk factors for heterosexual transmission are transactional or paid sex, concurrent sex partners, high number of lifetime sex partners, coinfection with viral and bacterial STIs, notably herpes simplex virus type 2 (HSV-2), and lack of male circumcision (Chen, Jha, et al., 2007).

Successful HIV prevention interventions have targeted the micro-social, economic, and political environments. Because gender inequalities (i.e., intimate partner violence, relationship power differentials) and lack of economic opportunities for both sexes often contribute to increased rates of HIV infection in women in sub-Saharan Africa, there has been recognition of the need for structural HIV prevention interventions such as microfinance programs. Microfinance programs seek to alleviate poverty by providing access to credit, savings, or business skills (Dworkin & Blankenship, 2009). In addition to providing economic benefits, microfinance may be an effective vehicle for women's empowerment, and newly acquired business skills may be accompanied by improvements in self-esteem and self-confidence, ability to resolve conflicts, household decision-making power, and expanded social networks (Kim, Watts, et al., 2007; Kim, Askew, et al., 2009).

The *Intervention with Microfinance for AIDS and Gender Equity (IMAGE)* study, implemented in South Africa, combined two elements: a poverty-focused microfinance initiative that targeted the poorest women and a two-phase learning and action curriculum of gender and HIV education. The *IMAGE* study's goal was to improve household economic well-being, social capital, and empowerment and thus reduce vulnerability to intimate partner violence and HIV infection. Over a 2-year period, rates of intimate partner violence were reduced by 55% in women enrolled in the intervention group compared to those in the control group; there was also improvement in numerous indicators of empowerment (e.g., challenging gender norms, autonomy in decision-making, communication within the household) (Pronyk, Hargreaves, et al., 2006). Regarding HIV outcomes, young women who took part in the intervention showed significantly higher levels of HIV-related communication, were more likely to have accessed voluntary counseling and testing, and were less likely to have had unprotected sex at last intercourse with a non-spousal partner (Pronyk, Kim, et al., 2008). However, the rate of unprotected sex among youth living in the households of intervention participants did not show a significant reduction (Pronyk, Hargreaves, et al., 2006). This result suggests that the intervention may be more effective for participants directly involved in the program than for those who received the intervention through diffusion (Dworkin & Blankenship, 2009).

Observational evidence has accumulated concerning the effectiveness of male circumcision for reducing HIV infection among men in sub-Saharan Africa. The causal association has been confirmed by three large randomized controlled trials conducted in South Africa, Kenya, and Uganda (Auvert, Taljaard, et al., 2005; Bailey, Moses, et al., 2007; Gray, Kigozi, et al., 2007). Among 3274 uncircumcised men aged 18–24 in South Africa, those randomized to immediate circumcision showed a protection from HIV infection of 61% after accounting for sexual risk behaviors (which increased in the intervention group) (Auvert, Taljaard, et al., 2005). Among 2784 men of similar ages in Kisumu, Kenya, the protection effect of circumcision was also 60% (Bailey, Moses, et al., 2007). Finally, in a trial in Rakai, Uganda, 4996 adult, HIV-negative men aged 18–49 were randomly assigned to either immediate circumcision or circumcision delayed for 24 months. HIV incidence among the circumcised men was significantly reduced compared with the uncircumcised (control) participants. The efficacy of circumcision for preventing incident HIV was 51% in the intention-to-treat analysis; adjustment for enrollment characteristics, behaviors, and symptoms of STIs did not affect this estimate (Gray, Kigozi, et al., 2007). All three trials were halted early by their respective data and safety monitoring boards (Padian, Buve, et al., 2008). The trials also assessed whether male circumcision could lead to sexual disinhibition because men might believe that they were protected against HIV infection after circumcision. In Kenya and Uganda, there was no evidence for an increase in sexual risk behaviors (Bailey, Moses, et al., 2007; Gray, Kigozi, et al., 2007). However, in South Africa, 21 months after the intervention, the circumcised men reported significantly greater numbers of sex partners per month than those in the delayed circumcision group (Auvert, Taljaard, et al., 2005). The success of this biomedical HIV intervention laid the foundation for rapid and intensive scale-up in some countries; however, in other countries, policy makers have been slow to support male circumcision (Padian, McCoy, Karim, et al., 2011).

Latin America and the Caribbean

In Latin America and the Caribbean, an estimated 1.7 million people were HIV positive in 2007, of whom 140,000 were newly infected (UNAIDS, 2010). More than half of Latin Americans living with HIV reside in the region's four largest countries: Brazil, Columbia, Mexico, and Argentina (Avert, 2011). Although MSM account for a significant proportion of HIV infections in Latin America, sex work and injection drug use have also emerged as significant routes of HIV transmission.

Among FSWs in Mexico, recent interventions have been primarily theory based, with an overlapping emphasis on FSWs' injection drug use behavior and on their clients' behaviors. As a result of these interventions, future directions have been identified that incorporate the risk environment. In Tijuana and Ciudad Juarez, FSWs were enrolled in a behavioral intervention to increase condom use under the premises of Social Cognitive Theory (Strathdee, Mausbach, et al., 2009). This intervention integrated motivational interviewing (e.g., key questions, reflective listening, summarization, affirmation, and appropriate use of cultural cues) and principles of behavior change. Improvements in self-efficacy were predictive of significant increases in condom use with clients among FSWs who received the intervention. And among FSW-IDUs, those who improved in HIV knowledge were more likely to increase condom use with clients (Strathdee, Mausbach, et al., 2009). Recognizing the need to integrate a harm reduction component promoting safer injection as well as safer sex negotiation, Strathdee and colleagues expanded the intervention for FSW-IDUs to include an injection risk reduction component (NIHReporter, 2011a). Additionally, clients of FSWs may serve as a bridge population for transmission of HIV from high- to low-prevalence populations (Goldenberg, Strathdee, et al., 2011).

Few behavioral interventions designed to reduce FSWs' risk of contracting HIV have considered the FSWs' clients. To address this lack, one intervention that is based on Social Cognitive Theory targets US and Mexican clients of FSWs in Tijuana. It uses motivational interviewing, active participation, and problem solving to increase clients' use of condoms with FSWs (NIHReporter, 2011b). In the US-Mexico border region, extensive research has identified numerous factors in FSWs' risk environment that can be taken into account for the development of future interventions for FSWs and FSW-IDUs. The factors range from aspects of the microphysical environment (sex work locations, monetary incentives for condom use by FSWs), the social environment (injecting drugs with clients, social norms such as *familismo*, abuse histories, and violence perpetrated by intimate partners and clients), the economic environment (job training opportunities), and the political environment (unjustified policing practices, NEPs, institutional incentives for promoting condom use) (Larios, Lozada, et al., 2009; Ulibarri, Strathdee, et al., 2011; Strathdee, Lozada, et al., 2011).

Successful HIV prevention programs have been implemented for IDUs in select countries such as Brazil, Argentina, and Mexico. A law implemented in the state of Sao Paulo in 1998 paved the way for Brazil to implement an extensive network of harm reduction programs across the country. The Brazilian Ministry of Health has firmly supported an infection control policy related to the use of psychoactive substances. Brazil has been recognized throughout the region for its National AIDS Program, a leading example of an integrated program for HIV/AIDS prevention, care, and treatment in a developing country.

Despite many differences between the epidemics within different countries, all countries in this region have to contend with rigid and restrictive social-cultural norms regarding gender roles and sexuality and contraception. These factors pose barriers to the development of effective HIV prevention interventions (Huedo-Medina, Boynton, et al., 2010). Three cultural beliefs relating to HIV risk that are predominant in this region are (a) *machismo* or "male pride," which is the belief that men should be dominant, have multiple sex partners, and engage in unprotected sex; (b) *simpatía*, which endorses a traditional female role emphasizing sexual submission and women's sexual inexperience; and (c) *familismo*, associated with traditional family values which conflict with less socially acceptable forms of sexual expression, such as condom use and homosexuality (Huedo-Medina, Boynton, et al., 2010). Addressing these social factors will facilitate reductions in HIV infections through promotion of safer sex behaviors in all risk populations.

Implications

Global approaches to HIV prevention have varied by geographic region and risk population. Additionally, appropriate theoretical frameworks and risk environment factors at the micro- and macro-levels have been integrated and targeted in HIV prevention interventions. As the HIV epidemic has evolved, most geographic regions have shifted from interventions that focus solely on the individual level to those that also integrate social networks, peers, communities, and biomedical-based (e.g., male circumcision, microbicides) approaches. There has also been a shift from a narrow focus on prevention to a focus to include treatment of HIV-positive individuals (i.e., treatment as prevention). These different approaches may be preferentially suited to certain populations or for certain periods of an individual's life.

Conclusions

Understanding the complexities of behavioral medicine in HIV/AIDS (i.e., the disease itself and infectious processes that surround it) is critical to the comprehensive development and implementation of comprehensive HIV/AIDS treatment and prevention strategies. Because the life expectancy for people with HIV has increased dramatically, there are challenges that must be faced regarding aging with HIV/AIDS. Comorbid conditions such as substance abuse, trauma, mental illness (e.g., depression, dementia), and incidental factors such as stigma may influence adherence to ART and must be taken into account in HIV treatment regimens. Overall, reduced infectiousness among HIV-positive individuals can be achieved only through proper adherence to ART medications and treatment of co-occurring STI. Treatment as prevention in reducing HIV transmission is a focus of ongoing trials to curb new infections.

When designing and applying HIV prevention interventions, researchers and health officials differ in the ways that they use behavioral theories, biomedical models, and the risk environment approach depending upon the geographic region and with the risk levels of the targeted populations. Risks in high-risk populations also frequently overlap. For example, an epidemic among IDUs may ignite an epidemic among FSWs due to the interaction between injection drug use and sex work, as when men and women who inject drugs also purchase or sell sex. Overall, some interventions, even theory-based ones, could conceivably have been more efficacious if they had taken components of the HIV risk environment into account.

HIV prevention experts agree that no single prevention strategy will be 100% effective nor acceptable and applicable to all populations (Kurth, Celum, et al., 2011). Behavioral interventions will be a necessary, but not solely sufficient, component of a successful prevention program worldwide. A number of biomedical interventions such as male circumcision, microbicides, and PrEP have been shown to have a significant impact on curbing new HIV infections in various at-risk populations. Combination HIV preventions that not only incorporate evidence-based behavioral and biomedical approaches but also take account of the risk environment must be developed to be appropriate, acceptable, and deliverable with high levels of coverage and adherence (Kurth, Celum, et al., 2011; Strathdee, Hallett, et al., 2010). Comprehensive combination HIV interventions will be those that address risk factors at the individual, dyadic, social, economic, and political levels, while accounting for the stage of the HIV epidemic in a particular region.

Geographic regions will vary in their approaches to combination HIV interventions. Some are well positioned to proceed with designing such interventions whereas others need to strengthen their political response to the HIV epidemic in populations most at risk. Combination interventions, particularly when implemented at scale, pose significant evaluation challenges, including how best to determine impact and how and whether to measure the effectiveness of component strategies (Padian, McCoy, Karim, et al., 2011; Padian, McCoy, Manian, et al., 2011). Nonetheless, as an initial step, in 2010, as part of the National HIV/AIDS Strategy in the United States, the CDC implemented a high-impact prevention approach. By using combinations of scientifically proven, cost-effective, and scalable interventions targeted to the right populations in the right geographic areas, this approach promises to greatly increase the impact of HIV prevention efforts (Centers for Disease Control and Prevention, 2011b). Additionally, to mark the third anniversary of the National HIV/AIDS Strategy, a new Federal initiative focused on "the HIV care continuum" (also referred to as the HIV treatment cascade) was launched to increase the proportion of individuals who are aware of their HIV status, are successfully linked to care and remain in care, receive ART, and adhere to their treatment to achieve viral load suppression. If the CDC "high-impact prevention approach" (which has clear and measurable targets to be achieved by 2015) proves successful in the United States, a critical challenge will be how to effectively and efficiently disseminate this approach globally, particularly in countries with limited political will to curtail the HIV pandemic. Ultimately, delivery of effective combination prevention packages could represent a new era for HIV prevention and a turning point for both HIV-positive and at-risk populations (Kurth, Celum, et al., 2011; Warren & Bass, 2013).

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Psychology, Mental Health, and Quality of Life

32

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Behavioral medicine has multiple and varied connections with mental health.[1] Many in behavioral medicine have been trained in clinical psychology, psychiatry, social work, or other professions with a primary focus in the area. For others, interest in mental health emerges from the growing recognition of how a range of psychosocial factors, including mental health problems, contribute to the etiology and complicate disease prevention and management. For all, an integrated view of health problems generally includes psychological, social, and biological dimensions. Problems are best prevented and treated from such an integrative perspective.

Addressing all the issues involved in this area would require several books and, so, is far beyond the reach of this chapter. Here, we set out some of the scope of the problems of mental health worldwide and then of interactions of mental health problems with prevention and care of other health problems, emphasizing maternal health and child development, diabetes, cardiovascular disease, cancer, and HIV/AIDS. We give substantial attention in this chapter to how we think about and conceptualize psychological problems and their roles in physical disease. An important area of progress is the inclusion of treatment for mental health problems in general healthcare systems, in contrast to being relegated to separate agencies, separate funding arrangements, separate treatment facilities, and separate professionals. A benefit of such integrative thinking may be recognition of how concepts previously thought limited to mental health, e.g., the role of early experience, social construction, and stigma, apply as well to other chronic diseases that have clearly biological

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[1] Throughout this chapter, "mental health" and "mental illness" are used as summary terms for a broad range of phenomena referred to by a variety of terms such as "psychopathology," "abnormal behavior," and "psychiatric disorder." This usage is primarily pragmatic and not intended to convey or privilege any conceptual model as to the nature, causes, or fundamental characteristics of this broad range of phenomena.

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bases. At the same time, there are important ways in which schizophrenia, depression, anxiety disorders, personality disorder, and substance use disorder are *not* "just like any other illness." The field is headed toward an integration built on shared themes and approaches, but not an assumption of equivalence of all instances.

This chapter closes with a description of some noteworthy approaches to treatment, prevention, and intervention around mental health and psychological aspects of health. The interventions included are a sample of a much larger field but are chosen to illustrate the innovative and integrative approaches emerging in the field. We start, however, with epidemiology.

Global Burden of Mental Health Problems

A 2009 review examined WHO World Mental Health (WMH) surveys in 28 countries. Across these, the inter-quartile range (25th to 75th percentiles) of lifetime prevalence of any of a combination of anxiety disorder, mood disorder, externalizing disorder, and substance use disorders (SUDs) was 18.1–36.1% and that for 12-month prevalence was 9.8–19.1%. "Serious disorders" include non-affective psychosis (including schizophrenia), bipolar disorder, substance dependence with a physiological dependence syndrome, suicide attempts, or substantial functional impairment. With this definition, 12.8–36.8% of those with any disorder were rated as serious (inter-quartile range = 18.5% to 25.7%) (Kessler, Aguilar-Gaxiola, et al., 2009). Table 32.1 presents some of the details of these global estimates, disaggregated by WHO region and individual countries contributing data to the report.

As described in Table 32.1, the lifetime prevalence of anxiety disorders (including agoraphobia, adult separation anxiety disorder, generalized anxiety disorder, panic disorder, post-traumatic stress disorder, social phobia, specific phobia) ranged from 4.8% in the People's Republic of China to 31% in the USA. Similarly, the lifetime prevalence of mood disorders (including bipolar disorder, dysthymia, and major depressive disorder) ranged from 3.6% in the People's Republic of China to 21.4% in the USA. The lifetime prevalence of any disorder ranged from 12.0% in Nigeria to 47.4% in the USA.

Table 32.2 documents the disability-adjusted life years (DALYs) attributable to a variety of mental and neurological disorders (Collins, Patel, et al., 2011). According to the WHO (2016):

> One DALY can be thought of as one lost year of "healthy" life. The sum of these DALYs across the population, or the burden of disease, can be thought of as a measure of the gap between current health status and an ideal health situation where the entire population lives to an advanced age, free of disease and disability. DALYs for a disease or health condition are calculated as the sum of the Years of Life Lost (YLL) due to premature mortality in the population and the Years Lost due to Disability (YLD) for people living with the health condition or its consequences.

That is: $DALY = \text{YLL} + \text{YLD}$

Disaggregating DALYs into years of life lost (YLLs) and years lost to disabilities (YLDs) shows important trends that underscore the importance of mental health. A 2015 study of global trends in mortality and disability (GBD 2013 Dalys, Hale Collaborators, et al., 2015) shows that, over the past decades, life expectancy has increased substantially, largely through improvements in treating communicable diseases. This results in general aging of the population. As the population ages, however, age-adjusted YLDs are not declining – that is, the likelihood of, e.g., an 80-year-old having disability from a health problem has not changed. There are two trends then that need to be understood: generally increasing life expectancy and stable age-adjusted rates of YLDs associated with mental health and substance use disorders as well as musculoskeletal, neurological, and hearing and vision disorders and diabetes. Together these have led to a greater total of YLDs and aggregate disease burden. The authors of the report point out important implications for behavioral medicine:

> We believe that the historical focus of health research funding on causes of YLLs was probably appropriate. However, health progress now means that more research investment is needed for the disorders that debilitate, rather than kill. With each

Table 32.1 Lifetime prevalence estimates of DSM-IV/CIDI disorders in the WMH surveys[a,b] (From: Kessler, Aguilar-Gaxiola, et al., 2009)

	Any anxiety disorder		Any mood disorder		Any externalizing disorder		Any substance disorder		Any disorder	
	%	(se)	%	(se)	%	(se)	%	(se)	%	(se)
I. *WHO Region: Pan American Health Organization (PAHO)*										
Colombia	25.3	(1.4)	14.6	(0.7)	9.6	(0.8)	9.6	(0.6)	39.1	(1.3)
Mexico	14.3	(0.9)	9.2	(0.5)	5.7	(0.6)[c]	7.8	(0.5)	26.1	(1.4)
USA	31.0	(1.0)	21.4	(0.6)	25.0	(1.1)	14.6	(0.6)	47.4	(1.1)
II. *WHO Region: African Regional Office (AFRO)*										
Nigeria	6.5	(0.9)	3.3	(0.3)	0.3	(0.1)[d,e]	3.7	(0.4)	12.0	(1.0)
South Africa	15.8	(0.8)[f,g]	9.8	(0.7)[h]	–	–[c,d,e,i]	13.3	(0.9)	30.3	(1.1)
III. *WHO Region: Eastern Mediterranean Regional Office (EMRO)*										
Lebanon	16.7	(1.6)	12.6	(0.9)	4.4	(0.9)[e]	2.2	(0.8)	25.8	(1.9)
IV. *WHO Region: European Regional Office (EURO)*										
Belgium	13.1	(1.9)	14.1	(1.0)[h]	5.2	(1.4)[c]	8.3	(0.9)[j]	29.1	(2.3)
France	22.3	(1.4)	21.0	(1.1)[h]	7.6	(1.3)[c]	7.1	(0.5)[j]	37.9	(1.7)
Germany	14.6	(1.5)	9.9	(0.6)[h]	3.1	(0.8)[c]	6.5	(0.6)[j]	25.2	(1.9)
Israel	5.2	(0.3)[f,g]	10.7	(0.5)	–	[c,d,e,i]	5.3	(0.3)	17.6	(0.6)
Italy	11.0	(0.9)	9.9	(0.5)[h]	1.7	(0.4)[c]	1.3	(0.2)[j]	18.1	(1.1)
Netherlands	15.9	(1.1)	17.9	(1.0)[h]	4.7	(1.1)[c]	8.9	(0.9)[j]	31.7	(2.0)
Spain	9.9	(1.1)	10.6	(0.5)[h]	2.3	(0.8)[c]	3.6	(0.4)[j]	19.4	(1.4)
Ukraine	10.9	(0.8)[f,g]	15.8	(0.8)[h]	8.7	(1.1)[d,e]	15.0	(1.3)	36.1	(1.5)
V. *WHO Region: Western Pacific Regional Office (WPRO)*										
PRC[k]	4.8	(0.7)	3.6	(0.4)	4.3	(0.9)[d,e]	4.9	(0.7)	13.2	(1.3)
Japan	6.9	(0.6)[f]	7.6	(0.5)	2.8	(1.0)[d,e,i]	4.8	(0.5)	18.0	(1.1)
New Zealand	24.6	(0.7)[f]	20.4	(0.5)	–	–[c,d,e,i]	12.4	(0.4)	39.3	(0.9)

[a] Anxiety disorders include agoraphobia, adult separation anxiety disorder, generalized anxiety disorder, panic disorder, post-traumatic stress disorder, social phobia, and specific phobia. Mood disorders include bipolar disorders, dysthymia, and major depressive disorder. Impulse control disorders include intermittent explosive disorder and reported persistence in the past 12 months of symptoms of three child-adolescent disorders (attention-deficit hyperactivity disorder, conduct disorder, and oppositional defiant disorder). Substance disorders include alcohol or drug abuse with or without dependence. In the case of substance dependence, respondents who met full criteria at some time in their life and who continue to have any symptoms are considered to have 12-month dependence even if they currently do not meet full criteria for the disorder. Organic exclusions were made as specified in the *Diagnostic and Statistical Manual of Mental Health Disorders*, Fourth Edition

[b] Impulse disorders restricted to age ≤ 39 (China, Ukraine, Nigeria) or to age ≤ 44 (all other countries)

[c] Intermittent explosive disorder was not assessed

[d] Attention-deficit hyperactivity disorder was not assessed

[e] Oppositional defiant disorder was not assessed

[f] Adult separation anxiety disorder was not assessed

[g] Specific phobia was not assessed

[h] Bipolar disorders were not assessed

[i] Conduct disorder was not assessed

[j] Only alcohol abuse with or without dependence was assessed. No assessment was made of other drug abuse with or without dependence

[k] People's Republic of China

> passing year, the shift towards YLDs as the leading causes of disease burden will be more evident. Action is needed now to develop preventive, curative, and ameliorative strategies for these conditions rather than waiting until this shift is even more obvious. (GBD 2013 Dalys, Hale Collaborators, et al., 2015, p. 2182)

Mental Health and Chronic Disease

Surveys from six low- and middle-income countries (China, Ghana, India, Mexico, Russia, and South Africa) examined the prevalence and

Table 32.2 Global burden of mental, neurological, and substance use disorders (millions of lives affected) and rank of causes worldwide and disaggregated by high- and low-/middle-income countries[a] (Adapted from Collins, Patel, et al., 2011)

	Worldwide		High-income countries		Low- and middle-income countries	
Rank	Cause	Millions	Cause	Millions	Cause	Millions
1	Unipolar depressive disorders	65.5	Unipolar depressive disorders	10.0	Unipolar depressive disorders	55.5
2	Alcohol use disorders	23.7	Alzheimer's and other dementias	4.4	Alcohol use disorders	19.5
3	Schizophrenia	16.8	Alcohol use disorders	4.2	Schizophrenia	15.2
4	Bipolar affective disorder	14.4	Drug use disorders	1.9	Bipolar affective disorder	12.9
5	Alzheimer's and other dementias	11.2	Schizophrenia	1.6	Epilepsy	7.3
6	Drug use disorders	8.4	Bipolar affective disorder	1.5	Alzheimer's and other dementias	6.8
7	Epilepsy	7.9	Migraine	1.4	Drug use disorders	6.5
8	Migraine	7.8	Panic disorder	0.8	Migraine	6.3
9	Panic disorder	7.0	Insomnia (primary)	0.8	Panic disorder	6.2
10	Obsessive-compulsive disorder	5.1	Parkinson's disease	0.7	Obsessive-compulsive disorder	4.5
11	Insomnia (primary)	3.6	Obsessive-compulsive disorder	0.6	Post-traumatic stress disorder	3.0
12	Post-traumatic stress disorder	3.5	Epilepsy	0.5	Insomnia (primary)	2.9
13	Parkinson's disease	1.7	Post-traumatic stress disorder	0.5	Multiple sclerosis	1.2
14	Multiple sclerosis	1.5	Multiple sclerosis	0.3	Parkinson's disease	1.0

[a] World Bank criteria for income (2009 gross national income (GNI) per capita): low income is equivalent to US$995 or less; middle income is $996–12,195; high income is $12,196 or more

impacts of multimorbidity, defined as two or more of eight common chronic diseases (angina pectoris, arthritis, asthma, chronic lung disease, diabetes mellitus, hypertension, stroke, and vision problems) (Arokiasamy, Uttamacharya, et al., 2015). The prevalence of multimorbidity was 21.9%, ranging from as low as 20.3% in China to as high as 34.7% in Russia. As expected, multimorbidity increased with age and decreased with greater socioeconomic status. Moreover, the number of chronic diseases was associated with greater depression, poorer self-rated health, and more limitations in activities of daily living (ADLs).

Amidst the many forms in which mental health issues complicate health and illness, several stand out: depression, anxiety disorders, substance use disorders, personality disorders, psychological distress, and serious mental illness. We review here the epidemiology of each of these.

Epidemiology of Major Depression Depression is a common mental disorder. WHO estimated that the 12-month prevalence of mood disorders (including different subtypes of depression) in developed countries was between 3.1% (Japan) and 9.6% (USA).

Lifetime prevalence estimates for depression are as high as 21%, with a preponderance in women. Depression affects both an individual's personal life and the society as a whole. The estimated lifetime prevalence of suicide in patients with depression is between 2% (outpatients) and 6% (inpatients). A first episode of depression often occurs early in life; the median age of onset for mood disorders ranges from 25 to 31 years. The natural course of depression varies substantially between patients. Some patients have a full remission after an index episode (20%), many have either residual symptoms (12%) or recurrence after full remission (40%), and chronicity is rather high (28%). Furthermore, interindividual differences in the duration of a depressive episode are large, with a median duration of 3 months. However, the distribution is skewed toward much longer episodes, and nearly 20% of patients do not recover within 24 months. Furthermore, each depressive episode leads to increased damage on psychological, biological, and social levels, which further increases an individual's vulnerability for another depressive episode.

Thus, large heterogeneity exists in the natural course of patients presenting with depression, with a subgroup of patients having persistent or recurrent episodes.

Risk factors for the onset of depression include social factors, such as low education, social defeat, and loneliness; psychological factors, such as a high degree of neuroticism, early life stressors, and minor depressive complaints; and biological factors, such as genetic risk, specific medication and recreational drugs, and physical illness. Epidemiological data suggest that any medical chronic disease carries an additional risk factor for depression. In the USA, Egede (2007) showed that the risk for major depression was increased 2.6 times if a somatic disease was present, with a prevalence of comorbid depression ranging from 7.9% in patients with heart failure to 17% in patients with end-stage renal disease. The WHO World Mental Health Survey reported on depression prevalence based on ICD-10 criteria from 60 countries in all regions of the world and found a significantly higher prevalence of depression in people with at least one comorbid somatic complication (23%) than in people without comorbid somatic complication (3%) (Demyttenaere, Bruffaerts, et al., 2004).

Anxiety Disorders The US National Institute of Mental Health defines anxiety disorder as worry or fear that does not go away and may worsen over time, causing significant impairment to an individual's life (National Institute of Mental Health, 2015). According to the *Diagnostic and Statistical Manual of the American Psychiatric Association*, Fifth Edition (2014), anxiety disorders include separation anxiety disorder, selective mutism, specific phobia, social anxiety disorder, panic disorder, agoraphobia, generalized anxiety disorder, anxiety due to medical conditions or substances, and other/unspecified anxiety disorders (Anxiety and Depression Association of America, 2015). This category is separate from obsessive-compulsive disorders and trauma or stressor-induced disorders (Regier, Kuhl, & Kupfer, 2013). Anxiety, particularly generalized anxiety disorder (GAD), often coincides with major depression (Moscati, Flint, & Kendler, 2016), and the DSM-5 includes a new diagnostic category, "mixed anxiety/depression" (American Psychiatric Association, 2014).

The Global Burden of Disease Study estimates indicate that of the 183.9 million disability-adjusted life years (DALYs) attributed to mental and substance use disorders, 14.6% are attributable to anxiety disorders (Whiteford, Degenhardt, et al., 2013). The estimate of the current global prevalence of anxiety disorders is 7.3%, which corresponds to approximately 1 in 14 people experiencing an anxiety disorder at any given time (Baxter, Scott, et al., 2013). Globally, women are nearly twice as likely to have an anxiety disorder as men. In a sample of adults from the USA ($N = 20{,}013$), women had significantly higher rates of panic disorder (OR = 1.70, $p < 0.05$), agoraphobia (OR = 1.46, $p < 0.05$), generalized anxiety disorder (OR = 1.83, $p < 0.05$), and specific phobia (OR = 1.96, $p < 0.05$) (McLean, Asnaani, et al., 2011). Anxiety disorders are also more prevalent in younger adults (ages 35–54, who later may "grow out" of them), Euro/Anglo cultures, developed countries, and conflict populations (Whiteford, Degenhardt, et al., 2013).

Anxiety disorders are believed to run in families, with twin studies yielding heritability estimates of 30–40% (Rapee, 2012). While there does appear to be a genetic component in anxiety disorders, the influence of genetics does not appear to be as strong as is observed in other disorders, such as substance use disorders and schizophrenia. One consistent and well-documented environmental risk factor is childhood sexual abuse. Other factors related to parent-child interactions, such as overprotectiveness, may also serve as risk factors.

Anxiety disorders pose an enormous burden to both mental and physical health (Comer, Blanco, et al., 2011). In their study of over 43,000 US adults, Comer et al. (2011) found that individuals diagnosed with an anxiety disorder scored significantly lower on multiple dimensions of a health survey when compared to individuals without an anxiety disorder. As a group, individuals with anxiety disorders were significantly more likely to report hypertension, angina, tachycardia, ulcers, gastritis, arthritis, poor social functioning, limitations due to emotional problems, and lower overall well-being. Of all the anxiety disorders, GAD posed the greatest challenges to health. Individuals with GAD reported significantly more medical comorbidities, especially non-cirrhotic liver disease and heart disease other than myocardial infarction.

The relationship between anxiety disorders and cardiovascular illness has been documented in other recent studies. In a study of 1015 adults with coronary heart disease at an outpatient clinic, individuals with GAD experienced a significantly higher rate of cardiovascular events (HR = 1.62, $p < 0.01$) (Martens, de Jonge, et al., 2010). This relationship was maintained even when controlling for health behaviors, disease severity, and biological mediators. Similarly, a meta-analysis of individuals with coronary heart disease found that individuals suffering from anxiety were at a significantly higher risk of cardiac death than non-anxious persons (HR = 1.26, $p < 0.0001$) (Roest, Martens, et al., 2010).

Substance Use Disorders Substance use disorders (SUDs) occur when frequent use of a particular substance results in significant impairment or problems in various areas of life, such as health, work, or relationships (U.S. Department of Health and Human Services, 2015). The DSM-5 combines different categories of abuse and dependence into one disorder, with severity measured on a continuum (American Psychiatric Association, 2014). Common SUDs include alcohol use disorder, tobacco use disorder, cannabis use disorder, stimulant use disorder, hallucinogen use disorder, and opioid use disorder (U.S. Department of Health and Human Services, 2015).

Data from the 2010 Global Burden of Disease, Injuries, and Risk Factors study indicated that mental and substance use disorders were the primary causes of years lost to disability (YLDs), with illicit drug use disorders accounting for 10.9% and alcohol use disorders for 9.6% of all disability-adjusted life years (DALYs) caused by mental and substance use disorders (Whiteford, Degenhardt, et al., 2013). Of the 8.6 million years of life lost (YLLs) to mental and substance use disorders, 81.1% resulted specifically from SUDs. Although the worldwide prevalence of most mental disorders remained fairly stable between 1990 and 2010, SUDs increased significantly during this time. Young adults account for the largest proportion of the global burden, with peak prevalence occurring between ages 20 and 29 (Merikangas & McClair, 2012).

A major risk factor for SUDs is family history; children of substance abusers are two times as likely to develop a substance use disorder as children of non-abusers, and this risk is even higher when the substance involved is alcohol or marijuana (Merikangas & McClair, 2012). Males are significantly more likely to have a substance use disorder than females, and individuals who frequently use or abuse a variety of substances (polysubstance abuse) are more likely to develop SUDs than individuals who only use one substance. Experiencing stressful life events such as losing a job, divorce, terrorism, and natural disasters is associated with increased substance use (Keyes, Hatzenbuehler, & Hasin, 2011). Adverse childhood experiences, particularly childhood maltreatment, consistently predict subsequent development of SUDs across studies (Enoch, 2011; Keyes, Hatzenbuehler, & Hasin, 2011). In young adults, additional risk factors include peer substance use, low academic achievement, moving away from home, and attending college, while protective factors include work, marriage, and graduating from college (Stone, Becker, et al., 2012).

SUDs frequently co-occur with other mental disorders and can severely impact health in a number of ways (U.S. Department of Health and Human Services, 2015). For example, individuals with SUDs are significantly more likely to be infected with HIV than individuals without SUDs (Prince, Walkup, et al., 2012). They are also significantly less likely to adhere to a prescribed medication regimen for type 2 diabetes (Kreyenbuhl, Dixon, et al., 2010) as well as for schizophrenia and bipolar disorder (Jónsdóttir, Opjordsmoen, et al., 2013). Pregnant women who abuse substances are more likely to miscarry and deliver prematurely than non-abusers (Gopman, 2014; Wendell, 2013). Tobacco use during pregnancy is one of the leading causes of preventable infant mortality and morbidity (Wendell, 2013). Alcohol abuse during pregnancy also results in poor birth outcomes, including fetal alcohol syndrome. Preventing the onset and reducing the prevalence of SUDs are therefore a priority for improving both mental and physical health outcomes.

Personality Disorders Individual differences in character, habitual ways of thinking, feelings, and behaviors are part of normal variation. When individual characteristics are manifest in a maladaptive manner, they are clinically identified as personality disorders. Intrinsic to such a definition is the social context within which these behaviors occur, since acceptable behavioral patterns vary across social contexts (Newlin & Weinstein, 2015). For example, highly submissive and deferential behavior may be required in some relationships and cultures but may be dysfunctional and socially unacceptable in other relationships and cultures. Personality disorders are common, estimated to occur among 10% of the general population, and even more common in clinical populations as they coexist often with chronic diseases and health problems (Samuels, 2011).

The DSM-5 currently identifies 10 types of personality disorder: paranoid, schizoid, schizotypal, antisocial, borderline, histrionic, narcissistic, avoidant, dependent, and obsessive-compulsive (American Psychiatric Association, 2014). These are classified into three categories or clusters: cluster A (paranoid, schizoid, schizotypal) characterized by odd, eccentric, aloof, paranoid, or bizarre thinking; cluster B (antisocial, borderline, histrionic, narcissistic) characterized by instability of behavior, mood, and relationships; and cluster C (avoidant, dependent, and obsessive-compulsive) characterized by obsessive, fearful, or anxious thoughts. However, definitions and distinctions among these are difficult, and alternative ways of grouping and characterizing them remain controversial and the object of discussion and research (Gotzsche-Astrup & Moskowitz, 2016; Widiger, 2015).

Personality disorders are associated with poorer outcomes and higher healthcare utilization across a wide range of health problems. One systematic review found personality disorders associated with sleep disturbances, back pain, incontinence, chronic pain, obesity, and varied chronic health conditions including allergic rhinitis, arthritis, asthma, cardiovascular disease, diabetes, gastrointestinal disease, HIV+ status, hypertension, ischemic heart disease, liver disease, stroke, and venereal disease (Dixon-Gordon, Whalen, et al., 2015). In national surveys from the USA including 34,653 adults, a variety of personality disorders were associated with cardiovascular disease, arthritis, diabetes, and gastrointestinal conditions (Quirk, El-Gabalawy, et al., 2015). In a recent systematic review of health service utilization among those with mental disorders in the UK (Twomey, Baldwin, et al., 2015), the presence of a personality disorder, in addition to neurotic symptoms, comorbidity, and several demographic characteristics, were among the variables shown to predict a variety of types of health and behavioral health service utilization, including primary care contacts, medication usage, contacts with psychiatrists, attendance at psychotherapy, inpatient days, accident and emergency admissions, and a total service utilization score.

Interpersonal problems are at the core of personality disorders (Hengartner, von Wyl, et al., 2015) and especially those identified as "borderline personality," characterized by extremely labile relationships and frequent vacillation between all-or-none negative and positive views of self and others. As a result, patients with personality disorders and especially borderline personality presenting in medical settings are often experienced as "difficult" or "high maintenance." This may be related to insecure/avoidant or disorganized attachment styles characterized by fear of abandonment and also fear of closeness (Bowlby, 1980; van Dijke & Ford, 2015). Importantly, individuals with personality disorders are often not aware of the impact of their behavior on others, and working with them requires a willingness to understand their perspective while maintaining appropriate boundaries (Newlin & Weinstein, 2015). As personality disorders often co-occur with other mental health as well as medical diagnoses, treatment involves multiple components.

For borderline personality disorder and cluster B (antisocial, borderline, histrionic, narcissistic), there is evidence that psychological therapies and in particular dialectic behavior therapy are beneficial. A Cochrane review concluded that findings "support a substantial role for psychotherapy in the treatment of people with BPD [Borderline Personality Disorder] but clearly indicate a need for replicatory studies" (Stoffers, Vollm, et al., 2012). Although frequently prescribed, there is little evidence for the effectiveness of psychopharmacological treatment in this patient group (Stoffers & Lieb, 2015) although medication may be helpful for other problems not part of personality disorder per se (Kendall, Pilling, et al., 2009).

Psychological Distress In addition to the specific kinds of disorders detailed in the preceding paragraphs, general psychological distress has emerged as an important consideration in behavioral medicine and especially in chronic disease management. The term distress was introduced in the early 1970s by the Hungarian physiologist Hans Selye to distinguish between stress initiated by negative, unpleasant stressors and positive stress (eustress). Psychological distress is conceptualized as a measure of current state as opposed to a static, personality trait. Thus, it is treated as a continuous variable that can vary in response to different stressful situations and was defined by Ridner as "the unique discomforting, emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporary or permanent to the person" (Ridner, 2004). The harm mentioned in this definition refers to negative emotions, such as irritability, fear, nervousness, and sadness, which are burdensome in their own right, associated with low well-being and social functioning, but are not necessarily pathological. Thus, distress is defined as an emotional response toward adverse or unpleasant stressors, whereas the definition of depression is based solely on a count of symptoms, irrespective of cause or context.

Increased psychological distress (or simply distress) is prevalent in medical patients and is often regarded as a normal response to the burden of diagnosis and treatment, discomforting symptoms, and negative social implications. As noted by De Ridder and colleagues (de Ridder, Geenen, et al., 2008), chronic illness challenges patients' habitual coping strategies. Although most eventually reach good psychological adjustment, for about 30% the adjustment phase is long lasting or unsuccessful. In a community-dwelling Japanese population, Nakaya et al. (2014) noted increased nonspecific psychological distress in people with self-reported somatic diseases compared with people claiming to have no somatic disorder. The risk of psychological distress was increased by 20% for hypertension and hyperlipidemia; 30% for diabetes; 50% for cancer; 60% for myocardial infarction, arthritis, and osteoporosis; and 130% for stroke (Nakaya, Kogure, et al., 2014). The differences in prevalence across these different diseases suggest a role for disease characteristics such as prognosis, symptom burden, and specific treatment requirements. Epidemiological studies of depression in different somatic patient populations might offer opportunities for research into causes looking into shared psychological (e.g., coping) and biological (e.g., inflammation, hypothalamic-pituitary-adrenal axis) pathways across different medical disorders.

Serious Mental Illness Serious mental illness is defined by the conjunction of diagnosis, duration, and disability (Goldman, Gattozzi, & Taube, 1981; U.S. Department of Health and Human Services, 2014). More specifically, serious mental illness is defined as (a) a mental, behavioral, or emotional disorder that is currently diagnosable or diagnosable within the previous 12 months, (b) of sufficient duration to meet diagnostic criteria as outlined in current diagnostic and statistical manuals, and (c) resulting in functional impairment which limits one or more major life activities, such as school or work (U.S. Department of Health and Human Services, 2014). Qualifying diagnoses often include especially debilitating disorders such as schizophrenia, bipolar disorder, or major depression. Other disorders such as anxiety disorder, post-traumatic stress disorder (PTSD), and obsessive-compulsive disorder may also be included. Developmental and substance use disorders, however, are not qualifying diagnoses for serious mental illness. Disability can be indicated by *eligibility* for social services such as, in the US Supplemental Security Income (SSI) or Social Security Disability Income (SSDI). (Because the process of enrolling in these programs can take years, eligibility rather than coverage is taken as the criterion for disability.) Duration can be defined in terms of a single episode of psychiatric hospitalization in the previous 5 years of at least 6 months or two or more hospitalizations within a year (Goldman, Gattozzi, & Taube, 1981).

In 2013 in the USA, for example, there were an estimated 10 million adults – or 4.2% of all US adults – aged 18 or older with diagnosed serious mental illness within the previous 12 months (U.S. Department of Health and Human Services, 2014). Best current estimates suggest a lifetime prevalence of bipolar disorder to be approximately 2.6% of all US adults, 9.1% for depressive disorders, and 1% for schizophrenia and other psychotic disorders (U.S. Department of Health and Human Services, 2014). Furthermore, recent prevalence data suggest that nearly 40 million people in the USA (18%) experience an anxiety disorder in any given year, and over 7 million adults in the USA could be diagnosed as having PTSD at any given time (U.S. Department of Health and Human Services, 2014).

Persons with serious mental illness have high rates of co-occurring substance use disorders. Estimates suggest that up to 8.4 million adults in the USA have co-occurring serious mental illness and substance use disorder (U.S. Department of Health and Human Services, 2014). For many persons with serious mental illness, the combination of untreated mental illness and substance use can be associated with a number of poor outcomes, including violence, treatment and medication nonadherence, difficulty accessing much-needed social and medical services, homelessness, and frequent criminal justice contacts (Clark, Ricketts, & McHugo, 1999; Drake & Mueser, 2001; Horsfall, Cleary, et al., 2009; Steadman, 2000; Theriot & Segal, 2005). Moreover, individuals with serious mental illness who are also involved with the justice system have difficulty accessing housing and social services and have high recidivism rates (Cloyes, Wong, et al., 2010; Gagliardi, Lovell, et al., 2004; Lovell, Gagliardi, & Peterson, 2002; Mallik-Kane & Visher, 2008; Skeem & Louden, 2006).

Persons with serious mental illness have higher rates of chronic health conditions and a reduced life expectancy compared to the general population (Chwastiak, Rosenheck, et al., 2006; Colton & Manderscheid, 2006; Daumit, Pratt, et al., 2002; Dickey, Normand, et al., 2002; Hansen, Arnesen, & Jacobsen, 1997; Joukamma, Heliövaara, et al., 2006). Compared to the general population, for example, persons with schizophrenia are at greater risk for colon and breast cancers (Hippisley-Cox, Vinogradova, et al., 2007). Among the persons with serious mental illness, heart disease remains the leading cause of death (Dembling, Chen, & Vachon, 1999; Saha, Chant, & McGrath, 2007). Those diagnosed with schizophrenia also have an increased risk of metabolic syndrome and type 2 diabetes, explained both by lifestyle factors and metabolic effects of antipsychotic medication (Olsson, Westman, et al., 2015; Ward & Druss, 2015).

In addition to the heightened likelihood of disease, the physical health needs of persons with mental illness often go unmet (Colton & Manderscheid, 2006; Druss, Rosenheck, et al., 2002; Salsberry, Chipps, & Kennedy, 2005). There is a speculation that the unmet physical health needs of persons with severe mental illness are due to problems in both primary care and specialty mental healthcare. Primary care providers may view care for persons with serious mental illness as too specialized for primary care (Lester, Tritter, & Sorohan, 2004). On the other hand, mental healthcare providers may lack training and confidence to treat the medical problems of persons with serious mental illness (Unützer, Schoenbaum, et al., 2006). These barriers may be joined by a combination of consumer, provider, and system-level factors (Druss, Rosenheck, et al., 2002), supported by clinical guidelines endorsed by both primary care and mental health professionals (e.g., de Hert, Dekker, et al., 2009).

Key Life Course Phases

There are several areas and points in the lifespan in which mental health issues are especially important in general health and well-being. Here we will highlight three phases: parental health and early child development, adolescence, and adult development and aging.

Parental Health and Child Development

Childhood environment, including parental mental health, parental attachment and parenting styles, and socioeconomic status, impacts child development and subsequent mental and physical health. Mental health problems such as depression or substance use may be linked with parenting characteristics such as neglect that then impact childhood development (Hanington, Ramchandani, & Stein, 2010; Norman, Byambaa, et al., 2012). These parental characteristics can place a child at future risk for a myriad of poor health outcomes, including a range of mental disorders, drug use, and sexually transmitted infections (Hanington, Ramchandani, & Stein, 2010; Norman, Byambaa, et al., 2012). Conversely, a positive childhood environment, characterized by authoritative and attentive parents, can foster healthy psychosocial development and both mental and physical health (Kiuru, Aunola, et al., 2012; Steinberg, Elmen, & Mounts, 1989; Vollmer & Mobley, 2013).

Parental Mental Health Numerous adult health problems are linked to parental characteristics that subsequently have an impact on childhood development. Chief among these health issues is parental depression. Research has demonstrated that maternal mental health problems in pregnancy and/or postpartum place children at risk for poor global, behavioral, cognitive, and socioemotional development (Kingston & Tough, 2014). As recently reviewed by Atif and colleagues, the prevalence of prenatal depression averages 15.6% and postnatal 19.8% and is associated with a number of problems, including preterm birth, low birth weight, and poor infant growth and cognitive development (Atif, Lovell, & Rahman, 2015). Negative impacts are not only associated with maternal depression but paternal depression as well. Parental depression impacts cognitive and socioemotional development in children, both directly and indirectly (Cummings, 1994). Directly, parental depression affects the parent's emotions, thoughts, and behaviors, which in turn influences child development (Cummings, 1994; Hanington, Ramchandani, & Stein, 2010). For example, depressed parents exhibit more unsupportiveness, negativity, and intrusiveness toward their children compared to nondepressed parents (Field, Healy, et al., 1990; National Research Council (US) and Institute of Medicine (US) Committee on Depression, 2009; Zajicek & De

Salis, 1979). Parental depression may enter into relationships with children through criticism, disengagement, lack of responsiveness, coldness, and physical abuse (Panaccione & Wahler, 1986; Webster-Stratton, 1990). A child's prolonged exposure to these, in turn, has been linked to the development of childhood depressive behavior (Cohn, Campbell, et al., 1990; Hanington, Ramchandani, & Stein, 2010). More indirectly, parental depression may affect children by altering patterns of parent-child attachment and interaction (Cummings, 1994), discussed in the next section.

Parental Attachment and Parenting Styles Parental attachment and parenting styles have important impacts on child development and health. Bowlby described how children naturally seek proximity to caregivers in times of need, developing attachment relationships (Bowlby, 1976, 1980). He also noted differences in attachment systems, including secure and insecure attachment. Parental warmth, sensitivity, and responsiveness to bids for support and proximity facilitate secure attachment and build positive mental representations of self and others (Cummings & Cicchetti, 1993; Zeanah & Zeanah, 1989). This formation of secure attachment fosters a child's development and well-being (Mikulincer & Shaver, 2012) However, when a child's caregivers are not reliably available or supportive, insecure attachments result in children viewing others as unreliable and themselves as unworthy (Bretherton, 1985) and lacking self-efficacy (White, 1959). These may in turn lead to childhood depression (Mikulincer & Shaver, 2012) and numerous other disadvantageous patterns of development.

In addition to child-parent attachment, parenting styles have been identified as a way of understanding child development. Psychologist Diana Baumrind identified three major parenting styles – permissive, authoritative, and authoritarian – each with different impacts on child behavior (Baumrind, 1966). Permissive or "laissez faire" parenting is nonpunitive, accepting, and indulgent of children's impulses, desires, and actions. This style creates few expectations for children and, so, may lead to increased aggression and unscrupulous behaviors (Baumrind, 1966). Contrasting sharply with the permissive style, an authoritarian style attempts to control children's behaviors and attitudes with close supervision and high demands. These may foster rebelliousness, passivity and dependence, or low self-assertiveness. In addition to these two styles is authoritative parenting. This directs children's activities in a rational, issue-oriented manner while also encouraging autonomy and self-will (Baumrind, 1966). The warm, firm, and fair parenting characterized by authoritative parentings leads to healthy psychological adjustment (Gray & Steinberg, 1999).

Socioeconomic Status, Parenting, and Child Development As is well known, low socioeconomic status (SES) has a significant influence on mental and physical health. Research has examined how the influence of SES begins in childhood. Children of lower SES have higher rates of many diseases and risk factors for disease (Colhoun, Hemingway, & Poulter, 1998; Hegewald & Crapo, 2007; Wright & Subramanian, 2007). The realities of low SES teach persistent patterns of responding to threatening, negative, or ambiguous stimuli in a manner that leads to more and stronger stress responses compared to children of higher SES (Chen, Langer, et al., 2004). This accentuates stress and can induce significant biological changes in children through increasing allostatic load, which can exert long-term effects on physical and mental health (Danese & McEwen, 2012). Essentially, the allostatic load is a body's cumulative wear and tear; it is the physiological consequence of chronic exposure to stress (McEwen & Stellar, 1993). It serves as the mediator through which the chronic stress many children of low SES face negatively impacts their subsequent physical and mental health.

SES not only has an impact on childhood development through the stress response but also through the early resources that are denied as a result of this status. Proper nutrition during infancy and toddlerhood are essential because these periods are critical for growth and brain development; insufficient energy and nutrients during this time may negatively impact the structural and functional development of the child's brain (Uauy & Dangour, 2006). Research has illustrated that mothers with a lower education level are more likely to have poor infant feeding practices than their more highly educated counterparts, thereby potentially impeding their children's growth and brain development (Emmett & Jones, 2014). Putting these several streams together, low SES may lead to poorer mental and physical health outcomes as a result of both fostering stress and limiting critical resources.

Adolescent Development

Adolescence is an age of both learning and confusion. Because this transitional time allows individuals to explore independence and self-identity, it forces youth to face dilemmas that were previously unknown. Adolescents navigate new issues – sexuality, drugs, alcohol, and socialization – at the same time, they are working to form a clear identity. It follows that emotional distress is an important component of the adolescent experience and adolescent health (Merikangas, He, et al., 2010).

Adolescent behaviors and development have often been framed in terms of the importance of peer influence, social modeling, and observational learning (Carter, Bingham, et al., 2014; Cruwys, Bevelander, & Hermans, 2015; Gerbasi, Richards, et al., 2014; Suleiman & Deardorff, 2015). These factors are significant especially in the roles they play in encouraging or discouraging many risk behaviors in adolescence. We must not ignore, however, the influence of an adolescent's psychological experience and mental health. Here, we explore the emotional aspects of adolescent health and development. Because adolescence is an age of discovery and exploration, it is also an age of increased susceptibility to psychological distress. This distress can have negative impacts on development, physiological health, health behaviors, and overall mental and social well-being. This transitional time is critical to healthy development and the formation of healthy habits that persist into adulthood.

A person's self-concept encompasses beliefs about one's self, such as academic performance, gender identity, sexuality, and ethnicity (Shavelson, Hubner, & Stanton, 1976). These beliefs can significantly change during adolescence due to increased self-consciousness and peer influence (Sebastian, Burnett, & Blakemore, 2008). However, stress may also have a significant impact on self-concept. There are numerous sources of stress and anxiety for adolescents – including academic pressures, bullying, self-esteem issues, and body consciousness – that can manifest as a negative self-concept (Benedict, Vivier, & Gjelsvik, 2015; Rawana & Morgan, 2014; Wenz-Gross, Siperstein, et al., 1997). For instance, high academic stress and low emotional support are related to a low academic self-concept, and high peer stress and low peer companionship are associated with low social self-concept (La Greca & Harrison, 2005; Michie, Glachan, & Bray, 2001; Wenz-Gross, Siperstein, et al., 1997). In addition to its importance in its own right, a negative self-concept damages mental and social well-being. It is associated with a broad range of mental and social disorders including depression, suicidal tendencies, eating disorders, anxiety, violence, and substance abuse (Mann, Hosman, et al., 2004; Rosenberg, 1985).

Unfortunately, such disorders are common. Anxiety disorders are the most common mental disorder in adolescents, with nearly a third of adolescents suffering from them, followed by behavior disorders, mood disorders, and substance use disorders, as per DSM-IV (K. R. Merikangas, He, et al., 2010). Approximately 40% of adolescents with one class of disorder also meet criteria for another class. These disorders can be debilitating – over one in five adolescents with a mental disorder suffer severe impairment and/or distress (Merikangas, He, et al., 2010).

There is a patterned distribution of mental disorders across adolescents. Mood and anxiety disorders are more prevalent among females, whereas males have higher rates of behavior and substance use disorders (Merikangas, He, et al., 2010). With respect to parental characteristics, the prevalence rates of anxiety disorders, substance use disorders, and behavior disorders are higher for adolescents whose parents are divorced or separated compared to married or cohabitating (Merikangas, He, et al., 2010). Lastly, adolescents whose parents are not college graduates have an increased risk for all disorders (Merikangas, He, et al., 2010).

Numerous biological factors both drive and result from adolescent psychological distress. During this life stage, there is an increased responsiveness to sex and stress hormones, and these hormones may influence the risk for mental disorders via their effect on dopamine neurotransmission that is important in feelings of enjoyment and motivation (Sinclair, Purves-Tyson, et al., 2014). With regard to the biological effects that result from psychological distress, the adolescent brain may be particularly sensitive to stress with important consequences on an individual's immediate and long-term health and well-being. There is strong evidence that stress exposure during adolescence can lead to short- and long-term changes in limbic and cortical structure and function, with important behavioral repercussions (Eiland & Romeo, 2013). Beyond its effects on the brain, psychological distress has additional physiological impacts. Even as early as the pre-teenage years, stress increases systolic blood pressure and assists the formation of arterial plaque, placing an individual at higher risk for cardiovascular disease later in life (Roemmich, Lambiase, et al., 2014).

Not only is psychological distress disagreeable in itself and through its direct biological affects, but it can have poor repercussions on adolescents' health behaviors. For instance, stress promotes unhealthy behaviors, including snacking on unhealthy foods and reduced physical activity, which places an individual at risk for obesity (Roemmich, Lambiase, et al., 2014). Furthermore, distress and negative health behaviors such as substance use, risky sexual behaviors, and eating disorders often co-occur (Santos, Richards, & Bleckley, 2007; Waller, Hallfors, et al., 2006). Depression, eating disorder, and substance abuse symptoms tend to increase over time during adolescence, and increases in each of these symptoms are associated with increases in other symptoms (Measelle, Stice, & Hogansen, 2006; Merikangas, He, et al., 2010). In particular, depression has been shown to predict increases in eating disorders and substance abuse symptoms (Measelle, Stice, & Hogansen, 2006; Santos, Richards, & Bleckley, 2007).

The influence of psychological distress on health behaviors is especially important in adolescents facing chronic conditions (Bender, 2006). For this population, depression and risk behaviors may be associated with nonadherence to medications, poor treatment outcomes, and even death (Bender, 2006). In a study of the Pediatric Diabetes Consortium registries, depressive symptoms were found in 13% of adolescents with type 1 and 22% of adolescents with type 2 diabetes (Silverstein, Cheng, et al., 2015). Stress may have negative indirect effects on glycemic control in adolescents with diabetes via stress's impact on diabetes treatment and monitoring, such as nonadherence to meal and exercise plans (Marcovecchio & Chiarelli, 2012). In adolescents with asthma, depression might lead to hopelessness that interferes with adherence and other health-promoting behavior, and depression may even impact asthma directly via altering immune response (Bender, 2006).

Older Adulthood

Setting the stage for psychological development in older adulthood (usually defined as age 55 and above) is a pattern of declining capacity in many domains. Because of an inverted U pattern of development of many cognitive and physical abilities, risks for health problems increase with advanced age. Yet structural factors such as gender, class, and ethnicity also influence health across the lifespan, so that, for example, older adults at high socioeconomic status will tend to be healthier than midlife adults at low socioeconomic status (Connell & Janevic, 2003). Additionally, older adults tend to be more likely to engage in many positive health behaviors. An important demonstration of the capacity of older adults to adopt healthy behaviors was in the Diabetes Prevention Program. The relative advantage of its lifestyle condition (loss of 7%

bodyweight and 150 min of moderate physical activity per week) relative to metformin was greater than among younger participants (minimum age = 25 years, mean across conditions = 50.6) (Diabetes Prevention Program Research Group, 2002).

The declines that accompany aging have psychological effects. Some cognitive abilities (e.g., mechanical or fluid intelligence and pragmatic or crystallized intelligence) decline with age while others, such as "wisdom or knowledge about the meaning and conduct of life" (Connell & Janevic, 2003), may increase with years of experience. Older adults report declines in both perceived and objective control (Bandura, 1997). Again, however, these declines are subject to other influences. On the one hand, increased physical illness and decreased capacities such as with balance may decrease self-efficacy. On the other hand, greater experience with self-management might increase efficacy for things like managing chronic diseases that often emerge in older adulthood. Across several psychological and cognitive dimensions, complex interweaving of changing capacities and factors associated with functioning underscores the importance of recognizing the dynamic interplay among influences in older adulthood (Connell & Janevic, 2003).

Complementing changes in the capacities of the older adult, changes in their social contexts influence psychological status and well-being. Widowhood, illness of spouses and partners, and death of friends may all reduce the support available and individuals with whom to share activities. A classic study (Lowenthal & Haven, 1968) documented the negative impacts on emotional status of level of social interaction. Older adults reporting low levels of social interaction were much more likely to report low levels of morale based on items assessing satisfaction with life, happiness, usefulness, positive mood, and planning, 85% of those low on social interaction versus 42% of those high on interaction (p. 24). Changes in social interaction, however, were substantially moderated by answers to a simple question regarding the availability of a confidant, "Is there anyone in particular you confide in or talk to about yourself or your problems?" Among those whose level of social interaction had decreased, only 44% of those with a confidant reported low morale, but among those without a confidant, that percentage rose to 87% (p. 26). Similarly, among those who had been widowed in the previous 7 years, 45% of those with a confidant reported low morale, but 73% of those without a confidant reported low morale (p. 27). Again, dynamic interweaving of influences characterizes health and well-being among older adults.

Mental health problems are prominent among older adults. In the USA, the Centers for Disease Control and Prevention has estimated that "20% of people age 55 years or older experience some type of mental health concern" including "anxiety, severe cognitive impairment, and mood disorders (such as depression or bipolar disorder)" (Centers for Disease Control and Prevention & National Association of Chronic Disease Directors, 2008). Among these mental health burdens, older men have the highest rate of suicide, "45.23 per 100,000 compared to an overall rate of 11.01 per 100,000 for all ages" (Centers for Disease Control and Prevention & National Association of Chronic Disease Directors, 2008). Nevertheless, the vast majority of older adults do not report serious mental health problems. In national surveys in the USA, only 4.9% of those 65 years old or older reported current depressive symptoms (McGuire, Strine, Allen, et al., 2009) and only 2.7% reported "serious psychological distress," assessed by frequency of feeling "nervous, hopeless, restless or fidgety, so depressed that nothing could cheer you up, that everything was an effort, or worthless" (McGuire, Strine, Vachirasudlekha, et al., 2009). The relationship between age and reported serious psychological distress is complex. In several countries, those 65 years and older report lower levels than those in middle age and younger adulthood (McGuire, Strine, Vachirasudlekha, et al., 2009) although one study reported the highest prevalence among those 80–84 years old (Clarke, Piterman, et al., 2008).

Ways in Which Psychological Problems Are Manifest in Common/Major Diseases

The manifestations of psychological problems and psychopathology in diseases are more varied and numerous than a single chapter can review in detail. Table 32.3 provides key examples of how psychological problems can be risk factors for, can complicate, and can result from physical disease.

Integration of Biological, Psychological, and Socioeconomic Influences

A central challenge is how we conceptualize the interaction of social, economic, psychological, developmental, and biological influences in health, well-being, and disease. Other chapters in this volume detail the social determinants of health (see Siddiqi et al., Sherlaw et al., *infra*), interactions of genetic and behavioral/environmental influences (see Nater, *infra*), as well as cultural influences (see Baumann, *infra*). Here we will focus on the question of how social and psychological influences "get under the skin" to influence biological processes, a question that is central to understanding the complexity of relationships between mental health and chronic disease (e.g., Uchino et al., *infra*, as well as Cohen, Tyrrell, & Smith, 1991; Uchino, 2006; Uchino, Bowen, et al., 2014).

As a model, we will focus here on the ways these processes may interact in diabetes and depression. Depression and stressful life events can lead to the activation of the hypothalamic-pituitary-adrenal (HPA) axis and complex hormonal interactions which might be involved in the pathogenesis of metabolic disorders. These complex hormonal interactions can give rise to a wide range of metabolic and cardiovascular abnormalities which characterize diabetes and are increasingly observed in people with depression, thus creating a vicious cycle of psychological and physical ill health (Axelrod & Reisine, 1984; Ma, Kong, et al., 2007).

Once diagnosed with diabetes or depression, treatment for one may affect the severity or progression of the other. Although requiring considerably more research, there have been reports of metabolic effects of medications used to treat psychological problems as well as reports of effects on mood and behavior of medications that have been used to treat diabetes mellitus and obesity (Boekholdt & Peters, 2010; Burch, McKenna, et al., 2009; Koval, Rames, & Christie, 1994; Lustman, Griffith, et al., 1997; Lustman, Williams, et al., 2007).

Starting with epigenetic effects of early maternal care (Meaney & Szyf, 2005; Strahler, Mueller-Alcazar, & Nater, 2014), there are a variety of ways in which social, psychological, and biological influences may interact in the etiology and course of both depression and diabetes, accelerating the psychological and metabolic abnormalities of each (Golden, Lazo, et al., 2008). As symptoms and complications of diabetes increase, associated psychosocial stress and reduced coping ability may contribute to depression. Additionally, the psychological burdens of diabetes treatments, such as insulin injection or blood glucose self-monitoring, can increase negative emotions and maladaptive behaviors and lead to a loss of interest, low energy, abnormal eating patterns, sleep disturbance, poor treatment compliance, and poor concentration. As diabetes may exacerbate depression, likewise evidence indicates deleterious effects of coexisting depression on clinical status, subsequent complications, mortality, and increased healthcare expenditures (Black, Markides, & Ray, 2003; de Groot, Anderson, et al., 2001; Katon, Rutter, et al., 2005).

What Are We Preventing, Treating, and Managing? Key Definitional and Conceptual Issues

In order to develop comprehensive approaches to the effective prevention and/or management of psychological and physical health, it is necessary to clarify just how the problems and their interrelationships are to be approached. The term

Table 32.3 Manifestation of psychological concerns in common diseases

Linkage 1 – Psychological concerns are risk factors for physical disease
Cancer
• Depression influences immune activation and inflammation, which is associated with increased cancer risk (Currier & Nemeroff, 2014)
• Major depressive disorder is associated with accelerated biological aging, measured by shortened telomere length (Verhoeven, Revesz, et al., 2014)
Cardiovascular disease
• Depression independently elevates risk for various forms of cardiovascular disease (Van der Kooy, van Hout, et al., 2007)
• Major depressive disorder and bipolar disorder are recognized as risk factors for advanced atherosclerosis and early cardiovascular disease in pediatric patients (Goldstein, Carnethon, et al., 2015)
• Women diagnosed with schizophrenia are at a higher risk of acute myocardial infarction (Wu, Chen, et al., 2015)
• Ethnic minorities with severe mental illness are at an elevated risk for cardiovascular disease (Carliner, Collins, et al., 2014)
Chronic Obstructive Pulmonary Disease (Bronchitis, Emphysema)
• Nicotine dependence is a major risk factor for COPD, such that among smokers, the shorter the time to first cigarette after waking, the greater the COPD risk (Guertin, Gu, et al., 2015)
• In Taiwan, COPD is more prevalent in individuals with schizophrenia than the general population (Hsu, Chien, et al., 2013)
Diabetes
• In a meta-analysis of 23 longitudinal studies, depression was highlighted as a major risk factor for incident type 2 diabetes (Rotella & Mannucci, 2013a)
• Individuals reporting high levels of psychological distress were 33% more likely to develop type 2 diabetes than individuals reporting low levels of distress (Mommersteeg, Herr, et al., 2012)
HIV/AIDS
• Among Medicaid beneficiaries, individuals with a substance use disorder were 3.1 times more likely to receive an HIV diagnosis than individuals without a substance use disorder (Prince, Walkup, et al., 2012)
• Among cocaine users, severe psychological distress increases needle sharing behavior, a major risk factor for HIV infection (Lévesque, Bruneau, et al., 2014)
Maternal and child health
• Compared to women without a history of mental illness, mothers with bipolar disorder are more likely to have adverse pregnancy outcomes, specifically, low birth weight, small for gestational age, and preterm birth (Lee & Lin, 2010)
• Children of mothers with comorbid mental disorders are at a higher risk for internalizing disorders (Hser, Lanza, et al., 2015)
Linkage 2 – Psychological concerns complicate physical disease
Cancer
• Depression is related to higher mortality rates among cancer patients (Pinquart & Duberstein, 2010)
• Individuals with mental illness are less likely to undergo routine cancer screenings (Aggarwal, Pandurangi, & Smith, 2013) and more likely to have metastases at diagnosis (Kisely, Crowe, & Lawrence, 2013)
Cardiovascular disease
• Neuroticism is associated with poorer quality of life in patients with chronic heart failure (Samartzis, Dimopoulos, et al., 2014)
• Individuals with coronary heart disease that also have severe anxiety are more likely to experience cardiovascular events than individuals without anxiety symptoms (Martens, de Jonge, et al., 2010; Moser, 2011)
• Among patients with acute coronary syndrome, depression is recognized as a major risk factor for poor medical outcomes (Lichtman, Froelicher, et al., 2014)

(continued)

Table 32.3 (continued)

Chronic Obstructive Pulmonary Disease (Bronchitis, Emphysema)
• Anxiety and depression are known to exacerbate symptoms in COPD (Abrams, Vaughan-Sarrazin, & Vander Weg, 2011; Laurin, Moullec, et al., 2012)
• COPD patients with anxiety tend to have poorer outcomes than those without anxiety; specifically, they have greater difficulty with exercise and report more functional limitations (Eisner, Blanc, et al., 2010)
Diabetes
• Persons with diabetes and severe mental illness are significantly more likely to require re-hospitalization within a month after discharge (Lydia A. Chwastiak, 2014)
• Individuals with substance abuse disorders are less likely to adhere to a type 2 diabetes medication regimen (Kreyenbuhl, Dixon, et al., 2010)
HIV/AIDS
• Depressed individuals with HIV have worse outcomes than nondepressed individuals with HIV, with reduced treatment adherence and quality of life (Nanni, 2015)
• HIV patients with major depressive disorder and psychiatric comorbidity have particular poor outcomes (Gaynes, 2015)
• Depression is thought to increase HIV disease progression to AIDS (Schuster, Bornovalova, & Hunt, 2012)
Maternal and child health
• Mothers who use antidepressants while pregnant are more likely to have preterm births (Einarson, Choi, et al., 2010) and preeclampsia (Palmsten, Setoguchi, et al., 2012)
Linkage 3 – Psychological concerns result from physical disease
Cancer
• Many cancer patients suffer from psychological distress after receiving a diagnosis, and a recent meta-analysis suggests that prevalence rates of clinical depression range from 8 to 24% amongst adult cancer patients (Krebber, Buffart, et al., 2014)
• After receiving a cancer diagnosis, adolescents and young adults are at a significantly elevated risk for suicidal behavior (Lu, Fall, et al., 2013)
Cardiovascular disease
• Myocardial infarctions have been shown to be causal factors of both depression (Meijer, Conradi, et al., 2011) and PTSD (Edmondson & Cohen, 2013; Guler, Schmid, et al., 2009)
Chronic Obstructive Pulmonary Disease (Bronchitis, Emphysema)
• Exacerbations in COPD symptoms lead to a subsequent rise in symptoms of PTSD (Teixeira, Porto, et al., 2015)
• Likewise, patients with COPD have an elevated risk for anxiety (Eisner, Blanc, et al., 2010)
• COPD confers elevated risk of suicide after controlling for psychological status and history. Risk increases with stage of COPD progression (Chung, Han, et al., 2014; Strid, Christiansen, et al., 2014)
Diabetes
• Patients diagnosed with diabetes mellitus are at a significantly elevated risk to develop depressive symptoms (Rotella & Mannucci, 2013b), severe psychological distress (Shin, Chiu, et al., 2013), and anxiety disorders (Smith, Béland, et al., 2013)
• In addition to its relationships with depression and quality of life, diabetes and the burdens and stressors it entails may cause diabetes distress that may also complicate management of the disease (Fisher, Gonzalez, & Polonsky, 2014)
HIV/AIDS
• HIV infection is correlated with a substantially higher risk for major depressive disorder (Bhatia, Hartman, et al., 2011; Ciesla & Roberts, 2001)
• HIV patients may experience emotional distress and suicidal ideation (Kalichman, Heckman, et al., 2000)
Maternal and child health
• Medical difficulties during pregnancy and delivery are associated with a greater risk for maternal postpartum depression (Blom, Jansen, et al., 2010)
• Both infant complications and obstetric emergencies are associated with the development of PTSD symptoms in mothers (Andersen, Melvaer, et al., 2012)

"comorbidity" connotes two well-defined and distinct clinical entities, occurring simultaneously and each tending to occur more frequently in the presence of the other. Viewing comorbid conditions as distinct entities, however, may not capture important relationships and interactions between them. Here we review conceptual approaches to relationships between or among co-occurring conditions, again taking diabetes and depression as a model.

A Dimensional Versus Categorical View of Each of Diabetes and Depression Both depression and diabetes are commonly defined categorically with specific criteria used to classify individuals as having either depression or diabetes. Within each of depression and diabetes, subcategories are increasingly refined based on emerging insights from genomics and phenotyping. These confirm the heterogeneity of the broader categories.

An alternative to categorical definition of depression has been a dimensional characterization of mood or dysphoria, often using standardized instruments such as the popular Beck Depression Inventory which was originally developed and validated as a measure of depressed mood, not of categorical depression (Beck, Ward, et al., 1961; Roy, Lloyd, et al., 2011). As an example of the dimensional perspective in diabetes, the success of preventing incident diabetes in high-risk subjects has led to the identification of a dimension of dysglycemia including varying degrees of insulin resistance and deficiency that underlie manifest abnormalities in glucose metabolism. Supporting the dimensional perspective, "graded relationships" between depression and both myocardial infarction and all-cause mortality suggest that depression "is best viewed as a continuous variable that represents a chronic psychological characteristic rather than a discrete and episodic psychiatric condition" (Barefoot & Schroll, 1996).

With each of depression and diabetes, categorical definitions may be superimposed on the dimensional by defining the diagnostic category according to a convention of some criterion score as in common definitions of hypertension.

Single Problem Versus Group of Problems In addition to the difference between viewing problems as distinct categories and viewing them as dimensions, diabetes and depression may each be categorized as part of a broader class of problems, cardiometabolic abnormalities for diabetes and negative emotions for depression. For example, studies of depression in various groups, such as patients with cancer (Brown & Kroenke, 2009) or asthma (Lavoie, Bacon, et al., 2006), indicate high co-occurrence of depression, anxiety, and other varieties of psychological distress (Hjerl, Andersen, et al., 2002). Similarly, studies in cardiovascular risk indicate the utility of grouping together a set of negative emotions that includes depression, anxiety, hostility, and stress (Williams, Barefoot, & Schneiderman, 2003) for understanding their complex interactions in pathways related to cardiovascular pathogenesis (Brummett, Boyle, et al., 2010). Recent work in diabetes, too, indicates that diabetes distress may be more closely related to metabolic control than measures of depressed mood alone (Fisher, Mullan, et al., 2010). Parallel to the overlap among measures of psychological disorder and distress, hyperlipidemia, central adiposity, and hypertension often co-occur with "prediabetes" or diabetes, leading some to refer to the group as comprising a "metabolic syndrome" (Eckel, Grundy, & Zimmet, 2005).

Whether depression and diabetes are best viewed as distinct or as members of broader categories is controversial. For example, some argue that, however much they may co-occur, one needs to treat the individual cardiovascular and metabolic problems encompassed by the term "metabolic syndrome" with appropriate medications for each of diabetes, hypertension, and hyperlipidemia (Kahn, 2008). Similarly, one may argue that beyond the co-occurrence with anxiety, hostility, and stress, depressed mood alone has a specific and distinctive role with each of diabetes and cardiovascular disease requiring specific treatment rather than a more generalized approach.

Viewing diabetes or depression as distinct entities or as parts of broader syndromes may depend on the lens through which the problems are viewed. For example, Valderas and colleagues (Valderas, Starfield, et al., 2009) noted that the value of different models of comorbidity would vary according to the perspective taken by specialist, primary care, public health, or health services. From the perspective of clinical care of individuals, differentiating among specific problems, depression, anxiety, and hostility on the one hand and diabetes, hypertension, and hyperlipidemia on the other may make great sense. Whether with psychotherapy or psychopharmacology, management of depressed mood generally differs from treatment of hostility or anxiety, just as medication for diabetes differs from that for hypertension or hypercholesterolemia. At the population level, however, co-prevalent problems may share common treatment and prevention targets, such as healthy diet, physical activity, and weight management for diabetes and cardiovascular disease, or, for negative emotions, socioeconomic well-being and communities and families that encourage cooperation and satisfying relationships among neighbors. Thus the broader categories of cardiometabolic abnormalities and negative emotions may help guide population-wide prevention and treatment campaigns. At the same time, the individual components of these broad categories are duly the focus of clinical intervention.

Heterogeneity of Depression and Distress Depression is often discussed as a unitary "thing," when in fact it is quite heterogeneous. A study among Dutch adults examined differences in severity and symptom patterns to identify three subtypes of depression: (1) moderately severe, (2) severe melancholic, and (3) atypical that is "characterized by increased appetite, weight gain, leaden paralysis (e.g., leaden, heavy arms and legs), and to a lesser extent hypersomnia and is associated with female sex, being overweight, and the metabolic syndrome" (Snoek, Bremmer, & Hermanns, 2015). This latter, atypical type may be especially related to diabetes.

In addition to heterogeneity among types of depression, Snoek and his colleagues (Snoek, Bremmer, & Hermanns, 2015) point out varied connections between depression and diabetes distress. Separate from generally depressed mood, diabetes distress is focused on the stressors and demands of diabetes and its management and emotional responses to these. Items from a popular measure of diabetes distress include, e.g., "Feeling overwhelmed with the demands of living with diabetes," "Feeling that I am often failing with my diabetes routine," "Not feeling motivated to keep up my diabetes self-management, " and "Feeling angry, scared, and/or depressed when I think about living with diabetes" (Fisher, Glasgow, et al., 2008). Depression and diabetes distress are related, but not as closely as one might think. L. Fisher and colleagues, for example, have argued that, because it is more closely related to diabetes management and problems with it, distress is more predictive of glycemic control than depression (Fisher, Mullan, et al., 2010).

Snoek and colleagues outline a model of the four combinations of the presence/absence of each of distress and depression and possible treatment strategies for each. Those who are distressed by their diabetes but not depressed, for example, might benefit from "psychoeducation or supportive counseling to help improve their problem solving skills and coping with the daily demands of diabetes self-care" (Snoek, Bremmer, & Hermanns, 2015). This might best be delivered in close coordination or as part of their diabetes care. On the other hand, those who are both depressed and distressed are perhaps "most psychologically vulnerable … [among whom] the interaction between mood and diabetes-related issues deserves special attention … [so that patients] are likely to benefit most from diabetes-specific depression treatment" (Snoek, Bremmer, & Hermanns, 2015).

Separate "Comorbidities" or Depression and Distress as Part of Normal Clinical Picture of Diabetes Snoek and his colleagues conclude their review of depression and distress by arguing for the inclusion of both within our broader understanding of diabetes; "both … deserve to be assessed routinely" among both adults and children with diabetes (Snoek, Bremmer, & Hermanns, 2015). Consider foot ulcers, routinely viewed as an important part of diabetes deserving special attention because of their importance in the development of lower extremity complications and potential for amputations. A 2008 study among older adults with diabetes found an 8% yearly prevalence of foot ulcers (Margolis, Malay, et al., 2011). In contrast, depression affects 10–20% of those with diabetes (Roy & Lloyd, 2012).

Viewing diabetes and depression as part of broader groupings or syndromes may also make sense *across* the categories of mental health and medical illness. Research such as from the Diabetes Prevention Program (Rubin, Knowler, et al., 2005; Rubin, Ma, et al., 2008) raises the possibility that depression is an early sign or precursor of diabetes. Thus, as we think of the comorbidity of diabetes and depression, we might consider whether they are best viewed as distinct clinical entities that occasionally exist together or as components of a broader syndrome encompassing both psychological and physical problems. More generally, the term, "depression" needs to be understood as referring to mood changes that may be combined with a large – probably larger than currently recognized – number of problems and syndromes, rather than as a single entity.

In an integrated approach, the treatment of depression becomes a routine part of diabetes care, just as foot care and yearly retinal checks. So, too, the psychological or medical treatment of depression may be expanded to address its routine metabolic and cardiovascular dimensions. Consider physical activity, often included in diabetes self-management and increasingly recognized as helpful in reducing depression (Penedo & Dahn, 2005; Teychenne, Ball, & Salmon, 2008). When promoting physical activity in diabetes self-management, one should routinely consider reticence to engage in exercise as potentially linked to mood problems. Additionally, one should structure goal setting and monitoring to maximize the possible benefits not only of physical activity itself but also of the mood-elevating effects of achieving a personal goal (Piette, Richardson, et al., 2011). At the same time, promoting physical activity as part of depression treatment may draw added emphasis from the recognition of its value not only in increasing mood but also in reducing cardiovascular risks to which those with depression are prone.

Biosocial Propensity to Chronic Disease and Psychological Distress Bringing together a number of the points developed in this volume, Fig. 32.1 outlines a biosocial complex of determinants of disease, ranging from genetic and epigenetic effects including those of maternal

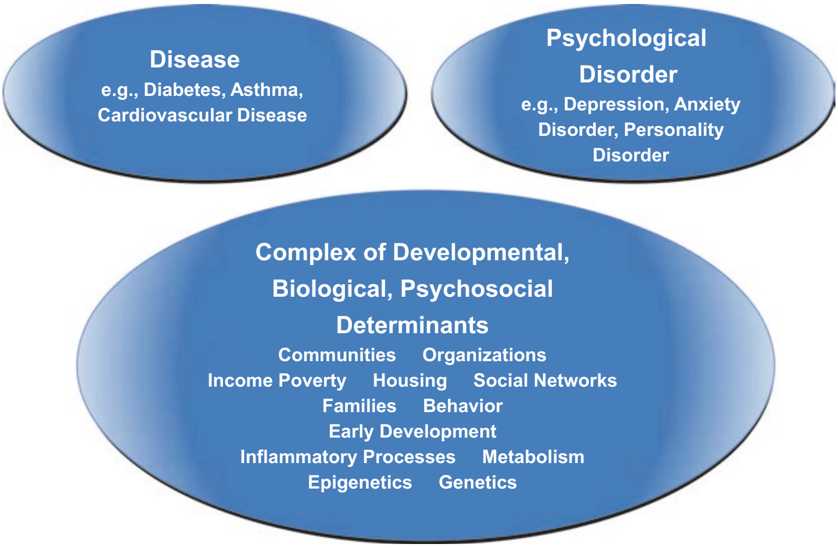

Fig. 32.1 Biosocial complex of determinants of disease and psychological disorder

nurturance during early childhood, to community design. Given sufficient deficiencies in this complex, some kind of disease, whether diabetes, asthma, or others, is very likely as is some variety of appreciable psychological distress or psychopathology. The particular expression of this biosocial complex in one or another disease and one or another type of psychological problem may be hard to predict, but the likelihood of at least one of each – disease and psychological distress – is great. In casual survey of practicing primary care clinicians, the common response is "That's half of my waiting room."

Figure 32.1 raises an important point, "What is fundamental that requires attention?" The fundamental appears to be the biosocial complex of events that makes expression in diabetes and depression or some other varieties of medical and psychological morbidity highly likely. The particular choice of expressions may be almost accidental or perhaps guided by some specific factors such as a particular genotype or type of aggravating experience such as in exposure to trauma and PTSD, but the likelihood of such expressions is almost assured.

Interventions

Peer Support

Among strategies for integrating clinical and preventive, individual and population approaches to treatment of psychological disorders and chronic diseases, peer support (e.g., "community health workers," "lay health advisors," "*Promotores*") may deserve special attention. Peer supporters can assist individuals in adopting and provide encouragement to help sustain the behaviors that comprise psychological and chronic disease management (Fisher, Boothroyd, et al., 2012). They may also provide emotional support and encourage problem-solving to address depression and other emotional distress (Rahman, Malik, et al., 2008). From the perspective of reaching populations, peer supporters can also engage and benefit those who otherwise fail to receive appropriate care (Fisher, Ballesteros, et al., 2015; Fisher, Strunk, et al., 2009; Sokol & Fisher, 2016). All of these can assist in identifying and recruiting into treatment those with psychological disorders and chronic diseases and in helping them take full advantage of resources available.

Both the social isolation or lack of a confidant that often accompany psychopathology and distress (Fisher, Chan, et al., 2012; Lowenthal & Haven, 1968) and the importance of simple social contact and emotional support (Harlow, 1958) suggest that simple, frequent, affirming, and pleasant contact from a supporter may be especially helpful to those with emotional distress.

"Lady Health Workers" and Peer Support in Maternal and Child Health In a striking cluster randomized evaluation in Pakistan, "Lady Health Workers" implemented a cognitive-behavioral, problem-solving intervention (Rahman, 2007) for women who met criteria for major depression during the third trimester of their pregnancies. Relative to controls, the intervention substantially reduced depression 12 months postpartum (OR = 0.23, $p < 0.0001$) (Rahman, Malik, et al., 2008). In India, peer support for depression, anxiety, and other mental health problems included education about psychological problems and ways of coping with them (e.g., deep breathing for anxiety symptoms) as well as interpersonal therapy (de Mello, de Jesus Mari, et al., 2005), all delivered by lay health counselors with backup by primary care and monthly consultations from psychiatrists. Results included a 30% decrease in prevalence of depression and other common mental disorders among those meeting criteria at baseline, 36% reduction in suicide attempts or plans, as well as reductions in days out of work (Patel, Weiss, et al., 2011).

Research with the Lady Health Workers has also considered the roles of socioeconomic determinants in the development of chronic diseases and psychological disorders. If a program reduces the effect of low-income status on some important outcome, for example, then it would be reducing disparity related to low income. In Pakistan, the Lady Health Workers intervention for postpartum depression eliminated the impact of factors such as lack of financial empowerment which, in the absence of intervention, sharply differentiated those becoming depressed (Rahman, Sikander, et al., 2012).

An important consideration among concerns for more effective and affordable care is the relationship between psychological disorders and frequency of hospitalizations among those with chronic diseases. Evidence indicates peer support may have a useful role in this regard. In a randomized study among adults with diabetes in Hong Kong, all received JADE (Chan, So, et al., 2009), a standardized, systematic model of care incorporating quarterly reports to patients providing appraisal of clinical status and self-management recommendations. In addition to JADE, half of the participants were randomized to receive PEARL, telephone-based peer support provided by trained peer supporters. Reflecting patterns familiar to those working in health policy and services, the 20% of patients with elevated levels of depression, anxiety, and/or stress were more likely to be hospitalized (34%) than those without distress (20%). Among this group with heightened distress, the PEARL peer support intervention improved distress scores relative to JADE alone ($p = 0.03$) and reduced overall hospitalizations (relative risk = 0.15, $p < 0.001$), a reduction to the "normal" level of those low on distress measures (Chan, Sui, et al., 2014). That is, among the fifth of patients with the highest scores on distress and who account for greatly disproportionate hospital care, the addition of peer support to standardized, high-quality clinical care substantially reduced distress and lowered associated hospitalization rates to normal levels.

An important impact of psychological distress in chronic disease is its role in complicating efforts to reach and engage patients in recommended care. Peer support may be an especially effective strategy for reaching those who are too often "hardly reached" (Sokol & Fisher, 2016). Asthma coaches pursuing a nondirective, flexible, stage-based approach were able to engage 89.7% of mothers of Medicaid-covered children hospitalized for asthma. The coaches sustained that engagement, averaging 21.1 contacts per parent over a 2-year intervention. Of those randomized to the asthma coach, 36.5% were rehospitalized over the 2 years, relative to 59.1% randomized to usual care ($p < 0.01$) (Fisher, Strunk, et al., 2009).

Other examples illustrate the ability of peer support to reach those too often hardly reached. In a successful peer support intervention for diabetes management among patients of safety net clinics in San Francisco (Thom, Ghorob, et al., 2013), participants were categorized as low, medium, or high medication adherence at baseline. The peer support led to greater reductions in HbA1c than in controls across all groups, but the differential impact of peer support was greatest among those initially in the low adherence group (Moskowitz, Thom, et al., 2013). In a peer support intervention among veterans with diabetes (Heisler, Vijan, et al., 2010), improvements in blood glucose measures were substantially more pronounced among those with low initial levels of diabetes support (p for interaction <0.001) and those with low health literacy (p for interaction <0.05) (Piette, Resnicow, et al., 2013). A systematic review of peer support interventions for hardly reached groups found that 94% reported significant benefits favoring peer support relative to control conditions (Sokol & Fisher, 2016).

Stress Management, Cancer, and HIV

Chronically ill individuals, particularly those with diseases perceived as potentially life-threatening and stigmatizing, such as HIV and cancer, face substantial stressors. These stressors occur as part of people's experiences adjusting to a diagnosis as well as living with and managing a serious, chronic disease. Disease management stressors commonly include undergoing treatments and experiencing side effects, facing one's mortality, feeling stigmatized or isolated from others, and experiencing illness episodes, pain, disability, and strained relationships (Antoni, Lutgendorf, et al., 2006; Brown & Vanable, 2008; Grassi, Caruso, & Costantini, 2015; Scott-Sheldon, Kalichman, et al., 2008). Often individuals with chronic diseases are also exposed to serious life stressors due to psychosocial factors, such as poverty, substance abuse, psychological distress, and childhood trauma (Brown & Vanable, 2008; Scott-Sheldon, Kalichman, et al., 2008).

For diseases like HIV and cancer that are immune mediated, not only is stress more prevalent, but researchers have also found that greater stress, anxiety, and depression, as well as limited skills for coping with these, prospectively worsen disease progression (Antoni, Lutgendorf, et al., 2006; Artherholt & Fann, 2012; Atkinson, Schönnesson, et al., 2008; Balbin, Ironson, & Solomon, 1999; Kalichman, Heckman, et al., 2000; Leserman, 2008). These findings are due, at least partly, to mediating psychoneuroimmunologic effects of stress on disease, through stimulation of the autonomic sympathetic nervous system and the hypothalamic-pituitary-adrenocortical axis, which in turn interact with the immune system (Antoni, 2003; Antoni, Lutgendorf, et al., 2006; Artherholt & Fann, 2012; Balbin, Ironson, & Solomon, 1999; Leserman, 2003, 2008; McGregor, Antoni, et al., 2004; Segerstrom & Miller, 2004). With HIV, for example, psychological distress has been associated with increases in disease progression, including lower CD4 immune cell counts, fewer natural killer cells, and elevated levels of virus in patients' blood (Ironson, Balbin, et al., 2005; Leserman, 2008). Similarly, growing evidence demonstrates that stress and stress-related behavioral factors may contribute to cancer growth and metastasis through their effect on both the hypothalamic-pituitary-adrenocortical axis and the sympathetic nervous system, resulting in the release of glucocorticoids, catecholamines, and other factors that directly or indirectly influence malignancy (Artherholt & Fann, 2012). Affected pathways include the cellular immune response, inflammation, tumor angiogenesis, and tumor cell signaling pathways. Stress is also believed to influence physiological health because it can interfere with individuals' abilities to adhere to medical recommendations (Brown & Vanable, 2008).

In response to evidence that stress is both elevated and worsens the health of HIV and cancer patients, researchers over the last two decades have focused on designing and testing interventions to help patients enhance their capacity to cope with and reduce stressful experiences. These interventions aim to improve both psychological and physiological health outcomes.

The theoretical conceptualization of stress and its effects on clinical outcomes in the setting of chronic illness is based primarily on Lazarus and Folkman's Transactional Model of Stress and Coping (Lazarus & Folkman, 1984, 1987), which builds from Lazarus' book *Psychological Stress and the Coping Process* (Lazarus, 1966). The Transactional Model of Stress and Coping emphasizes the role of cognitive appraisal and the processes ordinary people use to deal with everyday distress. It also emphasizes the relationship between the nature of the stressor and the capacities and skills of the individual. As Lazarus and Folkman defined it in their classic work, *Stress, Appraisal and Coping,* "Psychological stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman, 1984, p. 19). Simply put, stress occurs as a result of the imbalance between demands and resources. *Coping,* then, is composed of the behaviors and thoughts individuals use to manage the internal and external demands of stressful circumstances. In an effort to capture the complex multidimensional processes humans use to address threats, coping styles are typically categorized as "problem focused" (directly addressing the stressor), "emotion focused" (deregulating negative and enhancing positive emotions), or "appraisal focused" (changing the way one thinks about the stressor) (Folkman & Moskowitz, 2004). Stress management interventions have used this framework to reduce the stress of individuals facing chronic illness by enhancing their coping resources. Researchers at the University of Miami were among the first to design manualized, multi-session, cognitive-behavioral group programs, known as cognitive behavioral stress management (CBSM), to help HIV-infected and cancer patients manage stress (Antoni, 2003; Antoni, Lehman, et al., 2001).

Specifically for patients with HIV, there is now a substantial body of evidence that CBSM and similar approaches offer a promising adjunct to HIV management. For example, two systematic reviews (Brown & Vanable, 2008; Harding, Liu, et al., 2011) and a meta-analysis (Scott-Sheldon, Kalichman, et al., 2008) found generally positive effects of stress-management or coping interventions on physical and psychological health outcomes among people living with HIV. Two additional reviews examined studies of cognitive behavioral interventions to reduce anxiety in people with HIV (Clucas, Sibley, et al., 2011) and comparing the effect of CBSM on outcomes of HIV-infected patients with a history of trauma or post-traumatic stress disorder (PTSD) (Seedat, 2012), respectively.

In Brown and Vanable's (2008) review of 21 randomized, controlled trials of CBSM interventions, all of the interventions utilized cognitive and behavioral stress management strategies designed to facilitate adaptive coping and to decrease the negative impact of stress. Moreover, these interventions highlighted the value of active, problem-focused coping strategies as well as cognitive restructuring, or modifying one's stress appraisal process to match a new coping ability. Emotional regulation strategies and decreasing psychological distress were also often identified as objectives. Three quarters of the interventions included relaxation training and most encouraged strategies to enhance the use of social support networks. Interventions varied in number, length, and timing. All but one of the interventions used a group-based intervention approach. Most used multiple sessions (range 6–20; mode = 10) with a duration of 1–2.5 h (mode = 2). Overall, most studies that assessed the outcome found many improvements in perceived stress, depression, anxiety, global psychological functioning, social support, and quality of life. Effects on the coping and immune function markers, however, were mixed. One study that looked at stress hormone levels found stress effects on norepinephrine and testosterone but not on epinephrine or cortisol levels (Antoni, Cruess, et al., 2000; Cruess, Antoni, et al., 2000). Other assessments found greater naive T cells (Antoni, Cruess, et al., 2002) and higher cytotoxic T cells (Antoni, Cruess, et al., 2000), both cells that facilitate the function of the immune system, respectively, in the intervention groups at follow-up. No studies, however, found any effect on CD4 cell count, which would indicate improved health. Furthermore, most studies did not control for other important factors and most had only brief follow-up periods. Scott-Sheldon et al.'s (2008) meta-analysis of 46 stress management interventions in 35 randomized controlled trials drew similar conclusions (Scott-Sheldon, Kalichman, et al., 2008).

In Harding et al.'s (2011) systematic review of 28 interventions aimed at improving HIV coping strategies, 21 involved psychological interventions (as opposed to others that used medications, diet and exercise, and informational or spiritual approaches), most of which were CBSM (Harding, Liu, et al., 2011). Harding specifically evaluated intervention effects on coping skills. Of all 28 studies, 17 (60%) had a positive effect on coping skills; those that used CBSM, however, were noted to be most promising although comparison across studies was limited by heterogeneity in the measures of coping. Similarly, the reviews of studies specific to HIV-infected patients with anxiety and trauma/PTSD concluded that CBSM was generally most effective at improving psychological distress (Clucas, Sibley, et al., 2011; Seedat, 2012).

All five of the reviews cited above noted the promising nature of CBSM for improving health outcomes in HIV; yet they pointed out the need for further understanding of the mechanism by which the interventions acted and that most studies they had reviewed had been conducted in gay and bisexual white men and called for more targeted interventions of diverse populations. Yet one study, the Stress Management and Relaxation Training/Expressive Supportive Therapy (SMART/EST) Women's Project, was designed specifically to address the unique experiences of minority women living with HIV (Jones, Owens, et al., 2010). While the intervention was generally ineffective, those in the intervention group who increased their self-efficacy also had reduced depression and anxiety. These findings suggest that additional adaptation of CBSM interventions may be required to more fully enhance the cognitive behavioral self-efficacy of women to better address their psychological distress.

More recently, investigators at the University of Miami, as well as others, have sought to adapt and test their 10-week CBSM group intervention for cancer patients, particularly those with prostate cancer (Parker, Pettaway, et al., 2009; Penedo, Dahn, et al., 2004; Penedo, Molton, et al., 2006; Penedo, Traeger, et al., 2007; Traeger, Penedo, et al., 2013) and early stage breast cancer (Carpenter, Stoner, et al., 2014; Groarke, Curtis, & Kerin, 2013; Lechner, Whitehead, et al., 2014; McGregor, Antoni, et al., 2004; Nápoles, Ortíz, et al., 2015; Stagl, Antoni, et al., 2015). Although, to date, no systematic reviews of these trials have been conducted, review of the studies indicate more diverse study sample than those seen in many of the HIV trials.

Among an ethnically diverse group of men who had undergone treatment for localized prostate cancer, CBSM increased men's finding benefits of their cancer experience (Penedo, Molton, et al., 2006), emotional well-being (Traeger, Penedo, et al., 2013), and overall quality of life (which was mediated by stress management skills) (Penedo, Dahn, et al., 2004; Penedo, Molton, et al., 2006), but not in their illness perceptions (Traeger, Penedo, et al., 2013). Women with early stage breast cancer undergoing an adaptation of the same 10-session group CBSM not only increased their "benefit finding," but this increase also mediated their improved immune function 3 months later (McGregor, Antoni, et al., 2004). The intervention also improved sleep quality and reduced fatigue (Vargas, Antoni, et al., 2014) and impressively led to fewer depressive symptoms 5 years after the intervention (Stagl, Antoni, et al., 2015) and better all-cause mortality at 11 years follow-up (Stagl, Antoni, et al., 2015). In another study of the same intervention among underserved African American breast cancer survivors, however, both arms showed significant improvements in mood and perceived stress with no differences between groups (Lechner, Whitehead, et al., 2014). Among monolingual Hispanic men, in addition to overall well-being, physical, emotional, and sexual well-being (often affected by the impact of prostate cancer treatment on urinary and sexual function) were all shown to improve significantly more in the CBSM group (Penedo, Traeger, et al., 2007).

Some studies have assessed whether less intensive CBSM interventions could be effective. One study assessing an individually and presurgically delivered and shorter (two sessions plus two booster sessions) cognitive behavioral stress management program for prostate cancer patients showed immediate benefit on mood and improved physical (but not mental health) quality of life 1 year after surgery (Parker, Pettaway, et al., 2009) suggesting the shorter approach may be a useful adjunct to standard care when longer group sessions are not feasible. Similarly, Groarke et al. (2013) found that a five-session CBSM with breast cancer patients reduced global stress and anxiety while improving benefit-finding, but the effects were also not sustained after a year. Of note, women with greater global stress at baseline responded more to the intervention. More recently, researchers have begun to assess the effectiveness of an online CBSM for breast cancer as an alternative means to facilitate dissemination (Carpenter, Stoner, et al., 2014).

Mindfulness-Based Therapy

Mindfulness meditation has gained popularity as a stress-reduction technique that appears to support general health and well-being (Goyal, Singh, et al., 2014). Mindfulness-based programs are now offered all over the world, in hospitals, schools, workplaces, prisons, and health centers (Kabat-Zinn, 2003). Mindfulness has also been incorporated into a variety of health interventions (Mars & Abbey, 2010). Jon Kabat-Zinn, a leader in introducing mindfulness to Western psychology (Baer, 2003), describes the practice as "the awareness that emerges through paying attention on purpose, in the present moment, and nonjudgmentally to the unfolding of experience moment by moment" (Kabat-Zinn, 2003), p. 145). Mindfulness can be developed through meditation, specifically through the practice of focusing one's attention on thoughts, bodily sensations, and external stimuli, without evaluation or judgment (Baer, 2003).

Mindfulness-based therapy includes several therapeutic approaches that incorporate mindfulness practice (Piet, Wurtzen, & Zachariae, 2012), most notably mindfulness-based stress reduction (MBSR; Kabat-Zinn, 1990). MBSR is an 8-week, group-based program that incorporates formal in-person mindfulness meditation practice with homework assignments for individuals to practice mindfulness throughout the week (Vøllestad, Nielsen, & Nielsen, 2012). MBSR has been shown to be effective in reducing stress and psychological symptoms, improving coping strategies, and enhancing quality of life in both clinical and nonclinical populations (Grossman, Niemann, et al., 2004; Vøllestad, Nielsen, & Nielsen, 2012). A meta-analysis of eight randomized controlled studies highlighted the positive impact of MBSR on the mental health of individuals suffering from chronic diseases, with effect sizes of 0.26, 0.24, and 0.32 on depression, anxiety, and psychological distress, respectively (Bohlmeijer, Prenger, et al., 2010.

Among its positive psychological impacts, mindfulness increases self-efficacy and emotional processing (Grossman, Niemann, et al., 2004) and decreases symptoms of anxiety and depression (Goyal, Singh, et al., 2014; Khoury, Lecomte, et al., 2013; Vøllestad, Nielsen, & Nielsen, 2012). In one randomized controlled trial, individuals in a mindfulness meditation group had greater activation of the left-anterior hemisphere of the brain, which is associated with positive emotions, than a wait-list control group when brain electrical activity was measured (Davidson, Kabat-Zinn, et al., 2003). Carmody and Baer (2008) found that greater time spent practicing mindfulness meditation is associated with increases in various aspects of trait mindfulness, which mediates the relationship between mindfulness meditation practice and psychological well-being (Carmody & Baer, 2008). In another randomized controlled trial of undergraduates ($N = 82$), a mindfulness meditation intervention decreased negative mood, depressive symptoms, fatigue, confusion, and heart rate in comparison to control groups (Zeidan, Johnson, et al., 2010).

Mindfulness has been shown to support general health and well-being in a variety of health interventions (Mars & Abbey, 2010). Recent work indicates that mindfulness can promote healthy eating habits and decrease psychological distress in individuals with binge eating disorder (Dalen, Smith, et al., 2010; Katterman, Kleinman, et al., 2014), improve quality of life in multiple sclerosis patients (Schirda, Nicholas, & Prakash, 2015), and enhance social skills in autistic adolescents (de Bruin, Blom, et al., 2015). Davidson, Kabat-Zinn, et al. (2003) showed that mindfulness improved immune function. In their randomized controlled trial, subjects in both mindfulness meditation and control groups were given a flu shot immediately after the intervention ended. The mindfulness group had significantly greater increases in antibody titers in response to the flu vaccine than the control group ($t = 2.05$, $p < 0.05$).

Mindfulness also appears to help individuals with diabetes. In one randomized controlled trial, participants either participated in a diabetes education program that involved a version of mindfulness training called "Acceptance and Commitment Therapy" (Hayes, Strosahl, & Wilson, 2012) or an education-only program (Gregg, Callaghan, et al., 2007). After 3 months, patients in the Acceptance and Commitment Therapy group had enhanced coping strategies, better diabetes self-management, and were more likely to have glycated hemoglobin (HbA1C) in their target range. Other works support these findings and suggest that increased mindfulness can result in better glycemic control, reduced mean arterial pressure, and fewer depressive symptoms among those with diabetes (Hartmann, Kopf, et al., 2012; Rosenzweig, Reibel, et al., 2007; Tovote, Fleer, et al., 2014).

Cardiovascular health may also be improved by mindfulness. Loucks, Schuman-Olivier, et al. (2015) review the positive effects of mindfulness on known cardiovascular protective factors, such as physical activity, diet, and smoking cessation. They suggest a number of psychological pathways through which mindfulness may act on these factors, including enhanced attentional control, improved emotion regulation, and greater self-awareness. Tacón, McComb, et al. (2003) found that mindfulness practice reduced anxiety and reactive coping styles in women with cardiac diagnoses. In a randomized controlled trial of community-dwelling adults reporting high levels of stress ($N = 88$), individuals who had been assigned to an MBSR condition had greater decreases in both systolic and diastolic blood pressure after being exposed to a stressful task than individuals in the wait list control group (Nyklíček, Mommersteeg, et al., 2013). The MBSR group also had a significantly smaller increase in blood pressure during the task. Similarly, Ditto, Eclache, and Goldman (2006) found that participants in a meditation group had significant increases in respiratory sinus arrhythmia, which measures parasympathetic activity, compared to both control and progressive muscle relaxation groups. They suggest that meditation may be particularly valuable for individuals with hypertension or other cardiac issues. Additionally, results of a meta-analysis of four studies completed by Lawrence and colleagues demonstrated that MBSR was effective at reducing blood pressure and stress levels in patients at high risk for ischemic stroke (Lawrence, Booth, et al., 2013).

Finally, recent work has elucidated the ways in which mindfulness is beneficial for cancer patients. Campbell, Labelle, et al. (2012) found that an MBSR program effectively increased mindful attention and decreased ruminative cognitive patterns in women with cancer. In another study, MBSR significantly improved mood, breast- and endocrine-related quality of life, and well-being in women with breast cancer compared to standard care (Hoffman, Ersser, et al., 2012). In a meta-analysis of 22 studies, mindfulness significantly reduced symptoms of depression and anxiety in cancer patients and survivors (Piet, Wurtzen, & Zachariae, 2012).

Reflecting the broad evidence for mindfulness-based interventions, Merkes (2010) suggested that by incorporating mindfulness practice into primary care, providers may not only improve the health and well-being of their patients but also contain healthcare costs, as mindfulness is a relatively inexpensive therapy to offer.

Assertive Community Treatment (ACT)

ACT is an evidence-based practice for persons with serious mental illnesses (Dixon, 2000; Stein & Test, 1980). ACT is best viewed as a platform for delivering services such as medication management, vocational and housing services, and psychosocial interventions (Stein & Santos, 1998) and is a multidisciplinary, team-based approach with a small (1:10) staff-to-consumer ratio, 24-hour staff availability, and aggressive outreach (Bond, Drake, et al., 2001; Dixon, 2000; Phillips, Burns, et al., 2001; Stein & Test, 1980). ACT team members typically draw from a range of disciplines and are likely to include a psychiatrist, nurse, social worker, psychologist, substance abuse specialist, housing specialist, and vocational rehabilitation specialist. They deliver or arrange comprehensive services including medication management and psychosocial supports in the community. Members of the team might visit the patient in the community at least once or several times a week and might also work with the patient's family or others important in the patient's life. Importantly, these meetings address how the patient can manage difficulties they have and live well in their family or community surroundings, following a model more of chronic disease management than cure.

ACT is one of the most widely studied interventions for persons with mental illness with clear evidence that ACT reduces hospital admissions and days, keeps individuals engaged in services, and increases housing stability compared to standard case management practices (Bond, Drake, et al., 2001; Burns & Santos, 1995; Dixon, 2000; Marshall & Lockwood, 2000). The large literature on ACT also includes a number of qualitative studies that have examined consumers' perceptions of what they like least about ACT (McGrew, Wilson, & Bond, 2002), what is helpful about ACT (McGrew, Wilson, & Bond, 1996), and general experiences with the model (Watts & Priebe, 2002).

ACT adheres to strict criteria with respect to its staffing, organizational structure, and delivery of its services. Until recently, the Dartmouth

Assertive Community Treatment Scale (DACTS) (Teague, Bond, & Drake, 1998) was the standard for assessing the fidelity of ACT teams to its original clinical model, and the DACTS was used to develop evidence in a number of randomized trials that demonstrated that high fidelity is associated with reduced psychiatric hospitalizations (Dieterich, Irving, et al., 2010; McHugo, Drake, et al., 1999). The DACTS was recently replaced by the Tool for Measurement of Assertive Community Treatment, or TMACT, which was developed as a recovery-informed update of the DACTS (Monroe-DeVita, Teague, & Moser, 2011). Similar to the DACTS, there is evidence that TMACT scores are associated with lower psychiatric hospital use (Cuddeback, Morrissey, et al., 2013).

ACT has realized a variety of adaptations and applications over the last 30 years, including urban and rural adaptations (Becker, Meisler, et al., 1999; Calsyn, Morse, et al., 1998; Dixon, Friedman, & Lehman, 1993; Lehman, Dixon, et al., 1997) and adaptations for persons with mental illness and co-occurring substance use disorders (Ackerson, 1995; Drake, McHugo, et al., 1998). Evidence-based practices such as integrated dual-disorder treatment (Ackerson, 1995; Drake, McHugo, et al., 1998), illness self-management (Mueser, Clark, et al., 2004), and supported employment (Gold, Meisler, et al., 2006) have successfully been added to the ACT model and ACT can be adapted to align with contemporary recovery practices (Kidd, George, et al., 2011; Kidd, George, et al., 2010; Salyers & Tsemberis, 2007).

ACT is an ideal setting in which to integrate mental health and physical healthcare. This is especially important given the high rates of chronic physical health issues experienced by persons with serious mental illness (Colton & Manderscheid, 2006). Indeed, integration of services, in general, is recognized as a key attribute of the ACT model (Bond, Drake, et al., 2001), which is promising in light of evidence that integrating primary and behavioral healthcare increases access to preventive health services and cardiovascular healthcare, improves engagement with primary care providers, and improves quality of life for adults with mental illness (Gilbody, Bower, et al., 2006; Katon, Lin, et al., 2010; Rosenthal, 2008; Sheridan, Draeger, et al., 2011). Due to its aggressive, community-based outreach, integrated primary care ACT has the potential to be highly effective at engaging patients and keeping them connected to much-needed primary care services.

Integrative Role of Self-Management and Problem-Solving

Self-management programs in chronic disease may provide important models for approaches to psychopathology and distress in general as well as in the context of physical diseases. Surely the elements of self-management – healthy diet, physical activity, adherence to medication regimens, stress management, problem-solving, and cultivating family and friend support – would all seem equally pertinent to management of mental as well as physical health. Along these lines, a meta-analysis of interventions for depression and diabetes identified diabetes self-management education as contributing to the metabolic benefits associated with cognitive behavioral interventions (van der Feltz-Cornelis, Nuyen, et al., 2010). The "collaborative care" model of Katon and his colleagues (Katon, Von Korff, et al., 2004) stands as an important model of the integration of multiple behavioral objectives in self-management as well as the integration of self-management with clinical care in treating depression and other mental illnesses.

Within self-management, problem-solving may have a special role in integration of care for emotional distress and physical disease. Problem-solving is central to almost all models of self-management in chronic disease (Bodenheimer, Lorig, et al., 2002; Fisher, Brownson, et al., 2005; Funnell, Brown, et al., 2011; Hill-Briggs & Gemmell, 2007; Lorig & Holman, 2003). At the same time, problem solving has emerged as a prominent approach to psychotherapy for depression and other problems (D'Zurilla & Nezu, 1999). Indeed, research indicates that the benefits of cognitive behavior therapy for depression rest largely on the more behavioral, skill-oriented components of problem-solving and "behavioral activation" (Cuijpers, van Straten, & Warmerdam, 2007; Dimidjian, Hollon, et al., 2006; Dobson, Hollon, et al., 2008). In a recent elaboration of peer support interventions, such as those discussed earlier (de Mello, de Jesus Mari, et al., 2005; Patel, Weiss, et al., 2011; Rahman, 2007; Rahman, Malik, et al., 2008), an intervention delivered by lay counselors and focusing on problem-solving, behavioral activation, and activation of social networks showed impressive initial benefits with severe depression (Chowdhary, Anand, et al., 2016). Thus, problem-solving can address the needs of both metabolic control and emotional management. For example, helping individuals to set objectives for increasing physical activity, take steps to accomplish those objectives, and reflect on the pleasure of reaching them may advance both self-management of chronic disease as well as mood and well-being.

Cautions when embracing problem-solving should consider the observation of Detweiler-Bedell and colleagues (Detweiler-Bedell, Friedman, et al., 2008) that self-management objectives for patients with a chronic illness and coexisting psychological or quality of life objectives are not necessarily synergistic or even compatible. With several conditions needing to be managed, "depletion of self-regulatory resources" (p. 1426) may lead to "under-regulation" of one. Also, effectively regulating one condition (e.g., mood repair by increasing pleasurable activities, e.g., dining) can negatively affect self-management of the other (e.g., compromised healthy diet for diabetes management), resulting in what the authors coin "misregulation." What is needed is an integrated model of managing several problems, rather than organizing management of several problems as entailing separate management plans for each.

In addition to its effectiveness in both mental and physical health domains, an emphasis on problem-solving may provide just the integrative, coherent framework to which Detweiler-Bedell and colleagues point. Organizing care of multiple chronic diseases and psychological challenges as problem-solving or self-management to achieve healthy diet, physical activity, adherence to medications, stress management, and maintenance of satisfying social and community engagements may provide patients a coherent framework for accommodating the changes that emerge inevitably in the natural history of chronic disease. It may also avoid concerns about stigma surrounding depression, other forms of emotional distress, or chronic diseases in many cultures.

It is often suggested that emotional distress must be addressed before individuals may be expected to marshal sufficient energy to manage chronic disease or address risks such as smoking cigarettes. There appears however to be little or no evidence to support this tactic. Indeed, the commonalities among the tasks of chronic disease management, prevention, and emotional well-being (e.g., physical activity) and the role of self-management and problem-solving as an integrating theme recommend encouraging patients' healthy *behaviors*, including adherence to appropriate medical treatments, without drawing hard distinctions between emotional and physical health or concentrating on which should be treated first.

Self-management procedures emerged largely out of research on self-control and related processes in psychology, behavior therapy, and health psychology (Mahoney & Thoresen, 1974; Rachlin & Green, 1972; Stuart, 1967). This might lead one to expect great attention to self-management approaches to depression and other mental health problems that psychology has traditionally addressed. This does not, however, appear to be the case. In the diabetes literature, for example, a search of PubMed (12/31/16) for papers with "self-management" and cognates of "diabetes" in their titles yielded 1180 references, while a parallel search for papers with "self-management" and cognates of "depression" in their titles yielded only 84. When expanded to include mention in abstracts, results were 3282 for "self-management" with cognates of "diabetes" and 950 with cognates of "depression." Further, many of those mentioning depression were focused on self-management of other diseases and simply included a measure of depression, not the focus of the self-management program. It should be noted that mental health researchers may use other terms, such as "psychotherapy," "supportive therapy," "bibliotherapy," to refer to similar services as "self-management." Nevertheless, it appears that the *combination* of proactive medical treatment and self-management that constitutes the state of the art in many areas of chronic physical disease (Yarnall, Hayes, et al., 2012) has not been fully recognized in the treatment of mental health problems. This appears to be an area in which behavioral medicine and its strong models of self-management and chronic disease management may make substantial contributions to mental health prevention and care.

Closing Thoughts on Interventions

One hundred years ago, interventions for mental illness in the formal healthcare systems of Europe and North America consisted of hospital confinement, a very few medical and surgical procedures, individual psychotherapy – just emerging in psychoanalysis and limited to a very few recipients – and social service programs. Today, hospital confinement is drastically reduced although not necessarily improved, and medical and psychological interventions have grown enormously in number and in their evidence and differentiated application to specific problems and circumstances. At the same time, approaches addressing the community and social surround of mental health are emerging such as in the attention to community in ACT and in many peer support programs. Because of the limitations of a single chapter such as this, we have omitted important examples in addition to those described here. For example, the Triple P model of parenting and family support addresses a variety of developmental and psychological problems of children and their families. It entails multiple levels of intervention, from broad education of the community regarding the problems it addresses to parent skills training and family behavioral interventions (Guo, Morawska, & Sanders, 2016; Sanders, Mazzucchelli, & Studman, 2004). In Holland, Hogewey is a village designed to meet the needs of those with dementia. Staffed by professionals and volunteers, residents with dementia are able to lived "normally" within the village (Jenkins & Smythe, 2013).

Across all of these and the interventions reviewed in the preceding sections, a crosscutting theme is integration of approaches. Just as state-of-the-art care of diabetes, for example, is not left to "take insulin and stay off sweets," so state-of-the art care of complex mental illness is not just a single psychiatric medication or a single, weekly hour of psychotherapy. Especially pertinent to the integration of care are internet- and mobile phone-based psychological and behavioral (self-help) interventions that offer unique opportunities for expanding reach even to whole populations at low costs (Andersson & Titov, 2014). Online interventions also offer the advantage of anonymity and low risk of stigmatization. Evidence to date suggests that internet-based psychological interventions for mental health problems are effective in a range of psychological and somatic chronic diseases and problems (Andrews, Cuijpers, et al., 2010; Richards & Richardson, 2012; van Bastelaar, Pouwer, et al., 2011; van Beugen, Ferwerda, et al., 2014). An important feature of internet and "eHealth" applications is their ability to integrate information – clinical, behavioral, emotional, as well as environmental and neighborhood data – and integrate individuals and groups, including individuals with others facing similar problems, with families, or with professional and lay health workers.

Future Directions and Implications for Global Mental Health

Across the wide range of topics discussed in this chapter, integration stands out as an important theme, integration across (a) mental and physical disorders, (b) varieties and levels of psychological distress, from daily hassles and disease-specific distress to serious mental illness, (c) types and modes of care – medication, psychotherapy, community based, peer based, internet based, and (d) systems of care – specialty care, primary care, behavioral health, community health. In contrast, many of our health systems and our cognitive models of health reflect still a dualism that, in many respects, has not changed since Descartes. As much as the present authors are proponents of integration, our writing does not always serve our intentions. The astute reader will note that we have several times distinguished between psychological or emotional problems and physical disease or physical illness in the pages that precede this. In addition to needing integrative models, the field needs, perhaps, integrative terminology.

In 1948, the World Health Organization announced an integrative definition of health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (World Health Organization, 1946). This was important in including the realms of "mental and social well-being" as part of health and of moving toward a definition of health as positive and substantive, not just the absence of something – "disease or infirmity." Since then, and with the growing global burden of chronic disease, living well with a chronic condition or challenge has emerged as an important model of well-being but one that surely does not meet the criterion of "complete physical, mental and social well-being."

A "dynamic" model of health has emerged (Huber, Knottnerus, et al., 2011) that not only integrates physical, mental, and social well-being but looks at them within the context of the natural incursions of health problems in the life course. So, health is not being 90 years old with no aches or pains, no problems remembering names, and the energy of a 21-year-old. Rather, health is being 90 with the "ability to adapt and self-manage" amidst the problems that 90 years may have brought. Rather than a "static" definition of health, we should pursue "a more dynamic one based on the resilience or capacity to cope and maintain and restore one's integrity, equilibrium, and sense of wellbeing" (Huber, Knottnerus, et al., 2011; Larson, 1999).

Interestingly, this model of resilience or ability to cope can be considered at the physiological level as in resistance to the virus bringing the yearly flu, at the mental level as in the ability to cope, say, with the decline of favorite abilities with age, or at the social level as in the ability to revise one's social ties following the changes brought about by retirement from work. This dynamic approach that balances the challenges to health on the one hand with the resources of the individual to cope with them also accommodates the "disability paradox" in which individuals with appreciable physical disease may nevertheless rate their health as good, referring apparently to their ability to live well amidst their health challenges, not eliminate them (von Faber, Bootsma-van der Wiel, et al., 2001).

From such a perspective, then, this chapter's examination of the co-occurrence of psychological and emotional problems with biological problems and challenges (we can no longer use "physical disease") reflects both an integrative and dynamic model. Over the life course, biological, psychological, and social challenges are normal and sometimes grow to the extent they may earn the label of "disease" or "pathology," again, biological, psychological, or social. Health and well-being are not the absence of these, but the ability of the biological, psychological, and social resources of the individual to meet or accommodate the challenges faced. The present chapter points then to the wide range of types and degrees of such psychological challenges and the correspondingly wide range of ways to assist individuals in coping with them and achieving wellbeing.

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Part VI

Interventions to Enhance Quality of Life

33

Quality of Life and Person-Centered Outcomes: Considerations for Behavioral Medicine

Sarah D. Kowitt, Hairong Nan, and Jane Speight

Introduction

> QoL is such a subjective evaluation and so specific to the individual patient that there is no substitute for asking patients what is important to them, how good these things are in their life and how the elements of their life affect each other and their overall QoL. (Walker & Bradley, 2002, p. 144)

The coining of the modern day term "quality of life" (QoL) has been attributed to a speech made by US President Lyndon Johnson in the 1960s, in which he is reported to have stated that progress on social goals "cannot be measured by the size of our bank balance. They can only be measured by the quality of the lives our people lead" (Cummins, 1997, p. 117). Since that time, a broadening of the scope of medicine has been evident, to encompass a more person-centered approach in which a "life of quality" is sought, alongside optimal biomedical outcomes. QoL is frequently considered an important endpoint, in addition to biomedical outcomes, in clinical trials, and is becoming increasingly commonplace in routine clinical practice. Indeed, according to *PubMed*, since 1959 there have been some 34,000 papers published with "quality of life" in the title, 31,000 of which have been published since 1990. This reflects an increasing interest in the past 25 years in a more holistic approach to health and the evaluation of medical treatments.

The development of QoL as a concept reflects a number of interrelated phenomena: the demise of a purely medical model and rise of the biopsychosocial model (Engel, 1977); the rise of the patient as an active participant or consumer in healthcare (Bury & Taylor, 2008); growing recognition that improvements in medical outcomes entail ever higher financial costs for diminishing returns, thus driving a search for alternative ways to prioritize available treatments and technologies (Murphy & Topel, 2003); and the changing face of global disease burden, whereby the aging population and the inexorable rise of long-term conditions requires that the focus is not so much on "curing" disease but on enabling individuals to live successfully with these conditions. With

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few curative treatments available, a focus on managing the condition suggests that maintaining or improving QoL may be among the most realistic of healthcare goals.

In this chapter, we examine QoL – how it is conceptualized, operationalized, and measured in research and practice. Given that life expectancy has increased significantly in the past century, and an increasing number of people living with one or more medical conditions, the effects of chronic care management and collaborative approaches to healthcare delivery are discussed alongside behavioral interventions to improve QoL. With the growing emphasis on QoL in clinical care and recent policy initiatives, considerations for how to integrate QoL into a complex environment will be introduced and explored.

Conceptualizing QoL

Definitions of QoL: Shared Attributes

> There are almost as many quality of life definitions as there are people. (Liu, 1976)

Most people, in the western world at least, are familiar with the term QoL and, intuitively, have some understanding of what it involves, typically emphasizing components of happiness and life satisfaction. It may seem obvious that QoL is a personal evaluation of how good or bad one's life is (McGee, O'Boyle, et al., 1991) but attempts to agree on a universal definition of QoL have met with limited success. Those who have attempted to define QoL generally debate the nature of what is important philosophically for achieving a life of quality. Is it more important to have what one needs or what one wants? Is it more important to function (at a minimal standard) or to enjoy? Compelling arguments exist on both sides of this debate but there is no consensus. Some have argued that human needs (e.g., health, mobility, shelter, food) are the foundations for QoL and that the degree to which those needs are met is what defines QoL (Hörnquist, 1982). We believe this definition to be flawed; however, as it will be clear to most people in the western world that having one's basic needs satisfied does not necessarily lead to contentment. Calman's "expectations model" ('Calman's Gap') suggests that QoL is a measure of the difference between an individual's hopes and/or expectations and the individual's present experience (Calman, 1984) and is concerned with the difference between perceived and attained goals. Calman qualifies his approach by indicating that the goals must be realistic. This definition has inherently more appeal than the needs-based approach because it is concerned with an assessment of what the individual actively wants from his/her life rather than what the individual needs in his/her life. Probably, the truth lies somewhere in between the two approaches.

Although a consensual definition of QoL may not exist, there is agreement as to what attributes reflect its components. First, it is generally accepted that QoL is highly subjective. People will rate their QoL from their unique perspective based upon their own feelings, experiences, and priorities. Thus, while two individuals may experience the same objective health condition, their assessment of QoL may differ according to expectations, prior experiences, traits, etc. Inherent within this argument is that QoL may be best assessed by an individual rather than by proxies, such as clinicians, providers, or family members. This argument will be explored further in section "Source of Report." Second, is the understanding that the QoL is a multidimensional construct (Cella, 1994). If each respondent thinks about different aspects of their life when attempting to evaluate their QoL, this suggests that QoL has several dimensions. However, while there may be agreement that QoL is multidimensional, there is less clarity about what these dimensions may include. At the minimum, there is consensus that physical, psychological, and social dimensions are all important to QoL. However, many definitions of QoL have also included other domains, such as role functioning, spiritual aspects, and environmental considerations (WHOQOL group, 1995). A third characteristic of QoL is that it is "a dynamic construct" (Carr, Gibson, & Robinson, 2001), meaning that assessments of QoL not only differ *between* individuals but will change over time *within* an individual, dependent upon his/her priorities, experiences, and circumstances. This creates an inherent instability in the meaning of QoL, which raises some methodological concerns (examined in section "Response Shift") but also means that QoL may improve or worsen depending on the time, situation, and psychological factors, such as adaptation, coping, expectations, and so on. The final characteristic of QoL is that it includes both positive and negative attributes. This represents a departure from previous deficit-based definitions of health and means that QoL may be inclusive of both negative aspects (e.g., negative emotions, pain, fatigue), as well as positive attributes (e.g., contentment, mobility) (WHOQOL group, 1995).

Reflecting the four characteristics described above, we find the following definition of QoL useful, referring (albeit in general terms) that multidimensional aspects of life are likely to be important for most people in achieving and maintaining a life of quality. QoL is defined as:

> individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. (The World Health Organization Quality of Life Group, 1995)

Encompassed within the WHO's definition are six broad domains: (1) physical, (2) psychological, (3) level of independence, (4) social relationships, (5) environment, and (6) spirituality, religion, and personal beliefs (WHOQOL group, 1995). Although aspects of this definition may be critiqued on the grounds that it is too broad, the WHO's operationalization of QoL has been extensively validated and referred to in the development of other more widely used QoL measures.

Distinctions and Similarities Between QoL, Health, and Health-Related QoL

> Health is a state of complete physical, mental and social well being, and not merely the absence of disease or infirmity. (World Health Organization, 1948)

Given the breadth of QoL, one may also wonder how QoL differs from health, especially given the WHO's definition of health as "a state of complete physical, mental and social well being, and not merely the absence of disease or infirmity" (World Health Organisation, 1948). This confounding of terms is both understandable in the context of healthcare and medical treatments and logical given the similarity between the definitions. Yet, as will be argued, one may have limited functional or health status and still achieve considerable QoL – and vice versa. Thus, QoL should be viewed as broader and more comprehensive than health status, functional status, and a number of other related terms. In fact, when measured simultaneously, studies have found that while QoL and health status may be correlated, a substantial number of individuals experience discrepancies between the two. For instance, in a study of health status and QoL in a sample of older adults, almost 15% who reported moderate pain also reported very good or excellent QoL (Covinsky, Wu, et al., 1999). Conversely, over 15% who reported the highest physical capacity had fair or poor QoL (Covinsky, Wu, et al., 1999). In a meta-analysis to determine how individuals make determinations of QoL, researchers found that QoL and health status were conceptually distinct constructs, with different path models, estimates, and predictors (Smith, Avis, & Assmann, 1999). Interestingly, when rating QoL, individuals gave greater weight to mental health, and when rating health status, physical functioning was perceived as more important (Smith, Avis, & Assmann, 1999). The authors concluded that if a questionnaire aims to assess only health status, and this assessment is used as the basis for measuring QoL, important domains, mainly regarding mental health, will be missed (Smith, Avis, & Assmann, 1999).

Thus, health status is typically distinguished from QoL by the absence of indicators that are unaffected by health, illness, and treatment. For instance, a QoL measure may include indicators for quality of environment, political freedom, standard of living, education culture, religion, or socioeconomic status, whereas a health status measure will theoretically assess only those indicators most directly related to health (e.g., functionality, pain, mobility, emotional well-being). However, this raises a difficult issue – mainly that while health status refers solely to aspects of QoL that pertain to health, it can often be difficult to differentiate between QoL domains that may affect health and those that do not. For instance, while standard of living may not typically be included within any health status questionnaire – as anyone familiar with public health is surely aware – one's living situation may still affect health and one's health may still affect one's living situation.

Due to general conflation between QoL and health, the term "health-related quality of life" (HRQoL) was coined. HRQoL was intended to narrow the focus of QoL in a medical context onto the effects of health, illness, and treatment (Ferrans, Zerwic, et al., 2005). HRQoL refers to:

> the extent to which one's usual or expected physical, emotional, and social well being are affected by a medical condition or its treatment. (Cella, 1994)

Thus, HRQoL is typically distinguished from the concepts of health/functional status and QoL by referring to the impact of health, illness, or treatment on broad aspects of life that are important for overall QoL, i.e., requiring an attribution to be made regarding how aspects of life are affected by health, illness, or treatment. For instance, while a QoL measure might include an assessment of absolute satisfaction with aspects of life (e.g., working life or family life), and a health status measure might not include these aspects of life at all, a HRQoL measure would ask the respondent to assess the impact of health, illness, or treatment upon those aspects of life (e.g., working life or family life). Unfortunately, the literature is replete with confusions between these concepts and their operationalization. For example, some measures referred to as assessing HRQoL include domains assessing QoL and health status. Thus, differentiation between QoL and HRQoL is often easier to understand in theory than in practice – and the two terms are often used interchangeably.

In one of the earliest conceptual models of HRQoL, Wilson and Clearly theorized that HRQoL would be composed of interactions among biological function, symptoms, functional status, general health perceptions, and how these influence overall QoL (Ferrans, Zerwic, et al., 2005). The takeaway from this model and others is that HRQoL is about the interrelationship between health factors and overall QoL (with the latter being a broader concept, which is influenced also by nonmedical factors). This suggests that when health, HRQoL, and QoL are used, their definition should be specified, their purpose clarified, and their domains identified. Furthermore, while health status, functional status, and symptoms may affect QoL (and be affected by QoL), and represent components of HRQoL and QoL, they should not be thought of as proxies for QoL. In general then, we recommend that QoL be viewed as a broad yet distinct construct with various domains, one of which may be health (Anderson & Burckhardt, 1999).

The Importance of Assessing QoL

> To the lay person, quality of life is of the highest importance and acts as the driving force behind all actions. (Leplège & Hunt, 1997, p. 47)

Now that some clarification of the concept QoL has been considered, we can turn our attention to why QoL assessment is important and why measurement of QoL has proliferated over the past few decades in health research and, increasingly, in clinical practice. As will be demonstrated below, QoL places the individual, rather than his/her condition, medical treatment or other healthcare processes, at center stage. It also adds to the evidence base concerning the overall success of treatment by facilitating an understanding of medical outcomes from the perspective of the individual, which serves a number of purposes discussed below. Lastly, measurement of QoL provides important information to medical providers, patients, and policy makers – all of whom influence the direction of healthcare.

Understanding the Impact of a Medical Condition

Interest in QoL assessment has expanded rapidly in the past 25 years "as a valid indicator of whether or not a medical treatment is beneficial" (Spilker, 1996; Spilker & Revicki, 1996).

Measurement of clinical indicators is integral to healthcare systems. Typically, the focus is on laboratory and clinical tests offering objective markers such as pulse, blood pressure, blood glucose, lipids, and X-rays. More subjective markers are also used, such as pain assessment, strength, and mobility. Why not QoL also? For example, children with mild-to-moderate reduction in kidney function have reduced QoL in comparison with their peers due to impaired growth and reduced stature (Gerson, Wentz, et al., 2010), whereas treatment would not usually be instigated until kidney function was more significantly impaired; early intervention with salt supplementation or growth hormone improves QoL (Gerson, Wentz, et al., 2010). Similarly, people undergoing chemotherapy may experience significant reductions in QoL due to neutropenia (Nirenberg, Parry Bush, et al., 2006). People with diabetes experience significant reductions in QoL due to the impact of dietary restrictions (Bradley & Speight, 2002), which arguably affect their willingness to adopt clinicians' treatment recommendation (Wolpert & Anderson, 2001). QoL screening can be employed to identify those whose QoL is at risk from the negative consequences of their illness or treatment and to guide intervention where appropriate.

Understanding Patients' Priorities and Preferences

Typically, an individual's self-assessment of their condition or medical treatment may differ substantially from the judgments of their healthcare professionals, their caregivers or family members, or the general population. The use of patient-reported outcome (PRO) measures is regarded as a way of ensuring that healthcare is "person-centered" (McGrail, Bryan, & Davis, 2011). Certainly, having an understanding of how a person feels about their illness or treatment, or their level of satisfaction with a given treatment, is considered useful, but it does not provide sufficient information to make decisions about which treatment option would be best suited to the individual. Measures of well-being and satisfaction are used alongside biomedical markers in clinical trials to determine effectiveness without any regard to which of the outcomes are most important to the individual. For example, in arthritis, is a reduction in pain or an improvement in function most important? What degree of pain is acceptable for a given improvement in function, and vice versa? Can a new side effect be tolerated in exchange for improvement in both? Does an outcome that was important at diagnosis remain important several years later? Do trade-offs change over time? Some outcomes of particular importance to people with type 1 diabetes, e.g., dietary freedom, spontaneity, and independence (Bradley & Speight, 2002; Speight, Woodcock, et al., 2010), are rarely afforded prominence as endpoints in controlled clinical trials. Yet, where such endpoints are considered and become the target of new therapeutic efforts, significant long-term benefits may be observed because the treatment has been reframed from the individual's perspective (Wolpert & Anderson, 2001). Equally, the inclusion of such patient-relevant endpoints in real-world evidence trials can give much needed clarity to interpretation of adherence and primary outcome data (Price, Chisholm, et al., 2011).

Evaluation of New Treatments and Technologies

While the primary outcomes of clinical trials focus mostly on biomedical indicators, "explanatory" trials, where the focus lies in understanding the impact of treatment on a disease (e.g., evaluation of new treatments and technologies), can be more effective if consideration is given to the impact on QoL, in addition to change in clinical outcomes (Pocock, 1991). This is particularly true where treatments or technologies entail increased or reduced burden related to pain, lifestyle, psychological health, or self-care. By incorporating QoL assessment into clinical trials as co-primary or secondary endpoints, a more comprehensive evaluation of treatment outcomes can be made, both in respect to individual treatments and for comparisons between treatments. Such evidence is used increasingly by regulatory bodies in evaluating medicines and technologies and by payers and clinicians involved in market access and prescribing decisions (US Food and Drug Administration, 2009; European Medicines Agency Committee for Medicinal Products for Human Use, 2005). QoL may be included as a relevant endpoint in various scenarios:

1. QoL may be the primary endpoint – frequently the case in palliative care, when no cure is possible and QoL considerations may override those of quantity of life
2. QoL may be a co-primary endpoint – increasingly the case when new treatments are expected to non-inferior to the existing treatment option in terms of biomedical efficacy but where the newer treatment may offer QoL benefits
3. QoL may be a secondary or tertiary endpoint – when the treatment of interest confers small benefits in cure rates or improvements in biomedical indicators at the expense of a deterioration in QoL

Allocation of Medical Resources

One reason to assess QoL is to determine or justify allocation of scarce medical resources. Particularly relevant where there is no obvious differentiation in terms of biomedical outcomes, the QoL created, maintained, or unimpaired by a given treatment or care process may well be the critical factor in allocation decisions. Thus, in the case where not everyone in need can be treated, decisions can be made based on who would benefit most in terms of both quantity and quality of their remaining lives. The development of secondary metrics, such as the quality-adjusted or disability-adjusted life year, "QALY" and "DALY" (discussed further in section "QALY: Preference-Based Measures"), has quantified the economic implications of changes in quality of life and formalized this decision-making process (Sassi, 2006). Comparators such as these enable treatment evaluations to be made across and between conditions and reflect the views and preferences of individuals. However, such evaluations are not exempt from the limitations (e.g., lack of validity, sensitivity) inherent in any QoL measure(s) used. Furthermore, while they are employed to balance conflicting resource and economic demands, by their very nature, QALYs and DALYs entail ethical implications that arise when there is a deviation from the principle of equal allocation of healthcare resources (Hirskyj, 2007).

Assistance Toward Autonomous Decision-Making

In the twenty-first century, there is widespread recognition that the patient needs to be an active partner in decisions about medical treatments. This replaces a "paternalistic" approach to decision-making and is associated with both risk and benefit to clinicians and patients (Walsh & Swain, 2011). Much of the emphasis in medical decision-making has revolved around the provision of information to the patient. However, the need for information about treatment options and their impact needs to be framed not only in terms of medical outcomes but also in terms of helping the individual to understand how the specific treatment may impact on his/her life, in ways that are important to the individual, so that he/she can achieve a realistic evaluation of potential benefits or deficits to overall life quality. Use of QoL assessment in routine clinical practice can individualize care by enhancing clinician-patient communication about the ways in which the condition or its treatment impair various aspects of life and serving as the basis for joint decision-making about treatment options.

Measurement of QoL

> The quality of life construct has a complex composition, so it is perhaps not surprising that there is neither an agreed definition nor a standard form of measurement. (Cummins, 1997, p. 6)

Attempts to operationalize the concept of QoL have been as diverse as the definitions employed, and many authors (as discussed above) report using "QoL measures," which may or may not be conceptually valid, methodologically rigorous, or psychometrically sound. Rapley draws comparison with the medical field, asserting that "in an era when medicine is increasingly said to be 'evidence-based', the quality of research on QoL is … at best mixed and at worst unacceptably poor" (p. 29) (Rapley, 2003). Yet nothing could be more important than using a good QoL measure for, if we claim to assess QoL but measures are invalid, unreliable, or psychometrically unsound, then the possibility of Type II error is raised and potentially beneficial interventions may be found inadequate. This has serious ethical implications in terms of wasted funding, participant time, and missed opportunity if a valuable intervention is not demonstrated to be so. For these reasons, appropriate measurement of QoL is of utmost concern.

Development and Validation of QoL Measures: Qualitative Methodologies

Most QoL measures referred to later in this chapter are quantitative, and this is necessarily so because clinical trials, for instance, require the statistical comparison of endpoints over time and between treatment groups. However, qualitative research plays a very important role in both the development and validation of QoL measures. Regarding the former, qualitative research can assist with development of a conceptual framework, identification of appropriate wording for items, responses and recall periods, and clarification of relevant dimensions – all of which are necessary *before* creating QoL measures (Lasch, Marquis, et al., 2010). Regarding the latter, qualitative methodologies are particularly important for evaluating measures, ensuring content validity, respondent comprehension (i.e., of instructions, items, and response options), questionnaire comprehensiveness (i.e., that nothing of importance is missing), and minimal redundancy (i.e., ensuring that the measure does not overrepresent certain issues) (Lasch, Marquis, et al., 2010). Various data collection modes are often used under the umbrella of qualitative research, but two are particularly important to QoL research – "concept elicitation" and "cognitive interviewing."

Concept elicitation is used to identify domains, item content, and areas that individuals consider relevant and important to an overall concept of interest and is particularly important in the development of measures (Patrick, Burke, et al., 2011a). Lasch gives the example of concept elicitation interviews being conducted with people with irritable bowel syndrome to determine what symptoms and/or domains may be relevant to assess (Lasch, Marquis, et al., 2010). Questions could be broad, such as "what is a good day with irritable bowel syndrome (IBS)?" and "what is a bad day with IBS?" in order to determine (without leading) what is relevant to the individual (Lasch, Marquis, et al., 2010). Concept elicitation interviews can also be used to identify language used by the relevant target group and to gather information on frequency, severity, duration, or other issues that may be useful in the design of items.

After initial item development, qualitative research also plays a role in the validation of instruments. A type of validity of particular importance is content validity, which refers to "the extent to which the instrument measures the concept of interest" (US Food and Drug Administration, 2009) or the extent to which a measure is representative of the universe of content of the construct being measured. If the content validity of a measure is unsound, then claims made about the instrument and any outcomes derived from it will also be unsound. In the past decade, the US Food and Drug Administration (FDA) has taken a very active interest in the concept of content validity, due to the increasing number of pharmaceutical companies attempting to make product-labeling claims based upon patient-reported outcomes. The FDA notes in its definitive guidance to industry that "evidence of other types of validity … or reliability … will not overcome problems with content validity" (US Food and Drug Administration, 2009). This statement underpins the importance of solid measurement foundations. Ensuring content validity involves rigorous qualitative research with the target group (e.g., people with the condition or using the medical treatment) and documenting how items were generated.

One approach to ensure content validity is through "cognitive debriefing" interviews (or "think-aloud studies"), which focus on identifying the respondents' thought processes as they answer items on a questionnaire, evaluating the clarity of item measures, and determining if content within the measure is comprehensive (Patrick, Burke, et al., 2011b). Cognitive interviews can be useful in identifying how respondents may interpret items, response options, and prompts. For instance, a cognitive interview questionnaire may include [some of] the following questions:

1. What did [the particular item] mean to you?
2. What were you thinking about when you tried to answer [this particular item]?
3. What did [this specific item or phrase] mean to you?
4. Was [this particular item] easy or difficult to answer? Please explain.
5. Were the response options easy or difficult to understand? Please explain.

It is important that, for each of the above questions, the interviewer probes further to determine why the particular item, word, or response option might be considered problematic. This can help researchers determine if the measure assesses what it claims to assess. Given the importance of qualitative research in QoL measurement, extensive protocols and considerations have been proposed, including a noteworthy article by Lasch et al. (2010).

Source of Report

Patient-Reported Outcomes

Validity of QoL measures does not depend only on how items are developed, also of consideration is the *source* of report. If QoL is a subjective, multidimensional, dynamic construct of the difference between perceived goals and attained goals, then there is a case for adopting the principle that individuals should decide the extent to which their QoL is satisfactory based upon their own criteria for what constitutes good QoL for them personally. If this is accepted, then QoL needs to be defined as "what the patient says it is" (Joyce, 1994, p. 47) rather than what their health professional thinks is relevant or what the researcher decides to measure. While, intuitively, it may make sense that an individual would best understand and be able to evaluate his/her own QoL, the incorporation of PROs into regular healthcare assessment has been a relatively recent phenomenon. A PRO is any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else. Thus, the term PRO has come to be used as a better "umbrella" for assessments based upon the patient perspective, as opposed to QoL, which (as noted above) has a specific and broader meaning.

However, not all PROs assess QoL. There are two explanations for why researchers have been prone to label any and all PROs as QoL. First, in the absence of a universally agreed definition of QoL, the measurement of all psychological outcomes (as opposed to biomedical outcomes) has arguably fit under this broad heading. While all PROs may be important for QoL or related to QoL, as discussed above (section "Distinctions and Similarities Between QoL, Health and Health-Related QoL") they are not QoL per se. Second, the term QoL has become a buzzword in healthcare research, recognized as an important outcome in its own right. Indeed, major clinical trials in recent years have frequently included QoL (or, more usually, a related PRO) as a primary or secondary endpoint in an attempt to ensure holistic evaluation.

In recent years, a host of centers, databases, and quality initiatives have been devoted to PRO use and research (see Table 33.1), testament to the importance now vested in holistic, person-centered outcomes in health research and healthcare.

Proxy Reports

In certain circumstances, people may be unable to report on their own QoL or related outcome, e.g., young children, those with cognitive impairment or communication problems. Even beyond these circumstances, medical providers often make important decisions based on their

Table 33.1 Centers, databases, and quality initiatives devoted to PRO use and research

Name	Description	Website
ISOQOL: International Society for Quality of Life Research Institute	An international society that focuses on promotion of high-quality research concerning health-related quality of life and other patient-centered outcomes	http://www.isoqol.org
PCORI: Patient-Centered Outcomes Research Institute	A nonprofit organization that aims to improve healthcare delivery by promoting evidence-based research guided by patients, caregivers, and the broader healthcare community	http://www.pcori.org
PROMs: Patient-Reported Outcome Measures	In the UK National Health Service, PRO measures (PROMs) have been incorporated into the assessment of quality of care for specific procedures since 2009	www.england.nhs.uk/statistics/statistical-work-areas/proms/
PROMIS: Patient-Reported Outcomes Measurement Information System)	Funded by the US National Institute of Health (NIH), PROMIS includes "highly reliable, valid, flexible, precise and responsive assessment tools" to measure health outcomes from the patient's perspective	www.nihpromis.org
PROQOLID: Patient-Reported Outcome and Quality of Life Instruments Database	Developed by Mapi Research Trust (a nonprofit organization designed to facilitate access to patient-centered outcomes), PROQOLID includes over 800 clinical outcome assessment tools	http://www.proqolid.org

perceptions of their patients' QoL. In these situations, we refer to reports coming from proxies, most often caregivers and medical providers. While proxy reports may be *similar* to patients' own assessments, numerous studies have found discrepancies. In a study of adolescents with type 1 diabetes, the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) was used, which assesses QoL from the patients' perspective (McGee, O'Boyle, et al., 1991). Adolescents were asked to nominate five domains important for their overall QoL (Walker & Bradley, 2002). To this list, a sixth domain, "diabetes," was imposed, to determine its relative importance in the adolescents' lives. Surprisingly, the adolescents were unanimous in their nomination of three domains considered to be important for their QoL: "family," "friends," and "school." A further 22 domains were nominated, which could be grouped into ten overall categories, plus the "diabetes" domain. Only 4 of the 15 participants considered diabetes the most important aspect of life for their QoL, with the remainder rating it as fourth or lower on their list. The fact that diabetes was such a low priority for so many of the adolescents is indicative that "treatment strategies that take account of the importance of other aspects of life are more likely to be successful" (Walker & Bradley, 2002). Furthermore, when the diabetes specialist nurses, who had known most of these adolescents since diagnosis of their diabetes, was asked to rate each of the adolescents' QoL, their ratings were more closely related to the adolescents' most recent average blood glucose (HbA_{1c}) results than to the adolescents' own ratings. This indicates that while adolescents are most likely to rate their QoL in terms of family, friends, and school, their health providers are likely to rate it in terms of what they understand of their health outcomes.

Confirming these results, other studies have found that, in general, clinicians underestimate patients' presence and severity of symptoms (Sprangers & Sneeuw, 2000; Pakhomov, Jacobsen, et al., 2008; Basch, Jia, et al., 2009) and overestimate impairments to patients' QoL (Sneeuw, Aaronson, et al., 1998). Of course, this depends on the population, type of proxy, outcome, and setting. Understandably, clinician and patient reports tend to have higher concordance when assessing more observable outcomes (e.g., vomiting, diarrhea) than subjective outcomes (e.g., fatigue) and when evaluating physical functioning over mental or emotional functioning (Sneeuw, Aaronson, et al., 1998; Basch, Iasonos, et al., 2006). Additionally, patient and proxy reports are likely to be more similar to one another when the patient's QoL is either very good or very poor rather than for intermediate levels of QoL (Sneeuw, Aaronson, et al., 1998). Moreover, the length of time proxies spend with the patient, communication between the proxy and the patient, and the level of experience proxies have with medical care and/or the patient all affect the accuracy of proxy ratings (Addington-Hall & Kalra, 2001).

These findings confirm that estimating a individual's QoL is not intuitive and that routine assessment of QoL is needed if the patient's perspective is to be truly considered in treatment decisions. However, that is not to say that providers' assessment of patients' status are without merit. In fact, in one study, longitudinally collected clinician assessments of adverse symptom data better predicted unfavorable clinical events, whereas patient reports better reflected daily health status (Basch, Jia, et al., 2009). As noted by the authors, "patient and clinician perspectives of adverse symptoms appear to be complementary, together providing a more complete picture of the toxic impact of treatments compared with either perspective alone. Clinicians bring professional training and experience to their evaluations, whereas patients are in a better position to communicate their own subjective experiences" (Basch, Jia, et al., 2009). Perhaps then, given its subjective nature, assessment of QoL and many related outcomes may be best ascertained from the individual's perspective, but certain dimensions of QoL may be supplemented usefully by proxy reports, which offer complementary information.

Types of Measure

Generic Versus Condition-Specific

As discussed in section "Distinctions and Similarities Between QoL, Health and Health-Related QoL," measurement of QoL can be generic (i.e., overall QoL) or health-related (HRQoL). Similarly, QoL and related outcomes can be either generic, health-related, or condition specific, the latter referring to the impact of the specific condition (and/or its treatment) on QoL. Health and HRQoL measures fall into the "generic" category, as they can be completed by a person with any (or no) medical condition. Some examples of generic health status measures include the SF-36 (short form 36) (Ware & Sherbourne, 1992), which has domains for physical function, role limitations for physical health, pain, general health, vitality, social functioning, role limitations for emotional health, and emotional well-being and the EQ-5D (Brooks, 1996), which has domains for mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Generic measures are designed to be relevant to anyone, regardless of disease outcome and as a result can be used to compare the burden of diseases. For instance, in order to understand how health status differs for people with HIV/AIDS compared to those with other chronic conditions and those in the general population, Hays et al. conducted a study using generic HRQoL measures (Hays, Cunningham, et al., 2000). They found that people with HIV/AIDS had worse physical functioning than those with other chronic conditions (i.e., epilepsy, gastroesophageal reflux disease, clinically localized prostate cancer, clinical depression, diabetes) and significantly worse emotional well-being than the general population and those with other chronic conditions, except those with depression (Hays, Cunningham, et al., 2000). By using generic measures, these types of studies may be useful for policy makers who are tasked with allocation of resources, as well as clinicians who must understand the relative burden of disease and provide appropriate treatment (Hays, Cunningham, et al., 2000). One of the disadvantages of generic measures is that they may overlook issues of particular importance in a specific medical condition and focus on other issues of less relevance. For example, among people with diabetes or celiac disease, "food intake is often the most challenging and difficult to manage for individuals and clinicians alike" (Schlundt, Pichert, et al., 1996), yet dietary freedom is rarely included in generic health status measures, while mobility is typically measured but less relevant for these particular conditions.

Condition-specific measures, on the other hand, are targeted to individuals with a particular condition and may include items relevant to only that condition. For instance, the EORTC QLQ-C30 is designed to assess the QoL of people with cancer and includes dimensions for functioning, overall QoL, financial difficulties, and symptoms specific to cancer, such as fatigue, pain, nausea, appetite loss, diarrhea, and insomnia. While condition-specific measures do not allow for comparison with other conditions, they are likely to be more responsive than generic measures. This is because they have usually been informed by qualitative studies involving people living with the condition (see section "Development and Validation of QoL Measures: Qualitative Methodologies").

Both generic and condition-specific instruments have utility in different situations. For instance, generic measures may be more broadly applicable and able to detect unanticipated effects, whereas specific measures may be more acceptable to respondents (as they are perceived as highly relevant) and more responsive (i.e., sensitive to changes in treatment or circumstance) (Patrick & Chiang, 2000). Given the relative advantages and disadvantages of generic and condition-specific measures, clinical trials frequently use both to provide a holistic assessment (Patrick & Deyo, 1989). Such an approach allows for comparability and generalizability while also enabling the responsiveness that condition-specific measures offer (Patrick & Deyo, 1989). Of course, respondent burden can then become an issue, with trials and studies requiring participants to complete multiple (seemingly similar) PRO measures. Suffice to say, as reflected in other parts of this chapter, selection of measures, whether they are generic or condition-specific, will depend on the purpose of measurement, setting, resources, and individuals.

QALY: Preference-Based Measures

Measures can also be differentiated on the basis of whether they are "preference based" or not. With their origins in health econometrics, preference-based measures assign "values" to various health states to enable determination of a single health utility score. "Utilities" as they are known, reflect, in essence, an individual's preference with regard to various possible health outcomes or scenarios (Tolley, 2009). One of the most widely used preference-based measures for cost-utility analyses is the quality-adjusted life year (QALY). For QALYs, the amount of time spent in a health state is weighted by a utility score given to that health state (Phillips & Thompson, 1998). Thus, QALYs take into account not only life expectancy but also the QoL of remaining years. So for instance, if one intervention leads, on average, to individuals experiencing 4 years in a certain health state rated at .75, then three QALYs would be generated by that intervention. If, on the other hand, another intervention leads to 4 years in a health state rated at .5, then two QALYs would be generated. When costs of interventions (e.g., surgical procedures, medications, structured education) are entered into the equation, it is possible to figure out the cost-utility of those interventions.

The EQ-5D is a type of preference-based measure that was derived from the QALY. Within the EQ-5D, individuals are asked to rate the extent to which they (1) are mobile, (2) have pain or discomfort, (3) are able to take care of themselves, (4) have anxiety or depression, and (5) can perform their usual activities. Within each of these five health dimensions, there are three possible ratings: no problem, some problems, and major problems. The combination of these with the conditions "unconscious" and "death" enable description of 245 health states in total. For each of the possible 245 health states, utility scores were constructed from responses within a random sample of 3000 people in the UK, using the time trade-off method (Phillips & Thompson, 1998). This method asks people to consider the amount of time they would be willing (e.g., number of years) to sacrifice to avoid a poorer health state (Tolley, 2009). Other methods to assign health utilities include standard gamble where individuals are given a choice between a health state that is certain and a gamble with a better and worse outcome and rating scales (visual analogue scales, VAS) where respondents are asked to mark a point on a line (with anchors for best and worst possible health states) to indicate their current health state. The EQ-5D (Brooks, 1996) also includes a VAS. Each health state is then assigned a utility, which ranges from best possible health state to worse possible health state. To improve the sensitivity of the instrument and reduce ceiling effects, the latest version of the EQ-5D, the “EQ-5D-5 L,” contains *five* possible severity levels: no problems, slight problems, moderate problems, severe problems, and inability to function (Herdman, Gudex, et al., 2011). Validation and psychometric testing are currently ongoing (Herdman, Gudex, et al., 2011).

Preference-based measures, such as the QALY and EQ-5D may be used to compare the effectiveness of interventions, evaluate cost-utility, and inform allocation of resources; however, they may not be useful in all situations. For instance, QALYs may be less useful for people with medical conditions in which QoL is more important than quantity of life (survival) (Phillips & Thompson, 1998). The limitations of generic measures need to be considered carefully (as discussed in section “Generic Versus Condition-Specific”). QALYs also do not take into consideration age, life context, or impacts on caregivers, thereby making it difficult to compare the health status of different individuals (Phillips & Thompson, 1998). Additionally, there is concern over the complexity involved in obtaining utilities, the representativeness of utilities, and the ethical concerns over assigning dollar figures to QALYs (Patrick & Chiang, 2000). Regarding this last point, there is general consensus that interventions costing 50,000 USD per QALY are “cost-effective,” but what does this mean and how should it be applied? (Eichler, Kong, et al., 2004) Thus, while the benefits of QALYs and other preference-based measures should be acknowledged (e.g., for comparison across conditions, assistance with allocation of resources), their limitations need also to be considered.

Single Item Versus Multi-item

The last way in which measures may differ is whether they are single-item or multi-item measures. Typically, QoL and related measures include a number of items, the responses to which are summed or aggregated to provide a composite “scale” score. Some measures include multiple “sub-scales,” which measure various related dimensions of a particular construct. Conversely, single-item measures attempt to glean an overall assessment of the underlying construct with a single question. For example, a single-item, QoL scale might be worded “Overall, how would you describe your quality of life during the past two weeks?” (Response options can be ordinal (e.g., “excellent, good, fair, poor, terrible”) or a Likert-style rating scale with labeled anchors (e.g., “excellent” to “terrible”)). A single-item health-related or condition-specific QoL scale might be worded “Overall, to what extent has [your health/the condition] affected your quality of life in the past two weeks?” (Similarly, response options can be ordinal or Likert-style, using a unidimensional or a bidirectional scale.)

Single-item measures may impose less respondent burden than multi-item measures. However, the benefits of these single items (often referred to as global or “short-form” measures need to be balanced against their disadvantages. While such general questioning is broadly understood by the majority of respondents and allows each to define the concept in a way that is personally meaningful, responses can be less reliable and more difficult to interpret than the responses to a series of interrelated questions tapping into the underlying, latent, construct. Certainly, studies that have correlated single-item with multi-item scales have found the two to be related but not identical (Bradley, Todd, et al., 1999). Relatedly, despite the inherent appeal of single items (particularly to busy clinicians or wary patients), psychometric theory also favors multi-item scales because they are less prone to random measurement errors (DeVellis, 2011). In sum then, both may generate meaningful but different content that may be useful to researchers and practitioners depending on the situation.

Measurement Issues

Given the complexities discussed above, a number of measurement issues are raised in QoL research. For the sake of brevity, two such issues are discussed below. Further discussion of measurement challenges in QoL research can be found elsewhere (O'Connor, 1993).

Interpretation of QoL Measures

Even after determining which concept measure to use and considering all the issues above (e.g., who should be asked to report? should the measure be generic or condition-specific? should it be preference-based? should it be single- or multi-item?), it may still be difficult to interpret results. While differences between groups or changes over time in QoL scores are typically evaluated for statistical significance, one may be left wondering: will this information be meaningful to clinicians or useful in clinical practice? In other words, how do we tell how important it is to have moved X points on a given scale? Questions such as these have prompted research on the clinical significance of findings, or "minimally important differences," which refers to a change in scores that is "large enough to have an implication for the patient's treatment or care" (Wyrwich, Bullinger, et al., 2005). Without going into the specifics of how to determine clinical significance (which is discussed elsewhere (Cella, Eton, et al., 2002; Norman, Sridhar, et al., 2001)), two methods have been generally applied: anchor-based approaches and distribution-based approaches.

An anchor-based approach maps changes in PRO scores on to clinically relevant and important changes in other measures of treatment outcome. Wyrwich gives the example of a study in which it was determined (based on cross-sectional or longitudinal analyses) that 32% of those who score 40 on the SF-36 physical function can walk a block without difficulty, while 50% of those who score 50 on the same scale can walk a block (Wyrwich, Bullinger, et al., 2005). Given this information, when scores move 10 points from 40 to 50 or 50 to 40, then this would result in an absolute change of 18% of the population (=50−32), a relative increase of 55% (=18/32), and a relative decrease of 35% (=18/50) (Wyrwich, Bullinger, et al., 2005). This can be helpful in determining what changes in PRO scores actually mean in terms of other well-known parameters. While this is relatively straightforward to determine when the PRO measure is focused on a subjective rating of an outcome that can be determined objectively (e.g., mobility), it is less clear-cut for condition-specific QoL scores. For instance, scores on a measure of diabetes-specific QoL may not necessarily be closely related to the measure of average blood glucose (HbA1c), thus clinical significance may be better determined by a distribution-based approach than by an anchor-based approach.

An alternative to anchor-based methods, the distribution-based method for interpretation of QoL relies on measures of variation (e.g., standard deviation, standard error of measurement) to benchmark important changes or differences in the QoL measure. A well-known example of this would be Cohen's effect size, which can be used to classify an effect as small, moderate, or large (Wyrwich, Bullinger, et al., 2005). While both methods are imperfect, they are useful for determining what QoL scores mean, especially in clinical practice, where health professionals will be concerned less with statistical significance and more so with being able to interpret an individual's QoL scores.

Response Shift

Response shift is defined as "changes in the meaning and one's evaluation of quality of life resulting from changes in internal standards, values, or conceptualization" (Sprangers & Schwartz, 1999). According to Sprangers, response shift can result from (1) a change in the respondent's internal standard of measurement (scale recalibration), (2) a change in the respondent's values, and (3) a redefinition of the construct (i.e., reconceptualization) (Sprangers & Schwartz, 1999). Response shift is best illustrated with an example. A woman rates her QoL as relatively high. When evaluating her QoL, she thinks of her working and social life as being fairly important for her overall, and she rates them both highly. After being diagnosed with cancer, she begins to think about the importance of her family and her diminishing independence for her QoL. This woman has reconceptualized her QoL. Over time, the woman adjusts to her diagnosis and treatment, and her score on a QoL measure returns to a point roughly consistent with her score before diagnosis. This woman has now “recalibrated.” While the above is just an example, substantial evidence demonstrating response shift exists. For instance, many people with chronic illness report overall QoL scores that similar to those of healthy individuals or those with milder conditions (Sprangers & Schwartz, 1999), a phenomenon known as the “disability paradox” (Higginson & Carr, 2001). This is yet another example of why condition-specific measures may be more relevant than generic measures – that is, the focus needs to be placed not on understanding generic health or QoL but on the impact of the medical condition (and/or its treatment) on QoL.

If response shift is not accounted for in clinical research, then it will be difficult to assess if or how QoL may have changed (or not) from baseline. Additionally, response shift undermines the psychometric properties of QoL measurements, which thereby makes them difficult to analyze. Various study designs have been proposed to assess response shift, including qualitative in-depth interviews with patients, assessment of patients’ QoL for a previous time concurrently with a present time (which thereby means the same internal standards are used), and statistical methods, such as structural equation modeling or item response theory. Of note, while response shift presents some methodological challenges, it also represents important adaptations to conditions, which should be encouraged and celebrated in QoL research (discussed further in section “Post-traumatic Growth”).

New Methods for Measurement

In measures derived from traditional psychometric methods (i.e., classical test theory, CTT), a QoL score is often aggregated across various dimensions, which inherently assumes that dimensions are equivalent, e.g., physical health and mental health are of equal importance to QoL. However, this might not necessarily be the case (Cella, 1994). In response to the limitations posed by CTT, item response theory (IRT) is being used increasingly in the development, validation, and interpretation of health-related constructs, including QoL (Edelen & Reeve, 2007). IRT refers to “a set of generalized linear models and associated statistical procedures that connect observed survey responses to an examinee’s or a subject’s location on an unmeasured underlying (‘latent’) trait” (Hays, Morales, & Reise, 2000). While IRT is yet to be applied widely in health and QoL research, it offers several advantages for measurement, including the ability to (1) more comprehensively evaluate item characteristics, (2) assess group differences in item and scale differences, (3) evaluate scales containing items with different response formats, (4) improve existing measures, (5) use computerized adaptive testing, (6) model change, and (7) evaluate person fit (Edelen & Reeve, 2007).

One of these benefits, computerized adaptive testing (“CAT”), uses IRT item banks and computer technology to create a more tailored, individualized assessment (Cella, Gershon, et al., 2007). In this mode of administration, item selection is guided by a participant’s response to previous questions (Cella, Gershon, et al., 2007). Because each individual item in IRT measurement is calibrated in relation to the construct being assessed (rather than the entire scale being calibrated in relation to the construct, as is common in CTT), individuals may complete shorter assessments without compromising the precision or validity of results (Cella, Gershon, et al., 2007). In addition to real-time data entry, quick display of results, and ease of scoring, CAT allows for brevity and reduced testing burden for individuals, which may be of substantial value to both clinicians and researchers. Already used in large-scale testing initiatives, such as the “Graduate Record Examination” (GRE) (Cella, Gershon, et al., 2007), when and how to incorporate IRT and CAT into QoL assessment will represent one of the leading questions for the next generation of QoL researchers.

Summary

In summary, the selection of appropriate measures for any given situation will often require a trade-off between seemingly irreconcilable imperatives – sensitivity, specificity, brevity, robustness, reliability, validity, interpretability, burden, and cultural/language adaptations (best practices for cultural adaption of QoL measures are discussed further elsewhere (Guillemin, Bombardier, et al., 1993; Wild, Grove, et al., 2005)). While no single measure will be suitable for every situation, care taken in the development and selection of appropriate measures will be rewarded with achievement of robust data, from which valid and meaningful findings can be derived. That being said, it is important to keep in mind that when evaluating QoL measures, an instrument that works well for one setting, population, or purpose, may not work well in another. Indeed, even when measures are "validated," that does not necessarily mean that they can or should be used in other circumstances.

In the following sections, the term PRO is used as an umbrella term in preference to QoL. While every effort has been made to select studies in which the impact of health-related or condition-specific QoL has been assessed using appropriate instruments, the literature is replete with studies in which a related outcome, e.g., health status, has been assessed and interpreted as QoL. Where we, the authors, consider that such interpretations are reasonable, we have included them among our illustrations of how medical treatments can enhance or damage QoL. However, the reader is urged to consider the literature with a certain level of caution and constructive criticism.

Chronic Conditions and New Models of Healthcare Delivery: Impacts on QoL and Other Patient-Reported Outcomes

> As our society ages and chronic disabling conditions increase in prevalence, the traditional emphasis of our health care system on cure, longevity, and quantity of life has begun to shift to an emphasis on quality of life. (Institute of Medicine Committee on Assessing Rehabilitation & Engineering, 1997)

Challenges for QoL and Other PROs by Chronic Conditions and Their Management

Impacts of Chronic Conditions

The great increase in life expectancy is one of humanity's major achievements; however, population aging has, arguably, contributed to a worldwide epidemic of chronic diseases. With impacts on morbidity and mortality, chronic conditions may substantially affect the QoL for individuals who live with them, as depicted in Fig. 33.1. In addition to physical symptoms, such as pain, mobility, and nausea, which may extend for indefinite periods of time, individuals with chronic conditions are often live with increased stress, healthcare costs, emotional distress, stigma, and decreased social health (Institute of Medicine, 2012).

It is widely accepted that the symptom profile associated with a condition is a fundamental contributor to the QoL experienced (Testa, 2000). However, there are challenges inherent in understanding and interpreting the relationships between symptoms and QoL, particularly where medical interventions are concerned. For instance, various aspects of symptoms (e.g., frequency, severity, duration, and symptom-related distress or bother) contribute to an evaluation of QoL. Thus, the impacts of schizophrenia, which is highly stigmatized and characterized by relapsing symptoms and episodes, may have a very different impact on QoL than asthma, which can cause daily and weekly symptoms that affect physical and role functioning (Institute of Medicine, 2012). In addition to differential signs and symptoms, the medical treatments and management regimens required by chronic conditions also vary, as discussed in the following section.

Impacts of Chronic Disease Management

Traditionally, within healthcare, emphasis has been on biomedical efficacy and outcomes (and, hence, on treatment engagement also), but the growing emphasis on QoL derives from the fact that long-term conditions entail self-management rather than cure and the motivation to achieve better biomedical outcomes balanced with better life quality in terms of personally important aspects of life. Some chronic conditions (e.g., rheumatoid arthritis) need long-term pharmacological treatment and are often characterized by progressive physical disability and pain. Others (e.g., type 2 diabetes) are often asymptomatic, but the lifestyle changes or long-term pharmacological treatment required to optimize blood glucose levels and prevent long-term complications requires significant engagement in self-management regimens, which may impair QoL – in the absence of symptoms (e.g., pain) being reduced, optimal self-management can seem overwhelmingly burdensome in the trade-off for long-term health. Thus, through treatment burden and side effects, effects of the condition, and lifestyle changes, chronic diseases have the potential to induce profound changes in a person's life, leading to negative effects on well-being and QoL, as depicted in Fig. 33.1 (Sprangers, Regt, et al., 2000). It should be noted that various personal, social, and environmental factors can impact on the individual's medical condition and ability to cope, but these are not depicted in the model, as the intent is to focus on the impact of the condition.

As discussed in section "The Importance of Assessing QoL,", QoL is recognized increasingly as an important, valid, and reliable measure of the impact of a chronic condition, especially given the need to assess morbidity and impact of treatment (Rees, O'Boyle, & MacDonagh, 2001). However, there are some challenges to consider when assessing QoL outcomes related to medical conditions and their treatments. For instance, people living with diabetes often feel challenged by their condition and daily self-management routines. These demands can be substantial and can be overwhelming for people with type 2 diabetes, involving countless decisions every day regarding diet, physical activity, and self-monitoring – an often futile effort to achieve within target blood glucose levels. Medications, in particular insulin, can substantially affect QoL, either positively (by reducing symptoms of high blood glucose) (Hajos, Pouwer, et al., 2011) or negatively (by increasing symptoms of low blood

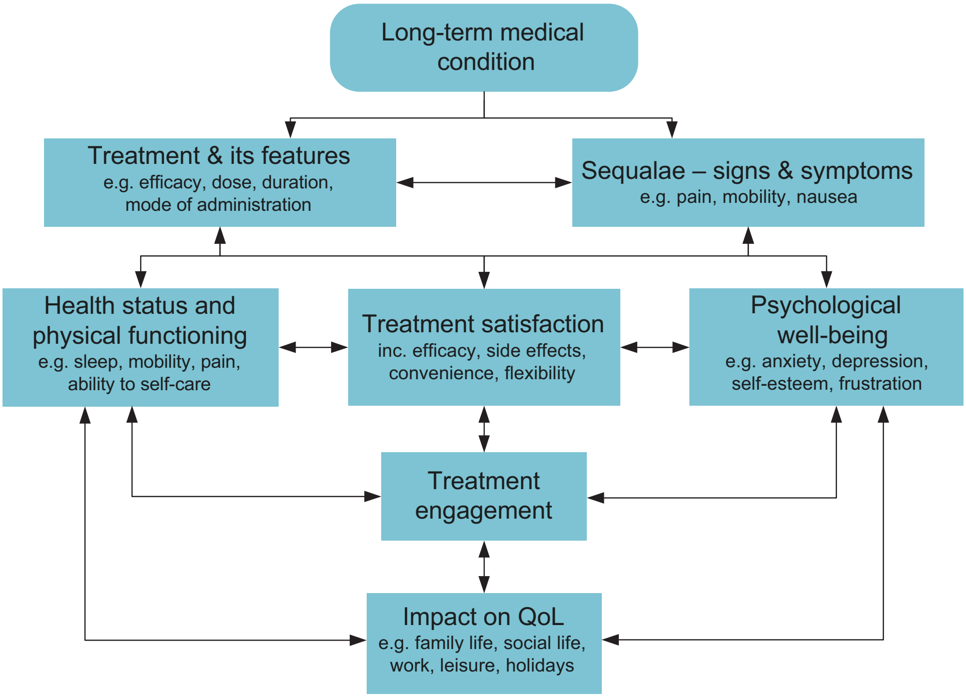

Fig. 33.1 Conceptual model of the impact of a long-term medical condition on QoL

glucose (Marrett, Radican, et al., 2011) and/or imposing restrictions on lifestyle). The problem is that this can be rather difficult to predict. Additionally, the psychosocial toll of living with diabetes is often heavy, and this can, in turn, affect self-care behavior, long-term glycemic control, the risk of developing long-term complications, and ultimately QoL (Rubin & Peyrot, 1999). Moreover, the presence of diabetes-related complications is associated with a more impaired QoL compared to those with no complications (Rubin & Peyrot, 1999).

Despite their potential to be lifesaving, many medical treatments have unpleasant side effects that can compromise QoL. Such side effects span a continuum from universally to infrequently occurring and may have physiological and/or psychological causes. Historically, a focus on "compliance" to medical treatments centered on patients not conforming to the clinician's better judgment, exhibiting apparently inappropriate attitudes and behaviors (Tilson, 2004). However, it is now more widely recognized that medication side effects may impair QoL and well-being (or cause other health concerns), which understandably lead to reduced treatment engagement (as the person makes a trade-off between treatment efficacy, side effects, and convenience/flexibility). Indeed, in more extreme cases, QoL may be compromised so severely that the person may miss treatment appointments or be unwilling/unable to continue treatment, regardless of whether medication is curative, management focused, or palliative (Morrow & Hickik, 1993). In cancer, for example, appetite and weight loss are significant side effects of both chemotherapy and radiotherapy. Clinical malnutrition, though rare, is associated with increased morbidity and mortality, while food aversions are relatively common and can affect daily routines and detract from QoL at a time when quality may outrank quantity of life (Jacobson, 1993). In cancer therapy, a number of solutions have focused on providing sufficient preparatory information (e.g., a tour of the oncology clinic, discussion sessions) to improve coping with treatment (Burish, Snyder, & Jenkins, 1991).

The behavioral aspects of treatment and their impact on QoL are well recognized, e.g., in terms of burden of treatment or self-management. However, unwanted physiological side effects of medically effective treatment regimens may also be detrimental to QoL. A prime example is that of antiretroviral therapy for HIV, which may entail significant adverse sequelae that threaten both QoL and engagement in treatment (Montessori, Press, et al., 2004). Similarly, the success of treatment for tuberculosis has been compromised in part by medication side effects (Forget & Menzies, 2006; Gleissberg, 2001). Such adverse effects are well recognized, but in other circumstances, treatment side effects may be overlooked or dismissed by health professionals. A pertinent example relates to side effects described by patients in the post-licensing period of a new medication and before a body of evidence has accrued regarding its long-term or real-world outcomes. If side effects have not been reported in significant numbers during pre-licensing trials (as might be the case where inclusion criteria are more tightly defined) but are then encountered in larger numbers post licensing, some time may pass before such side effects are widely recognized and acknowledged. Equally, new treatment regimens may also prove to have unwanted consequences.

Impacts on QoL for Partners and Caregivers

Over the past two decades, the prevalence of years lived with chronic disease and/or disability has steadily increased over time without any indication of slowing (Vos, Flaxman, et al., 2012). Improvements in (and rationalization of) healthcare have resulted in shorter hospital stays, while improvements in public health and nutrition have led to population growth and longer life expectancy. In the past, studies focused almost exclusively on the impact of the chronic condition and its management on the individuals' QoL. However, doing so ignores a large proportion of people also affected by the medical condition – the caregivers.

One prime example is Alzheimer's disease. From 2009 to 2013, there was a 17% increase in its prevalence, with the number of people with dementia projected to increase from 115 to 135 million by 2050 (ASD International, 2013). Alzheimer's is characterized by progressive cognitive decline usually beginning with impairments in the ability to form recent memories but inevitably affecting all intellectual functions and leading to complete dependence on others for basic functions of daily life and premature death. The symptoms, which include a broad range of distressing behaviors and psychological reactions, affect the health and QoL of not only the patient but also his or her caregiver (Callahan, Boustani, et al., 2006). Thus, the course of the condition creates many complex caring issues to the point that behavioral and psychological symptoms of dementia become a major challenge affecting an entire family's dynamic and well-being. From a QoL perspective, caregivers who look after people with Alzheimer's disease experience impaired physical, mental, and social well-being from the burden of living with the condition (Callahan, Boustani, et al., 2006).

Similarly, partners of people with cancer are more likely to experience significant severe cancer-related distress, treatment-related worries, and concerns about physical limitations and pain than the person with cancer themselves (Rees, O'Boyle, & MacDonagh, 2001). A number of studies involving people with cancer and their partners have also found that anxiety and depressive symptoms are more common among partners than patients and that many partners attempt to disguise their feelings (Rees, O'Boyle, & MacDonagh, 2001). For instance, among the partners of people with benign prostatic enlargement, despite the benign nature of the disease, 71% of partners were worried that their spouse had cancer and 59% were worried about the possibility of their partner requiring an operation (Sells, Donovan, et al., 2000). Carers of individuals with musculoskeletal disorders, spinal cord injuries, or rheumatoid arthritis have also been shown to have higher levels of depressive symptoms and lower health status scores than do non-carers (Weitzenkamp, Gerhart, et al., 1997; Brouwer, van Exel, et al., 2004). The level of morbidity in carers was only slightly less than that found in individuals with major depression. For carers of children with a mental illness or multiple types of disabilities, subjective well-being may be even lower than for carers of those with physical disability or chronic conditions (Hammond, Weinberg, & Cummins, 2014).

In general, partners who are caregivers face numerous challenges important for QoL, including impaired emotional well-being (fear of the future, hopelessness, depression/anxiety symptoms), deterioration in partner relationship and/or sex life, social isolation (incurred by looking after their spouse or loved one or finding it difficult to attend social functions alone), and struggling with combining their caregiving role with other responsibilities, such as looking after the family or work (Rees, O'Boyle, & MacDonagh, 2001). QoL can also be impaired by the great financial implications of managing chronic conditions and/or caregiving, especially for low-income families, e.g., costly medications, equipment, alterations to the home, or one or both partners needing to give up work to provide care (Rees, O'Boyle, & MacDonagh, 2001).

New Care Models for Chronic Diseases

Given the extensive QoL challenges experienced by people living with chronic conditions and their caregivers or loved ones, new models for organizing healthcare have been proposed. Not only have these models improved the delivery of healthcare and related processes but they also have shown promising benefits for QoL. The following section presents three such models: the chronic care model, the integrated model, and the collaborative care model.

Chronic Care Model

Although evidence exists that a structured, proactive, and person-centered approach helps to improve health outcomes, current delivery of care is often fragmented and event driven (DISMEVAL RC, 2012). To help medical practices improve their quality of care for individuals with chronic conditions, Wagner and colleagues developed the chronic care model (CCM) in the 1990s (http://www.improvingchroniccare.org) (Wagner, Austin, et al., 2001). Nowadays, the CCM has become the most widely referenced model for chronic disease management and prevention activities. The CCM emphasizes that care should be planned, proactive, and person-centered, rather than reactive and focused on acute episodes. Additionally, it is designed to improve care in health systems at the community, organization, practice, and patient levels. The model identifies six key elements as essential to the provision of high-quality care to individuals with chronic illnesses: (1) self-management support, (2) provision of clinical information systems, (3) delivery system redesign, (4) decision support, (5) improved healthcare organization, and (6) the use of community resources. For example, the element “delivery system redesign” focuses on transforming a system that is essentially reactive into one that is proactive, thus ensuring individuals interacting with the system receive structured and planned care, as well as follow-up consultations, as standard procedure (Petersen, Paulitsch, et al., 2014).

Interventions involving one or more elements of the CCM have shown beneficial effects on clinical outcomes and care processes. A comprehensive review of interventions to improve care for chronic illness identified 112 studies for inclusion in a meta-analysis (Tsai, Morton, et al., 2005). The authors concluded that interventions incorporating one or more CCM elements had beneficial effects on clinical outcomes and care processes, and these effects were consistent across a variety of chronic conditions, such as asthma, congestive heart failure, depression, and diabetes. Overall, the authors also found statistically significant effects for improved QoL and PROs, except for those studies involving asthma and diabetes, for which no effects were found. The authors were unable to conclude which elements of CCM were most effective (and it should be noted that CCM has been designed as a “complete package”), but results suggested that delivery system design and self-management support may be particularly promising.

Although the CCM is an evidence-based framework for improving chronic illness care, it is not without its limitations. In particular, some authors have noted that it lacks specificity for meeting the multi-faceted requirements of individuals with multi-morbidity and little is known about the extent to which it has been implemented in routine primary care. Additionally, management of chronic illness depends on both practice-level and individual-level factors that CCM may not be able to overcome. Demonstrating this, Petersen and colleagues collected baseline data from an observational cohort study involving around 160 general practitioners (GP) and over 3000 patients with multi-morbidity in Germany (Petersen, Paulitsch, et al., 2014). The Patient Assessment of Chronic Illness Care (PACIC) questionnaire was employed to assess CCM elements, with higher scores indicating higher levels of care. Multilevel hierarchical modeling was used to identify associations between PACIC (as a dependent variable) and independent variables at the patient level and the practice level. The main findings were that (a) elements of CCM were not fully implemented in primary care practices for individuals with multiple comorbidities, (b) patient-level factors (e.g., higher social support, higher autonomy) and practice-level factors (e.g., solo practices) were associated with higher PACIC scores, and (c) implementation of certain CCM elements (i.e., goal setting and follow-up/coordination) was lacking in comparison to other more developed CCM elements (i.e., system design). In other words, the study found that elements of CCM were only partially in place for people with multiple comorbidities, thereby suggesting a critical area for future translational studies (Petersen, Paulitsch, et al., 2014).

Integrated Care Model for People with Multiple Comorbidities

Given the complex needs of people with challenging chronic conditions or multiple comorbidities, the integrated care model was designed to combine and coordinate care modules to meet the needs of the person rather than the disease(s). A well-accepted definition of the integrated care model's aims comes from Kodner and Spreeuwenberg who stated that the model was designed "to enhance quality of care and quality of life, consumer satisfaction and system efficiency for patients with complex, long-term problems cutting across multiple services, providers and settings" (Kodner & Spreeuwenberg, 2002). Inherent in this definition is the significance given to QoL, which along with functional health, was chosen as the ultimate outcome goal. Indeed, various studies have confirmed the importance of integrated care teams on improvement of QoL. This may occur through two mechanisms. First, integrated care teams can address the varied physical and psychosocial concerns in individuals with chronic conditions (Grumbach, 2003; Provost, Pineault, et al., 2011; Kirby, Chong, et al., 2008). Second, by transcending disease-specific approaches, a multidisciplinary, integrated care team can address the multifaceted nature of symptoms and treatments of people with multiple comorbidities.

The integrated model includes both essential elements of care (that have been widely studied and used in the literature) and novel elements, which are more specific to people with multiple comorbidities and enable both the individual and their healthcare providers to establish health goals and outcomes that are not disease specific (Sampalli, Fox, et al., 2012). The essential elements of the integrated care model identified in the literature include (1) a comprehensive assessment of the multifaceted diagnosis and symptom profile, (2) evidence-based care plans, (3) supporting behaviors to improve engagement with care plans, (4) coordination of care across the integrated care team, and (5) primary care physicians, specialists, hospitals, and community resources. Novel elements include:

1. A medical management scheme that facilitates the care of the patient across the spectrum of diagnoses and symptom profile
2. Multidisciplinary care that includes rehabilitation to improve functional health and quality of life
3. Care coordination appointments integrated into key phases of care delivery to ensure patient engagement and confidence in whole-person care and self-management
4. Education modules that provide skills and coping strategies to help manage the needs of the person
5. Person-relevant and identified self-management and behavior management supports at key phases of care delivery that are specifically designed to motivate and enhance the life skills of individuals to manage their constellation of problems better

The proposed model comprises four key phases, i.e., intake, integrated care, transition, and discharge, which seek to improve functional health and QoL, as shown in Fig. 33.2 (adapted from Sampalli, Fox, et al., 2012). Education modules that impart skills and coping strategies to enhance self-management and facilitate healthy behavior are also an integral aspect of this type of care delivery. Of note, both the CCM and integrated care model emphasize the importance of self-management (discussed further in section "Self-Management Interventions") as an intervention strategy to enhance QoL.

Collaborative Care Models

Collaborative care is the last model of healthcare delivery discussed. Not only has collaborative care shown improvements in physical health for people with chronic physical illnesses but it has also been shown as successful for individuals with mental health disorders. For instance, a 12-month cluster randomized controlled trial was conducted among 581 adults individuals with doctor-diagnosed depression from 51 primary care practices in the UK (Richards, Hill, et al., 2013). Intervention group participants received a collaborative care intervention, which included depression education, medication management, behavioral activation, relapse prevention, and primary care liaison, being delivered by care managers. The control arm participants received usual care from family doctors' standard clinical practice. Compared to those in the control group, those in the intervention group reported statisti-

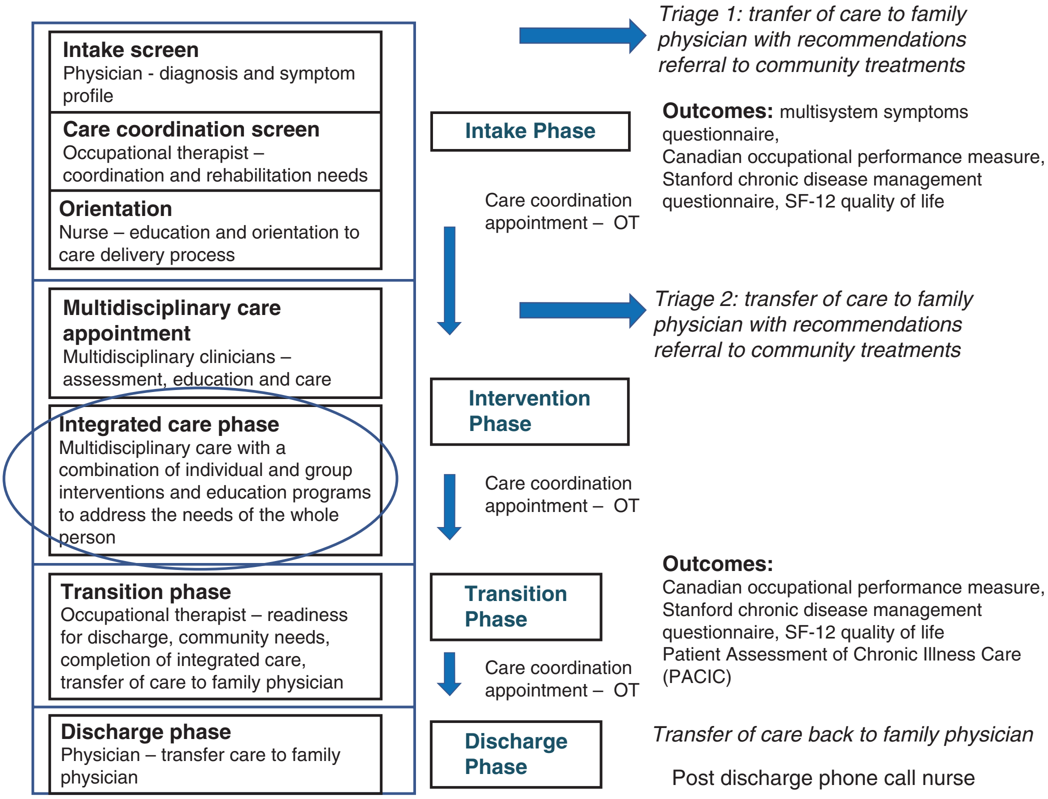

Fig. 33.2 A model of integrated care for people with multiple comorbidities (Adapted from Sampalli, Fox, et al., 2012)

cally significant improvements in depressive symptoms (PHQ-9) and mental health (SF-36) at 4 months. Furthermore, participants receiving collaborative care were significantly more satisfied with their treatment than their counterparts receiving usual care. The authors concluded that "collaborative care has persistent positive effects up to 12 months after initiation of the intervention and is preferred by patients over usual care" (Richards, Hill, et al., 2013).

With regards to the significant prevalence of comorbidities worldwide, these models suggests coordinated, integrated, and collaborative care may be appropriate for many individuals, particularly those with chronic illness, and lead to promising improvements in QoL and QoL-related dimensions, including physical, mental, psychological, and social well-being (Barnett, Mercer, et al., 2012; Bauer, Briss, et al., 2014).

Interventions to Enhance QoL

> "In light of findings that, with the exception of mood, health-related variables exert only indirect effects on quality of life, we must put into perspective any expectations we have of influencing our clients' life quality through health-related interventions." (Anderson & Burckhardt, 1999)

If QoL is conceptualized to include multiple dimensions, including mental and physical health, but also nonmedical factors, such as psychosocial variables, social and role participation, and spiritual well-being among others, then it follows that in order to improve QoL, interventions may need to focus more broadly than improvement of health alone (Anderson & Burckhardt, 1999). Even when interventions are designed to improve health, QoL improvements may result if changes in self-perception, perceived social support, or other psychosocial factors occur (Anderson

& Burckhardt, 1999). For these reasons, in this section, we present examples of how interventions may enhance QoL, not necessarily through improvements in health, but through other processes.

Post-traumatic Growth

Chronic illness affects multiple aspects of an individual's life, no doubt leading to significant impairment of QoL (discussed in section "Challenges for QoL and Other PROs by Chronic Conditions and Their Management"). However, there is also reason to believe that some people find coping (adaptive) strategies to become well-adjusted to their altered life circumstances – "people exposed to even the most traumatic events may perceive at least some good emerging from their struggle" (Tedeschi & Calhoun, 1996). This may be related to the need to "make sense" of or find meaning in adversity – a desire to see illness as part of life, a challenge, rather than to feel dominated by illness (Jacobi & MacLeod, 2011). It may also be related to response-shift (discussed in section "Response Shift"), in which people with chronic or life-threatening conditions may not rate their QoL as significantly poorer than people with milder conditions or those who are healthy (Higginson & Carr, 2001). In the context of behavioral interventions, this phenomenon is called "post-traumatic growth" and defined as positive change or transformation that may occur following a traumatic event (Tedeschi & Calhoun, 1996). Although it may seem counterintuitive, in response to traumatic events, some people report finding a life purpose, enhanced self-assurance, closer family relationships, emotional growth, increased desire to enhance relationships, appreciation for life, and strengthening of religious beliefs (Tedeschi & Calhoun, 1996). While this may not occur for all individuals, research has shown that many people with chronic disease reach a state of psychological adjustment, not merely from the passage of time or absence of distress, but as a separate phenomenon (de Ridder, Geenen, et al., 2008; Antoni, Lehman, et al., 2001).

If people can naturally experience growth after traumatic events, then there is reason to believe that interventions could also foster such growth, thereby improving QoL. Indeed this hypothesis has been confirmed, and interventions have been shown to positively enhance growth and meaning finding, especially among those with cancer (de Ridder, Geenen, et al., 2008). For instance, a cognitive behavioral stress-management intervention for solution-focused coping strategies (e.g., active coping and planning) and emotion-focused coping strategies (e.g., relaxation, emotional support) was implemented with women with breast cancer. Compared to control group participants, those in the intervention group had reduced prevalence of depressive symptoms, reported that having breast cancer made positive contributions to their lives, and increased generalized optimism (Antoni, Lehman, et al., 2001). Effects were strongest for women who were lowest in optimism at baseline, thereby suggesting that the intervention was most effective for women who needed it the most (Antoni, Lehman, et al., 2001). In another study, researchers asked women with early-stage breast cancer to write down their thoughts and feelings regarding breast cancer. Those randomized to the experimental condition experienced fewer visits for cancer-related morbidities at 3 months and decreased somatic symptoms (Stanton, Danoff-Burg, et al., 2002). Again, effects were most pronounced for those with the highest cancer avoidance – in other words, women who had intentionally attempted to avoid thoughts and feelings regarding cancer (Stanton, Danoff-Burg, et al., 2002). Post-traumatic growth interventions are noteworthy for two reasons: (1) they actively take a strength-based approach to improving health and well-being (i.e., focusing on the person's own positive factors and strengths) and (2) in addition to their effects on health, they also improve psychosocial outcomes related to QoL.

Social Support Interventions

Another psychosocial factor of importance for QoL is social support, which has been demonstrated as a clear protective factor for health. In fact, social support is so powerful that researchers have found a 50% reduction in the likelihood of mortality for individuals with strong social relationships, comparable with the benefit for mortality in those who do not smoke (Holt-Lunstad, Smith, & Layton, 2010). In addition to its health benefits, interventions have demonstrated consistently the importance of social support on QoL: "Although health may become an increasingly important determinant of quality of life as health status deteriorates, other influences – particularly interpersonal relationships – remain vital to individual judgments of life quality even in the presence of chronic illness" (Anderson & Burckhardt, 1999). A systematic review of factors affecting QoL in long-term survivors of breast cancer found strong evidence for social support as a significant predictor of decreased emotional distress and increased QoL (Mols, Vingerhoets, et al., 2005). Further evidence of the association between social support and QoL has been demonstrated for those with HIV/AIDS (Friedland, Renwick, & McColl, 1996), diabetes (Tang, Brown, et al., 2008; Fisher, La Greca, et al., 1997; King, Glasgow, et al., 2010; Gallegos-Carrillo, Garcia-Pena, et al., 2009), congestive heart failure (Barutcu & Mert, 2013) among others.

Despite the overall importance of social support in QoL research and practice, important questions remain with regard to translating these findings into practice. For instance, what type and quantity of support are needed? For what type of situation? Who should provide support? Should it come from people within an individual's existing social network or should it come from strangers? What are the relative advantages and disadvantages of both? When should support be provided? At what stage of a health condition? Does it matter what type of support the patient wants? Should we pay more attention to received social support or perceived social support? Can social support be harmful and in what circumstances? Although there may be no clear answers to these questions, considering them in the implementation of QoL interventions will help practitioners (and patients in delivery and receipt of support), especially given the need for translation of social support research into active intervention trials.

Self-Management Interventions

As discussed in section "New Care Models for Chronic Diseases," the importance of self-management has been demonstrated by its inclusion in modern models of healthcare delivery. While self-management may generally improve a person's health status, through promotion of necessary knowledge, skills, and motivation, it also includes benefits for QoL (de Ridder, Geenen, et al., 2008; Cochran & Conn, 2008; Thorpe, Fahey, et al., 2013). A notable example of the positive impact of self-management on QoL comes from the cancer literature. Although cancer has traditionally been viewed as an acute, life-threatening chronic condition, with recent improvements in the early detection, diagnosis, and treatment of cancer, people are living with cancer as a long-term condition and need to become skilled in self-management. Cancer as a chronic condition places new demands on individuals and their families to manage their own care, and it challenges old paradigms that oncology's work is done after treatment (McCorkle, Ercolano, et al., 2011). Over the past two decades, a number of intervention studies have demonstrated significant improvements in patient outcomes at various phases on the cancer care continuum. A systematic review analyzed 16 randomized controlled trials of self-management interventions with cancer patients and families in the treatment, survivorship, and end-of-life phases of the cancer care continuum between 1992 and 2007 (McCorkle, Ercolano, et al., 2011). The self-management interventions positively affected prognoses in terms of symptom distress, uncertainty, problem solving, communication, and general QoL. These interventions, however, depended on the organization of oncology practices (e.g., whether they were designed to help patients and families in self-management efforts), thereby suggesting the importance of self-management as integrated with improved models for healthcare delivery.

Similarly, in people with type 1 diabetes, structured self-management education programs focused on providing participants with the skills to manage insulin flexibly, thereby promoting dietary freedom, have also been shown to improve diabetes-specific QoL (DAFNE Study Group, 2002). Furthermore, such benefits for QoL are maintained in the long-term (demonstrated for up to 4 years) (Speight, Amiel, et al., 2010) and also when such programs are delivered as part of routine care (as opposed to a clinical trial setting) (Cooke, Bond, et al., 2013). Over the past decade, self-management interventions for individuals with diabetes have also incorporated innovative technologies to assist with glucose monitoring and QoL (Thorpe, Fahey, et al., 2013; Fisher, Thorpe, et al., 2007). For instance, fear of hypo- and hyperglycemia, especially at nighttime, is a common concern among individuals with type 1 diabetes (Barnard, Wysocki, et al., 2014). To alleviate these concerns, continuous glucose monitoring can provide real-time feedback, which can then alert individuals' insulin pumps to provide insulin slowly throughout the day and night depending on the individuals' physiological needs. These "closed loop" systems can prevent hypoglycemia, and studies have demonstrated their potentially positive impacts on QoL (Rubin & Peyrot, 2009).

Although benefits of self-management have been demonstrated consistently across various chronic conditions, it should be noted that such interventions do not *always* improve health or QoL; this variance may be tied to the extent that individuals view self-management programs (and self-management itself) as burdensome or not. In a study of 292 adults with diabetes, people who adhered to self-management activities reported more positive health outcomes (Weijman, Ros, et al., 2005). However, among people who viewed these activities as burdensome, poorer health outcomes were observed (Weijman, Ros, et al., 2005). Thus, an important question is raised regarding the utility and direction of self-management interventions designed to improve QoL. How can interventions help those who may be hard to reach? This question is especially pertinent given the often low retention and rates of engagement with self-management routines (de Ridder, Geenen, et al., 2008).

While the organization of this section may lead the reader to believe that interventions to improve QoL (i.e., post-traumatic growth, social support, self-management) may be distinct, research suggests that combining aspects of these interventions can lead to synergistic effects with particularly promising benefits for QoL. For instance, many studies have looked at social support combined with self-management and found significant benefits. Among strategies for improving QoL within interventions, peer support (e.g., "community health workers," "lay health advisors," "*promotores*") deserves special attention. In addition to helping provide encouragement and assistance with daily management of health conditions, peer supporters provide emotional support and encourage problem solving to address emotional distress (Rahman, Malik, et al., 2008). From the perspective of reaching populations, peer supporters can also engage those who otherwise not receive appropriate care (Boothroyd & Fisher, 2010; Fisher, Strunk, et al., 2009). Moreover, not only has peer support been applied to self-management of diabetes and other chronic conditions, e.g., (Fisher, Strunk, et al., 2009; Heisler, Vijan, et al., 2010; Thom, Ghorob, et al., 2013; Fisher, Boothroyd, et al., 2012), it has also been used with self-management for a variety of mental health problems (Rahman, Malik, et al., 2008). Thus, the combination of peer support and self-management regimens have shown promising improvements in not only QoL and components related to QoL but also other factors of importance, including intervention reach and sustainability.

Conclusions and Practice Implications

> Arguably, optimizing HRQOL may be the most substantial impact the health care team will have on the person. (Unruh, Weisbord, et al., 2005, p. 82)

Over the past few decades, a growing body of evidence has demonstrated the value of QoL measurement for various purposes: to identify the holistic impact of chronic medical conditions, to determine ways to improve medical treatments, and to guide the selection (and rationalization) of treatments and regimens. With the introduction and increasing use of brief instruments in clinical research, routine implementation of QoL assessment in clinical practice is closer than it was 10 years ago. However, before the true benefits of QoL assessment are to be realized, substantial barriers to the adoption of QoL measurement in clinical practice need to be overcome. In this section, we present the practice and policy implications needed for integration of QoL.

Practice Implications

While formal assessment of QoL in research settings is relatively straightforward and increasingly commonplace, QoL assessment has yet to be incorporated routinely into clinical practice. In 2002, Levine and Ganz (2002), p. 2216 identified "the challenge for the next decade": "How does the measurement of quality of life in groups of patients and the administration of a quality-of-life questionnaire to an individual patient ultimately improve care?" A decade on, readiness to incorporate QoL assessment into clinical practice is still less than optimal. In a time- and resource-limited clinic environment, formal assessment of the QoL of individuals is a competing procedure – albeit one which offers significant benefits if adopted – and often seen as secondary to the pursuit of biomedical improvements. A number of barriers to routine inclusion of QoL assessment in clinical care remain:

1. On a practical level, appropriate measures, clinic resources, and additional time are required to conduct meaningful and useful QoL assessment.
2. Interpreting outcomes at the individual level is challenging but necessary if truly person-centered care is to be achieved and QoL, medical outcomes, and treatment engagement are to be optimized.
3. Beyond a willingness to engage with QoL assessment in clinical practice, health professionals require training in the conduct and interpretation of results.
4. Health professionals may sometimes be reluctant to use QoL measures if they fear that clinical priorities and QoL preferences are irreconcilable; hence they may choose to focus more tightly on medical outcomes which they more easily understand and/or perceive to be of greater value.
5. Ethical considerations arising from QoL measurement may be challenging. For example, if QoL is to be assessed and measured, but unable to be influenced, then what is the purpose of measuring it? (Higginson & Carr, 2001) Should QoL measurement be the concern of the clinician or does it represent an "over-medicalization" of life and clinical interference in patients' lives? (Higginson & Carr, 2001) What should be done if people face terminal or catastrophic illness/injury and express a wish to discontinue medical treatment which may be life sustaining?

Even where QoL assessment has been adopted into clinical practice, there is a shortfall in the application of results into appropriate clinical care and/or strategies – "from assessment to action" (Katschnig, 2006). Given the difficulty in routinizing QoL measures into clinical practice, a number of authors have presented considerations for review (see Table 33.2) (Higginson & Carr, 2001). For further reference on implementation of QoL measures in clinical care, we also refer readers to the International Society for Quality of Life Research (ISOQOL), which has developed a User's Guide for Implementing Patient-Reported Outcomes Assessment in Clinical Practice (Snyder, Aaronson, et al., 2012) (available at www.isoqol.org).

Linking QoL to Medical Consultations

Despite the many challenges inherent in integration of QoL assessment and routine clinical care, discussing QoL outcomes with individuals is important for two related reasons: (1) it can help inform therapeutic changes based on shared decision-making and linked care pathways and (2) it acknowledges the importance of QoL as an outcome in its own right. Regarding the former, some studies suggest the promise of incorporating QoL assessment into clinical care. For instance, Velikova et al. found that routine, repeated HRQoL measurement with feedback of results

Table 33.2 Considerations when implementing QoL measures into clinical practice (Adapted from Higginson & Carr, 2001)

Phase	Key questions
Planning	What are the goals of the practice and purpose for using the QoL measure? What measures are already used? Which QoL measure should be used? Is the measure valid, feasible to use, interpretable, responsive, and clinically relevant? What should the timing of assessment be? What will be the mode of administration? Will other outcomes also be monitored? How can staff and patients be involved?
Implementation	Who needs to be trained for use of the use of QoL measures? Should a pilot testing of the use of the measure be conducted? Who will the results be reported to? What is the process for reporting results? What strategies can be used to respond to issues?
Assessment	What aids exist to facilitate score interpretation? What is the impact of the measure? How should impact be communicated?
Modification	How should the measure or processes for implementation be modified? What are next steps for continued use of the measure?

led to improvement in HRQoL and emotional well-being compared to those in attention-control and control groups (Velikova, Booth, et al., 2004). Regarding the latter, assessment of QoL by providers underscores the broader context of patients' lives that may not be reflected in conventional medical consultations. To this end, medical providers have begun incorporating QoL into their medical consultations – two examples of which are provided below for reference.

In response to guidelines from the International Society for Pediatric and Adolescent Diabetes calling for routine assessment of QoL, Eilander and colleagues (2016) implemented a QoL monitoring intervention in 11 Dutch pediatric diabetes clinics (Eilander, de Wit, et al., 2016). Prior to implementation, clinical teams were offered 1 day training on how to use and discuss QoL with adolescents. Annually, adolescents completed a web-based measure of diabetes-related QoL prior to periodic consultation with their diabetes providers. During in-person consultations, the clinical team discussed outcomes with their patients. Surveys after implementation showed that most providers believed that discussing QoL contributed to adolescents' health (66.7%) and felt that the tool had additional value to routine care (91.7%) (Eilander, de Wit, et al., 2016). Moreover, the majority of providers found that discussing QoL contributed to the recognition of psychosocial problems (94.4%), that the conversations helped to talk about QoL in more detail (86.1%), and that the conversation differed from their prior expectations (58.3%) (Eilander, de Wit, et al., 2016). Consistent with these findings, most adolescents felt they were "heard" by providers (85.2%), and most parents found the intervention beneficial to their child (78.8%) (Eilander, de Wit, et al., 2016). Despite these benefits and a high level of motivation to incorporate QoL assessment into routine care, clinics struggled with logistics, such as time, manpower, and workflow design (Eilander, de Wit, et al., 2016).

To assess the HRQoL of children with cancer, Engelen and colleagues (2012) asked children to complete an HRQoL assessment with four domains (physical, emotional, social, and cognitive functioning) and then instructed pediatric oncologists to discuss the items identified as a problem (compared to health norm scores or change in items over time) (Engelen, Detmar, et al., 2012). Prior to implementation, extensive formative research and training were conducted with providers and patients. Compared to control group participants in the intervention group, the use of the PRO increased the amount of psychosocial topics discussed in medical consultations (as recorded in audio consultations) (Engelen, Detmar, et al., 2012), increased discussion of emotional and psychosocial functioning (Engelen, Detmar, et al., 2012), and improved HRQoL related to self-esteem, family activities, and psychosocial functioning (Engelen, Detmar, et al., 2012). Importantly, these benefits occurred without lengthening the medical consultation visit (Engelen, Detmar, et al., 2012).

From both of these studies, three important considerations are noted. First, prior to implementation, medical practices were involved in considerable training and engaged in formative research on design, integration, and feedback on the use of QoL assessment. Given the significant barriers regarding implementation of QoL interventions discussed above, further research will be needed to explore organizational factors facilitating integration of QoL assessment. Second, in both studies, the majority of clinical providers discussing QoL with patients were doctors; however, to some extent, both studies also included nurses or nurse practitioners and emphasized the importance of involving different clinical team members, such as social workers, psychologists, nurses, and nurse practitioners. Integrating routine QoL assessment into team-based models of healthcare delivery, discussed in section “New Care Models for Chronic Diseases,” represents an important avenue for future interventions. Lastly, the studies demonstrated considerable QoL-related improvements from both the patients’ and providers’ perspectives, including notably, patient-provider communication, which is important in its own right for patient satisfaction and quality of care.

Despite the benefits that may result from integration of QoL into clinical care, two caveats are noted. First, we caution that assessment and use of QoL in clinical care should not be a substitute for genuine communication with patients, especially given that interpretation and use of QoL results is anything but guaranteed. Second, a question remains regarding the best way that clinicians can improve QoL. In other words, should providers start assessing QoL and incorporating measurement into practice? Or would it be more beneficial to listen to patients and work collaboratively with them (as discussed in section “New Care Models for Chronic Diseases”)? Clearly, integration of QoL measurement into clinical care should not replace communication with patients or other methods for improving QoL. Instead, it may be viewed as a complement to alternative methods, many of which may also improve QoL in more direct or indirect ways.

Policy Implications

“Person-centered care,” “comparative effectiveness research,” “patient-reported outcomes,” and “meaningful use in ‘electronic health records’” are all twenty-first-century buzzwords in health and healthcare. While they have different meanings and are used in different contexts, they all to some extent refer to and incorporate the importance of acknowledging pursuit of QoL – a life of quality. In fact, QoL assessment has reached the national policy agenda in the USA, with two of the four principle goals for *Healthy People 2020* being directly related to QoL: (1) “attain high quality, longer lives free of preventable disease, disability, injury, and premature death” and (2) “promote quality of life, healthy development and healthy behaviors across all life stages.” Given these goals, increased attention is being paid to QoL on local, state, and national levels. Similar initiatives exist in many other countries.

However, several emerging changes in the national landscape are worth mentioning. First, EHRs (also referred to as electronic medical records (EMRs) and personal health records (PHRs)) are gaining widespread acceptance, through which PROs are increasingly being measured. Yet, important questions remain: How can these measures be used by both patients and providers? How can usefulness be optimized? How should QoL and PRO assessment be integrated with other outcomes?, etc. Second, many local and national surveillance systems are incorporating QoL and PRO measures into routine assessment (e.g., PROMIS; Behavioral Risk Factor Surveillance System "BRFSS"). However, it remains unclear which QoL measures should be used, how frequently measures should be collected, how different databases should be integrated, etc. Third, it is still challenging and complex to link the information derived from QoL assessment into policy decision-making (Ahmed, Berzon, et al., 2012). As discussed in previous sections, two of the complexities involved in QoL research are (1) how to interpret QoL assessments and (2) how to make decisions based on results (e.g., what is a QALY worth?). For these reasons, future QoL research will need to focus on how policy makers may derive the benefits of QoL that individuals and medical providers are also beginning to see.

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End of Life Issues in Behavioral Medicine

34

Kevin S. Masters, Kristin M. Kilbourn, and Chad E. Barrett

Few topics that fall within the purview of behavioral medicine are as potentially contentious and politically charged as behavioral and medical intervention at the end of life. During the recent debate over universal healthcare in the USA, some activists accused the government of advocating a plan that would ration resources at the end of life and create "death panels" that would presumably make life and death decisions based on rigid bureaucratic algorithms. Earlier, the highly publicized case of Terri Schiavo, a patient in Florida who was kept alive via a feeding tube for approximately 15 years, served to highlight issues regarding advanced health-care directives, what it does and does not mean to be in a vegetative state, indeed, what is consciousness. The public debate surrounding this case lasted from 1998 to 2005. These are high-profile examples but everyday around the world individuals and their families must decide the course that their healthcare should take as they near the end of life.

Much of the current controversy is perhaps the inevitable result of changes that characterize the nature of life's final years in developed countries. Because of advances in medicine and allied fields, humans are now often confronted with information and related decisions regarding their end of life health-care preferences that were not imaginable throughout the overwhelming majority of human history. The case of Carnegie Mellon Professor Randy Pausch is illustrative. Professor Pausch is now well known worldwide for his *Last Lecture*, both an online video and best-selling book that capture a speech he gave at the university only months before his death due to pancreatic cancer. What makes this compelling for our purposes is that at the time of the speech Professor Pausch was keenly aware of his soon death because he had undergone advanced medical diagnostic procedures, but he felt very well. In fact, he performed several physical exercises during the talk to emphasize his high level of energy and good feeling. An individual with Professor Pausch's condition in previous generations would not have known what the future held and, therefore, would not have faced the same end of life issues. In fact, such is still the case in much of the undeveloped world.

Citizens in industrialized countries not only have more information and treatment options, but they also live longer and are much more likely to die slower deaths than in previous generations. Prior to the mid-twentieth century, compared to today, a much higher percentage of deaths were due to infections and accidents (Centers for Disease Control and Prevention, 2011b), and consequently the time from onset of illness to death

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was relatively short. However, improvements in public health (e.g., clean water, vaccinations), the advent of powerful antibiotics, and greatly improved emergency medical services reduced the percentage of deaths that occur quickly. Instead, residents of developed countries are more likely to live with chronic, often debilitating, illnesses for many years prior to their death, and the final years of life are often marked by increasing symptom profiles and a corresponding decline in functionality. Further, the advance of medical technology and the concomitant ability to extend life often leave individuals facing challenging issues and questions regarding the quality, type, and extent of care that they or their loved ones will or should receive as life's end nears. This situation is complicated because many people simply do not want to seriously engage these issues until they are no longer avoidable. Consequently at a time of emotional distress, they are forced to consider, perhaps for the first time, complicated treatment options with probabilistic outcomes sometimes conveyed in a language that is not comfortable or familiar to them.

Common End of Life Experiences

In the context of these quickly changing health-care practices and possibilities, it has become, at least in developed countries, difficult to characterize "normal" dying. Of course some individuals still die quickly with little or no advance indication that their end of life is near, and others die of natural causes in old age with no diagnosable pathology. But many others live with chronic disease for years, and though the degree of precision in predicting time of death varies depending on the particular disease and its physiological progression, the overall course leading toward death is often reasonably well known.

At the end of life, individuals often experience anticipatory grief as they face their mortality. Anticipatory grief refers to the cognitive, affective, social, and culturally appropriate reactions to expected death, over past, present, and anticipated losses (Cheng Lo, Chan, et al., 2010). Importantly, they not only grieve for their anticipated loss of life, but for the loss of their hopes and dreams and their relationships, especially within their families. They also grieve for the significant changes in lifestyle associated with a terminal illness such as increases in symptom and pain severity, decline in functioning, fatigue, loss of independence and mobility, and greater reliance on others for basic needs (Lindemann, 1994). Kubler-Ross (1979) described five stages of grief: denial, anger, bargaining, depression, and acceptance. Though, it is now known that patients do not necessarily progress sequentially through each stage, and may not experience some stages at all, it is common for patients to have at least several of these experiences. However, based on a review of the literature, Telford, Kralik, and Kosh (2006) cautioned that health-care workers who have uncritically accepted the stages of grief model may not listen openly when people tell their own unique stories but may, instead, selectively listen for evidence of denial. This observation is concordant with the current trend toward patient-focused understanding of end of life, i.e., an emphasis on the unique experiences of each patient. Though not necessarily a rebuttal of the work of Kubler-Ross, the current emphasis highlights the fact that individuals providing proper end of life care must be open to unique experiences and interpretations of the dying individual. Later we discuss particular issues and experiences that are both common and problematic at the end of life.

Developmental Issues

Concerns unique to particular developmental stages in the life cycle may differentially impact patients' psychological responses to life-threatening illness. Though end of life concerns are often thought of in the context of older adults, in fact, younger individuals must also sometimes face this difficult reality. Young adults, who are in the midst of establishing their independence, often struggle with ambivalence about having to again depend on their parents. They may view their condition as unfair and struggle with feelings of anger, sadness, and grief about the loss of future experiences. Parents with young children typically worry about the impact of their illness, and death, on their children, maintaining routines and normal lifestyles in order to avoid upsetting their family, and how to discuss their illness with their children. They also typically feel a great deal of sadness and grief about missing their children grow up. Older adults are often concerned with existential issues. Feelings of satisfaction or unhappiness with past achievements can mitigate or exacerbate emotional distress. Older patients, in particular, tend to worry about their surviving spouse. They may also see their illness as unfairly cheating them out of the opportunity to retire and enjoy the fruits of a lifetime of hard work and as a result feel angry, frustrated, disappointed, grieved, and sad. Patients of an advanced age may see the approach of death as a relief. However, this can depend on whether they feel at peace with the life they lived and what kind of attachments, and connections, they have that provide a sense of meaning and vitality (Block, 2006).

Place of Death

Another recent change regarding end of life is where death actually occurs. Throughout history this has been primarily in the home or local village, but in many parts of the world this is less likely the case today. A study (Ahmad & O'Mahony, 2005) covering 20 years (1981–2001) that examined all death certificates in Wales reported a significant shift in location of death from the community to hospitals and care homes. Specifically, deaths in hospital increased from 56.7% to 61.7% and in care homes from 5.7% to 16.2%, whereas deaths in the community decreased from 37.6% to 22.1%. Similarly, Gomes and Higginson (2008) analyzed trends in death from 1974 to 2003 in England and Wales and based on these data made projections to 2030. They noted that home death proportions fell from 31% to 18% overall, and the decline was even steeper for people aged 65 and over. This is noteworthy because it is expected that more people will die at an older age in the next 20 years. If these trends continue, fewer than 10% of the population in the UK will die at home in 2030. Similar trends were noted for Japan and Italy. On the other hand, the USA, Australia, and Canada have seen reductions in the percent of deaths in the hospital. Flory and colleagues (2004) reported that in the USA between 1980 and 1998, there was a 13% decline in inpatient hospital deaths. According to data from the US Centers for Disease Control and Prevention (CDC, 2011a; http://www.cdc.gov/nchs/nvss/mortality/gmwk309.htm), this trend continued between 1999 and 2005 with an additional 3% decline in inpatient hospital deaths. Additionally, in 1999, 22% of deaths occurred at home whereas 24% died at home in 2005. Curiously, in 1999 the CDC worksheets had no category for hospice deaths. In 2005 they report that 1.38% of deaths occurred in hospice facilities.

Where individuals die is the result of an extremely complex chain of events that is influenced by factors that include: (a) presence or absence of advanced medical directives that may include living wills and the interpretation of these directives, do not resuscitate orders, and non-hospital do not resuscitate orders; (b) insurance coverage and policies; (c) cultural norms and values; (d) availability and type of palliative care services; (e) patient and family values; (f) psychological aspects of dying (e.g., fear of being unattended and suffering); (g) availability of information regarding care options; (h) physical condition of the patient; and (i) the availability and capability of the patient's family and social network. Gomes and Higginson (2006) recently reviewed the literature pertaining to home death among terminally ill cancer patients and identified several additional variables that predicted home death including low functional status, intensity of home care, patient preferences, living with relatives, use of home healthcare, extended family support, and caregivers' preferences. Interestingly, geographic areas with greater hospital provision and availability of inpatient beds predicted decreased odds of home death. Nevertheless, in spite of the relatively low numbers of home deaths, well over half of individuals with a progressive illness indicate that they want to die at home (Higginson & Sen-Gupta, 2000) though clearly more research into this area is needed.

Terminology: Palliative Care and Hospice Care

The concept of choice of treatments for individuals with a life-limiting illness implies that there are options. Clearly some patients desire aggressive treatment, i.e., treatment whose goal is to cure the illness or, at least, delay death for as long as possible. This might be characterized as the traditional Western approach. Other patients seek options that are not intended to lengthen life but increase the quality of life as it nears its end. Several terms are used to describe this type of treatment, but they are not always employed consistently in the literature or common usage. Palliative care is a term that is often misused, can be confusing to both patients and providers, and may not have a universally agreed upon definition. The US federal regulations for participation in Medicare as a hospice provider define palliative care this way: "Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice" (§418.3, June 5, 2008). Noticeably absent in this definition is any mention of end of life though the fact that it is stated in federal regulations for hospice care allows that it might be interpreted as an end of life treatment. Both the National Palliative Care Research Center (NPCRC) and the World Health Organization (WHO) similarly define palliative care with an emphasis on relieving suffering, achieving the best possible quality of life, and attending to psychological and spiritual aspects of care. NPCRC, in reference to palliative care, states, "It is **offered simultaneously** with life prolonging and curative therapies for persons living with serious, complex, and eventually terminal illness" (National Palliative Care Research Center, 2011 emphasis in original) (What is palliative care?, para. 1), and the WHO definition similarly notes that palliative care "is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life…" (WHO definition of palliative care, para 1). Thus, although end of life care might include or in some cases entirely consist of palliative care, palliative care is not synonymous with end of life treatment and may, in fact, be administered in cases where death is far from imminent. Palliative care is not intended to either hasten death or extend life but is life affirming and supports the patients' and families' wishes including support for continuing treatments that attempt to cure or prolong life. Thus it is important to distinguish hospice care from palliative care.

Both hospice and palliative care share the goals of reducing suffering and improving quality of life, neither are focused on attempting to cure the illness, and both are typically offered by interdisciplinary treatment teams that include behavioral medicine professionals. But hospice is provided solely for patients for whom death is imminent, whereas palliative care may be provided both in cases of imminent death and in cases where death is not near. In a sense hospice care may be thought of as a subset of palliative care. It is also important to note that hospice care may be delivered in a number of settings, and thus describing care as "hospice" does not necessarily indicate that the individual must be treated in a particular facility. Hospice care may take place at home, in a designated hospice care facility, in a hospital, or in an advanced care treatment facility. In the USA the median length of provision of hospice service in 2009 was 21.1 days, and the mean was 69.0 days (National Hospice and Palliative Care Organization [NHPCO], 2010). Hospice care has been growing in the USA. In 1984 100,000 patients were treated by hospice whereas in 2009 the number was 1,560,000 (NHPCO), or approximately 41.6% of all deaths in the USA were under the care of a hospice program. Hospice has also grown in other countries, but the rates of growth are not uniform and are influenced by many factors including origins and establishment of hospice, connotation of language and symbols, religious considerations, cultural considerations, administration of hospice services, and governmental involvement (Glass, Chen, et al., 2010). Glass and colleagues (2010) provide an interesting review and comparative analysis of the development and acceptance of hospice in Japan, South Korea, and Taiwan. Though there are many similarities across the countries, there are also important differences in, for example, development of a national policy, degree of hospice home care, when hospice was started, and number of trained professionals and multidisciplinary nature of the treatment team.

Roles for Behavioral Medicine Practitioners in End of Life Care

Largely due to these changes in how end of life is often experienced in developed countries, behavioral medicine practitioners are potentially important members of interdisciplinary treatment teams. But it is essential that behavioral medicine providers are clear on their own ability to handle death and dying, and they must be attentive to signs of burnout, depression, or other emotional sequelae that may reduce their professional effectiveness. Not all behavioral medicine practitioners are personally well suited to manage the types of challenges that characterize these patients and this kind of treatment, but for those who are capable, they bring to the treatment team important and possibly unique skills. In many cases the roles for behavioral medicine are straightforward, whereas in others (e.g., spirituality) they may be more complex. The specific skills that capable behavioral medicine practitioners bring with them to end of life care include: (a) utilization of empathic listening and reflection in the context of relationship development; (b) implementation of cognitive-behavioral interventions to alleviate pain, insomnia, anxiety, and depression; (c) intervention with families to improve communication regarding difficult treatment decisions; (d) assisting patients and their families to understand medical terminology and the nature of medical treatments and options; (e) utilization of relaxation and self-control strategies; (f) providing psychotherapy for patients struggling with issues of guilt, regret, and grief as well as anger management; (g) helping patients and caregivers develop appropriate coping skills; and (h) leading group-based interventions for patients as well as their families and caregivers. Particular discussion of patient issues, caregiver concerns, and interventions will be addressed below as will the role of behavioral medicine in spirituality.

Patient-Oriented Issues in End of Life Care

Suffering is a common experience for patients and their families at the end of life. Feelings of sadness, grief, loneliness, despair, fear, anxiety, and anger may be present. The sources of psychological suffering at the end of life are many and include uncertainty about the future, unresolved issues from the past, and concern for loved ones. Physical symptoms, loss of autonomy and functioning, difficulties relating to physicians and health-care systems, and financial strain can also be sources of suffering. Pre-existing psychiatric disorders, difficult family dynamics, poor social support, and existential and spiritual struggles can exacerbate psychological suffering (Block, 2006).

Physical Symptoms in End of Life Care

In addition to changes that occur as part of the natural aging process, patients' experiences at the end of life may involve symptoms specific to terminal illnesses (Waldrop, 2008). Solana, Gomes, and Higginson (2006) conducted a review of 64 studies reporting the prevalence of common symptoms among end-stage patients with cancer, acquired immunodeficiency syndrome (AIDS), heart disease, chronic obstructive pulmonary disease, or renal disease. The following symptoms were commonly reported: pain (34–96%), fatigue (32–90%), breathlessness (10–95%), insomnia (9–74%), nausea (6–69%), constipation (23–70%), diarrhea (3–90%), anorexia (21–92%), confusion (5–93%), depression (3–82%), and anxiety (8–75%). The authors noted that the wide variations in prevalence were likely due, in part, to the range of patients' studied and methodological differences in the studies. The authors identified pain, fatigue, and breathlessness as the three most common symptoms reported. A large number of pharmacological treatments exist to promote symptom management in serious illnesses including analgesics for pain, soporifics for sleep, antiemetics for nausea, and various psychiatric medications for cognitive and emotional dysfunction. Though these medications are often effective, they may also produce iatrogenic problems and uncomfortable side effects, particularly in the elderly. Other methods of symptom management include the use of massage and other physical treatments.

Psychological factors are central to managing symptoms in end of life care, and symptom severity is associated with psychological distress (Kelsen, Portenoy, et al., 1995; Zara & Baine, 2002). Pain severity can increase anxiety, a sense of helplessness and hopelessness, and the risk of depression. Pain also significantly affects quality of life, mobility, physical functioning, and concentration. In addition, psychological factors can moderate patients' perceptions of pain. For example, fear, anxiety, depression, perceived uncontrollability of symptoms, appraisals of pain symptoms, lack of self-efficacy, certain reinforcement contingencies, and lack of sleep are associated with increased perceptions of pain and suffering (Raphael, Ahmedzai, et al., 2010). Patients' thoughts (i.e., their assumptions and expectations) also influence their experiences of pain. For example, engaging in catastrophizing appraisals increases perceptions of pain, pain interference, and anxiety (Bishop & Warr, 2003; Utne, Miaskowski, et al., 2009).

Many psychosocial interventions for pain management at end of life are based on cognitive-behavioral models designed to help patients identify, evaluate, and change maladaptive patterns of thinking and behaving that contribute to physical and mental suffering. The goal is to facilitate more adaptive coping that minimizes distress. Patients are also taught about the physiology of pain and how cognitive appraisals can affect physiological processes and perceptions of pain. Some behavioral medicine interventions also include relaxation training, deep breathing exercises, guided imagery, self-hypnosis, mindfulness meditation, and encouraging distractions such as talking to friends or listening to music (Raphael, Ahmedzai, et al., 2010).

There is evidence to support the use of these behavioral medicine interventions to manage symptoms in serious illnesses. Because specific application of these treatments to end of life has not been as thoroughly studied, we included highlights from the literature that addresses behavioral symptom management in diseases such as cancer or conditions such as chronic pain that are prominent among individuals receiving end of life care. To this end we note that Bolmsjo (2008); Pan, Morrison, Ness, Fugh-Berman, and Leipzig (2000); Raphael et al. (2010); and Waldrop (2008) reviewed studies examining the effectiveness of psychosocial interventions in treating symptoms and concluded that they were effective in reducing symptoms, especially perceptions of pain. Likewise, two meta-analyses (Devine, 2003; Morely, Eccleston, & Williams, 1999) concluded that cognitive-behavioral interventions, particularly relaxation training, were helpful in reducing perceptions of pain in patients with cancer.

Pan et al. (2000) also reviewed studies using psychosocial or alternative medicine interventions to treat symptoms of pain, dyspnea, nausea, and vomiting in end of life patients. Cognitive-behavioral interventions, involving psychotherapy, psychoeducation, relaxation training, guided imagery, and deep breathing training were effective in reducing these symptoms. More alternative medicine interventions such as transcutaneous electrical nerve stimulation, acupuncture, acupressure, massage, music therapy, and hypnosis also effectively reduced symptom severity.

Emotional Experiences of Patients in End of Life Care

Depression

Depression is one of the most common symptoms reported by patients with life-limiting illnesses, frequently ranking as one of the top 10 symptoms (Hotopf, Chidgey, et al., 2002). Prevalence rates for diagnosable depression vary widely from 3% to 58% depending on how depression is defined (Wasteson, Brenne, et al., 2009), the patients' illness, and the severity of their physical symptoms (Solana, Gomes, & Higginson, 2006). Untreated depression can increase the severity of patients' experience of pain and other symptoms, further undermine physical health and quality of life, and increase the probability of morbidity, mortality, and suicide (Irwin & Ferris, 2008). Depression is also associated with decreased treatment adherence, reduced will to live, and prolonged hospital stays (Block, 2006).

Distinguishing depression from grief in end of life care can be challenging, and views relevant to this issue continue to evolve. Currently (April, 2012) there is controversy regarding the diagnosis of depression and whether individuals experiencing bereavement should continue to be excluded from a diagnosis of depression when the next edition of the Diagnostic and Statistical Manual of Mental Disorders is published. It is clear that there is often considerable overlap between symptoms of depression and those of any serious illness. Hopelessness, helplessness, worthlessness, guilt, lack of pleasure, suicidal ideation, social withdrawal, irritability, and anxiety are key symptoms of depression (Block, 2006). In the context of end of life treatment, depression is commonly under recognized by health-care professionals and family members. Patients and their families are also sometimes reluctant to discuss emotional concerns with physicians. Even when recognized, depression is often undertreated. Many health-care professionals assume that depression is an unavoidable part of terminal illness, and they do not adequately address the patients' emotional distress. However, psychotherapy and antidepressant therapy can be effective in treating depression in end of life patients (Irwin & Ferris, 2008). Psychosocial interventions for depression are discussed later in this chapter.

Anxiety

Anxiety is also commonly reported by end of life patients, with some estimates of prevalence as high as 70% (Irwin & Ferris, 2008). Other studies found significant anxiety symptoms in 25% of patients with cancer (Derogatis, Morrow, et al., 1983), with 3% of advanced cancer patients meeting criteria for generalized anxiety disorder and 5% meeting criteria for panic disorder (Kadan-Lottock, Vanderwerker, et al., 2005). Two to 35% of cancer patients show symptoms of post-traumatic stress disorder (PTSD), with lower rates in studies using the Diagnostic and Statistical Manual of Mental Disorders-IV criteria (Block, 2006).

Recognizing anxiety in end of life patients can also be challenging. The symptoms of the illness may overlap with symptoms of anxiety because anxiety frequently presents with somatic symptoms that overshadow psychological and cognitive manifestations (Irwin & Ferris, 2008). These symptoms may include autonomic hyperactivity, hypervigilance, worry, apprehension, insomnia, diarrhea, sweating, palpitations, and dyspnea (Block, 2006). It should be noted that most patients experience worry, fear, and apprehension related to concerns such as death, pain control, disease course, separation from loved ones, interactions with unfamiliar caretakers, loneliness, and isolation. Typically, however, these concerns do not reach the level of an anxiety disorder. The key difference between expected worry or fear and diagnosable anxiety is the severity and pervasiveness of the worry and anxiety. When anxiety interferes with valued relationships, leads to avoidance and distrust of health professionals, causes symptom amplification, or is responsible for patients' delay in seeking treatment or proactive planning for end of life care needs (Block), it crosses the line and is recognized as pathological.

Psychosocial Interventions for Depression and Anxiety

Several literature reviews (Block, 2006; Bolmsjo, 2008; Fawzy & Fawzy, 1998; Waldrop, 2008) and meta-analyses (Himelhoch, Medoff, & Oyeniy, 2007; Meyer & Mark, 1995; O'Neil, Sanderson, et al., 2010; Rehse & Pukrop, 2003; Sheard & Maguire, 1999) conclude that psychosocial interventions can effectively reduce symptoms of depression and anxiety, as well as physical symptoms of serious illness, and improve overall quality of life for patients in end of life care. Group interventions appear to be as effective as individual interventions and are cost effective (Meyer & Mark, 1995; Rehse & Pukrop, 2003; Sheard & Maguire, 1999). Sheard and Maguire concluded that short but intensive treatments were more effective than longer interventions, whereas Rehse and Pukrop concluded that longer interventions were more effective, and recommended interventions last at least 12 weeks. The patient's medical status and prognosis must be considered when choosing an intervention as those of longer duration may not be appropriate for more advanced cases. Psychoeducation groups appeared to be the most effective, but no differences were found between other types of interventions, such as training coping skills, social support groups, and psychotherapy (Rehse & Pukrop, 2003).

We will next provide several prototypic or well-known examples of randomized controlled trials of the types of therapy that have been investigated in the research literature. One early and often cited study (Spiegel, Bloom, & Yalom, 1981) examined the effects of supportive-expressive group therapy for patients with metastatic breast cancer. Patients were randomized to group intervention (*n* = 50) or a no-therapy control group (*n* = 36) that received standard treatment. The intervention group met weekly for 1 year. Therapy sessions involved discussions of death and dying, family problems, communication problems, and living a meaningful life with a terminal illness. Group leaders encouraged patients to share their emotional experiences and emphasized group cohesion and emotional support. At 12 months patients in the treatment group showed significantly less anxiety, depression, confusion, tension, and fatigue than those in the control group. Goodwin et al. (2001) replicated the Spiegel et al. study and found similar improvements in mood and physical symptoms. The intervention was most effective among the most seriously distressed patients.

Linn, Linn, and Harris (1982) provided individual supportive psychotherapy to men with advanced cancer. Patients were randomly assigned to supportive therapy or a non-therapy control group that received usual care. No significant differences were found at 1 month follow-up, but at 3 months patients in the treatment group showed significant improvements in feelings of alienation, self-esteem, and depression. No differences were found in follow-up assessments beyond the 3 months.

Edelman, Bell, and Kidman (1999) provided group cognitive behavior therapy (CBT) to metastatic breast cancer patients who were at various stages in terms of their nearness to death with approximately 13% dying either before or during the intervention. Patients were randomized to either a standard care control group (*n* = 49) or a treatment group that received standard care plus group CBT. Participants attended eight weekly sessions of group CBT, followed by a family night, and three additional monthly sessions. Therapy included instruction in cognitive and behavioral techniques, encouraged expression of feelings, and sought to build group support. Participants were taught basic cognitive skills including how to identify, challenge, and replace maladaptive thoughts and beliefs (e.g., disputation of the thought "what's the point of trying, I'm only going to die anyway") and focus cognitions on active coping (e.g., "just relax, use relaxation skills"). Behavioral techniques were also taught and encouraged, such as deep relaxation/meditation, effective problem-solving, and effective communication strategies. Patients were also encouraged to utilize their available coping resources, including friends and family and pleasurable activities. Patients in the treatment group showed a significant improvement following the end of the program, but no significant differences were found at the 3 or 6 month follow-up assessments.

Typical of these treatments is helping patients develop their coping resources in light of the unique event they are currently experiencing, i.e., end of life. Discussions of death and dying are central to these treatments. As is true generally for depression and anxiety, confrontation of the feared object or event can bring about beneficial change. The treatments go beyond this, however, to guide the patients in development of behavioral (e.g., relaxation training) and cognitive (e.g., restructuring) skills to enhance their quality of life and relationships. Group formats are often used due to their advantages over individual treatments in terms of sharing common concerns and developing empathic relationships with others.

Delirium

Delirium also frequently occurs in end of life care. Up to 80% of patients with cancer or other terminal illnesses experience delirium, and one third of patients experience delirium when they are dying (Irwin & Ferris, 2008). Delirium is often frightening and distressing for patients, families, and caregivers and can impair the recognition and control of other physical and psychological symptoms. However, correctly recognizing and treating delirium can improve symptom management (Cobb, Glantz, et al., 2008; Irwin & Ferris).

Dignity

The advancement of a serious illness can be quite challenging because many patients experience a significant loss of both independence and control which often threaten their sense of dignity. Chochinov and colleagues proposed a model of dignity that consists of three broad categories: illness-related concerns (factors caused by, or associated with, the underlying illness), the social dignity inventory (social or externally mediated factors), and the dignity conserving repertoire (psychological and spiritual considerations) (Chochinov, 2002; Chochinov, Hack, Hassard, et al., 2002). Chochinov et al. (2006) asked patients to identify issues they felt were related to their sense of dignity. Over 80% identified the following experiences as being harmful of their dignity: "Not being treated with respect or understanding," "Feeling like a burden," "Feeling like you do not have control over your life," "Not feeling you made a meaningful or lasting contribution," and "Not being able to independently manage bodily functions." Chochinov and colleagues developed dignity therapy in order to enhance patients' sense of dignity (Chochinov et al., 2005a; Chochinov, Hack, Hassard, et al., 2002; Chochinov, Hack, McClement, et al., 2002; McClement, Chochinov, et al., 2007). In this approach, patients are encouraged to discuss their life histories, accomplishments, and experiences. The discussion is recorded and then transcribed into a manuscript that they can give to loved ones. The goal is to provide an opportunity to create and contribute something meaningful to others in order to decrease patients' psychological suffering and enhance their sense of meaning, purpose, dignity, and quality of life. Dignity therapy has been shown to increase patients' readiness for death, sense of dignity and purpose, and will to live. The families of patients also report that it is comforting for them.

Self-Perceived Burden

The sense that one has become a burden to others has been referred to as self-perceived burden and defined as, "empathic concern engendered from the impact on others of one's illness and care needs, resulting in guilt, distress, feelings of responsibility, and diminished self" (McPherson, Wilson, & Murray, 2007a, p. 425). Self-perceived burden is expressed by many patients nearing the end of life (McPherson, Wilson, & Murray, 2007b); however, patients are often reluctant to discuss their feelings because they worry that such self-disclosure will create further burden to caregivers (Grant, Murray, et al., 2003; Wilson, Curran, & McPherson, 2005). Further, patients with higher levels of self-perceived burden are less likely to seek help (Cousineau, McDowell, et al., 2003).

Seeing oneself as a burden has been associated with psychological distress. Self-perceived burden has been negatively related to quality of life (Cohen & Leis, 2002) and positively related to clinical depression (Wilson, Curran, & McPherson, 2005), a diminished will to live (Chochinov et al., 2005b) and loss of dignity (Chochinov, Hack, Hazzard, et al., 2002). In cancer patients, self-perceived burden was related to increased physical symptoms, depression, anxiety, loss of control, loss of dignity, and hopelessness (Wilson, Curran, & McPherson, 2005), and in patients with amyotrophic lateral sclerosis, self-perceived burden was more highly correlated with depression ($r = 0.64$) than with patents' functional status ($r = 0.35$) (Chio, Gauthier, et al., 2005).

In addition, self-perceived burden seems to influence treatment decisions by patients (Ashby, Op't Hoog, et al., 2005). Studies of hospitalized elderly patients found that not wanting to burden others was one of the top reasons for not wanting life-sustaining treatments (Cohen-Mansfield, Dorge, & Billing, 1992; Zweibel & Cassel, 1989) and for choosing where to receive care at the end of life (institution versus home) (Murray, O'Connor, et al., 2003; Tang, 2009). Self-perceived burden is also associated with the wish for a hastened death (McPherson, Wilson, & Murray, 2007b). Surveys of health professionals and family members suggest that they may underestimate the significance of self-perceived burden for patients. Recognizing and addressing patients' sense of being a burden may help alleviate their distress and influence their treatment decisions and willingness to seek help. Given that patients sometimes conceal symptoms in order to avoid burdening others, their care needs may go unmet (McPherson et al.). Self-perceived burden predicts depression, but research is needed to clarify whether self-perceived burden is a consequence or antecedent of depression (McPherson et al.).

It may seem that the issue of self-perceived burden would be particularly salient in societies where multiple generations of family members often live together, and thus the older population is attended to primarily by family members. For example, in many Asian societies, and communities, cultural norms emphasize the obligation of family members to care for their elders. Cultural norms also emphasize the importance of emotional harmony and the common good (Bowman & Singer, 2001). As a result one might expect patients at end of life to feel they are a burden on family members and thus be reluctant to discuss their symptoms and needs for fear of disrupting emotional harmony and causing further distress. At least four studies exploring attitudes and concerns about end of life care among Chinese (Bowman & Singer), Japanese (Kawa, Kayama, et al., 2003; Morita, Kawa, et al., 2004), and Korean (Kim & Lee, 2003) participants found that becoming a burden to others was a prominent concern. However, as far as we know, there is little to no cross-cultural examinations of self-perceived burden in Asian countries. It is possible that self-perceived burden does not generally differ between Asian and other populations in part because Asian culture often includes an expectation that family members take care of older adults and protect them from distressing experience or information. Thus, this expectation may actually ease feelings of guilt associated with self-perceived burden.

Though individuals at other stages of life may experience emotional distress related to feeling a loss of dignity and perceiving themselves as a burden on others, these concerns are particularly salient during end of life when patients' physical and mental capabilities are often diminished, and they are, in fact, more dependent on others for meeting their basic needs. This is complicated in the case of the dying by the realization that they will not be able to repay the caregiver in kind, and they may perceive themselves as reducing the caregivers' quality of life by requiring attention and care. The reality of lost independence and capacity presents a somewhat unique set of stressful events that for many have negative emotional consequences. As noted above, it is not clear if depression precedes perceived sense of burden or is consequent to it. The complex relations between these and similar mood-based constructs are yet to be fully investigated, but it is clear that the sense of lost dignity and increased burden are particularly important and somewhat unique experiences for those at end of life and as such deserve further investigation.

Coping Style

The experience of terminal illness poses significant challenges and requires patients to make psychological adjustments in order to cope (Block, 2006). Examples of coping styles include: seeking information, keeping busy, redefining options, resigning one's self, examining alternatives, and expressing feelings. In some cases, patients may cope with terminal illness by avoiding its reality. Avoidant coping responses (e.g., denial) can be adaptive if they reduce stress for patients and allow them more time to process and adjust or live in the moment and enjoy their remaining time. They can be maladaptive if they prevent patients from acknowledging the severity of their condition, properly adhering to treatment, or failing to make the proper arrangements for end of life care. Approach or active coping occurs when patients engage the stressful experience and attempt to utilize some method of changing it or their perception of it. They may, for example, seek alternative treatments, gather information, or begin self-management interventions. Obviously a key factor in determining the success of a coping strategy is how well that strategy is matched to the particular stressor that it is responding to. We are reminded of the serenity prayer that suggests that better functioning and quality of life likely lie in changing what can be changed, accepting what cannot be changed but only accepted, and the wisdom to know the difference. In fact, patients typically use a combination of approach and avoidant coping strategies. They often use avoidant coping strategies when they are most distressed, but switch to approach coping strategies when their distress subsides (Block; Weisman, 1984).

There has been interest in determining if coping styles are associated with reductions in recurrence and delayed mortality. This has been particularly discussed in the context of cancer patients where stories in the popular media often note how bravely an individual fought his/her cancer and, if not stated directly, imply that due to the patient's fighting spirit s/he lived longer than would have been the case otherwise. The converse implication in these stories is that if patients feel helpless they will die sooner. In general, studies examining which coping styles are associated with better or worse outcomes vis a vis recurrence and mortality have been equivocal. Specifically, a meta-analysis examining "fighting spirit" and helplessness/hopelessness as predictors of recurrence and mortality in patients with cancer found no evidence for an effect for different coping styles on mortality (Petticrew, Beill, & Hunter, 2002).

Spiritual and Existential Concerns

Spiritual and existential concerns often play prominent roles in patients' end of life experiences (Alcorn, Balboni, et al., 2010; Breitbart, 2001; Trevino, Pargament, et al., 2010). In one study involving hospice patients, 89% of the patients felt that being at peace with God was important to them (Pronk, 2005). In another study involving patients with cancer, symptoms relating to psychological distress and existential concerns were more prevalent than pain and other physical symptoms (Portenoy, Thaler, et al., 1994). Spiritual and existential concerns are strongly related to quality of life and psychological distress in patients with terminal illness (Balboni, Vanderwerker, et al., 2007; Tarakeshwar, Vanderwerker, et al., 2006). It is now widely recognized that quality palliative and end of life care addresses the spiritual and existential needs of patients (Puchalski, Ferrell, et al., 2009). The National Hospice and Palliative Care Organization (NHCPO, 2010) includes spiritual counselors as core members of interdisciplinary treatment teams, and the WHO (2011) definition of palliative care specifically notes the integration of spiritual aspects of care.

Religious coping involves dealing with stress through religious and spiritual means (e.g., prayer or seeking spiritual support) (see Pargament, 1997). A review of the literature on religious coping reported that 30–80% of individuals across various samples used religious coping (Harrison, Koenig, et al., 2001). Generally, religion and spirituality play a positive role in coping with illnesses such as cancer or HIV (Breitbart, 2001; Trevino, Pargament, et al., 2010). A review of the literature examining the relationship between religion and depression suggests that religious coping can reduce the risk of depression (McCullough & Larson, 1999). More recent advances in this area of research have challenged investigators to view religion/spirituality as multidimensional constructs whose various dimensions may differentially predict beneficial and malevolent outcomes. Consequently, though much research on religion/spirituality and health has utilized meta-level constructs (e.g., religious service attendance), the contemporary trend is for investigators to specify what aspect of religiousness or spirituality they are investigating and to avoid broad generalizations about the effects of "religion" or "spirituality." For example, a cross-sectional study of 367 men with prostate cancer found that intrinsic religious motivation ($r = -0.23$) and spirituality

($r = -0.58$) predicted lower levels of depression (Nelson, Jacobson, et al., 2009).

As implied above, religion/spirituality can also be a source of distress and increase the burden of illness (Fitchett, Murphy, et al., 2004; Pargament, Koenig, et al., 2004). Spiritual struggles are common in patients with terminal illnesses. Alcorn et al. (2010) recently explored the religious/spiritual themes in the experiences of 68 patients coping with advanced cancer. Many common themes reflected a sense of spiritual struggle. For example, many felt abandoned by or punished by God, angry at God, and/or doubted their faith as well as God's love and power. However, other themes reflected more positive religious coping responses. For example, more than half of the patients reported a desire to seek a closer connection with God and to find meaning in life and in their suffering. Using both cross-sectional and longitudinal designs, Trevino et al., (2010) investigated the relationships between positive religious coping and spiritual struggle in predicting viral load, CD4 count, quality of life, HIV symptoms, depression, self-esteem, social support, and spiritual well-being in 429 patients with HIV/AIDS. Positive religious coping predicted better outcomes whereas spiritual struggle predicted worse outcomes. Further, high levels of positive religious coping and low levels of spiritual struggle were associated with small but significant improvements over time.

Some writers suggested that religion allows patients to find meaning in the suffering caused by their illness (Breitbart, 2001). A sense of meaning and peace has been shown to mediate the negative relationship between intrinsic religious motivation and depression (Nelson, Jacobson, et al., 2009). Further, patients with a higher sense of meaning report greater satisfaction with their quality of life and show a higher tolerance for pain associated with severe physical symptoms (Brady, Peterman, et al., 1999). Thus, it seems that one of the most important elements of religion and spirituality is that they help patients find meaning. However patients can find meaning in their experiences without religion or spirituality. Interventions intended to enhance patients' sense of meaning have shown improvements in patients' feelings of anxiety and desire for hastened death (Breitbart, Rosenfeld, et al., 2010), as well as levels of self-esteem, optimism, and self-efficacy (Lee, Cohen, et al., 2006).

In order to address patients' needs for spiritual well-being and purpose in life, Brietbart et al., (2010) developed Meaning Centered Group Therapy (MCGP). Patients with advanced cancer ($n = 90$) were randomly assigned to either MCGP or a supportive group therapy, both for eight sessions. The goal of MCGP was to facilitate patients' sense of meaning and purpose through didactics, discussion, and experiential exercises. Patients in the MCGP group showed significantly greater improvement in spiritual well-being and a sense of meaning. These improvements became more substantial at the second follow-up assessment. Significant improvements were also noted in anxiety and reduction in desire for death. Interestingly, patients in the supportive therapy group showed no significant improvements in any of these variables.

The role of behavioral medicine providers in addressing spiritual and religious concerns deserves special comment. First, it is clear that spiritual issues are considered important in end of life care. The WHO, for example, highlights the importance of spiritual care in palliative care and emphasizes the *integration* of psychological and spiritual aspects of patient care (World Health Organization, 2011). Further, Domain 5 (Spiritual, Religious, and Existential Aspects of Care) of the Clinical Practice Guidelines for Quality Palliative Care (National Consensus Project for Quality Palliative Care, 2009) advocates for the integration of this treatment component into palliative care. *Integration* is important because patients prefer spiritual considerations to be integrated with their care, and integrated care is more likely to produce better outcomes than approaches that separate spiritual concerns from the rest of the patients' treatment (Nad, Marcinko, et al., 2008). Further, research indicates that many patients believe that spiritual issues are important to consider in the context of their medical care and treatment. As one of many examples, King and Bushwick (1994) surveyed 203 adult inpatients in Pennsylvania and North

Carolina and found that although 77% of the patients believed that family practice physicians *should* consider their spiritual needs, 68% indicated that their physicians *never* addressed them. (North Carolina is in the part of the USA often referred to as the "Bible Belt"; thus it is fair to speculate that the number of physicians never addressing spiritual issues may be higher in other regions of the USA.) Responding to this need, over 100 of approximately 126 medical schools in the USA now offer courses on spirituality and medicine (Puchalski, 2006).

The integration of spiritual and religious issues into treatment does, however, have its detractors. Prominent among these is Richard Sloan (Sloan & Bagiella, 2002; Sloan, Bagiella, & Powell, 1999). Sloan posits many reasons why religion and spirituality should be kept out of behavioral medicine practice, but principle among these are fears of coercion, violations of privacy, the possibility of doing harm, and discrimination against individuals for whom religion is not important. For a more complete discussion of Sloan's position and the present senior author's opposition, please see Sloan's original writings and Masters (2010). Clearly Sloan highlights important areas that every practitioner must be careful to handle with professionalism and compassion, always operating out of concern for the patient's welfare and respect for the patient's autonomy. It is beyond the space provided for this chapter to enter into a thorough discussion of the relevant issues including the lack of trained professionals who are competent and comfortable in addressing these concerns. But it is, nevertheless, clear that there is a trend for professional organizations to acknowledge the importance and legitimacy of religious and spiritual factors in the treatment context and perhaps nowhere more so than with end of life patients. We return to this issue in our concluding comments at the end of the chapter.

Reflections on Patient-Oriented Issues

Clearly patients face many challenges as they navigate the ends of their lives. Both physical and emotional symptoms may diminish quality of life. Of particular prominence are depression and anxiety and it is therefore important that treatments, including psychological, behavioral, and pharmacological interventions, be thoughtfully considered and implemented when appropriate. The issue of perceiving oneself as a burden on others stands out in this review as a problem that likely does not receive the attention it deserves, and consequently many patients may be left with this concern unaddressed. Understanding the particular phenomenology of individuals with particular life concerns is needed in all areas of behavioral medicine, and the constructs of dignity and burden are important in this regard as pertaining to end of life. Though they certainly overlap with better recognized constructs such as depression, they are also relatively unique psychological events often experienced by the dying. Understanding this nuanced aspect of the psychological phenomenology of end of life as experienced by at least some patients will advance behavioral medicine treatment. Finally, spiritual and existential issues are beginning to receive proper attention from healthcare professionals. Treating the whole patient at the end of life could hardly be deemed complete without adequate consideration of these issues and provision of openings for patients to engage them as they choose.

We next turn our attention to issues of concern for caregivers at the end of life. This group, too, faces many challenges, and though their challenges are similar to those faced by patients, they also differ in important respects. Behavioral medicine practitioners are particularly well suited to intervene with this population.

Caregiver-Oriented Issues in End of Life Care

The Challenges of End of Life Caregiving

In the USA, it is estimated that 25 million people provide an average of 18 hours per week of caregiving to seriously ill family members (Emanuel, Fairclough, & Emanuel, 2000). Not surprisingly, multiple studies document the emotional and physical impact of caregiving for a loved one at the end of life (Aneshensel, Pearlin, et al., 1995; Blanchard, Toseland, & McCallion, 1996; Clark, Reid, et al., 2008; Coristine, Crooks, et al., 2003; McMillian, 1996). Informal caregivers experience an array of stressors that include managing the physical and emotional needs of their loved one, communicating with health-care workers and family, and dealing with practical issues such as finances and insurance while concurrently managing their ongoing work, household, and self-care responsibilities. Caregivers of end of life patients typically encounter increased financial burden, work-related disruptions, negative social consequences, and an interruption of life tasks and goals (Covinsky, Goldman, et al., 1994; Freeborne, Lynn, & Desbiens, 2000; Haley, 2003). The constant demands of caregiving at end of life impact social, leisure, and religious activities resulting in social isolation, loneliness, and decreased life satisfaction (Carr, House, et al., 2001; Davis & Nolen-Hoeksema, 2001; Schulz, Williamson, et al., 1995). Caregiver depression can heighten this impact (Breslin, O'Keeffe, et al., 1995). For example, caregiver depression has been associated with increased likelihood and amount of time missed at work (Gallant & Conell, 1997). As a result of the disruption of their normal routines and activities, caregivers often experience a decrease in social interactions that can result in profound feelings of loneliness (Rokach, Matalon, et al., 2007). The decrease in social support can also impact psychosocial well-being and physical health (Uchino, Cacioppo, & Kiecolt-Glaser, 1996). Older caregivers typically experience additional burdens associated with aging such as the management of their own medical conditions, multiple losses (e.g., loss of function/independence, loss of social support), and financial stressors (Beery, Prigerson, et al., 1997). The strong emotions associated with grief and bereavement can be particularly challenging to caregivers given the high rates of mental, emotional, and physical fatigue associated with the caregiving experience (Burns, Nichols, et al., 2003).

Psychological, Physical, and Behavioral Reactions to End of Life Caregiving

Multiple studies have documented the emotional and physical impact of caregiving for a loved one who is at the end of life (e.g., Fleming, Sheppard, et al., 2006). In terms of psychosocial distress, caregivers show higher rates of depression, anxiety, and anger when compared to non-caregivers (Chentsova-Dutton, Shuchter, et al., 2000; Emanuel, Fairclough, & Emanuel, 2000; Flaskerud, Carter, & Lee, 2000). It is estimated that between 40% and 70% of caregivers of older adults suffer from depressive symptoms, and approximately half meet diagnostic criteria for major depression (Drinka, Smith, & Drinka,1987; Gallagher, Rose, et al., 1989; Redinbaugh, MacCallum, & Kiecolt-Glaser, 1995). An examination of psychiatric problems in caregivers of advanced cancer patients reported that 13% met criteria for a psychiatric disorder and 25% sought treatment for mental health concerns (Vanderwerker, Laff, et al., 2005).

The immense burden of caring for a seriously ill loved one places caregivers at increased risk for a variety of health problems (Schulz & Beach, 1999; Wright, Clipp, & George, 1993) such that caregivers are often referred to as "hidden patients" (Thompson & Doll, 1982). The cumulative stress and physical demands of caregiving are associated with a deterioration of caregiver physical health (Haley, 2003; Schulz, Newsom, et al., 1997; Stroebe, Schut, & Stroebe, 2007) and increased risk of caregiver illness or death (Christakis & Allison, 2006; Kiecolt-Glaser, Dura, et al., 1991). Studies examining biological outcomes in caregiver populations have reported neuroendocrine dysfunction (Mausbach, Mills, et al., 2006), immune decrements (Kiecolt-Glaser, Dura, et al., 1991; Mausbach et al.; Redwine, Mills, et al., 2004; Segerstrom & Miller, 2004; Vedhara, Cox, et al., 1999; Vitaliano, Zhang, & Scanlan, 2003; Von Känel, Dimsdale, et al., 2006), and elevations in inflammatory cytokines (Kiecolt-Glaser, Preacher, et al., 2003; Lutgendorf, Garand, et al., 1999).

The overwhelming physical and emotional demands of caregiving can lead to maladaptive behavioral reactions such as diminished self-care and poor health status (Gallant & Conell, 1997; Gaugler, Edwards, et al., 2000; Robinson-Whelen, Tada, et al., 2001). Caregivers often report significant alterations to their daily health routine, which may include less physical activity, decreased attention to diet and nutrition, and alterations in sleep patterns (Connell, 1994). The diminished quantity and quality of sleep can lead to increased fatigue, elevated distress, and neuroendocrine and immune dysfunction, which can impact long-term health and well-being and health-related quality of life (Persson, Östlund, et al., 2007). In addition, caregivers may become inattentive to their own medical needs, which can lead to exacerbation of chronic conditions or the emergence of new medical problems. There also is a strong association between stressful life events and increased use of alcohol, tobacco, or other drugs in those who tend to use passive coping strategies (Brady & Sonne, 1999; Breslin, O'Keeffe, et al., 1995). This combination of physical and emotional stress and changes in self-care behaviors can eventually result in "caregiver burnout" at which point caregivers may feel that they are unable to continue caring for their loved one and are forced to seek other forms of care (e.g., nursing homes, inpatient hospice care) (Gaugler, Edwards, et al., 2000). This can lead to extreme disappointment and guilt, as most caregivers have a strong desire to keep their loved one in the home as long as possible.

The quality of life for the end of life patient can have an enormous impact on the caregiver's psychosocial adjustment and quality of life (Gill, Kaur, et al., 2003). Steinhauser and colleagues' (2000) cross-sectional survey of end of life patients, families, and physicians found that patients and their families both ranked freedom from pain, coming to peace with God, and presence of family as the top three factors of importance at the end of life. Caregivers who are expending less energy worrying about their loved ones' comfort and care can focus more attention on self-care. This is important given that caregivers' often neglect their own health needs while caring for their loved one. It is crucial that the treatment team explicitly give caregivers permission to attend to their own needs and encourage them to engage in adaptive coping activities.

Grief and Bereavement in End of Life Caregivers

Caregivers of end of life patients typically experience pre-loss grief which is viewed as a normal, adaptive response to the anticipated loss of a loved one (Rando, 2000). Although anticipatory grief may lead to better adjustment following the death of the loved one, research is mixed on whether anticipatory grief ameliorates the bereavement process (Hogan, Morse, & Tason, 1996; Parkes, 1996). Family members who experience prolonged anticipatory grief may begin to feel overwhelmed resulting in emotional detachment or over-involvement with the patient as a means of avoiding their true feelings. It is clear that the time leading up to the death of the patient can have a significant impact on bereavement, and caregivers who use this time as an opportunity to attend to "unfinished business" will be better prepared to manage their post-loss grief (Worden, 2000).

Caregivers experience a wide range of reactions following the death of their loved one, and although grief and bereavement are universal experiences, individuals differ in how they react and adapt to loss. The intensity and magnitude of the emotions experienced following the death of a loved one are associated with a number of factors including: the nature and circumstances surrounding the loss, the relationship between the caregiver and the patient, the caregiver's experience and response to prior loss(es), and the caregivers' personality and availability of psychosocial resources. There are also a variety of social and demographic variables that relate to how the emotional response to the loss is experienced including age, gender, developmental level, social class, culture and religious beliefs and practices, family, and external and internal support (Doka, 1998; Rando, 1984).

In some cases caregivers may experience extreme reactions to the loss of their loved one which is labeled as complicated grief and is considered to be a unique affect distinguishable from depression and anxiety (American Psychiatric Association, 2000; Sanders & Adams, 2005). Complicated grief is characterized by elevated levels of separation distress and typically requires psychosocial or medical intervention (Prigerson, Frank, et al., 1995). Hudson (2006) reported that 7% of caregivers suffered from traumatic or complicated grief following the death of their loved one. Earlier we noted the current controversy regarding the diagnosis of depression and whether bereavement should continue to be excluded from the diagnostic criteria of depression in the next edition of the Diagnostic and Statistical Manual of Mental Disorders. This remains to be decided, but it is clear that for some caregivers, their experience of bereavement is sufficiently troubling to require intervention. Regardless of what is eventually decided regarding diagnostic criteria for depression and bereavement, it remains true that there has been limited research examining complicated pre-loss grief. Variables such as caregiver burden, an insecure attachment style with the patient, being younger, having lower perceived social support, previous episode of depression, lower income levels, higher severity of life events, and pessimistic thinking patterns appear to increase the risk of developing complicated pre-death grief (Beery, Prigerson, et al., 1997; Kelly, Edwards, et al., 1999; Tomarken, Holland, et al., 2008; Van Doorn, Kasl, et al., 1998).

In general, functioning prior to the loss is a good predictor of how well a caregiver or family member will handle loss. Caregivers with a history of psychiatric problems are at increased risk for developing complicated grief reaction. As those currently arguing for inclusion of grief under the diagnostic label of depression note, it is often difficult to distinguish a major depressive episode from complicated grief, particularly among those with a history of depression. Generally it is believed that depression tends to be more global in its impact on thoughts, feeling, and behaviors such that depressed individuals experience distorted cognitions directed at themselves, the world, and the future, whereas those suffering from complicated grief tend to report negative thoughts associated with specific aspects of their loss (Worden, 2002). Table 34.1 presents an overview of the signs and symptoms of complicated grief but clearly this issue is far from settled.

End of Life Caregiver Resources

The stress of caregiving is a multidimensional process that has an impact on almost every aspect of caregiver quality of life (QOL). The Transactional Model of Stress and Coping (TMSC) predicts that those who are able to handle and adapt to the challenges of caregiving will show lower levels of distress and higher QOL (Lazarus & Folkman, 1984). Coping strategies can have a significant impact on one's ability to manage stressful events such that adaptive coping strategies may lead to improved adjustment whereas maladaptive strategies can lead to increased distress and poor health outcomes (for a review see Penley, Tomaka, & Wiebe, 2002). Generally adaptive coping mechanisms such as acceptance, relaxation, or seeking social support were associated with less depressed affect in Alzheimer's patient caregivers (Williamson & Schulz, 1993). Similarly, DeMattei et al. (2008)

Table 34.1 Signs and symptoms of complicated grief in caregivers

1.	Extreme focus on the loss and reminders of the loved one
2.	Intense longing for the deceased
3.	Problems accepting the death
4.	Numbness or detachment
5.	Preoccupation with sorrow
6.	Bitterness about the loss
7.	Inability to enjoy life
8.	Depression or deep sadness
9.	Suicidal thoughts or feelings
10.	Difficulty moving on with one's life
11.	Trouble carrying out normal routines
12.	Withdrawing from social activities
13.	Feeling that life holds no meaning or purpose
14.	Irritability of agitation
15.	Lack of trust in others

found that active coping and problem-focused approaches helped to buffer caregiver-related stress whereas the use of avoidance coping was associated with increased distress. As with patients, caregivers experience a wide range of stressors, so it is particularly important that caregivers are able to distinguish between the controllable and uncontrollable aspects of the various stressors so that they can utilize the appropriate coping mechanisms. For example problem-focused coping strategies (e.g., decision-making, problem-solving) can alleviate controllable stressors, but they are not helpful for uncontrollable stressors which are, by definition, difficult to change but whose impact can be managed through emotion-focused coping strategies (e.g., venting, journaling, exercising, meditation, prayer).

The utilization of social support networks is especially important for caregivers given that they are prone to experiencing loneliness and feelings of social isolation as a result of their caregiving experience (Covinsky, Goldman, et al., 1994; Freeborne, Lynn, & Desbiens, 2000). Social support is an important predictor of adaptive outcomes (Haley, Levin, et al., 1987) and depressive symptomatology (Grant, Elliott, et al., 2006), and interventions that include elements to enhance social support are associated with improved outcomes (McMillan, Small, et al., 2005; Mittelman, Roth, et al., 2007). Additionally, it is important to note that there are different types of social support which may serve different roles in terms of relieving caregiver stress. For example, a study of family caregivers of frail elders found that social support that involved pleasant activities with friends and other family had a greater beneficial impact on caregiver burden when compared to other types of social support (Thompson, Futterman, et al., 1993).

Spiritual and religious coping strategies can help to buffer distress and assist with the process of grief and bereavement (Colgrove, Kim, & Thompson, 2007; Kim, Wellisch, et al., 2007). Family caregivers of hospice patients reported that higher levels of spirituality had significantly greater quality of life (Tang, 2009). Unfortunately, caregivers of end of life patients often report a number of unmet spiritual needs (Buck & McMillan, 2008). Interestingly, a recent review of the literature in the area of religion and spirituality and caregiver well-being noted either no association or mixed association between spirituality/religion and caregiver well-being (Herbert, Weinstein, et al., 2006). The authors speculated that the ambiguous results were a reflection of the difficulties defining and assessing religion/spirituality and the diversity of well-being outcomes.

Many caregivers describe the act of caring for a loved one at the end of life as an existential, potentially life-altering experience. Despite the large body of literature describing the negative consequences of end of life caregiving, it is important to note that a large proportion of family caregivers identify positive benefits. Caregivers often report that caring for their loved one at the end of life led to high rates of satisfaction and gave them a sense of meaning and purpose (Hudson, 2004, 2006). A meta-analysis by Pinquart and Sörensen (2004) examining the association between caregiver subjective well-being, caregiver stressors, and depression found that the positive aspects (e.g., "uplifts") of caregiving were associated with higher well-being and caregiver stressors were related to depression. It has been proposed that the positive elements of caring for a loved one may buffer some of the stressful aspects of caregiving (Hudson, 2004). Caregivers should be encouraged to reflect on how their experience has brought meaning to their life and to consider the challenges of caregiving as opportunities for personal and existential growth.

Psychosocial Interventions for End of Life Caregivers

The NIH "State-of-the-Science Conference Statement: Improving End-of-Life Care" included a recommendation for intervention trials that focus on family caregivers (National Institutes of Health, 2004). This led to a growing body of literature documenting the effectiveness of various psychosocial interventions for a variety of caregivers. The caregiver interventions, which included various combinations of psychoeducation, relaxation training, supportive counseling, cognitive-behavioral counseling, and health promotion, had varied results, ranging from no effect compared to controls to lower depression, decreased caregiver strain and burden, improved quality of life (QOL), caregiver competency, and physical activity (for reviews see Brereton, Carroll, & Barnston, 2007; Eldred & Sykes, 2008; Hudson, Aranda, & Kristjanson, 2010; Selwood, Johnston, et al., 2007; Smits, de Lange, et al., 2007; Sorensen, Pinquart, & Duberstein, 2002).

Although there have been a number of studies specifically examining interventions for caregivers of end of life patients, there are only a few strong evidence-based interventions within this area. Hudson, Aranda, and Kristjanson (2010) recently published a systematic review of psychosocial interventions for caregivers of palliative care patients that examined 14 intervention studies that included five randomized controlled trials (RCTs), two prospective studies that included comparison groups, five studies without comparison groups, and two qualitative studies. Of the identified five RCTs, three received high methodological quality ratings and two were assessed as "good quality." The goals of the RCTs included providing psychoeducation, improving coping skills, training caregivers in symptom management, improving sleep, and promoting family meetings. The outcome measures included caregiver distress, caregiver burden, quality of life, self-efficacy; patient reported symptoms and bereavement-associated depression. As summarized in Table 34.2, these five papers generally found that caregivers in the intervention conditions improved relative to controls in their ability to handle the caregiving role (e.g., more positive perceptions of caregiving, reduced caregiver burden, increased self-efficacy), but there were no differences between groups on many measures suggesting that the literature needs more high-quality, theory-driven, intervention studies.

Despite the small number of strong evidence-based interventions for caregivers of end of life patients, it is likely that evidence-based interventions that have been shown to decrease distress in highly stressed populations (e.g., various medical patients) may also improve adjustment in caregiver populations. Psychosocial interventions that integrate coping skills training with cognitive-behavioral strategies have been shown to improve adaptation to stressful life events (Antoni, Lehman,

Table 34.2 Randomized controlled trials of psychosocial interventions for caregivers of palliative care patients

Study	Caregiver patient sample	Interventions	Outcome
Hudson, Arvanda, and Hayman-White (2005)	Advanced cancer patients	1. Psychoeducation (provided specific caregiver information) 2. Standard services	No differences on most measures; psychoeducation group improved positive perceptions of caregiving role relative to standard service group
McMillan et al. (2005)	Advanced cancer patients	1. Usual hospice care 2. Usual hospice + three supportive visits 3. Usual hospice + three visits to teach coping skills	Coping skills treatment improved caregiver quality of life and reduced caregiver burden compared to other two groups
Walsh et al. (2007)	Specialist palliative care patients	1. Career advisor 2. Control	No difference between groups
Keefe et al. (2005)	Advanced cancer patients	1. Three session partner guided cognitive-behavioral pain management intervention 2. Usual care	No difference in patient specific measures; intervention group increased self-efficacy for helping loved one cope with pain
Haley et al. (2008)	Dementia patients who passed away	1. Enhanced counseling and support condition 2. Usual care	Lower depression scores in intervention condition both before and after patient's death; results maintained more than 1 year

et al., 2001; Marcus, Garrett, et al., 1998). Nevertheless, the interventions that have been used with other stressed populations are not always appropriate for short-term interventions or one-time consultations. Table 34.3 presents an overview of factors that can assist caregivers of end of life patients in their adjustment to the stress of caregiving. The list is designed to assist behavioral medicine practitioners who work with family members who are caring for loved ones at the end of their life.

Table 34.3 Enhancing psychosocial and physical adjustment in caregivers of end of life patients

1.	Be prepared to listen to caregivers and normalize their emotional reactions
2.	Assist caregivers in the identification of personal health risks (e.g., lifting/moving the patient)
3.	Promote self-care activities such as regular exercise, eating a healthy diet, maintaining a regular sleep pattern, and following medical advice (e.g., taking medications, attending regular medical appointments)
4.	Allow caregivers to gain a sense of control and mastery over certain aspects of their caregiving role
5.	Promote the use of problem-focused coping skills for controllable stressors
	Seek out information as needed; set realistic goals; request help when needed
6.	Promote the use of emotion-focused coping skills for uncontrollable stressors
	Use cognitive reappraisal and reframing; utilize humor; find healthy avenues to express emotions (e.g., psychotherapy/counseling, journaling, artistic endeavors, prayer, meditation); accept negative emotions as part of the grief process
7.	Discourage the use of nonadaptive coping techniques that may include denial and avoidance, overconsumption of food, alcohol, tobacco or drugs, holding in feelings, and poor self-care activities
8.	Encourage social connections with others
	Deepening the connection with the patient/loved one, maintaining relationships with friends and coworkers outside the realm of caregiving, and talking with other caregivers or former caregivers
9.	Encourage the caregiver to take frequent respites
10.	Support the caregivers search for meaning
11.	Refer to spiritual and/or psychosocial support services as needed

Reflections on Caregiver-Oriented Issues

Caregivers have been referred to as "hidden patients," and indeed research demonstrates that they are susceptible to disruption of immune system functioning leading to pathological health outcomes, engaging in maladaptive behaviors such as increased use of alcohol or other drugs, isolation and failure to garner social support, fatigue and lack of energy, and psychological difficulties including, prominently, depression. The fact that caregivers experience decreased quality of life seems obvious in light of the stresses that they engage daily. Complicated grief is a particular concern and one that behavioral medicine practitioners should be aware of and vigilantly monitor caregivers for. Fortunately, many caregivers are able to employ adaptive coping strategies, engage social support networks, and utilize their religious and spiritual faith to make meaning out of their experience. In fact, some caregivers find a sense of meaning and purpose in the care that they extend to a loved one. Research into the area of caregiver interventions, i.e., interventions designed to improve the functioning of caregivers, is young, and strong evidence of efficacy and effectiveness is still lacking. Though it is likely that interventions that decrease distress in other highly stressed populations will be effective with caregivers, this awaits empirical verification.

Remaining Issues and Future Directions

Advance Directives

A growing body of literature examines decision-making in the context of life's end from empirical as well as ethical and moral perspectives. Decisions regarding the use of an advance health-care directive, living will, health-care proxy (or medical power of attorney), and addressing medical issues such as do not resuscitate orders require individuals to, in advance, consider how they want their end of life to be managed. For many this is an unpleasant task that is left undone. Though in the USA different states have different requirements and forms for advance health-care directives, in terms of accessing forms, the process has in fact never been easier. A Google search using the term “advance health-care directive” yielded 221,000 web sites, including a combination of federal, state, and private sites that offer standardized forms, information, and procedural detail. Nevertheless, significant barriers remain. A recent examination of legal statutes for all 50 US states and the District of Columbia (Castillo, Williams, et al., 2011) revealed both legal and content-related barriers that discourage implementation of these directives including poor readability, restrictions on surrogates or health-care agents, notarization or witness signatures requirements, and not accepting oral communications. In the USA it is estimated that only 11–22% of patients have some form of advanced health-care directive (Gross, 1998; Kemp, Emmons, & Hayes, 2004; Morrell, Brown, et al., 2008). Jones, Moss, and Harris-Kojetin (2011) studied three long-term care populations and found that 28% of home health-care patients, 65% of nursing home residents, and 88% of discharged hospice patients had at least one advance health-care directive. Differences were found in rates of directives based on race. African American home health patients were half as likely as white patients to have a directive.

Although the completion of an advance medical directive is a positive step in honoring patients’ preferences for end of life treatment, decision-making research indicates that the process is much more complex than most professionals and the public acknowledge. Peter Ditto is a leading investigator in this area and has conducted a series of empirical studies whose results challenge the efficacy of the advance medical directive as currently understood and practiced. An important finding from Ditto’s research is that patient preferences for end of life medical care are somewhat unstable over time and are highly influenced by contextual factors including whether they are currently hospitalized (Ditto, Jacobson, et al., 2006; Ditto, Smucker, et al., 2003). For example, when they are healthy, patients tend to indicate that they want more aggressive medical treatment, whereas during hospitalization this preference declines. However, 3 months subsequent to hospitalization, the preferences for aggressive treatment return to their pre-hospitalization level. The inherent plasticity of choices and preferences is a concerning factor. That measures of patients’ preferences may change from times when they are healthy, to circumstances surrounding diagnosis, through lengthy and often burdensome treatments, up to end of life represents not a failure of measurement but the nature of choices and preferences. Clinicians and policies need to recognize this natural changeability of preferences and develop procedures that best capture and represent the current wishes of patients and their families.

This raises important questions regarding what the patients’ true preferences are and how one would go about ascertaining them. Ditto (Ditto & Hawkins, 2005; Hawkins, Ditto, et al., 2005) also highlights the difficulty that surrogate medical decision-makers have in interpreting patient wishes even when they are relatively specifically detailed in writing. The fact is that the panoply of possible medical circumstances and decisions that can be encountered is large and characterized by varying levels of what is known and unknown, what is probable and improbable. Further it appears that patients largely desire to implement a type of advance directive wherein their values and overall goals are stated but where medical surrogates have liberty to use their best judgment and even, in some circumstances, to overrule the advance directive. But delving into this issue further reveals that beyond the generalization regarding preferences for relatively open directives, patients are highly individual in terms of when they would want a surrogate to have leeway in interpreting a directive, what types of decisions need to be strictly adherent to the directive, and what patients consider to be the most important considerations (Hawkins, Ditto, et al., 2005). Further, most advance directives now in use are designed to specify use of particular medical technologies and therefore do not conform to the type of decision-making process that patients, in fact, desire.

We have only briefly scratched the surface of this important issue, and space does not permit a detailed discussion. We hope that we have alerted readers to the complexities of advance medical directives and thus encouraged greater caution in clinical practice and greater engagement in research on this issue. Behavioral medicine professionals are in a strong position to lead the way in this work.

Communication

Good doctor-patient communication has been shown to promote healthy adjustment in end of life patients and their families (Block, 2006). Physicians need to allow patients the opportunity to voice their fears and concerns while providing support and reassurance. Although negative prognostic information may be initially conveyed by an oncologist or other specialist, the primary care physician typically has the task of providing detailed information to the patient regarding end of life care. It can be difficult to assess the informational needs of each individual, so it is typically best to ask patients what information they would like to know (e.g., all of the details or an overview), how they want to receive this information (alone versus with others, verbally and/or written format), and when they want to receive the information (immediately or later in the process). End of life patients often express anxiety and fear about the future including the fear that they will be abandoned by those near to them including their health-care team. Physicians and behavioral medicine providers can ease these concerns by providing honest and open information to patients and their families with continued reassurance that they are committed to their care, will not abandon them, and will do whatever it takes to alleviate patient pain and suffering.

Future Directions

Patients and caregivers of patients experiencing end of life concerns can both benefit from the kinds of services that practitioners of behavioral medicine provide. Existing research facilitates understanding of the experiences of these individuals, their needs, and how those needs might be met within the health-care system. But much remains to be done. Randomized controlled trials as well as research utilizing other methodologies are needed in this area to provide guidance for how to better intervene to enhance quality of life and reduce suffering. Importantly, this research needs to take an interdisciplinary focus. Physicians are key members of the treatment team, and, obviously, research relevant to physician behaviors and interventions is essential. But also to be included are nursing staff, chaplains and other clergy, as well as psychologists and social workers who are involved with the patients and their families and significant others. Sensitive adaptations of successful coping interventions used with other populations provide a good starting point, but the unique aspects of dealing with end of life concerns as well as adaptation following death of a loved one must be prominently considered.

Religious and spiritual issues are uniquely salient when dealing with the end of life. Unfortunately, many in the helping professions including psychologists and physicians have meager training in or understanding of these issues and are, statistically, less likely than the general population to embrace religious or spiritual beliefs (Curlin, Lantos, et al., 2005; Curlin, Chin, et al., 2006). Frankly, our personal experience over the years suggests that some are even fearful of these issues. Earlier we noted ethical concerns that are raised at the prospect of involving health-care professionals in spiritual concerns. Clearly we are not advocating any kind of proselytizing or aggressive introduction of religious and spiritual perspectives into patients' and caregivers' lives. But it is also clear that patients and caregivers often value discussion of these issues with their health-care providers and not just with clergy. If practitioners are going to communicate respect and value for the whole person, this will, of necessity, in many cases include consideration of religious and spiritual concerns. There is no reason to believe that health-care professionals are incapable of providing proper support around these issues and engaging patients and caregivers in ways that are sensitive and enhance their functioning and quality of life. Organizations that have recently called for increased sensitivity and better training of clinicians concerning management of religious and spiritual issues in assessment and treatment include the following: the American Psychiatric Association, American Psychological Association, Accreditation Council for Graduate Medical Education, Council on Social Work Education, Joint Commission on the Accreditation of Healthcare Organizations, American Academy of Family Physicians, American College of Physicians, and Association of American Medical Colleges (Larimore, Parker, & Crowther, 2002). The American Psychological Association, within the context of recognition of cultural diversity and the call for cultural competence, specifically indicates that psychologists must be competent regarding religious and spiritual issues in therapy. To their credit, medical schools have also begun paying at least some attention to religious and spiritual issues (Brokaw, Tunnicliff, et al., 2002), and in 2004 approximately 67% of US medical schools included something about it in the curriculum (Fortin & Barnett, 2004). Clinical psychology graduate programs housed in secular universities (as opposed to those housed in religiously based universities), on the other hand, are essentially silent on the issue or address it only in passing as it might come up during class discussions or, more likely, is initiated by a patient in therapy (Russell & Yarhouse, 2006; Schafer, Handal, et al., 2011). Clearly if providers are to adequately address these concerns in appropriate and sensitive ways, training in their advanced degree or postdoctoral setting is necessary.

Finally, health-care providers may feel uncomfortable working with patients in situations where the end of life is imminent. Finding ways to influence the prevailing culture to better understand death as a natural and integral part of the life cycle and attending to the personal needs of behavioral medicine specialists who work with patients and caregivers facing a limited life seem promising in terms of destigmatizing the end of life experience. Opening doors to greater discussion, collaboration, and understanding around the experiences of these patients, their families and significant others, and those entrusted with their care will improve the treatment experience for all involved individuals. The recent US health-care debate demonstrated clearly that misinformation and highly charged emotions around end of life care are easily disseminated but not likely to lead to improved care and more compassionate interventions. We hope that the behavioral medicine community will lead the way in research and practice that leads to greater understanding and acceptance of the important issues surrounding end of life and, ultimately, improves the quality of life and quality of death for all.

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Part VII

The Contexts of Behavioral Medicine Science and Practice

35

Values in Behavioral Medicine

Gerald C. Davison and Michelle C. Feng

It has been said that a fish doesn't know it is swimming in water. And yet being in water is an essential part of being a fish. So it is with values and ethics.

Often, the most important and influential forces in our immediate world are those that we think little about in our day-to-day life. If we are fish, our values are the water that surrounds us. They guide our thoughts, our questions, and our behaviors. They inform us if we are doing something "right" or "wrong" and can sway us in different directions, like the waves of an ocean. While this guidance, of which we are usually unaware, can be good in many ways, our values feel so natural to us – to the extent that we even think of them – that they can sometimes be mistaken for absolute truths.

We – both scientists and nonscientists – take certain values for granted, not even considering them an issue. For example, we can safely assume that most individuals would not tolerate a child banging her head against the wall. In fact, in certain situations such as working with children diagnosed with autism, health professionals have gone to great lengths, including heavy sedation and/or physical restraints, to prevent this behavior. Why? Well, it has to be because we as a society value keeping the human brain as undamaged as possible. But why do we value this? The reason has to be that we place a high value on children benefitting from life experiences that require as undamaged a brain as possible. These value choices result in our being prepared to take drastic measures to protect human brains. As social scientists and human beings, we certainly agree with this position, but it is a value-laden position, not an empirical one.

In the field of behavioral medicine, value judgments are made all the time regardless of whether the decision-makers are health practitioners, academic researchers, or administrators. It is our purpose in this chapter to examine some of these values and how they affect the way professionals construe problems and design interventions. We would not presume to propose specific solutions, especially in an international handbook. Instead we hope to shine a light on the influences of our values and discuss how they can affect the way we assess and treat patients, especially when there may be little explicit awareness of these values among professionals who influence others.

When referring to "values" in this chapter, we mean the goals and purposes that guide one's activities. Values embody what a person or group of persons deem desirable or even mandatory, the "shoulds" that impose proscriptions and prescriptions for behavior. Do we value collectivism, for

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example, or do we consider individualism more important to pursue? Do we think that being honest with loved ones is always more important than sparing their feelings if complete honesty would offend or hurt? Valuing one of these over the other inherently affects the way we behave, how we see ourselves, and how we see others.

People make value judgments all the time, as just indicated, but those whose expertise in health matters is sought out and paid for by people in pain or other states of unhappiness have especially to consider values, the good and the bad, and they have to be aware of the influence that these values can have over people who consult with them. (Note that the authors have just made a value judgment!)

We begin this chapter by arguing that science and practice within behavioral medicine (but not exclusively to this field) are never free from bias but instead are guided by underlying values, whether they are explicit or implicit. We then discuss in detail some specific values-laden topics that influence the field of behavioral medicine. We pay special attention to longevity, quality of life, suicide, euthanasia, and global and cross-cultural issues in research and practice. We believe these topics and values to be continually present in behavioral medicine and often shape what is viewed as valuable and ethical within the field on an international level.

To be clear, we wrote this chapter from the perspective of behavioral scientists who work in the United States. It goes without saying, though we want to say it explicitly, that values and ethics vary across countries and, in a heterogeneous country like the United States, across subgroups within a country. In addition, the very fact that this handbook contains a chapter like this one in itself is a values statement. That is, the editors and we value discussions about values! We will do our best to acknowledge such variations where appropriate but wish to concede at the outset a degree of ethnocentrism, if you will, that we believe is unavoidable when discussing values.

At the end of this chapter, we present a case study that will, we hope, illustrate many of the themes we are about to set forth. We are the kind of fish that should – a values statement in itself! – be aware of the water it swims in.

Nonobjective Features of Science and Practice

The fields of science, medicine, and other applied health disciplines are often thought of as being objective and ethically neutral**.** "Just give us the facts, ma'am," as the Joe Friday character would say on the old Dragnet series. However, we believe that it is not that simple.

In a landmark book published in 1962, *The Structure of Scientific Revolutions*, the physicist and philosopher Thomas Kuhn articulated a perspective on scientific discovery and theorizing that was underappreciated at the time and has since become normative when people reflect on the role of nonempirical factors in scientific inquiry (Kuhn, 1962).

Central to any application of scientific principles, in Kuhn's view, is the notion of a paradigm, a conceptual framework, or an approach within which a scientist works.[1] A paradigm, according to Kuhn, is a set of basic assumptions that outline the particular universe of scientific inquiry, specifying the kinds of concepts that will be regarded as legitimate as well as the methods that may be used to collect and interpret data.

A paradigm has profound implications for how scientists operate in any given time and place, for "[people] whose research is based on shared paradigms are committed to the same rules and standards for scientific practice" (Kuhn, 1962, p. 11). Paradigms specify what problems scientists will investigate and how they will go about the investigation. Paradigms are an intrinsic part of science, serving the vital function of indicating the rules to be followed. In perceptual terms, a paradigm may be likened to a general perspective or set, a tendency to see certain factors and not to see others.

In addition to injecting inevitable biases into the definition and collection of data, a paradigm affects the interpretation of facts. In other words, the meaning or import given to data depends to a considerable extent on a paradigm.

Let us provide an example. In space exploration, highly sophisticated satellites and robotic

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[1] This section on paradigms and outer space exploration is adapted from Davison and Neale (1974, Chap. 1).

explorers have been sent aloft to make observations. It is possible, however, that certain phenomena are missed because our instruments do not have sensing devices capable of detecting them. Consider what we regard as a classic discussion surrounding an announcement made on August 7, 1996, by the National Aeronautics and Space Administration (NASA). NASA reported that signs that life once existed on Mars may have been found in a piece of Martian rock. The rock, it is believed, was catapulted into space by an asteroid about 16 million years ago and was drawn into Earth's gravity about 13,000 years ago. Found in Antarctica in 1984, this rock was the subject of study and speculation by chemists and space scientists. Did it contain signs of Martian microbes from 3.6 million years ago? Some scientists believed it did, whereas others disagreed.

The general question was – and remains in all subsequent efforts – how one can decide whether there are indeed signs that life once existed on the now-barren planet. To even begin to address this question, sophisticated scientists have to ask how we can be certain that our own understanding of what is alive matches what may have once lived on Mars? Said a NASA astrophysicist at the time, "Everything we know about life we learned from Earth" (cited in Cole, 1996, p. A1). Another scientist put it this way: "We're working with a sample of one: life on Earth. That's like trying to learn about fruit by studying only apples. We have to look at a lot of apples and oranges" (cited in Cole, 1996, p. A29).

The simple yet profound fact is that we can look for life on another planet or heavenly body only with the instruments we have available, and the design of these instruments is determined not just by technology but by our preconceptions of what life is. Tests that are conducted on material from another part of the solar system rest on earthbound assumptions about the nature of living matter that may not match what might have evolved elsewhere.

This discussion of space exploration is one way of pointing out that scientific observation is a human endeavor that reflects not only the strengths of human ingenuity and scholarship but also our intrinsic inability to know fully what the nature of our universe is. Scientists are able to design instruments to make only the kinds of observations about which they have some initial idea. Thoughtful scientists realize that certain observations are not being made because their knowledge about the nature of the universe is limited.

Science, then, is bound by the limitations imposed on scientific inquiry by the current state of knowledge. It is also bound by the scientist's own limitations. Science is not a completely objective and certain enterprise. Rather, as suggested by Kuhn (1962), subjective factors as well as limitations in our perspective on the universe enter into the conduct of scientific inquiry.

Our position is that paradigms in both scientific inquiry and science-based application are, in Kuhnian terms, manifested as well when it comes to values and ethics. Neutrality does not exist. Science and practice are fundamentally guided by strong values at varying levels of influence. For example, treating the psychological effects from receiving a cancer diagnosis, helping individuals to stop smoking, and formulating techniques for reducing pain, these are all topics of focus in research and practice in behavioral medicine. But let's step back and ask why these questions and interventions are being pursued in the first place. Why do we care to study why people smoke and then help them stop smoking? It seems to us that these decisions derive from the value we place on longevity or quality of life. Is it because we believe that smokers will ultimately regret their actions when they are older and are potentially suffering from chronic health problems related to their smoking? Is it because we believe that regret is inherently a bad feeling that should be avoided? Does the individual's high-risk behavior become a societal concern because of the increased health costs to non-smokers? All of these value-laden questions are related to what we believe is good and helpful and important to us as human beings. Therefore, these judgments and interventions are not bias-free; in fact they are rooted in values that run deeper than we often spend the time to think about.

The shift from a biomedical model to the biopsychosocial framework can also be considered, in Kuhn's terms, a paradigm shift. The biomedical model, which takes a reductionistic approach to disease, also assumes a dualistic split between mind and body. Because of these Cartesian assumptions, the causes of disease within this model are seldom sought in psychosocial factors (Engel, 1977). In other words, measurable biological variables are the focus within a biomedical model. Research and practice conducted within this model have brought great advances in our understanding of pathogens and acute diseases; however, because of its restricted views on what is important in treating illness, knowledge gained within this framework can focus only on part of the picture.

The introduction of the biopsychosocial model allowed for a broader, more integrated view of health and disease which includes psychological, social, and environmental influences. This shift has encouraged new and exciting areas of interdisciplinary research and practice. Moreover, and of relevance to this chapter, the inclusion of psychological and societal factors opened the door to an increased role for value considerations in analyzing, preventing, and treating illness. Smoking addiction, for example, is often comprised of a combination of biological, psychological, and social factors. Interventions based solely on the biomedical model may not take advantage of the potential benefits that behavioral interventions and psychotherapy offer to promote smoking cessation and to alleviate urges to smoke.

Behavioral medicine as a field is based largely on the integration of various levels of healthcare to promote health and treat disease. As reviewed in other chapters of this handbook, this expanded, interdisciplinary focus has led to a wealth of research conducted toward understanding the social and environmental determinants of health-related behaviors, the influence of stress and negative emotions on the immune system, the effects of various types of social support on quality of life and general health, and the development of behavioral/psycho-social interventions for managing chronic illnesses. This field, therefore, appreciates the roles of both internal and external factors.

Longevity and Quality of Life

Perhaps two of the most valued outcomes in behavioral medicine are longevity and quality of life. Let us first consider why we value longevity at all. The urge to keep people alive as long as possible appears to be centrally guided by the high value that we place on our time on earth. This is why, we believe, machines such as the ventilator were invented. While such advancements seem like common sense, they are in fact value-laden. If our value were placed instead on natural selection and living in a world where we valued as little intervention as possible into the "natural" course of evolution, perhaps we may not have committed our time and efforts to inventing the ventilator. Instead, we may have viewed death more as a part of life than something to ward off. Perhaps our focus would be more on fate than on control.

Along with longevity, the quality of one's life is also valued by both practitioners and patients and therefore is a common outcome measure in behavioral medicine (e.g., Taylor-Ford, Meyerowitz et al., 2013). While longevity and quality of life are by no means mutually exclusive, there are points in time where choices need to be made that highlight the relative importance of these two factors, with the definition of quality of life often taking on several different meanings. Multiple self-report questionnaires have been created to capture what is viewed as an important factor in health-related issues (e.g., Cella, Tulsky et al., 1993). Generally, these questionnaires measure subjective feelings of well-being, quality of important relationships, components related to socialization and connectedness, as well as subjective ratings of health. Specific health-related quality-of-life measures have also been created for different illnesses such as prostate cancer in order to hone in on what researchers believe are particularly important for men and their families dealing with this illness (e.g., Cella, Bonomi et al., 1995; Esper, Mo et al., 1997). However, these measures do not specifically address who decides what is valued in life and what makes a person's existence meaningful at a given place and time. In other words, how does one define "quality" without making value judgments?

Consider hospice versus continued hospital care for individuals nearing the end of life. Hospice and palliative care facilities focus on the quality of the time left to terminally ill patients. Hospice also emphasizes emotional and/or spiritual personhood. This model is very different from the continued medical care model, which focuses on sustaining life more than on the quality of that existence. A host of procedures varying in invasiveness are made readily available to terminally ill patients seeking continued medical care, including antibiotic administration, medical respirators, feeding tubes, and resuscitation attempts.

In fact, in the medical field, the default option for physicians is to provide patients with whatever technologies are available that will keep the patient alive. These procedures can be painful and expensive. Or to alleviate pain, heavy sedation is used, which in itself can interfere with the patient's ability to engage his or her social environment. Opting out of all or some of these life-extending procedures requires individuals to think through difficult scenarios. Often the choices fall to those who have assumed decision-making responsibility for the patient deemed not competent to make their own decisions.

In addition, knowingly discontinuing life support or further treatment for a terminal illness can be extremely anxiety-producing because it is ultimately a conscious choice of valuing present quality of life over the hope of a potentially extended future. In the United States as well as most other Western societies, patients, physicians, and family members tend not to do a good job of confronting the possibility of death even when death is near and inevitable. Having said this, there are often other things that we value in addition to basic survival, and these values can become more and more important at different stages in our lives. The difficulty of these competing values and areas of focus is illustrated in a *New Yorker* piece written by Atul Gawande:

> People have concerns besides simply prolonging their lives. Surveys of patients with terminal illness find that their top priorities include, in addition to avoiding suffering, being with family, having the touch of others, being mentally aware, and not becoming a burden to others. Our system of technological medical care has utterly failed to meet these needs, and the cost of this failure is measured in far more than dollars. The hard question we face, then, is not how we can afford this system's expense. It is how we can build a health-care system that will actually help dying patients achieve what's most important to them at the end of their lives. (Gawande, 2010)

While we are not suggesting that obsessing over our remaining days is productive or even necessary, we want to highlight the significance of our values on survival and on quality of life as well as other meaningful priorities that can shift over the lifetime and especially at the end of life.

Indeed, our relative value on quality of life and length of life is dynamic and is often reactive to changes in life situations. Making medical treatment decisions can be affected by our shifting values over the life span. For example, as both healthcare providers and consumers, we often take into account whether a treatment is "worth it" – that is, whether the benefits of treatment outweigh the potential costs. However, the benefits and costs of certain interventions may be weighted differently depending on where that person is in the course of their life and what they view as important. When treating a life-threatening disease, one of the main goals is to extend life as long as possible. For a patient in their 20s, the focus may be on choosing treatments that offer the best chance of long-term survival. However, treatments for both acute and chronic illnesses can have negative health consequences and unpleasant side effects that appear years down the line. Other things being equal, younger patients are likely to live longer than older patients. In such circumstances, therefore, physicians may want to be especially careful of the long-term side effects of treatments.

Consider a 30-year-old and an 80-year-old individual with the same kind of cancer. Treatment options that are seriously considered may be the same or they may be different depending on the values of the physician and the patient. In other words, the costs and benefits of certain types of treatment may be weighted differently depending on how much longevity is valued compared to quality of life and/or eradication of the disease. Eradicating as many cancer cells as possible may be important to the patient, but in an 80-year-old, concerns of recurrence 20 years down the line may be less important than they would be to a 30-year-old.

Another way to view the relative importance of values such as longevity and quality of life over time is within the course of an individual's life. A decision made at, say, age 30 may well not fit with that person's wishes or values at age 70 or if that person becomes gravely ill at age 40. For example, a DNR (do not resuscitate) document signed when one is in good health in early adulthood, when one's timeline stretches out to the horizon, may look very different when that choice has to be made about life support when that person is terminal and in an intensive care unit at age 70. An old adage about religiosity holds that there are no atheists in foxholes.

The relative value of longevity and quality of life is pertinent also when discussing the push and pull factors surrounding chronic health issues such as obesity. Setting aside for purposes of discussion here biological factors in obesity, it is very challenging for overweight people to lose weight and to maintain weight loss. Any dieter knows that cutting back on calories and on certain foods, especially those that are high in sugar and carbohydrates, entails a level of self-denial that lowers their quality of life vis-a-vis sheer hedonic pleasure. Eating badly tastes good! Short-term reinforcement from the ingestion of unhealthful – in the long run – food and drink has to be set against longer-term benefits in terms of reducing the chances of cardiovascular disease, cancer, and longevity. (Note: for those with diabetes, the negative consequences of eating badly are more immediate.) The formidable challenge for anyone trying to lose weight and maintain weight loss is to deal with the short-term "pain" of eating better (and limiting unhealthy food) in service of benefits that are many years into the future.

But the picture is even more complicated than this. Especially if one is looking for a romantic partner and/or if one works and lives in settings where being overweight presents a short-term disadvantage, the hedonic payoff matrix shifts. Furthermore, the positive correlation of ingesting unhealthy foods and becoming more and more obese is far from one to one and is certainly affected by a host of potential known and unknown variables. For example, and partially bringing biological factors into the mix, many individuals have poor eating habits but are not obese. Additionally, while eating chocolate cake every day will most likely lead to weight gain (assuming all other variables are constant), anticipating the negative health effects of eating one piece of cake is difficult and its negative implications are abstract, especially when compared to the near certainty of the deliciousness of the cake. In this case, while an individual's value on longevity may be high, the negative correlation of longevity to a slice of cake is much weaker than the positive correlation of quality of life to cake.

Suicide and Euthanasia

Another uncomfortable example related to our value on longevity is suicide. We in the United States adopt sometimes extreme measures to prevent suicide, including incarceration, heavy psychoactive medication, and physical restraints, although strong tranquilizers have reduced our reliance on restraints. But why do we go to great lengths to keep people from killing themselves? Indeed, why do we make it legally mandatory in most jurisdictions that health professionals take steps to keep people from fatally harming themselves? The reason is that we value the continuation of human life even if the person states repeatedly that they wish to end their life. At least we do so in most Western cultures. There are, however, many belief systems, some of them religion-based, in which suicide under certain conditions is not only not prevented but even actively encouraged.

While fictional, the 1973 film "Soylent Green" provides an instructive example of a postapocalyptic world in which older adults are encouraged to commit suicide in order to create more room and sustenance for the younger generation. In this fictitious world, one would not see therapists or physicians having as their treatment goal the prevention of suicide among seniors. Instead, based on the values of the Soylent Green society, health providers would actually encourage older adults to act on their suicidal thoughts, regarding them as noble and realistic for a society whose resources are so stretched that the survival of younger generations relies upon converting into food the bodies of those who have died.

Physician-Assisted Suicide[2] Physician-assisted suicide has for a number of years been a highly charged issue. In the United States, it came to the fore in the early 1990s when a Michigan physician, Jack Kevorkian, helped a 54-year-old woman in the early stages of Alzheimer's disease to commit suicide. Not yet seriously disabled, she was helped by Kevorkian to press a button on a machine designed by him to inject a drug that induced unconsciousness and a lethal dose of potassium chloride that stopped her heart (Egan, 1990). Death was painless.

Kevorkian believed that it was ethically incumbent on physicians to ease patients' terminal suffering, and if that included helping them die, it was the right thing to do. For almost 10 years, Kevorkian played an active role in assisting more than 100 terminally ill people to take their lives, one such suicide even being videotaped and shown on CBS's "60 min" on November 22, 1998. At the same time, with steadfast intent, he provoked a searching and emotional discussion about the conditions under which a physician might ethically take the life of a dying patient – an issue made all the more heated by widespread knowledge that health professionals every day pull the plug on patients who are brain dead but who are being kept physically alive by sophisticated medical apparatus. Kevorkian was brought to trial several times but was not convicted of murder or professional misconduct until the spring of 1999, when he was found guilty of second-degree murder and sentenced to 10–25 years in prison. He was released on parole on June 1, 2007, on condition he would not offer suicide assistance advice to any other person. He died in 2011.

Right-to-life advocates have claimed that especially in this era of managed healthcare, patients will be pressured, albeit subtly, to ask to have their suffering lives terminated in order to spare their families the high costs of medical care. There is also the fear that physicians will lean in this direction, perhaps pressured by insurance companies that want to save money on expensive terminal medical care and will influence the patient and his or her family to end the person's life. Among the many criticisms leveled against Kevorkian is that he allegedly did not conscientiously enough assess the person's actual desire to commit suicide. Among powerful groups opposing assisted suicide have been the American Medical Association and the Catholic Church. In contrast, Kevorkian's supporters and others, such as the American Civil Liberties Union, believe that terminally ill people should have the right to end their suffering. Many of these supporters have for years objected to the intrusion of the state on what they regard as a person's inalienable right to make such life or death decisions.

Oregon is the US state in which the woman whom Kevokian first assisted in suicide lived. In 1997, it became the first state to have a law – the Death with Dignity Act, originally approved by voters in 1994 and reaffirmed by an even greater margin in 1997 – that made physician-assisted suicide legal. Washington and Montana followed. Similar laws exist in the Netherlands, Belgium, and a growing number of countries. The Oregon law permits a patient diagnosed by two physicians as having less than 6 months to live to seek a doctor's prescription for a lethal dose of barbiturates. But the law also requires that the prescribing physician determine that the patient is not suffering from depression or another mental illness and that there be a waiting period of 15 days before the prescription can be filled.

Decisions not to resuscitate terminally ill patients are made every day in hospitals. One informal estimate is that more than half the deaths in US hospitals follow a decision to limit or withhold access to the kinds of life-sustaining

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[2] Some of the discussion on physician-assisted suicide and suicide prevention is adapted from Davison and Neale (2001, Chap. 10).

equipment currently available. Furthermore, a report published in the *New England Journal of Medicine* in 1998 indicated that, over the course of their careers, close to 20% of physicians in the United States had been asked by terminally ill patients to help them die, and of this number, about 15% wrote at least one prescription to hasten death and about 5% administered at least one lethal injection. Such euthanasia, whether legal or not, occurs with some frequency (Meier, Emmons et al., 1998). Many people do not consider this practice euthanasia or suicide, however. Rather than ending life, “It is, rather, a desire to end dying, to pass gently into the night without tubes running down the nose and a ventilator insistently inflating lungs that have grown weary from the insult” (Begley, 1991, p. 44). Major legal, religious, and ethical issues whirl around decisions about ending dying among the terminally ill.

Suicide Prevention In bold and controversial publications on coercive suicide prevention, Thomas Szasz (1986, 1999) argued that it is both impractical and immoral to prevent a person from committing suicide. It is impractical because we cannot really force people to live if they are intent on committing suicide unless – and this is when morality especially becomes an issue – we are prepared not only to commit them but to enslave them via heavy medication or even physical restraints. Even then, hospitalized patients do manage to take their own lives. Szasz asserted further that mental health professionals, in their understandable desire to help their patients, open themselves up to legal liability because, by taking it upon themselves to try to prevent suicide, they assume responsibility for something for which they cannot be responsible. In effect, they are promising more than they can deliver.

Further, Szasz argued that health professionals should not assume such responsibility – even if it were practical to do so – because people, including those seriously disturbed, should be accorded freedom to make choices. He allows one exception for what he calls impulsive suicide, when people are temporarily agitated, perhaps truly deranged, and need to be protected for a short while from their uncontrollable impulses.[3] He draws an analogy with patients coming out of general anesthesia, when it is common medical practice to strap them down lest their flailing about involuntarily leads to unintended and preventable harm. But there are limits here as well, including, in our own view, how we can know when we are dealing with an impulsive act rather than an act that the person has been thinking about and planning for a period of time. Often, these decisions are guided by the relative values we place on the autonomy of an individual versus the responsibility we feel we have toward keeping them “safe.”

Szasz was not against advising a person not to commit suicide or otherwise treating problems, such as depression, that might have a good deal to do with self-destructive thinking. It is forcible prevention against which he railed. Indeed, he believed that if professionals excluded coercive suicide prevention from their intervention options, they would be able to be more empathic with their patients and perhaps more helpful. He also suggested a psychiatric will, in which a patient, when not feeling suicidal, agrees ahead of time about how to be treated if later on he or she wishes to commit suicide. If the patient opts for coercive prevention in this will, then it would be all right. This strategy brings to mind the instructions Ulysses gave to his sailors before they were to pass by the coast of the Sirens, sea nymphs whose song compelled hapless mariners to commit suicide by throwing themselves into the sea.

> He filled the ears of his people with wax, and suffered them to bind him with cords firmly to the mast. As they approached the Sirens’ island, the sea was calm, and over the waters came the notes of music so ravishing and attractive that Ulysses struggled to get loose, and by cries and signs to his

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[3] Presumably he would have broadened this protective stance in the case of children and adolescents, whose problem-solving abilities are not as well developed as those of adults and who therefore need extra social and professional support to protect themselves from impulsive acts. Another exception might be for adults whose problem-solving capacity is compromised by the reduced brain oxygen that can arise from a variety of medical problems, for example, congestive heart failure.

> people begged to be released; but they, obedient to his previous orders, sprang forward and bound him still faster. They held on their course, and the music grew fainter till it ceased to be heard, when with joy Ulysses gave his companions the signal to unseal their ears, and they relieved him from his bonds. (Bulfinch's Mythology, 1979, p. 243)

On the other hand, recall what we wrote earlier about it being very natural that people's values shift over time. It is disingenuous to assert that a person's preferences at Time A may not change years later and under other circumstances. The Ulysses story makes a serious point, but it must be borne in mind that it is just a story, a mythical tale composed by Homer to make a dramatic statement.

Global Research and Ethics

Our world, in a sense, has gotten smaller in the past few decades. We are able to travel around the globe faster, conduct business and research more easily between countries, and have greater access to global resources than ever before. With this increased global connectedness, enhanced in revolutionary ways by the Internet and other advances in communication, comes an opportunity – and in our view, an ethical obligation – to consider how values compare across countries and the different ethical issues that arise when dealing with health and illness on a global level.

Global Clinical Research The fact that clinical trials can be conducted more cheaply in certain countries has benefitted the bottom line of pharmaceutical and medical device companies. The cost of recruiting participants in countries such as China and India is usually lower than in Western countries, and regulations for conducting research in wealthier countries are often more complex and burdensome to investigators. But while there may be clear economic benefits to conducting clinical research in certain countries more than in others, these benefits also bring about challenging questions about ensuring that research subjects enjoy the same protections of their safety and integrity as those who participate in studies conducted in the countries from where the research emanates. While the problem is particularly acute in medical research, the issues apply as well to behavioral medicine and other domains of science and practice involving human beings.

Glickman and colleagues (2009) highlight several ethical issues that arise from the globalization of clinical research. They begin with the overarching question "to what extent should people in developing countries be enrolled in clinical trials [at all]?" (p. 819). To break this question down, we distinguish three specific issues.

First, is there an ethical obligation for treatments being tested in third world countries to be available and accessible to those countries? For example, if a potentially useful antihypertensive medication is being tested by a US drug company in a less developed country, should positive outcomes from the study benefit that country by taking steps to make it available there? Should it be made available at a cost that is generally affordable in that country, very likely at lower cost than would be the case in the United States? In other words, is care taken to maximize the translational value of a given study so that positive results can benefit the people in whose country that study is taking place?

Second, to what extent should the problem being addressed be directly related to something of real importance to the country in which the study is being conducted? It is likely that many of the trials conducted in low-income countries are not geared toward the most prominent medical and social issues concerning their populations. Rather, it is more likely that the trials concern problems of importance to the more economically advanced countries, the ones doing the research.

Third, to what extent are the findings from studies in third world countries applicable to first world countries? While the third question can be examined empirically by conducting multinational trials with representative populations, Glickman et al. (2009) found that fewer than 5% of multinational studies included in their published reports the number or percentage of participants recruited by country, making it difficult to assess the generalizability of each study.

These several questions highlight some ethical challenges that global research presents. On a practical level, understanding these challenges and the way that global research is designed and implemented is important because it plays a role in the way we interpret research findings and, ultimately, how we discuss options and treatment plans with patients.

Ethical Imperialism Versus Ethical Relativism Another important ethical and value-laden topic, particularly when adopting a global perspective, is the issue of ethical imperialism versus ethical relativism. Ethical imperialism refers to the extension of a set of ethical standards and beliefs of one group of people to other groups of people and cultures. To what extent do we believe that there is a set list of universal rules determining what is ethical and unethical? Consider the widespread assumption in the West that human suffering should be kept to a minimum, especially when health professionals are in the picture. But what if the suffering has a chance of resulting in a longer life, such as with cancer treatments or in recovering from surgery? Or in the case of behavioral medicine, dieting and exercise regimens seldom bring pleasure to overweight people, but this kind of suffering is presented to them as less important than the long-term benefits that can follow. Clearly, these “shoulds” are not clear cut.

In contrast to the ideals of ethical imperialism is the principle of ethical relativism, which is based on the awareness of individual cultures having their own set of values, all of which should be equally respected. A case in point, disturbing to most people in the West, is female circumcision and other forms of genital cutting in young women. A recent UNICEF report indicated, for example, that over 90% of women in Egypt have undergone this procedure (UNICEF, 2013). And gender equality, so highly valued for several decades in many parts of the United States, is far from valued in many parts of the world.

Cross-Cultural Perspectives on Self-Efficacy Emotional issues are of great relevance in behavioral medicine. Depression, for example, has been associated with a variety of medical problems, such as cardiovascular disorders, diabetes, and other chronic diseases (Glassman & Shapiro, 1998). Learned helplessness has been explored for many years as a cause of depression. Attributions – the ways people explain to themselves the causes of their behavior – have been invoked as linked to learned helplessness and depression (Abramson, Seligman, & Teasdale, 1978).

Not adequately appreciated, in our view, are the cultural biases inherent in this school of thought. In Western psychological research, self-attributions are often viewed as sources of either positive or negative emotions – positive if an event is defined as desirable, negative if an event is defined as undesirable. Thus, if something good happens, the tendency is to credit one’s own efforts or characteristics and to feel good about it. But if something bad happens, taking responsibility leads to negative emotions. This is part and parcel of an individualistic society that values independence and minimal reliance on others. More collectivistic societies as one finds in American Indian or many Asian cultures, however, place a higher value on support from others and, often, on the needs of the family, tribe, or group over those of the individual.

In the United States, we measure IADLs, *independent* activities of daily living, to determine how capable patients are in performing everyday tasks on their own. While these can be good measures of a patient’s physical health status, they also highlight our value on self-reliance and independence. That is to say, the very development of measures of independent living and their use as a measure of good outcome derives from a high value placed on not depending on others.

In a related fashion, personal control over events in our lives is assumed in Western psychology to be necessary for normal functioning. Even laboratory rats have been shown to be stressed more by electric shocks over which they have some control as compared to the same levels over which they have no control (Mowrer & Viek, 1948). And in a later study, the importance of perceived rather than actual control was demonstrated in humans (Geer, Davison, & Gatchel, 1970). Would such experiments have even been carried out by investigators in a societal milieu that did not value individual control over events?

Albert Bandura's concept of self-efficacy originally focused on the individual's belief in her or his ability to engage in a certain behavior. In contrast to beliefs about the effectiveness of some behavior on a desired outcome (e.g., how foregoing that chocolate cake might influence body weight), self-efficacy is the individual's confidence in her or his own ability to enact the specified behavior, in this instance, foregoing the chocolate cake. An impressive amount of research confirms the importance of self-efficacy in understanding whether a person will engage in a particular behavior at a given place and time (Bandura, 1997). This characteristically Western approach emphasizing individual control has been expanded by Bandura to consider perspectives of more collectivist cultures and has led to parallel considerations of collective agency (Bandura, 2000).

Case Example: Homosexuality

As a case study of the role of values in health matters, we examine a position that one of us took over 40 years ago in how mental health practitioners and scientists should address homosexuality (Davison, 1974, 1976, 2001). While the example here concerns psychotherapy, the issues apply to behavioral medicine and health psychology as well.

Until the end of the 1970s, psychotherapists from all theoretical orientations believed that when a homosexual individual asked for change – and even if they did not – the only acceptable course of action was to work toward a shift toward heterosexuality. At that point in time, homosexuality was still considered a diagnosable psychological disorder. All psychotherapists but perhaps behavior therapists in particular (including Davison) worked assiduously and creatively to design change regimens that would reduce homosexual attraction and behavior and increase heterosexual interests and behavior.

Things have changed a great deal in many countries since the 1970s – e.g., the US Supreme Court ruling in June 2013 that the federal anti-gay rights Defense of Marriage Act is unconstitutional or recent state decisions banning the use of "conversion therapy" for homosexuals (*New York Times*, August 19 and 29, 2013) – but the issues of values in societal and individual attitudes toward homosexuality remain the same. In addition, in most parts of the world, homosexuality continues to be viewed as sick, sinful, and/or illegal. In more than a few countries, homosexuality is even punishable by death, and the still widespread derogation of homosexuality has impeded AIDS prevention in Africa, China, and other areas. Whatever one's point of view, approaches to research and application are influenced by one's values, as we illustrate here with respect to therapy with homosexuals.[4]

We only want to help.
API (Apocryphal Press International, September 30, 1974). The governor recently signed into law a bill prohibiting discrimination in housing and job opportunities on the basis of membership in a Protestant Church. This new law is the result of efforts by militant Protestants, who have lobbied extensively during the past 10 years for relief from institutionalized discrimination. In an unusual statement accompanying the signing of the bill, the governor expressed the hope that this legislation would contribute to greater social acceptance of Protestantism as a legitimate, albeit unconventional, religion.
At the same time, the governor authorized funding in the amount of 20 million dollars for the upcoming fiscal year to be used to set up within existing mental health centers special units devoted to research into the causes of people's adoption of Protestantism as their religion and into the most humane and effective procedures for helping Protestants convert to Catholicism or Judaism. The governor was quick to point out, however, that these efforts, and the therapy services that will derive from and accompany them, are not to be imposed on Protestants, rather are only to be made available to those who express the voluntary wish to change. "We are not in the business of forcing anything on these people. We only want to help," he said.

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[4] The discussion of values issues in sexual reorientation for gays is adapted from Davison (1974, 1976, 1978, 2001).

The Myth of Therapeutic Neutrality The basic position of this chapter and in Davison's writings on the treatment of homosexuality is that therapists never make ethically or politically neutral decisions. In his important book, "The Politics of Therapy," Seymour Halleck wrote about these issues from the perspective of psychiatry. As he put it, "Any type of psychiatric intervention, even when treating a voluntary patient, will have an impact upon the distribution of power within the various social systems in which the patient moves. The radical therapists are absolutely right when they insist that psychiatric neutrality is a myth" (Halleck, 1971, p. 13).

Halleck's thesis played a major role in Davison's argument against therapists trying to change the sexual orientation of gays in a heterosexual direction. Most of the time, the very naturalness of and familiarity with our therapeutic practices – cf. the abovementioned metaphor of fish not knowing that they are swimming in water – blind us to the nonempirical biases that affect how we construe the patient's problems and the goals we regard as acceptable to work toward. It is better to be aware of and own up to our biases than to pretend that we have none.

Differences Do Not Imply Pathogens Sometimes those who argued in favor of sexual conversion therapies for gays and lesbians sought to justify their position by asserting that homosexuality is pathological and that there is a general and pervasive professional duty and right to set things straight (pun intended). One form that the argument has taken is that homosexuals differ from heterosexuals in a particular way, for example, in how they were raised, and that this difference ipso facto indicates something pathogenic. The classic study in this vein was by Bieber et al. (1962). Overlooking its serious methodological shortcomings, the logic of the findings took the following form: The parents of male homosexuals as compared to the parents of male heterosexuals more often reflect a pattern of a "close-binding intimate mother" and a cold and detached father. Ergo, homosexuality is a mental illness.

So ingrained and unexamined was the ethical bias against homosexuality that the inherent logical fallacy of the argument was not appreciated. Simply put, what is wrong with such child-rearing unless one has decided before the fact that homosexuality is an illness, which in this case is code for undesirable and worse?

No Cure Without a Disease It is fair to say that researchers and clinicians devote effort to developing and analyzing therapeutic procedures only if they are concerned about a problem. Until the 1980s therapists spent virtually all their time and effort trying to reduce homosexual attraction and increase heterosexual attraction in homosexuals (and for the most part, the target population was men only). Again, little if any time – and none at all when Davison made the argument in 1974 – was spent by mainstream therapists encouraging health professionals to change their biases against homosexuality and foster gay-affirmative attitudes and behavior in patients who happened to be homosexual. The question could be framed as follows: How can therapists honestly speak of nonprejudice when they participate in or tacitly support therapy regimens that by their very existence and regardless of their effectiveness condone the societal prejudice and perhaps also impede social change? As Begelman pointed out many years ago (1975), sexual reorientation therapies:

> …. *by their very existence constitute a significant causal element in reinforcing the social doctrine that homosexuality is bad.* Indeed, the point of the activist protest is that behavior therapists [and other therapists] contribute significantly to preventing the exercise of any *real* option in decision making about sexual identity by further strengthening the prejudice that homosexuality is a "problem behavior" since treatment may be offered for it…. homosexuals tend to seek treatment *for being homosexuals*…. contrary to the disclaimer that behavioral therapy is "not a system of ethics" (Bandura, 1969, p. 87), the very act of providing therapeutic services for homosexual "problems" indicates otherwise. (p. 180, emphasis in original)

Moreover, as Davison argued, the availability of a technique encourages its use. For example, Wolpe's (1958) systematic desensitization treatment for fears and phobias ushered in a revolutionary period in psychotherapy research and practice in which behavior therapists looked vigorously for problems that could be conceptualized in terms of anxiety and then treated with this approach. Thus, a problem like social isolation might be viewed at least in part as a consequence of unnecessary anxiety that could be desensitized. The assessment and problem-solving efforts of clinicians are channeled in ways conducive to the application of therapeutic techniques that are available and are believed to be effective. This is not a bad thing! But it does skew what the therapist sees and finds out about a patient, a topic we turn to next.

Clinical Problems as Clinicians' Constructions As argued elsewhere (e.g., Davison, 2001; Davison & Lazarus, 1995), clients seldom come to mental health clinicians with problems as clearly delineated and independently verifiable as what patients often bring to a physician. A client usually goes to a therapist or counselor in the way described by Halleck (1971):

> At first glance, a model of psychiatric practice based on the contention that people should just be helped to learn to do the things they want to do seems uncomplicated and desirable. But it is an unobtainable model. Unlike a technician, a psychiatrist cannot avoid communicating and at times imposing his own values upon his patients. The patient usually has considerable difficulty in finding the way in which he would wish to change his behavior, but as he talks to the psychiatrist, his wants and needs become clearer. In the very process of defining his needs in the presence of a figure who is viewed as wise and authoritarian, the patient is profoundly influenced. He ends up wanting some of the things the psychiatrist thinks he should want. (1971, p. 19)

That is, the person is unhappy; life is going badly; nothing is meaningful; sadness and despair are out of proportion to life circumstances; the mind wanders and unwanted thoughts intrude, etc. The constructivist argument is that the clinician *transforms* these often vague and complex complaints into a diagnosis or functional analysis, a set of ideas of what is wrong, what the controlling variables are, and what might be done to alleviate the suffering and maladaptation. The argument, then, is that psychological problems are for the most part *constructions* of the clinician. Clients come to us in pain, and they leave with a more clearly defined problem or set of problems that we *assign* to them. The same argument can be made for medical problems like "metabolic syndrome" (Fisher, Chan et al., 2012).

Davison's argument has been that when a homosexual went to a therapist, whatever psychological woes they had were generally construed as caused entirely or primarily by their sexual orientation. This happened because (a) their sexual orientation was usually the most salient part of their personhood, to the clinician and usually to the clients themselves because the negative salience homosexuality had been accorded by society and (b) it was regarded as abnormal, regardless of the avowedly **"**liberal**"** stance the clinician might take overtly. The clinician's perceptions and problem-solving were skewed in a direction that implicated homosexuality – no matter what the actual presenting problems were (cf. Davison & Friedman, 1981) – and, most importantly, implied the desirability of a change in sexual orientation.

None of this was intended to gainsay that being homosexual in our society has been easy psychologically and that it can create considerable distress – particularly two generations ago but even now – given the disproportionate exposure to hate crimes and simple everyday prejudice that homosexuals are still subject to in many parts of society and in the world at large. The moral point that Davison began making in 1974 is that health professionals have a responsibility at least to consider carefully the societal pressures that, sometimes subtly, channel our clinical problem-solving and decision-making into narrowly defined domains that result in a maintenance of a status quo that, in official pronouncements, we say we do not support.

As mentioned earlier, anti-gay attitudes have diminished in recent years both in North America and Western Europe, with some jurisdictions even sanctioning civil unions and marriage between same-sexed individuals. But at the time (1974) Davison formulated his position against sexual reorientation therapy, attitudes were negative, often strong, and sometimes virulent, with many people believing that homosexuals were sick and their behavior disgusting (Herek, 1994).

These negative attitudes took the form of open heterosexism – as when people directly insulted a gay person with epithets like *faggot* or *dyke* – or a more subtle, indirect kind of anti-homosexual stance – as when people told jokes that derided homosexuality without knowing (or caring) if a gay person was present. This prejudice created – and, in most parts of the world, maintains – what has been termed "minority stress," a source of pressure and tension that is a special burden of those in despised or feared minorities (Meyer, 1995) and no doubt was the major factor in gay and lesbian people suffering particularly high levels of depression (Herek, Gillis, et al., 1996).

In light of all this, it was not surprising that gays sometimes sought out sexual reorientation treatment. Being subjected to verbal and physical assault for being gay was not likely to enhance one's sense of comfort with and acceptance of one's sexual orientation. Davison's argument, therefore, has been that the expression of a desire to change sexual preference was not truly voluntary. And it fell to the clinician to take into account the societal conditions that were likely influencing homosexual individuals to seek a change in the direction of heterosexuality.

A Proposal Regarding Sexual Reorientation Therapy These several considerations led Davison in 1974 to make a proposal that had been present for a few years in the some of the gay activist literature (see especially Silverstein, 1977): *Therapists should stop engaging in change-of-orientation programs, whether the client makes the request or if someone else does*. The social pressures, discrimination, and in some cases violent hatred directed to people with homosexual inclinations made it highly doubtful that client requests for conversion therapy could be reasonably viewed as voluntary.

Long ago Perry London (1969) warned of an unappreciated danger in behavior control technology, namely, clinicians' increasing ability to engineer what we have tended to regard as free will on the part of our patients. In his view, therapists are capable of influencing patients to want what is available and what they believe their patients *should* want. Moreover, even if therapists assert that they do not work against the will of their patients, this does not free them from the responsibility of examining those factors that determine what is considered free expression of intent and desire on the part of our patients.

Psychotherapy, Politics, and Morality To conclude this discussion of the ethics of sexual reorientation intervention, it may be useful to place the issue within a broader social context. This perspective has traditionally been seen as the defining characteristic of community psychology. In Rappaport's (1977) terms, the argument is at an institutional level, whereby human problems are examined within a macrolevel frame of values and ideologies that shape the decision-making of a society. In behavioral medicine and health psychology, this perspective is referred to as the socio-ecological model (e.g., McLeroy, Bibeau, & Steckler, 1988; Stokols, Grzywacz et al., 2003). In contrast, most therapists and other interventionists operate at the individual level, where the assumption is that society is basically benign and that psychological and physiological suffering can best be alleviated by helping the patient adjust to prevailing values and conditions. Davison's argument was and is that issues surrounding therapy for homosexuality should be addressed at an institutional level and that greater societal acceptance of homosexuality as a normal variation of human sexuality rather than as a problem that needs to be fixed will, in fact, redound to the benefit of the individual by reducing the discrimination and oppression described earlier that, we believe, accounted for the distress that can be associated with homosexuality and ultimately the desire of some homosexual individuals to seek sexual reorientation.

Do therapists have some kind of abstract responsibility to satisfy a patient's expressed desires and wishes, as asserted by some (e.g., Sturgis & Adams, 1978)? No. Therapists constrain themselves in many ways when patients ask for assistance, and under some circumstances, therapists are legally required to break the confidentiality that is inherent in the relationship. In any event, requests alone have never been a sufficient justification for providing a particular service to a patient (Davison, 1978).

Concluding Comments

This case study on ethical issues in sexual reorientation for gays and lesbians highlights the important role played by values in our very conceptions of what it means to have a "disease" and in our decisions on whether and how to intervene to make changes. We believe that the themes raised are relevant to many behavioral medicine and population health issues discussed in this chapter, for example, obesity. In Western cultures, obese individuals are often stigmatized and blamed for physical and/or psychological ailments that are attributed, rightly or wrongly, to their weight. Societal judgments of health and beauty define body types as desirable or undesirable. Has anyone, for example, ever been stigmatized for having hair that is too shiny and teeth that are too white? This is not to say that obesity has no long-term negative effects, rather that the negative appraisals of people deemed overweight go beyond demonstrable negative effects on health.

Our relative values on autonomy and safety are related to the question of whose responsibility or right it is to change and to treat. What is the "best treatment" for each individual, what are the best prevention and health goals for populations, and who should be the ones to make these determinations? The patient, the healthcare provider, or the government?

In this chapter we have presented some ideas about values issues that permeate behavioral medicine and allied health-related fields in ways that are not always fully acknowledged but that nonetheless influence what we study, how we conceptualize the world, and how we intervene into the lives of others. The domains we have examined in some detail – longevity, quality of life, suicide, euthanasia, and global and cross-cultural issues in research and practice – are but a few of the issues that we believe should be considered when professionals presume or are asked to help people make changes.

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36

Behavioral Medicine and the Benefits of Healthcare: A Critical Appraisal and the Need for Exnovation

Robert M. Kaplan, David A. Chambers,
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The goal of healthcare is to enhance health, lengthen life, and reduce illness and disability. In order to work toward these objectives, it is necessary to understand the factors associated with longer life and reduced illness and disability. It is typically assumed that the mechanism for increasing life expectancy and reducing the burden of illness and disability is investment in medical care. However, a variety of different analyses using several different research methodologies have shown that medical care accounts for only a small portion of the variation in health outcomes (Murray, Vos, et al., 2012; Schroeder, 2007).

The traditional biomedical model is limited in its ability to foster health and well-being, in part because the biomedical model often focuses exclusively on measures of biological process rather than the more global goal of helping people live longer, higher quality lives. Understanding how to improve overall health and well-being thus requires perspectives beyond those of fundamental biology and clinical medicine.

Healthcare in the United States is the biggest sector in the biggest economy in the history of the world. In 2015, the United States will spend approximately 18% of its gross domestic product (GDP) on healthcare. This expenditure far exceeds the cost of healthcare in any other country. Unlike other industries, healthcare has not been held accountable for what it produces. Among 34 developed economies, we rank 30th in infant mortality, 25th in maternal mortality, and 26th in life expectancy (data from the Organization for Economic Cooperation and Development, OECD).

Because healthcare systems are very much creations of the countries in which they exist and because the authors have focused much of their work on the US system, the chapter is focused on that system and trends in it.

The Problem: Healthcare ≠ Health

One way of examining the relationship between healthcare and health is in terms of expenditures on care. Figure 36.1 uses OECD data to graph

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The views expressed in this chapter are those of the authors, and no official endorsement by the Agency for Healthcare Research and Quality, the National Cancer Institute, the US Department of Health and Human Services, or the US federal government is intended or should be inferred.

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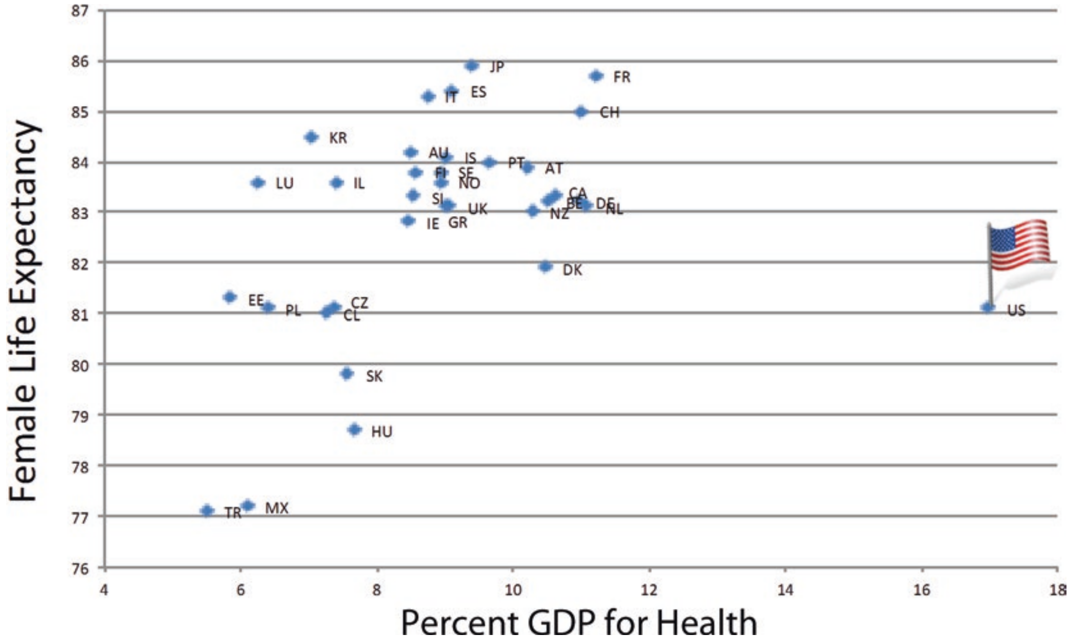

Fig. 36.1 Relationship between percent of GDP spent on healthcare and female life expectancy in OECD countries (Data from OECD, 2011. When missing life expectancy data estimates were imputed from prior year)

total healthcare expenditures for various countries (x-axis) against life expectancy (y-axis). The United States is an extreme outlier in terms of expenditures. We spend more than 18% of our gross domestic product on healthcare, while most of our economic competitors spend about 10%. The United Kingdom, for example, spends only about $0.40 per capita for each dollar spent in the United States, and more or less the same story holds in other developed countries: Belgium and Denmark spend only about $0.50 for each dollar spent in the United States, and Spain spends only about $0.33 (Reinhardt, Hussey, & Anderson, 2004). Nevertheless, US life expectancy is less than in many countries, several of which spend less than half of what the United States spends in terms of percent GDP. If the United States reduced its expenditures to the level of most European countries, we would save over $1 trillion per year—about equal to the total publically held debt of the US federal government.

Further, in spite of spending considerably more, studies tend to show that the increase in life expectancy of US citizens is not keeping up with other wealthy countries. One study from the National Research Council considered current life expectancy for 50-year-old women between the years 1955 and 2010 (Crimmins, Preston, & Cohen, 2011). Current life expectancy is the number of years of life on average remaining once a milestone age has been reached. So, current life expectancy for 50-year-old women is the median number of years of life remaining following the 50th birthday. In 1955 the United States was about 12th in the world on this indicator. By 2006, it had slipped to about 26th, just below South Korea and Malta. In a life expectancy comparison of ten wealthy countries, US women were third out of ten in 1955, but ninth out of ten in 2006. Among the many countries with more rapid increases in life expectancy were Japan, France, and Spain. Japan, for example, was considerably below the United States in 1955 and now is many years ahead.

In response to these findings, the US Office of Behavioral and Social Sciences Research along with the National Institute on Aging sponsored a study that compared life expectancy in the United States against 17 peer countries (Woolf & Aron, 2013). These comparison countries were primarily in Western Europe, but also included Australia, Japan, and Canada. The results of the comparison are quite revealing. Among the 17 countries, the United States had the second highest mortality rate from noncommunicable diseases. Mortality from communicable diseases, on the other hand, was fourth lowest for the United States. Arguably, this reflects sanitation and the availability of antibiotics in the United States, key for preventing communicable diseases, as opposed to risk factors critical for noncommunicable diseases: diet, physical activity, obesity, and tobacco and alcohol use. However, the AIDS incidence in the United States was 122 per million, third highest exceeded only by Brazil and South Africa and about nine times the average of countries in the OECD.

Although US life expectancies are increasing, the rate of increase is much slower than it has been in other wealthy countries. This trend has been developing over the course of several decades. Perhaps the most surprising finding in the NRC study concerned years of life lost prior to age 50 (Woolf & Aron, 2013). The committee considered international differences in the probability of celebrating a 50th birthday. On this indicator, the United States was last among the 17 comparison countries for both men and women. United States losses in life expectancy prior to age 50 are about double the rate observed in Sweden. Perhaps most disturbing is that this problem profoundly affects women. Figure 36.2 shows the trend in years of life lost in 21 high-income countries between the years 1980 and 2006. For men, the United States started at the low end of the distribution and worked its way to the bottom. For women, the United States started near the bottom and now has gone off the scale in relation to the comparison countries.

In addition to differences with other countries' costs and performance of healthcare, there is substantial regional variation in healthcare expenditures within the United States (Wennberg, 1990; Wennberg, Fisher, et al., 2005, 2008). For example, during the last phases of life, Medicare spends $1.80 in Los Angeles for each dollar that it spends in San Diego. The two cities are demographically very similar. The climate is the same, the nature of the industries is similar, and in many other ways, the communities are very much alike. What differs is the way healthcare is delivered. At the end of life, for example, residents of Los Angeles are significantly more likely to be hospitalized, placed in an intensive care unit, and to receive heroic interventions. Yet, there is no evidence that health outcomes for residents of Los Angeles are any better, and some evidence suggests that the quality of care and patient satisfaction is higher in San Diego (Kaplan, 2011). Patients in Los Angeles are receiving many procedures and tests that do not result in health benefit.

In spite of findings such as these, many Americans assume that the United States leads the world in quality of medical research and quality of healthcare. Clearly, there is much cause for concern about both healthcare research and healthcare quality.

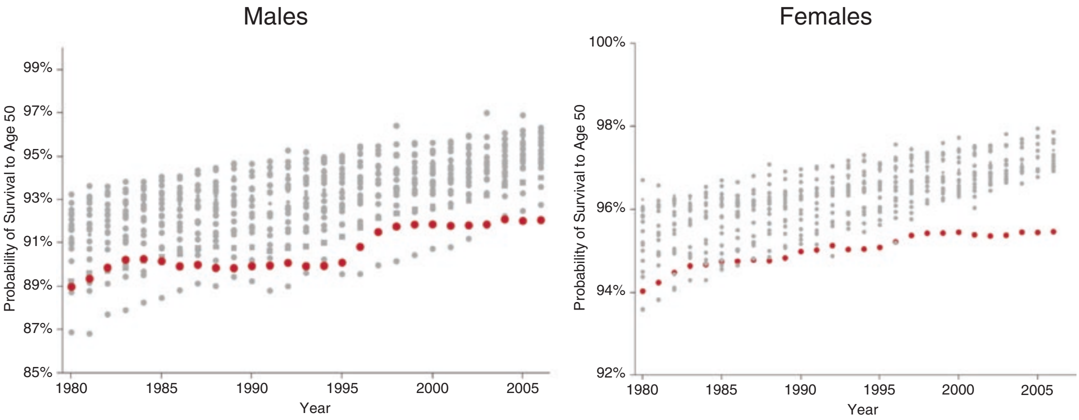

Fig. 36.2 Probability of survival to age 50 in 21 high-income countries, 1980–2006 (From National Research Council: explaining divergent levels of longevity in high-income countries, 2010)

Determinants of Health Outside the Health System

This chapter emphasizes the healthcare system and how it needs to change to do a better and more efficient job of promoting health and lives of quality. As a context of this focus on healthcare, it is important to note that most of the variability in health outcomes is attributable to factors outside of the healthcare system. A variety of different analyses estimate the proportion of health outcome attributable to factors within the healthcare system as opposed to factors outside of healthcare. (See chapters by Siddiqi and colleagues and by Sherlaw and colleagues, *infra*.) Schroeder suggested that medical care accounts for about 10% of the variation in health outcome (Schroeder, 2007). Behavioral and social factors, according to this analysis, account for about 55%. Although the exact number varies, most analyses suggest that behavioral and social factors account for at least half of the variation in health outcomes. One interesting example is provided in a report by Marmot and colleagues from the United Kingdom. An expert panel reviewed a variety of factors associated with life expectancy which demonstrated a systematic relationship between living in economically deprived neighborhoods and life expectancies (Marmot, Allen, et al., 2010).

A growing body of evidence reinforces the observation that social factors have a profound impact on life expectancy. For example, the Los Angeles County Public Health Department reports on life expectancy by gender and racial/ethnic background. The difference in life expectancy between Asian women with an average life expectancy of nearly 89 years and African-American men with a life expectancy of about 70 years is a full 19 years! There have been significant improvements in the life expectancy of Black males in recent years, but on average, White women still live about 9 years longer than Black men (Hoyert & Xu, 2012). To place this in perspective, the difference in life expectancy between a 35-year-old man with normal LDL cholesterol and a man with elevated LDL cholesterol is about 6 months. In contrast, the difference in life expectancy between young adults with less than a high school education and those with a graduate degree is at least 10 years.

Behavior, Systems, Populations, and Persons

If you are stuck in a hole, the solution is probably not to dig. Yet, in many ways, US healthcare resembles trying to dig one's way out of a hole. In spite of the trends of worsening care noted in the previous section, financial strategies in US healthcare have emphasized the continued search for fundamental science breakthroughs and ever more specialized care, arguably strategies that have caused us to neglect the ways out of the hole (Starfield, 2000). The US Patient Protection and Affordable Care Act includes a number of strategies to change this, placing greater emphasis on primary care, prevention, and patient education; services for support of patients with chronic diseases and disabilities; and initiatives to reduce rehospitalization for diseases like heart failure, coronary heart disease, and pneumonia (Cheng, Wise, & Halfon, 2014; Halfon, Long, et al., 2014). These provide opportunities for new directions.

Behavioral medicine along with public health and health services research offers perspectives that complement those of clinical medicine and may help lead us out of the hole. From public health, we learn to think about populations, how prevention and healthcare change the patterns of disease among all individuals affected, not just the individual patient in the examining room or the panel of several hundreds or even several thousands participating in a study of some specific intervention. From health services, we learn to think about how interventions and innovations work within the systems in which they are implemented and how characteristics of those systems influence the care they provide and the health of those they serve. And from behavioral medicine, we learn to examine the effects of interventions not only on the specific disease characteristics or risk factors they may target but on overall health and well-being as perceived and valued by the individual (Glasgow, Kaplan, et al., 2012). Combining the public health, health services, and behavioral medicine perspectives yields analytic frameworks to examine the performance of the healthcare system and identify directions for improving it.

Advances in Treatment ≠ Advances in Outcomes

If it were true that the United States has the very best medical care in the world, we might expect advances in medical therapies to have solved many of our healthcare problems. Recent clinical trials however do not show the level of benefit that the public expects from medical therapies. In fact, most recent large randomized clinical trials have failed to show expected benefits of medical and surgical therapies (Gordon, Taddei-Peters, et al., 2013).

More care is not necessarily better care. For example, one RCT randomly assigned patients with metastatic non-small cell lung cancer to palliative care or to standard cancer therapy. Those in the palliative care condition had higher quality of life and longer survival (Temel, Greer, et al., 2010). In systematic reviews of all of the trials supported by the National Cancer Institute over the last 50 years, the new treatment was found to be superior to standard care or placebo in only about a quarter of the studies (Djulbegovic, Kumar, et al., 2008).

Whose Perspective? Determining whether a treatment works and whether it works efficiently is not a simple task. Different people have different perspectives on what defines an effective treatment. A purely physiological perspective might focus on biochemical or anatomical changes that result from a treatment. A clinical perspective might focus on disease-specific criteria, such as blood pressure or, in diabetes, glucose control. A behavioral approach, on the other hand, leads to consideration of how the individual is living and enjoying life, not just how a particular organ is functioning (Glasgow, Kaplan, et al., 2012). It turns out that treatment decisions, or even the decision to continue to offer a particular service, may be different depending on whether they are guided by the perspective of the whole individual or that of a particular organ or disease state. For example, a treatment might be effective in lowering blood pressure and could be regarded as effective from the perspective of the doctor who prescribed the medication. However, the same treatment may increase cholesterol or make the patient sleepy and would be considered less effective from the perspective of a generalist physician—or the patient.

There are many examples of treatments that show benefit on some measures and lack of benefit or even harm on others. Trials considering intensive therapy for anemia suggest that agents that increase red blood cells do their job and bring hemoglobin counts toward normal. From a traditional perspective evaluating interventions in terms of surrogate endpoints, these trials achieved their goals. Yet patients in these conditions had a higher probability of renal failure requiring dialysis and other adverse outcomes (Drueke, Locatelli, et al., 2006). Large studies on hormone replacement therapy usually show that estrogen levels are raised toward normal premenopausal levels. Yet the consequences for patients, from an outcomes research perspective, are usually poorer rather than better (Chlebowski, Hendrix, et al., 2003).

Examples of Interventions Producing Minimal Benefit

ACCORD Aggressive therapy for the treatment of non-insulin-dependent diabetes mellitus was the focus of the ACCORD trial (Action to Control Cardiovascular Risk in Diabetes Study Group, Gerstein, Miller, et al., 2008). Patients were randomly assigned to standard therapy or to an intensive therapy. The intensive therapy significantly changed biological outcomes in the expected direction. Specifically, those assigned to intensive therapy had significantly lower levels of glycosylated hemoglobin. From a traditional perspective, the treatment had achieved its goal. However, long-term follow-up considered total mortality and deaths from cardiovascular disease. Considering all-cause mortality, those assigned to intensive therapy had a higher probability of death in comparison to the standard therapy condition.

Prostate Cancer Another example is provided by the Prostate Cancer Prevention Trial (PCPT) (Thompson, Goodman, et al., 2013). In this long-term study, 18,882 men at risk for prostate cancer were randomly assigned to the drug finasteride or to a placebo. All of the men were followed prospectively for at least 15 years using the National Death Index. Initially it appeared that the drug had worked successfully. Just over 10% of the men who took finasteride showed evidence of prostate cancer in comparison to nearly 15% in the placebo group. However, the percentage of men surviving for 15 years in the two groups was virtually identical: 78.0% versus 78.2%. The drug reduced the number of men with clinical prostate cancer, but the purpose for taking the drug in the first place was to reduce deaths. The analysis suggested that there was little progress toward that ultimate goal. Further, those men who took the active drug had significantly higher rates of complicating side effects.

Coronary Heart Disease The causes of heart disease are well understood. There is an initial injury to the endothelial wall of the coronary artery. Plaque builds up and narrows the artery and this results in restricted blood flow. Often, a fibrous cap on the lesion ruptures and a blood clot forms, totally occluding the flow of blood to the heart muscle. One solution for this problem is to perform angioplasty by placing a stent in the narrowed artery. The stent holds the artery open so that nourishing blood flow can continue.

It seems obvious that this procedure should reduce deaths associated with myocardial infarctions. Yet systematic studies do not always support this hypothesis. One of the most important studies was the Clinical Outcomes Utilizing Revascularization and Aggressive Drug Evaluation (COURAGE) trial (Boden, O'Rourke, et al., 2009). In this evaluation, 2287 patients who had objective evidence of narrowing of their coronary arteries were randomly assigned to undergo either angioplasty using a stent or to optimal medical therapy. The patients were followed for an average of 4.6 years, and the primary outcome was death from any cause or a nonfatal myocardial infarction. Over the course of follow-up, 19% of the patients in the stent group died or had a nonfatal heart attack. In comparison, 18.5% of the patients in the medical therapy group died or had a heart attack (Boden, O'Rourke, et al., 2009).

Schizophrenia Modern pharmaceutical approaches to the management of schizophrenia have been remarkably successful in the realm of severe mental illness. The most effective medicines are in the category of "atypical neuroleptics." These drugs include clozapine, olanzapine, quetiapine, and risperidone. The most important advantage of these medicines is that, in comparison to traditional neuroleptics such as Haldol (haloperidol), they control serious symptoms of schizophrenia but have fewer extrapyramidal side effects, including tremors, slurred speech, restless legs, anxiety, and a host of other psychological symptoms. Using registries from Veterans Administration Medical Centers, one study considered 38,632 patients with schizophrenia. Among these, 15,984 (41.4%) used typical neuroleptics and 22,648 (58.6%) were treated using any one of the atypical neuroleptics. The results suggest that schizophrenic patients treated with atypical neuroleptic medications have a 9% greater chance of developing diabetes in comparison to those taking the traditional medications (Sernyak, Leslie, et al., 2002). This result has been replicated in a variety of different settings (Vidarsdottir, de Leeuw van Weenen, et al., 2010). With respect only to schizophrenia measures or measures of neuropsychiatric side effects, the atypical neuroleptic medications perform well. However, considering total health, the picture is less clear (Rosenheck, Leslie, et al., 2008).

Aggregate Results Point to Diminished Returns

It is surely troubling that the number of recent null or negative clinical trials significantly exceeds the number of trials supporting the use of the interventions they propose (Gordon, Taddei-Peters, et al., 2013). We have placed such a high premium on innovative research, that we may have failed to invest sufficient resources to determine whether the research is replicable. Most medical innovations are introduced with great promise. However, the reported efficacy of many interventions declines over the course of time. Early trials showed stronger effect sizes for statin medications, but as time goes on, the effect size declined (Gehr, Weiss, & Porzsolt, 2006). This "decline effect" occurs in many different sciences (Schooler, 2011).

A growing number of papers acknowledge that clinical and experimental studies often cannot be replicated (Landis, Amara, et al., 2012; Pashler, Coburn, & Harris, 2012). One explanation is the "voltage drop" phenomena in which early trials are carefully controlled with high internal validity, while later studies involve more representative populations and evaluate interventions under circumstances closer to which they are applied in clinical practice (Chambers, 2011). When interventions are evaluated in the "real world" they produce less dramatic results. Some of this occurs when the characteristics of the population in which the intervention is applied differ from the study population in earlier trials. However, there are other problems. For example, publication bias favors the reporting of significant results. A study that offers a significant finding may have been an anomaly, and it is hard to determine this without systematic attempts to replicate.

In larger trials that have strong external validity, null or negative results are not uncommon. For example, a recent review of all major randomized clinical trials from the US National Heart, Lung, and Blood Institute shows that remarkably few are able to demonstrate that treatments resulted in the predicted improvements in patient outcomes. Among large NHLBI trials, defined as having budgets greater than $500,000/year, it has been 15 years since any trial demonstrated a reduction in all-cause mortality, and only two trials published in the last 15 years showed a significant benefit on the primary outcome variable (Kaplan & Irvin, 2015). In short, it has been common for large, well-controlled studies to challenge evidence supporting the use of common medical tests and procedures.

In summary, the effects of clinical medicine can be different when viewed from the patient's perspective. Randomized clinical trials in medicine often show benefits when the outcome is a measure of specific disease indicators or biological process, such as blood sugar or hemoglobin. But, when patient-centered clinical outcomes, such as survival and quality of life, are considered, the same trials often show null or negative results. Certainly, we need continually to evaluate promising new therapies. However, we also need to devote more attention to identifying and promoting those interventions that make real differences in length and quality of life.

Two Paths: Identifying What Works—And What Does Not

The previous sections make clear that we need better methods for deciding what works and to what we allocate the effort and resources of the healthcare system, the time, attention and efforts of individuals, and the dollars available. But as the previous examples also show, practices sometimes persist in spite of minimal evidence to support them. Thus, we also need methods to cull from the enormous healthcare enterprise those practices that contribute appreciable cost but little or no benefit. These two decisions what to include and what to exclude are discussed in the next sections. Patient-centered evaluations and comparative effectiveness research offer important improvements in identifying what to include. *Exnovation*, as will be discussed, provides pathways to identifying what deserves to be eliminated.

The Patient's Perspective and Comparative Effectiveness Research

In determining whether treatments work, perspective is important. As the previous section has shown, there are many circumstances in which treatments are regarded as effective from the perspective of treating a particular disease but not from the perspective of overall mortality or health. Evaluating treatments from the patient's perspective requires a whole set of new research methodologies.

The field of study that concentrates on the evaluation of the benefits and risks of healthcare from the patient's perspective is known as comparative effectiveness research (CER). Although the conceptual underpinnings of this line of scientific inquiry have been discussed for decades, CER did not exist as a formal field of study until 2009. In the early years of the Obama administration, there was extensive discussion among advisers about the costs, risks, and benefits of healthcare. During extensive debates about healthcare reform, the US Congress approved legislation to develop the infrastructure for comparing the effectiveness of healthcare interventions. The discussion was contentious at times. However, what emerged from the discussion was the basis for developing an important new infrastructure for comparing treatments and analyzing which interventions are most effective for patients.

US National Academy of Medicine (NAM) of the National Academies of Science defines comparative effectiveness as "the comparison of one diagnostic or treatment option to one or more others." The methods that are compared are designed to "prevent, diagnose, treat, and monitor a clinical condition or to improve the delivery of care." According to the NAM, the beneficiaries of CER include consumers, clinicians, purchasers, and policymakers. The NAM suggests that, ultimately, CER will help these groups "make informed decisions that will improve healthcare at both the individual and the population levels." The definition of treatments is very broad and includes traditional medical care as well as alternative approaches to improving health. The key to understanding CER is that it compares the benefits and harms of two or more alternatives.

By definition, CER encompasses more than traditional research methods and study designs such as cohort investigations, population studies, and randomized clinical trials. Beyond these, CER also includes systematic reviews of the literature and comparisons between medical services or different delivery systems.

In terms of identifying what works, the key feature of comparative effectiveness research is that it evaluates not how an intervention compares to placebo or minimal treatment but examines how it *adds to the benefits already available from common practices*. Put simply, it asks whether an intervention helps us do better than we are already doing. For example, one of the most interesting analyses concerns the frequency with which women should have Pap smears. It used to be common practice for women during their reproductive years to have this cancer screening test every year. Analyses have shown that women who are screened every third year have an increase in life expectancy on average of 70 days. If women get a Pap smear every other year as opposed to every third year, the number of expected added days of life increases from 70 to 71. If they get the test every year, the benefit is 71 days and 8 h. In other words, the advantage of getting a yearly Pap smear as opposed to a Pap smear every third year extends average life expectancy by about 32 h. Given the amount of time most women spend going to the appointments for these yearly tests, the added life span may be almost negligible. However, frequent tests also add costs. The cost of being screened every year is three times the cost of being screened every third year. An analysis of the incremental cost in relation to the incremental benefit is quite telling. For women screened every third year, the cost is about $2600 per life year gained. For women screened every single year, the cost is $83,000 per life year gained (Hagen, Garber, et al., 2001).

What Are Indicators of Effectiveness?

Quality of Life The recognition of quality of life as an important outcome was first stimulated by Paul Ellwood's 1988 Shattuck lecture (Ellwood, 1988). Ellwood advocated for what he referred to as "a technology of patient experience". In contrast to management of symptoms, Ellwood emphasized the importance of managing patient outcomes. He advocated that medical care should emphasize four techniques: (1) standards and guidelines that match treatments with patient desires, (2) measurement of patient well-being and functioning, (3) use of normative data to interpret patient outcomes within the context of other people, and (4) dissemination of information in ways that could affect decision makers.

This approach puts the patient at the center of healthcare and uses patient-centered reports to offer guidance and perspective for clinical care. More recently, the use of these technologies has come to be known as patient-centered outcomes research (PCOR). The use of PCOR is well represented in the Affordable Care Act and in the Patient-Centered Outcomes Research Institute (PCORI). At the center of PCOR is the measurement of outcomes from the patient perspective. Most of these measures emphasize health-related quality of life.

Cost of Care One key indicator is the cost of healthcare. Briefly, many healthcare analysts believe that healthcare policies should not consider cost. No one wants cost to be a factor in decisions about who lives and who dies. But costs of healthcare are a very important concern, and it is necessary to consider whether and how costs should be part of the healthcare decision process. Several countries have grappled with this issue, and some have decided that cost is necessarily part of the equation.

A Note on Evidence One of the provisions of the ACA was the required coverage of preventive health services, without co-payment. Services that will qualify for this coverage include those with an A or B rating by the US Preventive Services Task Force. There has been some controversy about how services obtain these ratings. For example, it is difficult to obtain A or B ratings without multiple randomized clinical trials (RCTs) that adhere to specific methodological criteria. The RCT is deservedly highly respected in assessing the value of medications and other interventions which can be rigorously isolated from their surroundings (see chapter by Freedland and colleagues, *infra*). Its value in assessing broader interventions such as in communities or in changes of health systems is questionable. Thus, the reliance on RCTs in grading interventions may be especially a challenge for many behavioral medicine interventions. Alternatives are discussed in the chapter by Allegrante et al., *infra*.

On the other hand, some services that obtain these ratings have relatively low population reach or have inconsistent results when different outcome measures are considered. For example, daily low-dose aspirin to prevent heart disease and colorectal cancer received a B rating, and only for those adults ages 50–59 years who have a 10% or greater 10-year CVD risk are not at increased risk for bleeding, have a life expectancy of at least 10 years, and are willing to take low-dose aspirin daily for at least 10 years. It received a C rating for adults 60–69 years of age and an insufficient evidence rating for adults younger than 50 and older than 70. Aspirin may prevent death from cardiovascular disease, but some studies show it has only a tiny health benefit from the perspective of total mortality (Sanmuganathan, Ghahramani, et al., 2001). European reviewers, who have considered the same evidence, do not advocate daily aspirin use on a population basis (Perk, De Backer, et al., 2012). The USPSTF review suggests some benefits, but encourages a balancing of these benefits with risks for bleeding (Guirguis-Blake, Evans, et al., 2016).

Exnovation

That an appreciable proportion of healthcare provides no or very little benefit raises an important question: *How do we recognize that something doesn't work and that we should stop doing it?* Innovation is defined as the action or process of introducing new methods, ideas, or products. There is no question that innovation is a core ingredient of science and a key to advancing healthcare. On the other hand, medicine and healthcare are plagued by innovations that have not lived up to their promise. In addition, many non-evidence-based practices have been widely adopted. Continuing to use suboptimal innovations uses resources and crowds out the opportunity to apply other approaches that may have a more beneficial impact. In this paper, we consider the need for exnovation—the science of identifying and reducing the application of methods, ideas, or products that do little good, unnecessarily use resources, and may produce harm.

Why Do We Need Exnovation? Although interventions are often identified as innovations, we argue that all care must be carefully evaluated to determine whether or not it actually provides health benefit. Those services that do not provide sufficient benefit should not be supported. We simply cannot have it all. Overtreatment can be dangerous—not just wasteful and inefficient.

We often hear that patients get the evidence-based treatment only about 50% of the time (McGlynn, Asch, et al., 2003). But, we seldom concentrate on the half or more of the services they receive that are not supported by evidence (Smith, Halvorson, & Kaplan, 2012). In addition to increasing the use of evidence-supported services, we also need to exnovate—to reduce the use of services that are not evidence-based or those that provide no incremental benefit beyond less expensive alternatives.

Despite the kind of evidence reviewed earlier, exnovation is difficult to achieve. Prasad and Ioannidis (Prasad & Ioannidis, 2014) suggested that entrenched practices and biases are resistant to new evidence on low effectiveness. Montini and Graham (Montini & Graham, 2015) offered the example of radical mastectomy to document how historical, economic, professional, and social forces help support an ineffective practice. Although systematic evidence played some role in exnovating radical mastectomy, forces outside science had a very powerful influence.

Examples of Services that Need Exnovation There are a wide variety of health services that use resources yet do not necessarily offer patient benefit (Fisher, Wennberg, et al., 2003; Kaplan, 2009). The use of cancer screening tests among populations of varied ages is a good example (Welch, 2004). There has been a long-standing controversy as to whether or not screening mammography for women under 50 produces the probability of breast cancer death and increases the life expectancy (Baum, Thornton, et al., 2010). A small number of randomized clinical trials have evaluated this question. The Cochrane Collaboration in Norway has systematically analyzed the trials and adjusted for methodological quality. They find no evidence that screening mammography increases life expectancy (Gotzsche & Nielsen, 2011). Some trials suggest that screening mammography results in small reductions in deaths from breast cancer, but there are compensatory increases in deaths from other causes. Recently, a series of quasi-experiments was also analyzed (Irvin & Kaplan, 2014). These studies, which have greater external validity than the randomized trials, similarly fail to support the use of screening mammography for women under age 50. At best, screening mammography may save the life of one woman among each of the 2000 screened. However, among the screened women, at least 10% will have false positives and may go through unnecessary evaluations, risky procedures, and anxiety. Some analyses suggest that as many as one third of women who are treated for breast cancer received unnecessary intervention (Bleyer & Welch, 2012).This is important because breast cancer treatment is not benign. It may have serious long-term adverse effects of the central nervous system (Deprez, Amant, et al., 2012) and the cardiovascular system (Ganz & Stanton, 2012). The best evidence suggests that screening mammography in this age group does not result in women living longer, even though it leads to the identification of more cases.

The mammography example may not be unusual for screening tests. Saquib, Saquib, and Ioannidis (Saquib, Saquib, & Ioannidis, 2015) reviewed the effects of a wide range of screening tests on disease-specific and all-cause mortality. They underscore that the goal of these tests is to identify disease early in order to help people live longer lives. Using meta-analysis for 39 different screening tests for 19 diseases, they considered 48 RCTs and 9 previous meta-analyses. They found only small reductions in disease-specific mortality and almost no evidence that screening tests resulted in reductions in all-cause mortality.

There are abundant examples of expensive interventions that appear to have little to no benefit from the patient's perspective. For example, each year, nearly 2.2 million adults receive epidural injections of glucocorticoids for the treatment of back pain resulting from lumbar spinal stenosis. A large systematic randomized clinical trial showed that glucocorticoids plus lidocaine provided no more benefit than lidocaine alone at 6 weeks (Friedly, Comstock, et al., 2014). Recent systematic reviews suggest that in

Table 36.1 Categories requiring exnovation and actions required

Category	Potential actions needed
Use of non-evidence-based procedure	Public disclosure Require patient consent Quality metrics that penalize non-EB interventions
Over-use or over-aggressive treatment	More research on side effects and unintended consequences Relate approvals and guidelines to dose-response data Require EHR checkoff that understand patient has comorbid conditions that may increase risk
Use of overly expensive procedures	Promote use of "MINC"[a] More emphasis on cost, cost-effectiveness, cost benefit More use of stepped care
Assumption that "more, and more frequent is always better"	Publicize what is known about frequency of testing Narratives and simulations on unintended consequences

[a] *MINC* minimal intervention needed for change

well-controlled studies, the failure to confirm the value of commonly prescribed treatment is common in many areas of medicine (Cummings, Morstorf, & Zhong, 2014).

Another important issue is incremental or *marginal* benefit. We usually compare a new treatment in relation to current practice. It is rare that we would do nothing for people with serious illness. Instead, we often need to know how much benefit accrues when we do something that is different from ordinary practice or if we do something that is expensive but provides little or no benefit over a simpler and less expensive approach. The example of Pap smears every year versus every 3 years is a good one. The yearly test relative to the triennial adds 32 h to expected life span (71 days, 8 h, versus 70 days) at a cost of $83,000 versus $2600 per life year gained for the test given every third year (Hagen, Garber, et al., 2001).

The Consequences of Failure to Exnovate Failure to discontinue an ineffective innovation has consequences. One of the most important concerns is that there are opportunity costs for continuing to use ineffective treatments. There are at least three different types of opportunity costs. First, there are financial opportunity costs. Expenditure on programs such as mammography or PSA screening uses resources that could have been applied to more effective treatments.

The second concern is the time opportunity cost. Patients have only a limited number of exposures to the healthcare system and healthcare providers. In primary care, providers are required to do more and more in less and less time. There are many different services that can be provided during this limited time. Continuing to use services that provide little benefit uses valuable time resources that could have been applied for more productive purposes.

The third concern, and perhaps most crucial, is the health opportunity cost. If patients are receiving suboptimal or even detrimental care instead of a more beneficial treatment, their health will be negatively impacted. Even a noneffective treatment or procedure may allow for the patient's condition to worsen, substantially affecting short and even long-term health outcomes. Categories requiring exnovation and strategies to achieve reduction in effective services are summarized in Table 36.1.

Pathways to Exnovation

Several years ago a provocative editorial in the *New England Journal of Medicine* was entitled "Waste, We Know You Are Out There" (Aaron, 2008). It has been estimated that at least 750 billion dollars a year is being spent on services that provide little value. Yet identifying and eliminating these services remains an important challenge (Smith, Halvorson, & Kaplan, 2012). Is it realistic that we can do something about it?

There are at least four pathways to identifying and eliminating the use of unnecessary services. These approaches involve control by payers, change of practices by providers, increased engagement in decision making by patients, and efforts to use research data to inform exnovation. We will consider each of these approaches.

Payer Control One way to exnovate is through the policy changes that allow those who pay for health services to restructure their policies and emphasize payments for services that provide value to patients. Under the Affordable Care Act, significant progress is being made. The Center for Medicare and Medicaid Services (CMS) innovation center (known as CMMI) was created to improve all aspects of patient care, including safety, effectiveness, patient centeredness, timeliness, efficiency, and equity. Ultimately, the center hopes to stimulate better health for the population by encouraging healthier lifestyles, promoting the avoidance of risky behaviors, and encouraging better use of primary and preventive care. They believe that promoting preventive medicine and improved coordination of healthcare will result in lower healthcare costs. A major part of this effort is in finding more efficient ways to reimburse healthcare providers. For example, bundled payments change the way providers are reimbursed. The old system rewarded a high volume of healthcare services. For example, when a patient received surgery, several different healthcare providers billed for their services and the hospital and supportive providers each were reinforced for adding components for this service. Under bundled payments, a single fee is generated for the entire surgery and the providers and hospitals must decide how to divide up the payment. Instead of rewarding inefficient volume, the strategy encourages efficiency and value for the recipient of care. The US Department of Health and Human Services recently announced plans to reward value over volume in payments made to providers in their Medicare programs (Burwell, 2015).

The innovation center also encourages greater use of primary care. A large literature suggests that overuse of medical specialists creates greater expense without improving patient benefit. CMMI is experimenting with programs that offer bonus payments to primary care doctors who achieve better coordination of care for their patients.

Provider-Based Exnovation Some organizations are beginning formal exnovation exercises. For example, the American College of Physicians (ACP) identified 37 screening tests that should be used less often (Qaseem, Alguire, et al., 2012). The ACP suggested that excessive and unnecessary testing costs $200 to $250 billion dollars per year. Some of the most commonly overused tests include imaging studies, CT scans for benign disease, and the overuse of electrocardiograms in patients without symptoms. The ACP considered both the value and the cost of tests. The exnovation exercise is not simply an attempt to cut high-cost tests. Some high-cost tests and treatments also provide high value to patients. For example, antiretroviral therapy for patients with HIV disease not only prolongs life but also reduces the probability of transmission to uninfected partners. These drugs, although very expensive, also provide exceptional benefit and are considered high cost plus high value (Fauci & Folkers, 2012). Conversely, some tests are inexpensive but also provide essentially no value. As stated previously, one example is the annual Pap smear for a low-risk woman. Although screening every third year provides substantial benefit, the incremental benefit of annual screening is remarkably small (Hagen, Garber, et al., 2001). Similarly, chest x-rays prior to surgery for healthy adults provide very little information. Although costs are relatively low, value is also low (Archer, Levy, & McGregor, 1993).

The ACP brought expert clinicians together to consider which tests needed exnovation. They created a working group and each member was asked to identify five screening or diagnostic tests that resulted in little value for patients. Tests that received unanimous consensuses among the groups were retained. If the test was identified as a candidate by at least two thirds of the group, it got further discussion and was only retained if the group ultimately reached consensus. Through this process, 37 commonly used tests were identified.

The group identified two basic principles for exnovation of tests. First, they suggested the tests should not be used routinely if the results would not alter their clinical practice. The second principle was that tests should not be used if the likelihood of a false positive exceeds the likelihood of a true positive. This can happen when the initial probability of a condition is very low. For example, for young men without any symptoms of cardiovascular disease, the likelihood of significant coronary artery disease is low. On the other hand, the probability of a positive exercise stress test is about 50% for women 40–59 years of age who did not have coronary disease and 66% for healthy women over age 60 (Cumming, Dufresne, et al., 1973). Those who have a positive test are then likely to get other diagnostic testing which might result in both psychological distress and, in some cases, physical harm. Costs of the unnecessary test go beyond testing costs. There might be additional time lost from work and costs associated with additional tests to rule out concerns raised by the false positive evaluation.

The "Choosing Wisely" initiative was developed by the ABIM Foundation and quickly spread to many specialty organizations. By 2013, at least 40 groups had created lists of five things providers should question. Although there is much to applaud about Choosing Wisely, important questions have also been raised. In particular, tests and procedures that are used much more frequently in some geographic areas often raise concerns, particularly when regional variation is unassociated with patient outcomes. Yet, there was considerable inconsistency in the listing of these high variation tests and procedures by some groups. The American Academy of Orthopaedic Surgeons questioned low-cost and perhaps harmless over-the-counter supplements and relatively low-cost durable equipment items but did not include several controversial high-revenue-generating procedures as items to question. Specialty groups often questioned activities provided by competing medical specialties, but were less likely to list tests and other medical services that generated significant revenue for their own specialty (Morden, Colla, et al., 2014). Although Choosing Wisely has enormous potential, we await evidence that it affects practice, particularly in relation to the reduction in the use of high-cost unnecessary services.

Consumer-Based Exnovation A major problem in healthcare is the imbalance between the knowledge and power of patients and providers. Often, physicians choose treatments on behalf of their patients. The problem is that physicians have substantial incentives to provide expensive and often unnecessary services. Because there is an imbalance in knowledge about the value of services, patients are at a disadvantage. Shared medical decision making is a process by which patients and providers choose among multiple, clinically appropriate interventions or strategies, taking into account the patients' values and preferences. In some cases, shared decision making simply gives patients more information about the choices they will encounter. In other circumstances, shared decision making involves assessment of patient preferences and values. For example, the value of aggressive surgical treatment for prostate cancer is uncertain (Andriole, Crawford, et al., 2009). However, aggressive treatment is likely to result in serious consequences including impotence. For some older men who are not sexually active, impotence is not a major concern. For others fear of impotence may play an important role in decision making. The shared decision making paradigm involves measuring preference for outcomes and integrating them into the decision process (Frosch & Kaplan, 1999). A variety of studies suggest that engagement in shared decision making is associated with more conservative patient decision making, lower costs, and greater patient satisfaction (Frosch, Kaplan, & Felitti, 2001, 2003).

When presented with the full picture of information about the risks and benefits of treatments, patients often make conservative choices (Kaplan, 2009). One example concerns surgery for back pain. The United States has a significantly higher rate of back surgery than any other developed country (Deyo, Mirza, & Martin, 2006). However, these surgeries are not always necessary, and in most cases, the surgery is elective and there is reason to believe that medication alone may produce equivalent results (Deyo & Ching, 2012).

A clinical trial compared surgery with prolonged conservative treatment for adults with radiologist confirming herniated disks. The surgery patients received surgical treatment within 2 weeks while the other group got physical therapy and medical support. Some of these patients eventually chose to have surgery. Although the surgery patients got better sooner, after 1 year, the outcomes for the two groups were equivalent.

Deyo reviewed a series of surgical trials and considered the question, "who needs back surgery?". He concluded that surgery may be necessary for those who have major motor deficits because of disk problems and those who have had trauma to the spine. Most people with herniated disks or spinal stenosis, according to Deyo, do not need surgery. Surgery may offer pain relief, but that comes with some risks. For most patients, shared decision making is the recommended method for finding the best pathway (Deyo & Ching, 2012).

Deyo and his colleagues conducted a systematic clinical trial to evaluate the effects of shared decision making. Three hundred ninety-three patients who were candidates for elective back surgery were randomly assigned to an interactive video explaining the risks and benefits of back surgery or to a control group. (Both groups got a booklet describing back surgery.) The study demonstrated that exposure to balanced information reduces the number of back surgeries without any adverse consequences on health outcome (Deyo, Cherkin, et al., 2000). The reduction was most likely in the clinical group that was least likely to benefit from surgery.

Research-Based Exnovation In addition to the use of payer, provider, and consumer efforts to reduce use of ineffective practices, a fourth pathway is through research. We see the value of the research field in enhancing all stakeholders' ability to identify and support exnovation. Research into the ongoing comparative effectiveness of different treatment and preventive interventions, for example, may show that even evidence-based practices are less effective than alternatives and should be withdrawn. This same research may be able to identify *for whom* a given intervention works and permit partial exnovation of a practice for those who do not benefit from it.

Research can also identify key strategies, at a given level (i.e., patient, provider, system) or across multiple levels to successfully exnovate a specific practice or set of practices. In the same way that researchers are actively testing strategies to promote adoption, implementation, and sustainability of effective innovations, they can also test strategies to reduce unnecessary use. With the evidence base for any specific intervention constantly evolving, we should expect that the next great innovation may someday be the target of rational exnovation efforts. Health systems, with research evidence, may be able to plan for future exnovation of practices, as well as substitution of an improved practice for that which is currently in use.

The Dividend for Exnovation

Conservative estimates suggest that about US$750 billion are spent on services that provide essentially no health benefit (Berwick & Hackbarth 2012). Others have suggested that the excess may cost as much as 1.2 trillion (Berwick & Hackbarth 2012).

Identifying and cutting these expenses will harm few people, although it will reduce the income of healthcare providers and hospitals. The flip side is that there will be substantial benefits because funds can be put to better use. We sometimes react to concerns for costs as the insertion of the values of business or "the bean counters" in places where only human outcomes should matter. "It doesn't matter how much it costs if it saves one life…." Consider, however, the concept espoused by Martin Luther King that "budgets are moral documents." They express the values of groups as they allocate resources to one or another purpose. For example, the component of the US global competitive index that reflects health and primary education investment, once among the highest in the world, has slipped to 42nd. Further, excessive spending on healthcare contributes to the federal deficit because nearly half of all health services are federally funded. In 2011, for example, the state component of the Medicaid programs used nearly a quarter of the average state budget (McCullough, Zimmerman, et al., 2012). Reducing payments for health services that provide essentially no health benefit would produce a windfall in revenues that could be used for infrastructure development, such as the development of safer communities, better education and nutrition programs, and improved transportation. It might also lead to greater fiscal stability and debt reduction and provide opportunities to support disease-preventing programs such as anti-tobacco campaigns, services for pregnant smokers, or drug use prevention.

Summary

Healthcare is the largest sector in the US economy. Despite spending significantly more on healthcare than any other country, health outcomes for Americans are not exceptional. Life expectancies for Americans are increasing, but the rate of increase is not keeping pace with other wealthy countries. From a consumer perspective, we are paying more, but getting less value.

Part of the problem with American healthcare is that we may be overpurchasing services that have little to no effect on health outcomes, while underpurchasing evidence-based services that have the potential to improve health. In addition, decisions about use of healthcare are often based on surrogate markers, such as blood glucose, rather than on patient-centered health outcomes. Sometimes changes in the surrogate measure are unrelated to improvements in outcomes that are meaningful to patients, including life expectancy and health-related quality of life. In order to address these problems, we need new approaches to health resource allocation that improve the dissemination and implementation of evidence-based services and decrease the use of unnecessary and ineffective services.

Innovation is at the core of medical research and the advance of healthcare practice. Innovative practices have greatly improved the care of patients. On the other hand, not all innovations result in better care and improved outcomes. A growing literature suggests that many expensive interventions provide essentially no benefit. At the same time, some interventions expose patients to unnecessary risk. In addition to the physical harms, overexpenditure has other consequences because of lost opportunities to use resources for services that benefit populations.

Exnovation is a process by which services that are not clearly supported by evidence are extracted from practice and replaced by other services for which there is a stronger evidence base. Although difficult, exnovation might be achieved through modification of payment to providers, through reform efforts initiated within healthcare practice groups, by greater activation of patients in the decision process, and by research on exnovation strategies. Successful exnovation might have broader societal benefits including reductions in the federal deficit, support for nonmedical social services that enhance population health, and greater patient participation in medical decision making processes.

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37

Impacts of Emerging Fundamental Science on Health, Behavior, and Their Interaction

Bradford W. Hesse

Biomedical Discovery in the Twentieth Century

In the first part of the twentieth century, major advances in world health came about primarily through insights garnered from studying populations of individuals and the environment in which they lived. Epidemiologic studies of the patterns of disease throughout a population coupled with fundamental research in microbiology and toxicology led to the revelatory knowledge that paying close attention to a community's water supply, sanitary conditions, and food sources could prevent some diseases altogether. Large public work projects were launched to improve the living conditions of communities and to combat the spread of bacterial or viral infections. Social scientists became engaged in the task of improving communication between public health officials and the general public, as mass media campaigns were initiated to raise awareness on how to improve living conditions and how to engage in self-protective, hygienic behavior. Social scientists were also heavily involved in offering evaluations of health programs in an effort to identify the techniques that were most successful in moving the needle on public health objectives (Colgrove, Markowitz, & Rosner, 2008).

At the midcourse of the twentieth century, in the era of prosperity following the Second World War, industrial nations around the world began investing in a framework of fundamental science and engineering that would soon lead to a "golden age" in clinical medicine. Advances in fundamental knowledge about biochemical processes, for example, would lead to the so-called miracle cures of the twentieth century. In 1952 the first randomized controlled trial was published (Daniels & Hill, 1952), ushering in an era of evidence-based medicine and establishing a pipeline for the industrial age pharmaceutical treatments emerging from the rapidly evolving knowledge base in biochemistry. Likewise, advances in physics would soon lead to a revolution in the ways in which physicians could diagnose disease or injury through radiographic imaging techniques and to the use of radiation to target and eradicate cancer cells (Mukherjee, 2011). Fundamental discoveries in biomechanics would soon lead to life-saving procedures for extending heart life, repairing aneurysms, filtering blood toxins, preventing long-lasting injury, and restoring function from broken or missing appendages. Behavioral scientists were called upon to enhance compliance with complicated therapeutic demands and to provide coping skills for living with the sequelae of invasive procedures.

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As a result of these fundamental discoveries and their interactions with public health and behavioral medicine, great strides were made globally. For example, in 1910 the life expectancy for a Chilean female was 33 years; by 2010 that life expectancy rose to 82 years, a remarkable gain of almost 50 years over one century (World Health Organization, 2010, 2012). In the United States, average life expectancy rose from 48 in 1900 to 74 in 2000 for men and from 51 in 1900 to 80 in 2000 for women (National Center for Health Statistics, 2010). Because of these strides, the World Health Organization has predicted that by 2050 the absolute number of older people aged 60 years and over is expected to increase from 606 million to 2 billion people. The repercussions of these fundamental discoveries will continue to be felt as families and policy makers seek to protect quality of living and promote independence among those benefitting from life-saving science (Fishman, 2010; World Health Organization, 2012). In the wake of these changes, practitioners of behavioral medicine have been called upon to contribute an understanding of the neurological effects of aging (Buscemi, Steglitz, & Spring, 2012), to support caregivers and community systems (Buman, Winter, et al., 2012), and to inform practice through data (Toobert, Glasgow, et al., 2012).

Funding for behavioral medicine began to flourish in the second part of the twentieth century as epidemiological observations of atherosclerotic cardiovasculature conditions uncovered the implications of lifestyle choice in the etiology of heart disease. Behavioral researchers and practitioners were brought in to help cardiac patients change their lifestyle choices, to lose weight, to select healthier diets, to exercise, and to stay adherent to prescribed regimens of preventative medical treatments. A more comprehensive biomedical understanding of the toxic relationship between tobacco smoke and lung disease was revealed in the 1964 Surgeon General's report on smoking and health (US Department of Health, 1964). It took decades of unrelenting behavioral research along with mission-focused public health practice to turn the tide against nicotine addiction at a population level. The first downward spiral of mortality rates from lung and bronchus cancer in the early 1990s in the United States marked a watershed victory in behavioral medicine (Hiatt & Rimer, 1999). Full utilization of those findings in the global arena has taken longer, with efforts from an international cadre of behavioral scientists needed to adapt findings to local, political, and cultural contexts (Eriksen, Mackay, & Ross, 2012).

Fundamental Discovery in the Twenty-First Century

To be sure, the medical victories of the twentieth century were substantive, as the director of the US National Institutes of Health (NIH) explained to members of the US Congress in 2004, but they fall short in meeting the challenges of the next century (Cullington, 2006). "Medicine in the 20th Century was reactive," he explained; it waited until the disease had fully occurred before intervening with ameliorative treatment. By that time, substantial tissue damage may have had already occurred, and care providers would be left trying to prolong life with expensive and invasive treatments. Life expectancy would go up, but quality of life – especially during the waning years – would remain poor. Medicine in the twentieth century was a legacy of the industrial age. Treatments were mass-produced to reach the widest swath of patients with a one-size-fits-all approach, an approach that was successful at extending reach globally and internationally but that often resulted in excessive waste or mismatched therapies at the personal level (Cullington, 2006).

Fundamental discovery in medicine is moving beyond the limitations of the previous century, the NIH director explained. Completion of the Human Genome Project in 2003 (an extraordinary international effort to document the 3 billion + base pairs of the human genetic code) ushered in an age of molecular medicine in which an understanding of the preclinical, cellular events leading to disease would eventually allow healthcare practitioners to identify early warning signs of risk before disease occurs

(Cullington, 2006). The future will be an era of "four P's" medicine; it will be *P*redictive, *P*reemptive, *P*ersonalized, and *P*articipative. It will be *predictive* in the sense that an improved understanding of molecular pathways leading to disease will allow practitioners to identify the predisposing conditions leading up to a deleterious health condition early in its genesis, well before visible symptoms occur and tissue damage begins. It would then be a relatively easy task to intervene in the disease process in a *preemptive*, rather than an ameliorative, way. These profiles of risk, detectable at a subcellular level, will differ from person to person. New fundamental discovery in microchip technology should make it possible to keep track of these changing risk profiles over time and to tailor treatments adaptively to the personal characteristics of each individual patient. In this sense, treatments in the twenty-first century will increasingly be more individualized, yielding results that are "orders of magnitude more effective" (Cullington, 2006) than industrial age approaches. Those movements from an industrial model to a *personalized* model will pragmatically and ethically require that care be given in an increasingly *participative* way. Patients will need to become part of the care team to minimize error, preserve quality of life, and optimize outcomes (Cayton, 2006; Cullington, 2006).

This overarching trend – turning medicine from an industrial, one-size-fits-all approach to one that is predictive, preemptive, personalized, and participative – is a central, organizing principle within this chapter. As new fundamental discoveries exert a "disruptive" influence on medicine (Topol, 2012), it will be incumbent on behavioral scientists and health system researchers to gather the evidence needed to serve the interests of the "whole patient," including the patient's psychosocial needs (Adler & Page, 2008). Practitioners of behavioral medicine will be needed to serve as the "linking pins" (Davis, McGregor, & Likert, 1989) between biomedical science and the platforms that will serve to empower patients, the general public, and the professionals who care for both. As medical technology becomes more advanced, the need to integrate an accompanying understanding of human behavior increases (Goetz, 2011).

Anticipating the Future

What will a new age of fundamental discovery mean for researchers and practitioners of behavioral medicine in the twenty-first century? To answer that question, it is useful to go beyond fundamental biologic discovery to examine predictions for how health and healthcare may be altered by innovations emerging across multiple scientific fields. Scientists at the Massachusetts Institute of Technology refer to this as an era of "convergence" between the life sciences, the physical sciences, and engineering (Massachusetts Institute of Technology, 2011). It will account for some of the fundamental discoveries that are sure to influence healthcare and wellness over the next century, from the predictive information that comes from increasingly fine-grained bioimaging and modeling technologies to the highly personalized treatment modalities made available through molecular medicine and nanotechnology-based delivery systems. Most of these new discoveries will be enabled by, or made available through, the context of highly networked, ubiquitous, and computationally sophisticated information systems (Hesse, 2008b; Nielsen, 2012; Topol, 2012).

A good source for predictions about the influence of these discoveries can be found in the reports generated by the *Institute for the Future* in Palo Alto, California. The institute was founded by a former group of RAND Corporation researchers in 1968 to take leading-edge research methodologies into the public and private sectors. The organization uses multiple techniques including the use of surveys, interviews, archival documents, statistical modeling, and comparative forecasting to do trend analysis for a variety of clients (Johansen, 2007). In 2009, the institute released a report from its Health Horizon's Program anticipating trends up until the year 2020 (Adler, Dunagan, et al., 2009). The report was organized around six mega-trends resulting from their analysis of changes in the scientific and organizational milieu surrounding health and healthcare. The megatrends provide a framework from which to view the continued pipeline of scientific development within the healthcare sector, and they offer a lens through which the interaction between fundamental discovery and behavioral medicine can be viewed. Each will be discussed below, with a predictive analysis for what each of these new fundamental changes might imply for behavioral medicine in the years to come.

Combinatorial Innovation in Health Information Technologies

The Trend

Fundamental advances in engineering have produced an age of ubiquitous computing in which microprocessors are finding their way increasingly into an interconnected network of smart mobile devices, sensors, advanced imaging devices, laptops, and desktops. Information architects have been working on the standard technological and semantic protocols necessary to interlink data from these independent devices into a seamless web of services available to users at any time and in any place through "cloud architectures" (i.e., configurable networks of servers, storage devices, applications, and services available to users remotely through the Internet). Moreover, because these networks span borders, they may provide access to medical knowledge and personalized service universally, regardless of geography or even language. Understanding how these technologies may change healthcare, though, means understanding how interconnected services change business practice.

A presage for the global changes to emerge within the health sector may be glimpsed from the transformations already wrought in international finance and world air travel (Friedman, 2007). The financial industry has morphed (for better or for worse) from a loose collection of parochially limited financial institutions to a broad consortium of globally facing financial networks, all interconnected through wide area networks running highly advanced translational algorithms to move large sums of money across currencies and across economies instantaneously. On the positive side, savvy consumers can find themselves in a world in which they have immediate access to their money, and information about their money, 24 h a day, 7 days a week through an international network of automated teller machines, online banking tools, interactive voice response systems, and mobile device "apps." On the negative side, the unanticipated consequences of an international investment system based on highly sophisticated, but increasingly obfuscated, computer algorithms were blamed with triggering many of the poor financial decisions leading to the global economic crash of 2008–2009 (Salmon, 2009).

Unanticipated effects notwithstanding, these sector-wide transformations based on networking and information technology have helped many sectors in the global economy realize productivity gains while reducing costs. Up until now, however, these benefits from information technology have been slow to stimulate cost savings in the healthcare sectors (Cutler, 2007, 2009). That was the trend that the US Congress attempted to change when it passed the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 (Title XIII of the American Recovery and Reinvestment Act). In anticipation of broader healthcare reform efforts in the USA, the Act was intended to spur economic savings and to improve population health by encouraging the "meaningful use" of health information technology (HIT) in the service of patient-centered care.

In translating the HITECH Act into practicable terms, the Office of the National Coordinator for Health Information Technology (ONC) in the USA is encouraging market-driven innovation based around an evolving set of standards for health information exchange (Williams, Mostashari, et al., 2012). The goal is (a) to invest in the standards and technologies needed to ensure protected data flow of health information and then (b) to allow the market to combine distinct elements from an emerging *health* *information technology* (HIT) marketplace into novel products and services that will ultimately improve personal and clinical health. This is the essence of "combinatorial innovation," to nurture an emerging ecosystem of health information technologies based on novel combinations of evidence-based innovations as depicted in Fig. 37.1.

Implications for Behavioral Medicine

For researchers and practitioners of behavioral medicine, this change in the philosophy of health services innovation should help drive a newfound relevancy for the theories, foci, and empirical methods of behavioral research. As the authors of a US-based National Research Council report on "Computational Technology for Effective Healthcare" explained, the target for innovation in health services research should no longer be on the development of new and more expensive technologies, but on the behaviors and context that will drive improved patient outcomes. Funding agencies should "rebalance" their portfolios away from pure technology development to emphasize the behavioral targets associated with providing better "cognitive support" for physicians, patients, and their caregivers (Stead & Lin, 2009).

As the market gears up to innovate on the myriad ways in which new technologies can be combined to support personal health, the work of behavioral scientists will be needed to help shape the technologies' designs in accordance with evolving theories of human health behavior (Riley, Rivera, et al., 2011). Failure to include the perspectives of behavioral scientists in the development and evaluation of these new health-related applications will simply lead to recursive failures in the marketplace in the most benign scenario (Mandl & Kohane, 2008, 2009), or to squandered opportunities for saving lives in the worst case scenario (Abroms, Padmanabhan, et al., 2011; Ahern, Woods, et al., 2011). By the same token, a failure to update the theories and methods of behavioral medicine to take full advantage of the enhanced capacity and real-time testing environments available within these new ecosystems will unnecessarily slow down development (Collins, Murphy, & Strecher, 2007) or could leave behavioral medicine behind as an irrelevant science (Riley, Rivera, et al., 2011).

When contemplating the role of these new emerging technologies, behavioral scientists will be the first to recognize that the new HIT ecosystem cannot – and should not – replace crucial person-to-person communications (Epstein & Street, 2007). Rather, the new ecosystem should serve to augment human capacity (Zuboff, 1988)

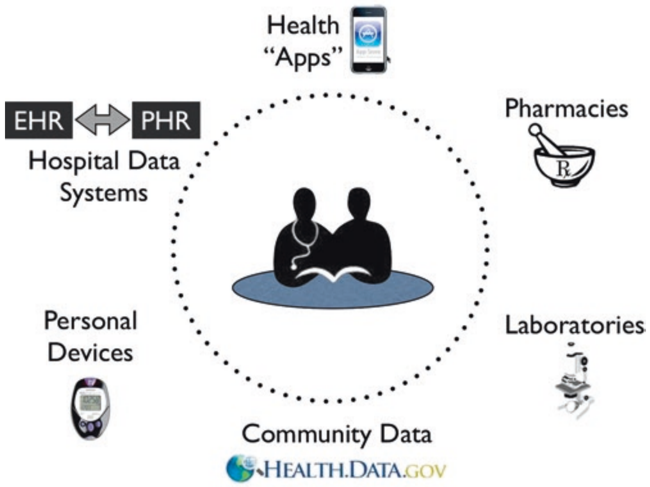

Fig. 37.1 The evolving health information technology (HIT) ecosystem

within the broader systems in which productive and essential conversations occur (Hesse & Shneiderman, 2007). In this sense, it is useful to bear in mind the basic precepts of a sociotechnical design perspective (Coiera, 2004; Pava, 1983): (a) that technical systems have social consequences; (b) that social systems have technical consequences; (c) that we don't design technology, we design sociotechnical systems; and (d) that the key for behavioral science in the future will be to understand how people and technologies interact. The work of communication scientists will be needed to improve the fidelity of signals passed between the patient and the healthcare system, between the patient and their associated networks of social support, and between components of the healthcare system (Hesse, Hanna, et al., 2010; Taplin, Mylks, et al., 2010; Taplin & Rodgers, 2010). Issues of intrinsic motivation will come to bear as system designers find ways to preserve a sense of patient autonomy in decision-making, while enhancing a sense of self-efficacy in mastering health-relevant behaviors and preserving or expanding the patient's sense of connectedness to important others (Hesse, 2008a; Williams, Lynch, & Glasgow, 2007).

From a sociotechnical perspective, there will also be a need for behavioral scientists to monitor the evolution of an HIT ecosystem from the population level (Abernethy, 2011; Forman, Greene, et al., 2010; Hesse, 2007). The work of sociologists and epidemiologists can contribute to our collective understanding of how well the individual components of the rapidly evolving system are working together to influence population health. Are some developments caustic, resulting perhaps not in improved health for all but in reduced health outcomes for some disadvantaged populations (Neter & Brainin, 2012)? If so, what are the policies needed to control for deleterious consequences or to promote alternative solutions? Are innovations lacking reach or diffusion, leaving pockets of the population unnecessarily at risk (Dearing & Kreuter, 2010)? If so, then what processes can be put in place to improve the diffusion potential of efficacious applications (Dearing & Kreuter, 2010; Kreuter & Bernhardt, 2009)? Behavioral medicine at a systems level can be applied to improve system-wide performance of a targeted innovation by monitoring inputs and outputs and by offering empirically based recommendations for improving reach, efficacy, adoption, implementation, and maintenance (Glasgow, McKay, et al., 2001).

The Health Data Marketplace

The Trend

Documenting the human genome introduced a new era of quantified medicine, one in which the molecular profile of individuals could be funneled through the increased processing power of high-throughput computing systems to enhance discovery at both the molecular and population levels (Collins, 2010a; Hesse, Croyle, & Buetow, 2011). It was the harbinger of what some have called "the fourth paradigm" in science (Hey, Tansley, & Tolle, 2009), that is, a succession of scientific capability from basic observation (first paradigm) to the evolution of theory (second paradigm) to hypothesis testing using statistical analysis (third paradigm) and now to the use of data-intensive computing (fourth paradigm).

Genomics pioneer Craig Venter projected that in this new paradigm, "genomic data will soon become a commodity" (Venter, 2010). As he explained it, the challenge of linking genetic variation with physiology and disease will be just as daunting, if not more so, than the original challenge of documenting the human genome. Individuals themselves will find ways of contributing data on their own biologic selves to the combined efforts of scientists in order to achieve progress in combating complex diseases. Setting the pace for a new era of personal data sharing, Venter himself became the first volunteer to make data on his own personal DNA inventory publicly available to researchers in 2007 (Levy, Sutton, et al., 2007).

Around the same time that Venter was making his personal genome fully available to researchers, the start-up company "23andMe" (named after the 23 chromosomes in a human cell) opened its virtual doors for business. The company was one of several efforts to take personal genomics technologies straight to consumers (Lee & Crawley, 2009). Its stated purpose was to "empower individuals" with information from their own genetic risk profiles, while "accelerating science" with data that could be accumulated and mined for new associations between genetic profiles and disease (see https://www.23andme.com/).

This latter point was a transformative concept. It pointed to a way in which citizens, connected directly to each other and to the scientific enterprise, could work together to advance the science and to make progress against diseases. To make the new concept tangible, the company in partnership with Google® enticed members of the 23andMe community to make their genetic information along with inquiries about their personal health and lifestyles available to researchers. With massive amounts of personal genomic information at hand, Google engineers sought to replicate the findings of an NIH study exploring links between a mutation of the beta-glucocerebrosidase gene (GBA, linked to clinical manifestations of Gaucher's disease) and risk for Parkinson's disease. Whereas the NIH study took 6 years to complete, the data-intensive parallelism of the 23andMe study took only 8 months to complete (Do, Tung, et al., 2011; Eriksson, Macpherson, et al., 2010; Lee & Crawley, 2009; Prainsack & Wolinsky, 2010).

"Citizen science" (Kremen, Ullman, & Thorp, 2011) is not a concept lost on governments, either. By investing in a program of "participatory sensing," the US National Science Foundation illustrated how citizens could volunteer to record and share air quality, noise level, geographic position, and even personal biologic data through sensors attached to their smart phones (Estrin & Sim, 2010; Mills & Curtis, 2008). In a similar vein, the European Grid Infrastructure project demonstrated how a high-throughput computing environment could be established to ease data sharing among participating countries within the European Union (Diomidous & Zikos, 2012). The public-facing "PatientsLikeMe.com" Web site extended the concept of citizen science to the multinational pharmaceutical sector by offering access to patient-contributed physiological and self-report data in exchange for an opportunity to accelerate progress toward reliable treatments (Wicks, Massagli, et al., 2010).

What each of these new developments illustrates is the emergence of a new data-intensive marketplace for discovery and innovation resulting from the proliferation of data-generating technologies in biomedicine. The genome sequencing devices on the market in 2011, for example, operate at a rate 50,000 times more quickly than the devices used to complete the first two copies of the human genome in 2003. Costs associated with data collection, storage, and processing have also gone down. In 2007, the asking price for a direct-to-consumer personal genomic risk assessment through 23andMe was $999. In 2011, that price had fallen to an introductory offer of just $99 with a small commitment of $9 per month for a 1-year subscription to the company's "personal genome service."

Implications for Behavioral Medicine

The implications of this new data-intensive ecosystem for behavioral research are themselves daunting. We know from human factors studies that *too much data* presented in the wrong way and at the wrong time can create confusion and paralysis (Nelson, Hesse, & Croyle, 2009; Shenk, 1997). On the other hand, a user interface that is designed to optimize the flow of information in ways that are compatible with human sensory and memory limitations can provide depth and clarity to decision-making (Albers, 2005; Shneiderman & Plaisant, 2010). Consider the simple, clean interface of the Google® Web site. The engineering work at the back end to funnel the right information onto the screen at the right time in accordance with a consumer-focused understanding of user needs has driven the value of the company to the top of its sector. In health, we know that "Dr. Google" often replaces visitation with a real doctor as the first source of contact with biomedical information (Hesse, Moser, & Rutten, 2010; Rochman, 2010). It is simple to use and easy to access (even by mobile telephones) and provides an immediate gateway to the exabytes of data on the open Web. Or consider the engineering accomplishment of channeling real-time satellite telemetry data on top of terabytes of geographical information system data to guide automobile drivers safely on the road aided by their own geographical positioning system (GPS). Engineers worked closely with cognitive scientists for over a decade of focused research to ensure that the data presented through the system did not overload the capacity of a potentially distractible driver.

In an October 2010 conference of the "Health 2.0" innovators' collaborative, computer publisher Tim O'Reilly explained that the ubiquity of health data access would be one of the most significant drivers of health system redesign in the coming decade. Data will become the new "Intel inside," he had been quoted as saying, for a health system striving to increase the personal engagement of individuals and families in preemptive strategies that are evidence-based and participative. What the health system needs, he explained, is an information nervous system; a system that provides all participants in clinical and public health with the right information, presented to the right people, at the right time based on credible data flows. Who would be better than researchers and practitioners in behavioral medicine to help health system engineers understand what the afferent and efferent qualities of a health information nervous system should be?

In the upcoming decades, it will be important for professionals in behavioral medicine to participate directly within these emerging health data markets and not to shy away from them. An exemplary vanguard in this sense is the CYCORE (standing for *Cy*berinfrastructure for *Co*mparative Effectiveness *Re*search) project funded as a collaborative effort between the MD Anderson cancer center in Houston, Texas, and the Supercomputer Center at the University of California at San Diego (UCSD) in La Jolla, California. The precipitating stimulus for the project was the recognition that "learning healthcare systems" must be able to take advantage of internal data flows in order to conduct the comparative effectiveness research needed to improve quality of outcomes while reducing costs (Institute of Medicine, 2011). In many of the discussions surrounding comparative effectiveness research, however, the data are often not available for testing behavioral interventions. The CYCORE project is tackling that problem directly by demonstrating how behaviorally relevant information can be included in the acquisition, storage, visualization, analysis, and sharing of data in a comparative effectiveness context (Patrick, Wolszon, et al., 2011).

Similarly, experts in medical decision-making will be needed to ensure that the presentation of data within a data-infused clinical context will conform to best practices in decision support (Tait, Voepel-Lewis, et al., 2010; Ubel, Smith, et al., 2010). It has been well documented that clinical professionals often underutilize base rate information, that they anchor on first impressions, that they are prey to decisional heuristics, and that they are prematurely dismissive of uncertainty (Montgomery, 2006). Decision scientists have been able to reverse these effects with decision aides that make the right information salient while reducing the burden of high cognitive overhead (Galesic, Garcia-Retamero, & Gigerenzer, 2009; Galesic, Gigerenzer, & Straubinger, 2009; Wegwarth, Gaissmaier, & Gigerenzer, 2009). These effective decision aides can reduce errors within systems while freeing up the clinician's time for more important judgments, such as assessing a patient's emotional and social needs rather than calculating Bayesian probabilities. In a data-intensive healthcare system, every interface to the system is a potential decision aide (Zheng, Padman, et al., 2009). It will be as important to engineer those interfaces to ensure optimal functioning in medical decision-making as it was to craft the geographic positioning systems to support safe driving.

In a truly participative environment, though, data should not simply be the provenance of medical professionals. Patients should be given the chance to review their laboratory findings outside of the office visit as well as in consultation with an appropriately trained medical professional. In this sense, it will be even more important for cognitive and decision scientists to assist in crafting the environment in which these data are presented to lay audiences. Lay audiences, of course, are subject to many of the same decisional heuristics as professionals (Nelson, Hesse, & Croyle, 2009; Schwartz, Woloshin, & Welch, 2007; Woloshin, Schwartz, & Welch, 2007), but without the medical or scientific background to interpret even basic statistical concepts such as probability (Nelson, Hesse, & Croyle, 2009; Reyna, 2008; Reyna, Nelson, et al., 2009; Schwartz, Woloshin, & Welch, 2007; Woloshin, Schwartz, & Welch, 2007). Communication research has demonstrated that it is possible to convey such otherwise complicated concepts as Bayesian conditionalities in formats that are more broadly understood by lay (and professional) audiences (Galesic, Gigerenzer, & Straubinger, 2009; Zhu & Gigerenzer, 2006). More work will be needed to ensure that patients are deriving maximal benefit from an environment that is moving toward evidence as a concrete basis for decision-making.

Reengineering Healthcare

The Trend

Needless to say, the movement from an industrial approach in medicine to one that is predictive, preemptive, personalized, and participative will require an organizational redesign of medical practice. Enervating the health system with actionable and reliable data is only the first stage. From there the challenge will be to create a new workflow in which patients are oriented toward best decisions for healthy living and preemptive vigilance early in their lives and then follow through with the supportive assistance of an interconnected healthcare "system" to add quality and longevity to their lives in proactive ways. In short, the system will need to move away from its current orientation as a provider of sick care to a more idealized and cost-effective provider of healthcare.

One of the most concise, and pointed, set of blueprints for how to redesign healthcare can be found within the set of documents produced by the Institute of Medicine related to their 2001 *Crossing the Quality Chasm* report (Institute of Medicine, 2001). That series of reports pointed to six goals for the redesign of healthcare. The first was to create a system that was *safe*, addressing the often-cited statistic of some 98,000 deaths occurring per year due to some preventable error within the medical system. The second was to create a system that was *effective*, capturing the ideal of moving toward a uniform system of care best on evidence-based guidelines for best practice. The third was to orient systems away from quality as measured by institutional parameters to move toward quality as measured by patients, that is, to move toward a system that was truly patient-centered in its orientation. The fourth and fifth goals had to do with improving the *efficiency* and *timeliness* of care, addressing the escalating costs within the healthcare sector that can be reduced by improving the efficiency through which information flows and actions propagate throughout the system. The sixth goal pointed to a need for *equity*, wherein all types of care – preventative and ameliorative – are offered equally to all populations served by the medical practice (Berwick, 2002; Institute of Medicine, 2001).

All of these goals are reflective of a movement toward creating a system that reliably delivers the best evidence-based treatment possible to every patient, regardless of who the patient sees or the locale in which the patient resides. The challenging nature of delivering high quality care reliably within the complexities of medical practice was revealed by a RAND study in which the study's authors proclaimed that American medicine "gets it right" – in terms of applying consensually approved guidelines for best care – only 54% of the time (McGlynn, Asch, et al., 2003). The remainder represents variation within practices and between practices, a remnant of the days when medicine was considered an individually practiced art form rather than a finely engineered technical system. A data-infused health system could at least help keep track of performance at a system level and, through principles of quality improvement, use that data to track and reduce error (Kohn, Corrigan, & Donaldson, 2000).

Accommodating new knowledge from fundamental discovery within redesigns for healthcare will remain one of the more challenging questions to answer for improving the systemic quality of healthcare. For example, in order to deliver on the promise of "personalized medicine" clinicians will effectively have to take into account information on a patient's individual genetic risk profile, an individual's molecular traces of cellular function or dysfunction, self-reports of risky lifestyle choices, as well as histories of exposure to environmental stressors (McClellan, McGinnis, et al., 2008). As the Institute of Medicine so aptly summarized in the chart depicted in Fig. 37.2, such a task will have long exceeded the cognitive capacities of individuals within the care team. Strategies will be needed to reduce the cognitive load on actors within the healthcare system by reengineering procedures to accommodate the benefits of these new fundamental discoveries without fatally disrupting workflow or exceeding human tolerances (Stead & Lin, 2009).

Implications for Behavioral Medicine

Redesigning the healthcare system to "get it right" reliably, across systems, may imply "rebooting the system" (Hesse, 2010) to include behaviorally oriented therapies as a matter of best practice. For example, results from an NIH study suggested that patients' adherence to a regimen of diet and exercise with a goal of losing just 5–7% of personal weight could successfully prevent or delay the onset of type 2 diabetes (Cullington, 2006). With the impending impact of a widely recognized "obesity epidemic," the amount of money saved and quality of life preserved by including routine support for patients' weight control objectives would save a considerable amount of money at the back end of care. The same goes for the highly preventable instances of tobacco-related illnesses that could be eliminated if the health system were reengineered to deliver substance dependency services reliably as a standard part of preemptive care.

At a broader level, behavioral scientists can offer a contextual understanding of how a redesigned system of care can help nudge desirable

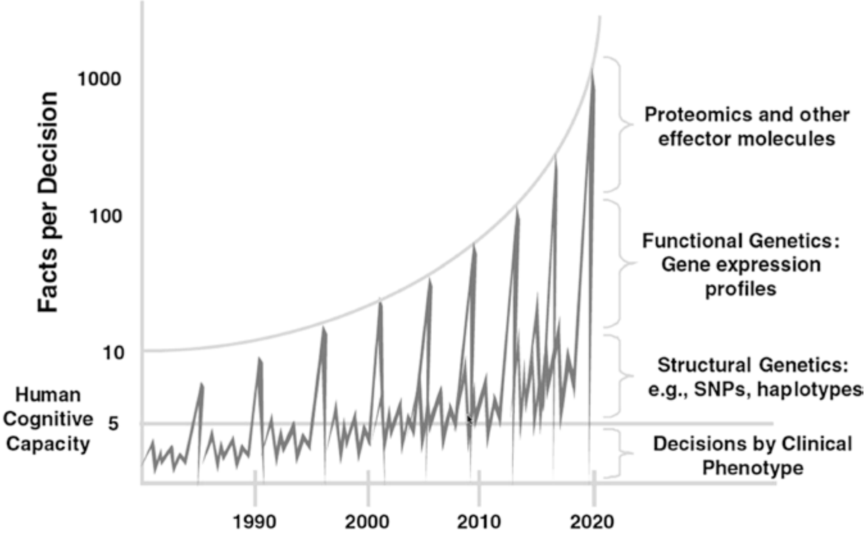

Fig. 37.2 Chart depicting the increased number of "facts" needed for personalized decision-making given explosive growth in fundamental science (Source: Institute of Medicine, "Evidence-Based Medicine and the Changing Nature of Healthcare," Meeting Summary, 2008)

health outcomes (Ahern, Woods, et al., 2011; Hesse, Ahern, & Woods, 2011). For example, electronic health record systems that have been used to offer routine reminders to patients and physicians for age-appropriate screening tests have excelled as an organizational intervention over other types of health system intervention (Klabunde, Lanier, et al., 2009; Nease, Ruffin, et al., 2008; Sequist, Zaslavsky, et al., 2009). Improved communication systems between patients and their care teams have been shown to improve adherence to self-administered treatments, prevent error, and save money in unnecessary office visits (Chen, Garrido, et al., 2009). In a meta-analysis of studies related to health information technology, investigators concluded that although most results of HIT implementation were positive, it was the "human element [that] is critical to health IT implementation" (Buntin, Burke, et al., 2011). Expertise in human system integration, implementation science, behavioral economics, and organizational theory will be needed to assist in the scale-up of effective systematic interventions.

Another challenge of system redesign will be to understand how to bring patients more actively into the process of their own care (Cayton, 2006). To illustrate, the demands of enhanced diabetes management will require patients to keep close tabs on their blood glucose level, to self-medicate as appropriate, and to monitor progress jointly with health professionals. Advances in telecommunications will likely automate the shared monitoring process by sending signals from remote sensors to a centralized gathering place for analysis. A host of implementation questions should then emerge regarding the appropriate frequency of measurements and reports, the format of data for actionable self-management, the creation of warning systems between patients and their providers, and the calibration of equipment to produce optimal signal against the backdrop of real-world noise. As the adoption of personal sensors spreads to international markets, behavioral scientists can use the RE-AIM (extending reach, effectiveness, adoption, implementation, and maintenance) model to adapt the technologies and protocols to be consistent with the mores, norms, and linguistic exigencies of local cultures (Glasgow, Dickinson, et al., 2011; Oldenburg & Absetz, 2011).

Providing support for patients' self-management of conditions takes on special significance within aging populations. Issues of health literacy, impaired memory, or cognitive disorientation can lead to deadly lapses in treatment adherence and self-management (Wolf, Curtis, et al., 2012). With the aging of some of the largest demographic cohorts in world history (World Health Organization, 2012), health system designers will need to consider ways of honoring seniors' wishes to remain at home with a sense of personal independence, rather than follow an automatic path into assisted living or communal care facilities. Honoring these wishes, while at the same time protecting the system from unsustainable economic costs, will likely become an area of acute focus across many nations in the years to come (Fishman, 2010).

Reengineering healthcare should benefit greatly from international comparisons and cooperation (Glasgow & Sanchez, 2011). Most countries differ in the degree to which healthcare is fragmented or centralized, to which preventive care is emphasized over ameliorative approaches, and to which paraprofessionals or teams of professionals engage in care. These naturally occurring experiments present an opportunity for implementation scientists to gather data for the benefit of health service researchers worldwide (Bezruchka, 2012). Comparisons between contexts can offer early evidence for which types of services produce higher quality care in the most cost-effective ways. Behavioral scientists can inform the conversation by orienting analysts toward the appropriate targets for cross-system comparisons and can enrich the discussion with data (Collins, 2010a).

As countries embrace World Health Organization guidelines for data reporting (World Health Organization, 2008), it may also become possible to expand the reach of traditional surveillance systems to achieve regional or global efficiencies. Imagine the power of a "learning healthcare system" that could monitor and report early instances of an avian flu virus in remote regions of the South Pacific, stimulate production of an antivirus in northern France, and then adjust supply chains to prevent or treat disease as needed worldwide. Understanding the complexity of building such a responsive, knowledge integration network could fall within the purview of many "team science" (Stokols, Misra, et al., 2008) experts who could help bridge differences in medical culture while strengthening ties within international consortia (Falk-Krzesinski, Borner, et al., 2010).

A Neurocentric View of Health

The Trend

One of the more intriguing and cautionary predictions from the Institute for the Future's report is the observation that a proliferation of sophisticated, affordable, and pervasive brain scanning technologies is "thrusting the brain into the center of the healthcare ecosystem." Real-time and delayed time images collected through functional magnetic resonance imaging (fMRI), positron emission tomography (PET scans), and fluorescent probes are illuminating the circuitry of the brain in ways that appear to make the inaccessible now accessible. At the very least, the techniques are capturing the imagination of funders and the public as neuroscientists seek to understand the precursors to organic brain dysfunction and as they investigate links between neural processes and converging evidence of parallel cognitive activity.

The power of these new imaging techniques accompanied by a growing understanding of the biochemistry of the brain is beginning to yield substantive leaps forward in our scientific knowledge about neural functioning. Through the use of *neuroinformatic* techniques – a combination of in silico modeling and networked data linking capacities – psychophysiologists are working to combine their knowledge about diverse aspects of neural functioning into a global anatomical map, much in the same ways in which pioneers in human genetics combined their knowledge into a working model of the human genome (Phillips, Nuechterlein, et al., 2011; Toga, Thompson, et al., 1996). The US-based National Institutes of Health has committed some $30 million in its strategic blueprint for neuroscience research to assemble converging evidence on how the 100 billion neurons and 100 trillion connections in the human brain may be implicated with specific sensory, muscular, and cognitive tasks.

The results should be a better understanding, collected through noninvasive techniques, of how the brain functions under both ordinary conditions and under the influence of pathology. Some scientists have begun to patent techniques for observing specific neural signals in relation to pain, a state-based condition that has been notoriously dependent on self-report previously (Goldeen, 2009). With this type of very specific, medical measurement in place, biomedical researchers can begin to work with pharmaceutical companies to create more effective intervention strategies for chronic pain. With the pinpoint accuracy of expanded prediction models, physicians should be able to prescribe more localized and specific types of analgesia. Surgeons may be able to focus their ameliorative procedures on relieving pressure on very specific points of the pain-inducing pathways. By observing the differential functioning of regions within the map over time, neuroscientists should be able to add greater specificity to their predictive models for Alzheimer's, Parkinson's, and other debilitating diseases as well.

Furthermore, these imaging techniques are expanding neuroscience's grasp of basic brain functioning. New knowledge is being gained on how sensory perceptions may vary over individuals or on how conflicting stimuli may serve to short circuit fundamental memory formation processes. Computer simulations of information processing patterns are providing important cues in how the parallel wiring structures of the brain can learn from changes in the contextual environment, while distilling information for higher order processing. New models are being introduced and refined based on this new incoming knowledge for how the brain formulates memories, how it connects disparate memories to derive insight, and how it filters out unwanted information to provide focus in thought. Modeling the consequences of disruption in processing can give new insight to the pathological processes associated with schizophrenia and other mental disorders (Cannon, 2011; Wizemann, Pankevich, et al., 2011).

The wide availability of these neurological imaging techniques has also given new analytic power to professionals working in unusual places. Advertising specialists working to sell consumer products have begun doing their own comparative studies with fMRIs in order to understand how gustatory memories can be triggered by visual stimuli and how "message sensation value" (i.e., the arousal-producing effects of quick-paced videographic techniques) might interfere with message retention (Langleben, Loughead, et al., 2009). That work can have serious public health impact if used to market tobacco products to vulnerable populations or to increase appetites for sugar-sweetened beverages or fat-laden foods (McClure, Li, et al., 2004). Computer software engineers have begun applying the concepts of parallel processing into a particular style of machine learning modeled on brain anatomy referred to as "neural network programming." Although these software programs are a long way off from achieving truly artificial intelligence, they have been applied to the task of delivering superior information selections directly to users and improving the "intelligence" of consumer electronics (Modha, Ananthanarayanan, et al., 2011).

Implications for Behavioral Medicine

Perhaps the rise of a neurocentric view of health, more than any other trend identified by the Health Horizons report, speaks to the importance of behavioral medicine as a guide to the future. Certainly, as the world's population ages through life-extending medical discoveries, the need to predict and preemptively intervene to prevent cognitive decay will be crucial. Population modeling suggests that morbidity from Alzheimer's disease could be reduced by as much as 50% if the onset of the disease could be delayed by only 5 years (Breitner, 1991). Understanding that preemptive therapies might have an influence on delaying onset of the disease, whether that be through the introduction of chemopreventive agents to prevent neural plaque buildup or through intellectual exercises to help keep neural circuitry activated, will be the key to preserving mental functioning in older ages. Researchers and practitioners in behavioral medicine will be needed to provide guidance on diagnosis, prevention, and treatment of this and other neurological conditions.

Outside of the strictly neurological diseases, evidence is emerging to explicate the influence of environmental stressors on neurological functioning and its concomitant influence on other disease processes (McDonald, Antoni, et al., 2005). It has long been understood that stimulation of the adrenergic pathways will influence heart functioning and cardiovascular dynamics, with an activated "flight-or-fight" response stimulating the heart muscles and raising blood pressure. Cardiovascular therapies have therefore included the use of ß-blocker and other adrenergic agonists to control the influence of additional stress when heart function is impaired. Investigations are underway to understand what influence activation of other neurological pathways, such as the dopaminergic and serotonergic pathways, might have on tumor growth and metastasis, on glucose metabolism, and other disease precursors. Specialists in behavioral medicine can contribute to a richer understanding of how psychopharmacological treatments may be needed to accompany traditional treatments for non-neurological disease, either to improve the action of the original treatment or to prevent undesirable side effects (e.g., so-called chemo brain for cancer patients on chemotherapy).

Another contribution from behavioral medicine in the area of neurological functioning is to help explicate the nuanced links between genetic predisposition and health behaviors (Willcutt, Pennington, et al., 2010). As an example, individual genetic differences have been detected in gustatory preferences, metabolic processes, structural bone morphologies, and in other aspects of basic physiology that may predispose some patients to a higher risk for obesity. In a new era of genomic medicine, behavioral practitioners can work with patients to tailor a regimen of food consumption and exercise to mesh with these inherited nutrigenomic tendencies (Kenny, 2011). Likewise, specialists in behavioral aspects of addiction can work to ensure that fundamental improvements in psychopharmacologic treatments are translated into lasting, and personalized, behavior change (Maze & Nestler, 2011).

A Cautionary Note

The report from the Institute of the Future included a cautionary note about the rise of a neurocentric view of health. The field must strive to build on its momentum and expand on its knowledge base; but at the same time, it must strive to avoid the seduction of premature prediction or overselling. Fortunately, the neuropsychologists and psychiatrists operating in the field of behavioral medicine have long understood the dangers of "over-medicalizing" certain behavioral conditions, such as shyness, while taking full advantage of the therapeutic advantages of psychopharmacologic agents for more serious mental health conditions, such as bipolar depression or schizophrenia. Psychophysiological researchers within behavioral medicine have been able to make painstaking leaps forward in going beyond general stress models to identify the specific neural pathways underlying the influence of neural processes on disease. Researchers and practitioners specializing in the aging processes understand fully the risk factors that have already been documented for organic brain dysfunctions and are cautious in prescribing preventions that do not have at least some evidentiary basis.

Personal Health Forecasts

The Trend

As data are generated from multiple quarters to accelerate understanding of biomedical processes, and more sophisticated models are derived to deal with the high dimensionality of those data, the healthcare sector will begin to benefit more routinely from the algorithms biostatisticians create to predict health outcomes. Gradually, the benefit of these actuarial forecasts will begin to enter into the decision support processes used by clinical teams. New data will inform the predictive value of parameters within those models, and new visualization techniques will be constructed to steer decision-making around informative "what if" scenarios. The result will be a set of data-based predictive forecasting techniques that can be used universally to minimize future risk and maximize life goals.

Biotechnology firms are focusing much of their fundamental research and development programs around creating techniques for forecasting future biologic events based on an assessment of personal history and molecular processes. Innovations in the assessment of genomic predispositions, improvements in the ability to predict cellular dysfunction early based on biomarkers in the blood, and the ability to update forecasts based on incoming data from routine medical encounters should all help in making the kinds of early warning health decisions that will help avoid serious illness and extend life (Collins, 2010b). For many, this is the essence of personalized medicine: to create a highly personalized health forecast that will serve to guide health decisions for patients and their care teams over the course of their lives.

As medicine moves more toward preventive strategies, these personalized forecasts should help guide a patient's basic preemptive health choices throughout their life spans. A recorded prevention plan, for example, could trigger individually tailored recommendations for precautionary screenings updated to reflect best evidence for efficacy within risk groups. The plan could offer personalized recommendations for diet and exercise, based on best evidence for how genetic predisposition may influence individual metabolism, and it can offer recommendations for chemoprevention when changes in diet are insufficient. The difference will be to move the decision points earlier in life when a patient can do more with their health decisions, than later in life when repair is more difficult.

The perennial difficulty faced by medical preventionists is in figuring out how to make the consequences of early life decisions apparent to individuals early. Some cutting-edge computer laboratories are tackling this problem by using graphical imaging techniques to illustrate what the consequences of early health choices might be later in life. Using avatars, or three-dimensional representations of persons, these researchers can illustrate what may happen when overexposure to the sun ages skin prematurely or raises the risk for melanoma. The effects of caloric intake and sedentary life style can be modeled on the avatar by showing what a trend toward obesity might look like over a decade or two of unmodified weight gain. Early reports suggest that these types of very engaging illustrations might do a lot in reorienting individuals to think about their future selves and not just focus on present desires.

Implications for Behavioral Medicine

Motivational psychologists have long understood the role that short-term and long-term goals may play in guiding behavior change (Chan & Cameron, 2011). Weight watchers, a dieting strategy cited by researchers as being one of the most effective plans for helping individuals to maintain weight goals, focuses its members on (a) setting goals for ideal weight, (b) sharing those goals with supportive others, and then (c) monitoring nutritional intake en route to achieving those goals often (though not necessarily) in an open, social, manner (Dansinger, Gleason, et al., 2005). Sports psychologists focus heavily on goals as well, helping athletes orient practice toward specific visualizations of desired performance goals and then setting short-term, proximal, goals to achieve the longer-term objective (Maxwell, Hilden, et al., 2011).

The problem with many health behaviors, though, is that communications have been offered at a very broad, diffuse level. People may generally know that it is important to “stay healthy,” without having a clear concept of what they can do in their lives to reduce their own personal risks (Cameron & Leventhal, 2003; Cameron, Marteau, et al., 2011). Personal health forecasting may help in this regard. By offering tailored feedback on how to cope with personalized risk – as has been done with patients experiencing abnormally high levels of hyperlipidemia – it may be possible to offer a more compelling strategy psychologically for organizing behaviors to help stay healthy. Greater specificity in statistical modeling may help physicians and their patients reach superior decisions for alternative treatments when illnesses do occur. Patients can look at alternative “what if” scenarios for their decisions and then can watch how comparative risks may rise or fall when compared to similarly situated patients.

Simulations might even help at a community or organizational level. By modeling the consequences of passing or not passing a smoke-free business law, public health advocates may be able to inform the debate based on data-driven hypotheses rather than loose or hyperbolic conjectures. Resource allocators could use simulation tools to model the long-term benefits of investing in certain types of preventive interventions. Localized forecasts for the health of communities might help stimulate civic and personal action much in the same way that personal forecasts might stimulate goal-driven personal health behaviors.

An understanding of how personalized risk profiles influence behavior from the perspective of behavioral medicine is largely incomplete at this stage, however. In a 2009 article in the journal of Health Psychology, Smerecnik and colleagues found that respondents who were unaware of a genetic predisposition to salt sensitivity, and who were then exposed to a news story about such a predisposition, were less likely to endorse engagement in preventive behavior (i.e., reduce their salt intake) than those who were already aware that such a genetic predisposition existed. For these respondents, the news story seemed to convey a false sense of safety (I don’t think I’m genetically predisposed, so I must be safe) – at least under the conditions of the airport intercept study. The authors concluded that “we are in dire need of more empirical research on this matter before informing the general public about the existence of genetic risk factors" (Smerecnik, Mesters, et al., 2009).

The problem is that with such rapidly escalating progress in biotechnology it is not feasible to wait "until more empirical research" is conducted on the matter before exposing the public to genetic risk factors. Access to personal genetic information from direct-to-consumer genomics companies is fully permissible in at least 23 states in the USA. The good news is that the release of personally relevant genomic data directly to individuals has not caused the uproar, misuse of services, or paralysis once anticipated. Many healthcare providers tend to treat that moment in which the patient arrives at the office with preordered genetic data as a teachable moment. Exposure to raw data on the Internet has created an opportunity for patients and providers to work together in deciphering the otherwise perplexing world of probabilities, rare occurrence, and comparative science (Hesse, Moser, & Rutten, 2010). Studies evaluating exposure of multiple risk messages from genetic tests to patients presented that education and counseling can typically remove the patina of confusion of those confronting the information for the first time (Kaphingst, McBride, et al., 2010).

What is needed, then, is a better understanding of how to shape these personal health forecasts to be optimally useful to individuals and communities striving to use the information to achieve health-related goals.

The Rise of the Therapeutic City

The Trend

In the world of public health, cities have long been centers of both crisis and innovation. John Snow's mapping of the 1854 cholera epidemic, tracked to contaminated well water in London, was a seminal example of public health in action to solve the problems of many people living in close proximity. Knowledge generated by that early public health investigation set the stage for better environmental planning both within the London cityscape and around the world. Throughout the industrial revolution, cities were constantly under siege from conditions of poor air quality, crowding, noise pollution, and the irresponsible dumping of toxic waste materials. Urban planners have spent the better part of the past century considering ways of minimizing the damaging effects of urban blight, while finding ways of improving community living. Innovations in mass transit, architecture, and protected green spaces have all helped to revitalize many spaces within urban settings.

New developments may move even further toward creating cities that are experiments in healthy living. Investments from national health agencies have helped create stellar research hospitals within cities. These academic medical centers will be large enough and have enough resources to put some of the best and most varied care resources in a region available within short proximity for city dwellers. Allied specialty care will generally not be too far away from these academic centers, with skilled primary care physicians and patient navigators serving to steer patients proactively toward the collection of closely located services as they are needed. Health system administrators can easily experiment with load-balancing techniques in urban environments to reduce the wait time for emergency and routine visits across facilities and teams of providers. Grants for translational research will give the academic centers incentives for pushing their knowledge out of the laboratory and into the community. In this way, other surrounding hospitals may begin to benefit from the infusion of funding into successful research institutions.

Apart from healthcare, urban planners are experimenting more broadly with new technological frameworks for enhancing services. Municipalities within the USA have been experimenting for a time with provisions for broad public access to wireless computer networks connectable through laptops and mobile devices. New, emerging, frameworks include support for GPS technologies to help citizens and visitors locate services on a digital map or through "augmented reality" (i.e., location-sensitive labels placed contiguous to a landmark when viewed through an "app" on a smart phone). Some utility companies are experimenting with "smart grid" frameworks in which consumers can monitor and control their energy consumption remotely, or they can preprogram household appliances to optimize efficiencies either singly or in concert with each other. All around the world, cities are pursuing aggressive plans to offer pervasive computing infrastructures in a bid to attract world-class businesses. Following its "U-City" (for ubiquitous computing) concept, the Korean municipality of Incheon-Songdo defines itself as an "information friendly, intelligent city where anyone can get information services through any device on any network at any time" (Leem & Kim, 2013).

Implications for Behavioral Medicine

Taken in concert, these trends for urban design should allow specialists in behavioral medicine to consider the new "therapeutic cities" as living laboratories for a new generation of more effective, preventive, and therapeutic interventions (Stokols, Grzywacz, et al., 2003). Being successful in this regard will mean working across disciplines and seeking to influence the design of real city environments for the betterment of the urban community (King, Stokols, et al., 2002). Environmental psychologists and socioecologists should be able to offer their perspective into the mix as city planners think through best ways of encouraging natural exercise through bike lanes, walking paths, and dedicated green spaces (Stokols, Grzywacz, et al., 2003). So, too, nutritionists and population analysts should be able to work directly with chambers of commerce and city planners to make healthy food options a proximal choice for all neighborhoods, effectively diminishing the deleterious influence of "food deserts" (Beaulac, Kristjansson, & Cummins, 2009; Shinkle, 2010). Tobacco control specialists have already had substantive influences in such cities as San Francisco and New York, where smoke-free laws are cleaning up the environment for nonsmokers and making it easier for ex-smokers to avoid relapse (Frieden, 2010).

As large, urban medical centers continue to attract funding for cutting-edge research, there will be a positive pressure to move fundamental discovery from the laboratory into practice (Westfall, Mold, & Fagnan, 2007). The medical centers will then become hubs of innovation as the barriers between the laboratory and the clinic become blurred. Likewise, the ability to connect sensors and devices to an urban infrastructure of smart, ubiquitous computing will allow accountable care organizations to extend innovative models for care delivery into homes and communities. Behavioral informaticians can contribute within this new environment by evaluating user needs and helping to design the channels, interfaces, and applications to extend the benefits of therapeutic care beyond the walls of the hospital (Ahern, Woods, et al., 2011). Undoubtedly, their goal will be to begin with a firm theoretical notion of how best to empower patients and their families. They can then work within a network of supportive care services, perhaps based around a coordinating "medical home" model, to be sure that there are no weak links in the seamless connections of support available from within the therapeutic community (Glasgow, Dickinson, et al., 2011).

Behavioral economists can fulfill a role as they consider the ways in which the environment influences everyday decision-making. In the days of industrial blight, that influence on behavior was often unhealthy or exploitative. In redesigning the therapeutic city, behavioral economists can offer specific design and policy recommendations centered on principles of improved support for everyday, healthy living. This means understanding:

(a) *incentives*, or what motivates city dwellers to connect and thrive in their environments
(b) *mental models* – that is, the cognitive maps brought with them to interpret the world around them
(c) *defaults,* in order to make healthy behavior – such as walks in the park or buying fresh

produce – the easy path to choose in thriving daily

(d) *feedback* mechanisms to provide individuals and communities the data they need to improve performance relative to explicit goals

(e) tolerances for *error*, thus making it easy within the therapeutic city to reschedule appointments or get back on the wagon after a relapse into unhealthy behaviors

(f) *structures for decision-making*, making the safety paths for reducing risk explicit and easy to follow (Thaler & Sunstein, 2009)

Conclusions

Fundamental scientific discovery is changing the milieu in which world health is produced from an approach that was anchored on industrial age, reactive principles to an approach that is *predictive*, *personalized*, *preemptive*, and *participatory*. Such a movement will be necessary to continue progress against the more serious chronic disease epidemics of the twenty-first century, from the seemingly irrevocable onslaught of the multiple diseases associated with the "obesity epidemic" to the debilitating effects of Alzheimer's disease and cancer in an aging world population. What's more, this movement is occurring not solely because of strategic investments from the biomedical research community, but as a result of converging forces outside of the world of medicine.

Unlike the era of public health advances at the beginning of the twentieth century or the era of miracle medicine in the second half of the twentieth century, this movement is both personal and global. Patients are flocking onto government and academic Web sites looking first hand for information on how to deal with the "vital decisions" of health for themselves and their families (Fox & Rainie, 2002). Virtual communities are springing up to self-regulate based on data, who are taking the matter of accelerating biomedical science into their own hands (Olsen, Saunders, & McGinnis, 2011). The 17-year travail from discovery to implementation is no longer considered tolerable at a broader social level (Topol, 2012). Patients are demanding to be given personal access to medical data so that they can be brought into the conversation about their own healthcare first hand (Walker, Leveille, et al., 2011). Confronted with this onslaught of demand, some bioethicists and biostatisticians are beginning to conclude that having access to personal data may not just be a patient's fanciful desire, but an inherent "civil right" in the information age.

In the context of these changes, specialists in behavioral medicine must increasingly assume the role of linking pin between fundamental scientific discovery and patient well-being. This is an important, albeit subtle, change in the context in which behavioral medicine must thrive in the next century. Behavioral researchers can no longer afford to be isolated in focusing on only one aspect of patient care, say on mental disorders or substance abuse and addiction. To be sure, those areas of practice will continue to be important within the next century, but professionals in behavioral medicine must also be brought into the transdisciplinary teams that will solve translational issues across the spectrum of care.

As fundamental discovery yields new knowledge, the systems we have for interpreting and implementing that knowledge will begin to break. Left unattended, the costs of administering inefficient care based on a diminishing understanding of evidentiary trends will consume an unsustainable proportion of countries' economies. Medical errors – the costs of an inefficient system stretched beyond capacity with new, and more invasive procedures – will continue to proliferate, eclipsing other epidemics in reach and societal impact. With behavioral scientists in collaboration, however, it might just be possible to bend the curve on the most challenging and consuming health issues of the next century.

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Behavioral Medicine of the Future: From Disease to Health and Well Being, from the Individual to the Community and the Global, from Causes to Complexity

38

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Behavioral medicine is a broad and diverse field. As illustrated by the chapters in this book, it's conceptual bases range from genetics to health policy. Its concerns include all areas of prevention, health, illness, injury prevention, treatment, and disease management as well as related issues such as quality of life and wellbeing. Its application and programs include those implemented with individuals in clinical settings, programs applied to families or through worksites and communities, and those intended for entire populations. The very diverse range of perspectives and approaches underpinning the field of behavioral medicine makes any comprehensive summary of the field very challenging and difficult. Indeed, a summary runs the risk of distorting that breadth and diversity.

Instead of attempting to summarize the previous chapters in this one, we shall discuss future directions for behavioral medicine and its many roles. We discuss these future directions according to three broad themes, (1) understanding the individual and the relationships between behavior and health, (2) the global spread of the field of behavioral medicine. Perhaps most important is (3) developments within the epistemology that undergirds behavioral medicine and how these developments will change our research, scholarship, and conceptualizations of behavior and behavioral medicine within the broader domains of health, health care and prevention. A recurrent

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theme is behavioral medicine's breadth, diversity, and transdisciplinarity and how they will influence health, health care and prevention in the next decade and beyond. Reciprocally, we shall also examine ways in which developments in health will stimulate growth of behavioral medicine in the coming years.

Understanding the Individual and the Relationships Between Behavior and Health

1. *Interactionism and Complex Systems*. Those trained in behavioral science and medicine in the twentieth century learned to carry out research designed mostly to detect main effects, the drug that cures a disease regardless of differences among those taking it, or the intervention that brings about smoking cessation or weight loss without being limited by differences among users. Indeed, in the middle of the twentieth century, most investigations were limited by statistical computing capacity that could not easily extend beyond a two-way interaction. Recent decades, however, have seen the development of statistical methods accommodating integrated analyses of multiple influences, the availability of larger, population based data sets and, more recently, "big data." With these tools and growing concern for inequities among countries and among populations within them, attention has turned to studying the relations among influences on health and ways in which individual influences are contingent on their contexts.

   The main effect remains pleasing in its clarity. It is increasingly recognized, however, as an abstraction of an object of analysis but not as a complete, accurate, or representative portrayal of problems as they exist and need to be addressed.

   As the distinguished psychometrician and theorist, Jane Loevinger (Loevinger, 1948, 1976) noted in discussion following her receipt of an award from the American Psychological Association, "The world is not orthogonal." This simple observation, pointing to the ubiquity of interactions among influences is important for our understanding of health and the application of behavioral medicine. With the exception of relatively few problems, such as phenylketonuria, the *general model for health problems* needs to be the interactive influence of genes, epigenetics, environment, development, behavior, and psychology, along with social, cultural, economic and policy influences. This book has sought to reflect this breadth of influence, although the very structure of a book of individual chapters may fail still to capture the importance of the interactions among the many topics the chapters have covered. Clearly, however, the reader works in an environment that is increasingly cognizant of these interactions.

   That health – and healthcare – rest upon such a wide variety of interactive determinants provides opportunity for behavioral medicine based on it's broad conceptual perspectives and accomplishments addressing a variety of influences. Indeed, with its broad perspectives and accomplishments, behavioral medicine has already led in examination of the fundamentally interactive and dynamic processes shaping health and health care. With increasing opportunities afforded by advances in statistical and empirical methods, behavioral medicine is poised to accelerate our understanding of these dynamics.

2. *Broadening "Personalized Medicine" to "Personalized Care."* Recent years have seen exciting developments in genomics and in its application to medical treatment such as in tailoring medications according to individual genotypes rather than what now appear to be relatively superficial symptoms and clinical patterns. This "Personalized Medicine" is an important and exciting development. But the emphasis on personalization is not limited to biological markers or clinical interventions. Growing knowledge of behavioral influences across the lifespan as well as the broad range of influences on behavior and health leads to tailoring also of behavioral, social, community, communications, and even policy inter-

ventions according to the nuances of those groups or settings to which they are applied.

In this context we will also see a significant increase in precision of the measurement of cognitions, emotions and behavior, such as by ecological momentary assessment (EMA) using mobile phone technology and "sensors" or fit applications. More precise measurement will help to tailor psychological and behavioral interventions to individual needs and circumstances.

The availability of digital technologies and wearable devices that facilitate individuals' monitoring their own behavior and health indicators is bringing about a "quantified me" that also leads to greater emancipation and participation of patients in their own care and decisions regarding it. Experiential learning, patient-generated data, and patient preferences will be the basis for shared decision making as the norm for medical consultation and care.

3. *Lifespan Approach*. Understanding of early development has also increased greatly in recent years. This includes epigenetic studies of the influence of the prenatal environment and early childhood, influences through which individuals may become psychologically as well as biologically programmed toward health or illness. This research has greatly increased our understanding of the development of our bodies, our psychology, and our lives. At the same time, research has articulated the evolution of adult lives and aging. Clearly, behavior and health change and continue to change throughout the lifespan, posing important challenges for interventions as well as policies. Behavioral medicine will become more nuanced as it addresses not only differences among people and their settings but differences within and throughout lives as well.
4. With the aging of populations and the epidemiologic transition (discussed below) in which disability-adjusted life years are increasing, this incorporation of a lifespan approach will pay increasing attention to aging, palliative care, and care towards the end of life (e.g., Masters et al. *infra*).
5. *Positive and Protective Factors: Adaptation and Resilience*. With more attention to the breadth of individuals' concerns and interests, not just their disease states, will also come more attention to positive and protective factors, adaptation, coping, and resilience. This emphasis will also be encouraged by a lifespan perspective that incorporates the inevitability of disease and illness, complementing prevention with attention to how individuals cope with the health problems they do not prevent. Beyond coping, increasing emphasis will be placed not on reducing or "managing" illness so much as on "flourishing" and leading good, satisfying lives with the health problems that individuals do face.

Dissemination and Spread of Behavioral Medicine

1. *Population Health.* Across the globe, there is great and growing concern for population health. Disparities and inequities contribute to this concern. So, too, does the size of health care systems and health care budgets amidst countries' economies. To be affordable, health care will have to become more efficient and more focused on ways of improving and investing in health at a societal level relative to the availability of funding. Responding to these concerns requires that planning consider the distribution of prevention, health care, and health status across populations and the identification of where improvements can be made. Leaving choices of health care to the services that provider groups choose to offer and to individuals' decisions to access them has been shown to lead to care that fails to reach all it should and to unnecessary and ineffective care that many resource-constrained nations cannot afford.
2. *Scalability and Dissemination*. If they are to reach populations, behavioral medicine interventions need to be conceptualized, planned, developed and evaluated in terms of their potential to be "scaled up" and to reach large numbers of those they may benefit. This

includes interventions delivered to individuals that are sufficiently efficient to be affordably implemented with large numbers. Within the health care system, interventions that are feasible within primary care may reach the large proportions of populations that visit a primary care provider at least yearly. Reaching populations also includes approaches that may be integrated within existing, low-cost channels so that unit cost is minimal, such as through web-based or mass media approaches. Who provides health care and prevention may also expand as in the growing global utilization of peers support provided by community health workers, *Promotores de salud,* and others (Buttorff, Hock, et al., 2012; Fisher, Ballesteros, et al., 2015; Perry, Zulliger, & Rogers, 2014; Rahman, Malik, et al., 2008) (See Fisher et al. chapter on Peer Support, *infra*.) Community approaches and policy approaches may reach whole populations without any individual being the focus of intervention.

3. *Global Disparities***.** As much as life expectancy is increasing worldwide, nevertheless disparities remain a prominent feature of global health. These are the focus of important behavioral medicine activities such as in community health promotion and policy approaches to promoting disease prevention as well as access to and use of preventive services and chronic disease care. These programs have been shown to be effective as is evident in the chapters describing community health promotion approaches (Ramanadhan & Viswanath, *infra*), as well as approaches to obesity and cigarette smoking (Johnston et al., *infra*; Borland & Yong, *infra*). However, sustaining these programs and their benefits is a challenge that requires policies that will fund and support them, still lacking in many health systems.

   In New Zealand and the US, anticipated impacts on health disparities are being considered in research funding decisions. For example, ethical issues have been raised concerning allocation of government research funds to study expensive tests that are not covered by health care financing plans and, so, may serve to increase disparities rather than reduce them. Increasing recognition of the costs associated with disparities and the ability of preventive and population approaches to reduce those costs should prompt more enlightened policies creating greater opportunities and demand for behavioral medicine in these areas.

4. *Differences and Variability Among Countries and Populations*. Although health is a global concern and fundamental behavioral and biological processes affect all humans, there is great differentiation of need, capacity, and challenges across countries. In addition to economic and system constraints, cultural and social differences have great impacts, especially on prevention and disease management initiatives that need to engage behavior in social and organizational contexts. Metformin may remain metformin and may act similarly wherever it is taken, but a family, group, or community initiative to prevent diabetes through dietary changes will be shaped by the families, groups, or communities through which it evolves. Merely packaging and shipping medicines to those who need them serves very poorly as a model for disseminating *behavioral* medicine. (Indeed, the behaviors needed to obtain a prescription, recognize its value, fill the prescription, and adhere to the instructions for its use will all vary according to cultural and social dynamics. Consequently, simply "packaging and shipping medicines to those who need them" is a poor model even for dissemination of medicines.) Future dissemination research and practice will succeed by considering and finding ways to address how "knowledge management" needs to be a creative, organic synthesis of innovations as well as the characteristics, needs, and strengths of the groups and settings in which they are to be implemented.
5. *Epidemiologic Transition*. The global burden of disease is inexorablly moving from acute disease to chronic disease. Along with this, the more important outcome of health care is moving from mortality to years of life lived with disability, YLD. Life expectancy is increasing worldwide. As much as this is a good thing, it also has the effect of providing people more years in which to develop chronic diseases. With those chronic diseases, especially mental health, substance-use, musculoskeletal, and

neurological disorders, diabetes, and hearing and vision loss come disabilities and complications with which people may live for many years. Thus, total YLDs are increasing as lifespan is increasing (GBD 2013 Dalys, Hale Collaborators, et al. 2015). This creates many needs and opportunities for behavioral medicine interventions to improve management and coping with chronic disease, as well as community and policy interventions to support living well with chronic diseases and including "Health in All Policies." As the authors of a key paper on these issues have noted:

> We believe that the historical focus of health research funding on causes of YLLs [years of life lost/mortality] was probably appropriate. However, health progress now means that more research investment is needed for the disorders that debilitate, rather than kill. With each passing year, the shift towards YLDs as the leading causes of disease burden will be more evident. Action is needed now to develop preventive, curative, and ameliorative strategies for these conditions rather than waiting until this shift is even more obvious. (GBD 2013 Dalys, Hale Collaborators, et al., 2015, p. 2182)

6. *National and International Policies that Influence Behavior and Health Behavior such as "Health in All Policies."* As discussed in several chapters in this book (especially Sherlaw et al. and Siddiqi et al. *infra*), policies in diverse areas including housing, transportation, education, labor and welfare are all important determinants of health, well-being and quality of life. Clearly, the understanding and practice of behavioral medicine is important for all of these. Although international policies and agreements such as the United Nations *Sustainable Development Goals: 17 Goals to Transform our World* (United Nations, 2015) promise improvements that can significantly benefit health globally, their endorsement and implementation are usually sporadic and modest.
7. *New Problems that Affect Life and Health.* Health in All policies expands our understanding of the ways in which health, illness, and quality-of-life are influenced by a variety of factors we may sometimes view as unrelated to health and healthcare. Clearly, global warming, water quality, violence (including gun violence, violence toward women, and violence toward stigmatized groups), inadequate housing, and a variety of other factors affect health either directly or indirectly such as in the influence of domestic violence and violence against women on the spread of HIV and care of HIV/AIDS (Maman, Mbwambo, et al., 2002).

The Zika virus illustrated the confluence of nature-driven and culture-driven phenomena through which new diseases, epidemics, and other problems emerge. In addition to the Zika virus posing unprecedented risks to the fetuses of pregnant women, natural evolutionary processes are leading to "superbugs," and cultural movements in some regions are promoting anti-vaccination beliefs that, in turn, are lowering vaccination rates. Because of its foundation in behavioral science, behavioral medicine includes approaches that can address these issues ranging from individual or family interventions for reducing violence to broad policy, community, and communications initiatives to raise awareness of problems and promote approaches to reducing them.

An interesting dialectic emerges in the interplay between influences that are conventionally seen as part of health and health care, and those that are conventionally seen as separate from them. On the one hand, we may promote behavioral and public health perspectives for considering challenges often not seen as in the realm of public health. In the U.S., for example, advocates for greater regulation of access to guns cite policies mandating automobile seat belts that have greatly reduced the incidence of closed head injuries and fatalities. In the other direction, behavioral medicine and public health may benefit by importing policy and conceptual approaches from areas that are considered unrelated to health. Consumer economics has been translated through behavioral economics to be applied to health in a number of areas. Additionally, models such as those from successful educational or labor policies may be applied to enabling groups and individuals to develop patterns of living that prevent disease and enhance quality of life.

General Themes, How We Study Behavior and Health, *Weltanschauungen*

1. *From Bench and Clinic to Community*. The recognition of diverse influences on health and well-being will continue to drive attention to interventions outside of individual biology and the clinical setting, engaging the families, neighborhoods, and communities in which people live. "Citizen Science" approaches to health behavior research are important models for such growth and expansion of what we mean by health, prevention and care, and knowledge of these (King, Hekler, et al., 2016). Evaluation of these kinds of interventions will pay more attention to lives as they are lived in their diverse contexts, not limited to markers of clinical status or illness.
2. *Big Data*. It is now possible to predict flu outbreaks by monitoring Google queries about symptoms. The applications of big data however reach far beyond epidemiology. Consider, for example, how analyses of millions of individuals' emails over a number of years might identify patterns indicative of risk for dementia. As Google queries may project flu outbreaks better then reports of cases from primary care, might these kinds of analyses of massive amounts of data across large numbers of individuals lead to better indicators of risk and disease progression then clinical markers?

   With big data comes also sharing of data among those who provide it. As discussed in the chapter by Ramanadhan & Viswanath (*infra*) how might big data analyses of community trends encourage greater cooperation and effective action within communities to address challenges they face? Parallel to the empowering influence of individually generated data and the "quantified me," above, how might community generated data empower communities?
3. *Analyzing Complexity***.** Interestingly, genetics may provide helpful models for understanding the non-orthogonal complexity of multiple determinants of behavior. Genetics too entails impacts that are complexly dependent on multiple interacting influences. Figure 38.1, for example, portrays genetic 'signatures' with poor and good prognosis for survival of breast cancer (van

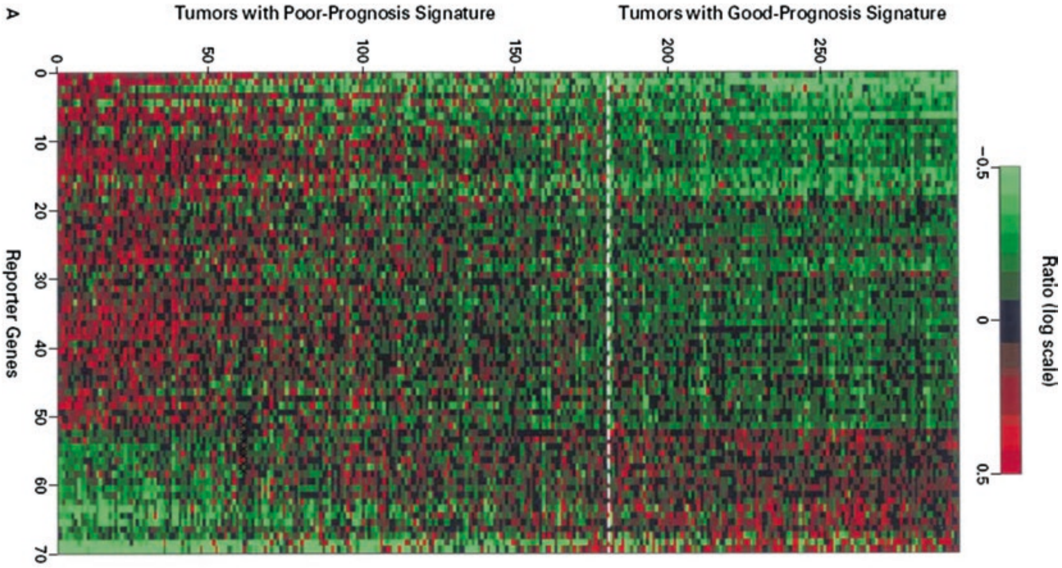

Fig. 38.1 Gene arrays among women with poor or good prognosis signatures for subsequent metastasis following incident breast cancer (van de Vijver 2002)

de Vijver, 2002). It is clear that no element of either signature is necessary or sufficient for survival or death. Rather, complex arrays of elements alter the probability of survival. Similarly, current research on the role of gut microbiota in obesity and diabetes examines interactions among genetics, diet, and the "community structure" of "microbial communities," again examining complex, multivariate influences on and among members of those communities (Ussar, Griffin, et al., 2015). Such analyses from highly respected areas of life sciences may provide useful models for examining the complex, interacting influences – no one necessary, no one sufficient – that surround behavior, health, and disease. Similar to gene arrays' associations with varying likelihood of disease, complex arrays of elements and features of communities and the settings of individuals' lives alter the likelihood of healthy or unhealthy behaviors. Studying those elements in their complexity, instead of trying to isolate them by randomization, may be a valuable strategy. Agent based modeling approaches (Maglio & Mabry, 2011), for example may be an approach for studying not only interactions among varied entities within a system but also the effects of those interactions on the system as a whole.

4. *Ethics and Values*. Recognition of the diversity of influences on our lives changes our understanding of the role of the individual. Autonomy and individual choice are no longer natural givens for which individuals are responsible, but become objectives to be enhanced through humane policies and practices. The community and its policies become responsible for enabling individuals to lead good lives and to make healthy choices in those lives. Indeed, research shows that individualism and collectivism are not opposite ends of a spectrum but tend to be positively correlated (Coon & Kemmelmeier, 2001).

   There can arise a tension among the values that might be used to guide health care and prevention. Should these be the assumed aspirations of people? Should they reflect the goals of the individual? Collectivistic values such as familism might be more recognized and valued for their strengths and potential benefits, as well as promoted in health behavior research and interventions.

   Individualism often entails an assumption that the government and community can "stay out of our lives." However, the fundamental research and conceptual perspectives on which behavioral medicine is based (see Rachlin et al., *infra*) makes clear that the community cannot merely be neutral, leaving things to the individual. Whether by what it does or by what it fails to do, the community *will* influence the lives of those within it. Morality is then not leaving people alone to make their own choices, but enabling their having choices and being able to pursue them. The cornerstone of ethics becomes choice, the availability of alternatives and the opportunities and means to pursue them.[1]

5. *The Place of Behavior and Quality of Life***.** A general model that has characterized much of behavioral medicine and public health has construed behavior as an input that influences disease and illness which, in turn, influence quality of life.

$$\text{Behavior} \rightarrow \text{Disease} \rightarrow \text{Quality of Life}$$

However, the change in focus from avoiding acute disease to living well amidst periodic and chronic disease brings greater attention then toward behavior and quality of life as the outcomes of greatest concern, with diseases as important determinants of them. Instead of preventing or minimizing disease and assuming that quality of life will then be

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[1] This emphasis on choice and the availability of choices as a central criterion in judging the ethical quality of interventions was suggested to EF as a student by Leonard Krasner around 1970. At the time, Krasner was a central figure in controversy about the ethical qualities of behavioral control and behavioral influence in behavior modification and behavior therapy.

automatically achieved, we will see greater focus on approaches that seek directly to enhance quality of life. After all, if longer lives lead to more years in which health problems may occur (GBD 2013 Dalys, Hale Collaborators, et al., 2015), the challenge is not so much avoiding all disease, but promoting productive, satisfying and relatively healthy lives amidst the likelihood of some disease as lives go forward. Avoiding or minimizing risk and managing disease and disability surely have a place in this, but rather than being the primary outcomes with benefits in quality of life assumed, they are objectives among others which, in their aggregate, may promote good lives. Healthy diet, physical activity, supportive social relationships, strong families and social networks, work that provides a sense of purpose as well as income, and communities and policies that support all of these improve our lives directly while also reducing the intrusions of disease in those lives.

Table 38.1 Transitions in *Weltanschauungen,* world views

Illness as micro, discreet, individual	Health as macro, complex, behavioral, social
Illness – Focus on clinical indicators and outcomes	Patterns of living – Focus on behaviors and quality of life
Micro effects	Molar effects and patterns
Key relationship: Doctor/ Provider-Patient	Key relationship: Community-people
Technical Challenges	Adaptive challenges
Data on individual events, e.g., Blood pressure, disease stage	Mass data • Many events within individuals over time • Many events across many individuals
Individual as isolated locus of disease and change	Individuals as social, situated; "It takes a village"
Greatest scientific status accorded main effects, dominant effects of individual agents	Greatest scientific status accorded illumination of complexity, interactions among influences; "The world is not orthogonal"
Energy from the individual	Energy emerges from the community

6. *Weltanschauungen.* The aggregate of these trends may be summarized as a change in *Weltanschauung,* in the view of the world from health as micro, discrete, and individualistic to health as macro, complex, behavioral and social. Some features of such a change in world view are outlined in Table 38.1 (Fisher, 2016). To explain a few of these, the model on the left sees illness as a micro, discreet event at the level of the individual. In contrast, the model on the right sees health as a macro, complex and social set of events. Accordingly, the two models go from illness and the focus on clinical indicators to patterns of living in the focus on quality of life in a community or population. In community and people-powered movements to enhance health (as championed by the Nesta Health Lab in London, Khan, 2016), we go from data on individual events like a blood pressure reading to mass data – either a mass of data points across an individual's experience or across many individuals. We go from looking at the individual as the site of disease and as the locus of change to the individual as socially situated; as in Hillary Clinton's book title, "It takes a village." In going from micro to molar effects, we are not so interested in what the individual with diabetes eats today but in what she or he eats over 30 or 40 years of living with diabetes. Instead of looking for a unique and dominant effect of a single intervention, we recognize that interactions among influences are the rule and seek to understand the complexity of those interactions. From a statistical perspective and as Loevinger noted, the world is not orthogonal. Finally, we go from seeing motivation and energy as based in the individual to seeing energy as emergent among individuals and from communities. More generally, instead of putting responsibility – and too often blame – on the individual to guide her or his own health, we seek to under-

stand how communities enable individuals to lead healthy lives and look for ways to help communities do that better.

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Index

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