

Christine M. Hunter  
Christopher L. Hunter  
Rodger Kessler *Editors*

# Handbook of Clinical Psychology in Medical Settings

Evidence-Based Assessment  
and Intervention

 Springer

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# Contents

## Part I Introduction

- 1 Psychology and Population Health Management** ..... 3  
Alan L. Peterson, Jeslina Raj and Cynthia Luethcke Lancaster
- 2 A History of Clinical Psychology in Medical Settings**..... 19  
Mark Vander Weg and Jerry Suls

## Part II Professional Issues

- 3 Preparing the Next Generation for Integrated Care in Medical Settings: Training in Primary Care as a Foundation**..... 41  
Barbara A. Cubic and Abbie O. Beacham
- 4 Core Competencies for Psychologists: How to Succeed in Medical Settings** ..... 77  
Anne C. Dobbmeyer and Anderson B. Rowan
- 5 Ethics and the Law**..... 99  
Lois O. Condie, Lisa Grossman, John D. Robinson, and Don B. Condie
- 6 Evidence-Based Practice: Concepts and Techniques for Translating Research into Practice** ..... 125  
Barbara B. Walker, Charlotte Collins and Hope C. Mowery

## Part III Practice Issues

- 7 Marketing Health Psychology**..... 151  
Steven M. Tovian
- 8 Balancing Value and Cost**..... 169  
Ronald R. O'Donnell, Nicholas A. Cummings and Janet L. Cummings

<b>9 The Practice of Psychology in Medical Settings: Financially Sustainable Models</b> .....	199
Daniel Bruns, Rodger Kessler and Brent Van Dorsten	
<b>Part IV Population Specific Consideration</b>	
<b>10 Competency for Diverse Populations</b> .....	219
Geneva Reynaga-Abiko and Tiffany Schiffner	
<b>11 Working in Pediatrics</b> .....	239
Robyn S. Mehlenbeck, Michelle M. Ernst and Leah Adams	
<b>12 Psychological Problems at Late Life: Holistic Care with Treatment Modules</b> .....	261
Lee Hyer and Ciera Scott	
<b>13 Practice in a Rural Setting</b> .....	291
Robert J. Ferguson, Amber Martinson, Jeff Matranga and Sandra Sigmon	
<b>Part V Medical Specialties and Settings</b>	
<b>14 Clinical Psychologists in Primary Care Settings</b> .....	309
Anne C. Dobbmeyer and Benjamin F. Miller	
<b>15 Women’s Health: Obstetrics and Gynecology</b> .....	327
Pamela A. Geller, Alexandra R. Nelson, Sara L. Kornfield and Dina Goldstein Silverman	
<b>16 The Hospital-Based Consultation and Liaison Service</b> .....	369
Michelle M. Ernst, Carrie Piazza-Waggoner, Brenda Chabon, Mary K. Murphy, JoAnne Carey and Angela Roddenberry	
<b>17 Endocrinology</b> .....	417
Felicia Hill-Briggs, Stephanie L. Fitzpatrick, Kristina P. Schumann and Sherita Hill Golden	
<b>18 Gastrointestinal Conditions</b> .....	459
Tiffany Taft and Megan Riehl	
<b>19 Cardiovascular Disease</b> .....	495
Jeffrey L. Goodie, Paula Prentice and Kevin T. Larkin	
<b>20 Chronic Pulmonary Diseases Across the Life Span</b> .....	527
Allison G. Dempsey, Christina L. Duncan and Kristina M. Kania	

<b>21 Primary Insomnia and Sleep Apnea in Pediatric and Adult Populations</b> .....	565
Stacey L. Simon, Christina L. Duncan and Janelle M. Mentrikoski	
<b>22 Managing Chronic Pain in Primary Care</b> .....	589
Don McGeary, Cindy McGeary and Robert J. Gatchel	
<b>23 Evidence-Based Practice in Clinical Behavioral Oncology</b> .....	625
Jamie L. Studts, Michael G. Mejia, Jennifer L. Kilkus and Brittany M. Brothers	
<b>24 Physical Rehabilitation Programs</b> .....	673
Erin E. Andrews and Timothy R. Elliott	
<b>25 Neurology and Neuropsychology</b> .....	691
Dennis J. Zgaljardic and Lynn A. Schaefer	
<b>26 Preoperative Mental Health Evaluations</b> .....	719
David B. Sarwer, Scott Ritter, Traci D’Almeida and Robert Weinrieb	
<b>27 Behavioral Dentistry</b> .....	739
Cynthia Luethcke Lancaster, Ashley M. Gartner, John P. Hatch and Alan L. Peterson	
<b>28 Conclusion: Final Thoughts from the Editors</b> .....	767
Christine M. Hunter, Christopher L. Hunter and Rodger Kessler	
<b>Index</b> .....	769

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**Part I**  
**Introduction**

# Chapter 1

## Psychology and Population Health Management

Alan L. Peterson, Jeslina Raj and Cynthia Luethcke Lancaster

Population health management, broadly defined, is an integrated approach to improve the health of an entire population by targeting the systems and policies that affect health care quality, access, and outcomes [1]. From a clinical psychology perspective, population health involves clinical applications and interventions targeted at an entire patient population rather than individual patients. The traditional practice of clinical psychology in medical settings has targeted the assessment and treatment of individual patients most often seen for one-on-one counseling. Decades of applied clinical research has resulted in the development of evidence-based cognitive-behavioral interventions for psychological, medical, and dental conditions that can be delivered by clinical psychologists. Indeed, the largest effect sizes and greatest improvements in clinical symptoms can most often be obtained using these empirically supported treatments delivered to individual patients. For a variety of reasons, however, it is only a minority of patients who have access to and benefit from these cognitive-behavioral therapies. Less intensive clinical interventions delivered to an entire population of health care beneficiaries have the potential to have an even greater impact on the overall patient population than more effective treatments delivered to a small percentage of patients.

Population health interventions are often integrated into standard clinical settings, with a shift in emphasis from individual patients with identified disorders or

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diseases to a larger target population. One example is the routine screening of all patients for tobacco use in a family medicine clinic followed by a brief intervention or referral for care [2]. Brief interventions can be provided by a variety of health care professionals. One of the best models for brief interventions in medical settings is the use of psychologists serving as behavioral health consultants within an integrated primary care clinic [3]. Other population health interventions can be linked to the health care system but delivered outside of the medical setting, often through information technology approaches that are alternatives to face-to-face therapy. These approaches capitalize on recent advances in technology and social networking by using multimedia tools such as telehealth, the Internet, and digital video devices.

Population health approaches provide the opportunity for clinical psychologists working in medical settings to have an even greater impact on the psychological and physical health of a population of patients. This chapter begins with a brief overview of the history of population health. It then provides definitions of population health, disease management, and related terms used to target the overall health of a population. Because tobacco use, overweight and obesity, and excessive alcohol use are the three greatest contributors to mortality in America [4, 5], this chapter will focus on population health outcomes and interventions in these areas. The sections on population-level interventions explore interventions that can be disseminated to a population to influence health determinants and improve health outcomes.

## **Population Health Management: An Overview**

Concepts related to population health have existed for centuries. A classic example in history of the use of a population health approach is John Snow's discovery of the source of the 1848 cholera epidemic in London [6]. He created a map of the city, marking the location where people had died from cholera. In reviewing these data, Snow found that deaths due to cholera were highly correlated with locations surrounding certain water pumps. He then theorized that cholera might be spread through contaminated water supplies. When an outbreak began to affect the Broad Street area of London, Snow suggested that the town remove the handle from the water pump that he suspected was the source of the contaminated water causing the cholera. When the handle was removed and local people stopped using the water from that pump, the outbreak ended. Though Snow's efforts in this area were not recognized during his lifetime, he is now a well-acknowledged pioneer of population health.

The late psychologist George Albee is a modern-day pioneer of population health. He provided one of the most concise descriptions of the field of population health when he wrote, "no mass disorder afflicting mankind is ever brought under control or eliminated by attempts at treating the afflicted individual or by attempts at producing large numbers of individual practitioners ([7], p. 24)." The modern-day field of population health emerged because the traditional approach of explaining and treating illness on an individual level was too limiting.



## Definitions of Population Health and Disease Management

From a historical perspective, clinical and research applications in population health management emerged from an area called “disease management [2].” In many health care settings, disease management refers to clinical interventions and approaches for individuals who have already developed a specific disease. This would include, for example, the optimal management of the most common and costly acute and chronic disease states, such as diabetes. However, others define disease management more broadly to include the spectrum of approaches from primary prevention to intensive tertiary treatments [8]. This might include, for example, early interventions targeting healthy nutrition, weight management, and exercise in individuals at risk of the development of diabetes. However, many physical and mental health conditions co-occur. Therefore, Schrijvers ([9], p. 9) defined disease management as follows:

Disease management consists of a group of coherent interventions designed to prevent or manage one or more chronic conditions using a systematic, multidisciplinary approach and potentially employing multiple treatment modalities. The goal of disease management is to identify persons at risk for one or more chronic conditions, to promote self management by patients and to address the illnesses or conditions with maximum clinical outcome, effectiveness and efficiency regardless of treatment setting(s) or typical reimbursement patterns.

To better reflect modern changes in the field of health care, one of the most popular research journals changed its name in 2008 from *Disease Management* to *Population Health Management* [1, 10]. In the most obvious sense, this new field of population health management can be defined as the sum of each of its terms. Population refers to a large group of individuals belonging to a certain category, such as a particular ethnicity, socioeconomic status, or religion [11]. A population could also refer to the group of patients within a particular type of health care system, such as medical beneficiaries served by the Department of Defense (DoD) or Department of Veterans Affairs (VA). Health can be defined in the negative sense, as in an absence of illness, and also in the positive sense, as in the presence of wellness [11]. Therefore, the aggregate definition of terms defines population health management as interventions or approaches to promote the absence of illness and presence of wellness in a group of specified individuals.

However, over time this field has come to encompass more than just this aggregate definition. For example, it has previously been used to refer to health determinants or to health outcomes within a population [11, 12]. Health determinants are the independent variables upon which health outcomes depend [11, 12]. For example, an increase in the prevalence of smoking in VA patients, a health determinant, would increase the rates of lung cancer in that population, a health outcome. Due to the interacting relationship between health outcomes and determinants, the most helpful definition of population health should encompass both of these concepts as well as the dynamic relationship between them. Kindig’s [11] definition fits this criterion. He defined the framework of population health as “health outcomes and their distribution in a population achieved by patterns of health determinants...over

the life course produced by policies and interventions at the individual and population levels ([11], p. 141).”

Population health management includes a combination of primary, secondary, and tertiary prevention programs. The 1957 Commission on Chronic Illness was the first to propose these categories of preventive care [13]. Primary intervention is implemented in a healthy population to prevent the occurrence of a disorder or an illness. For example, a primary prevention strategy might include a tobacco-use prevention program delivered in a pediatric clinic. Secondary prevention intervenes with an at-risk population to prevent full onset of an illness. This might include approaches to identify asymptomatic individuals who have known behavioral health risks or preclinical disease. An example is intervening with overweight patients to increase physical exercise and improve their eating habits before the onset of comorbid conditions. Tertiary prevention intervenes in populations already diagnosed with an illness to help control symptoms and severity. Examples include interventions for symptomatic patients to reduce the consequences of their disease, such as weight management for diabetics.

Clinical psychologists have much to contribute to population health management, such as the identification of valid measures for health surveillance, the proactive delivery of prevention and intervention services, and evidence-based strategies for outcome measurement [14]. Surveillance includes methods to measure or assess the health status of a population. The ability to assess the population health status of health care beneficiaries has been improved with the development of electronic health records in some health care settings such as the military and VA. Surveillance might include a review of electronic medical records to determine the prevalence of tobacco use or obesity in a specified population. Surveillance can also be accomplished through the prospective implementation of routine assessment of patients seen in a health care setting. For example, a primary care clinic might assess tobacco use and body weight during routine clinical visits.

Population-level cognitive-behavioral interventions can be administered by psychologists in a variety of ways. Some interventions can change behavior passively through behavior changes that automatically happen when the environment is altered [15]. An example of this type of intervention includes John Snow removing the handle on the water pump that accessed the contaminated water. This produced an automatic behavior change, in that the population that usually used that pump had to get water from a different pump. An example of another intervention that automatically improved dental health was observed after fluoride was added to water supplies [15]. Individuals drank the water that was available to them, which included additional fluoride, and dental health automatically improved [15].

There are four primary categories of environmental factors that can be modified to significantly affect population behavior: (1) availability, (2) physical structures, (3) social structures and policies, and (4) media and cultural messages [16]. Altering one of these four factors can have an automatic influence on trends in health behaviors within the whole population exposed to the changed environment. For example, planning a new community environment that supports and encourages walking or biking has been shown to influence physical activity, eating behaviors, and obesity

in children [17]. However, these environmental changes usually require high-level interventions at an organizational leadership or even governmental level. While this field of study is relevant to some psychologists who help to inform organizational or government officials and policy makers, the focus of most clinical psychologists' practice is within their own clinic, university, or hospital.

Interventions disseminated in a clinical setting typically require active and purposeful effort on the part of the patient to produce a behavior change. This type of intervention may be designed to change individuals' behaviors or cognitive strategies to help them adjust, alter, or augment their personal lifestyles in healthful ways [15]. Traditionally, these interventions are implemented through one-on-one counseling sessions with a therapist. However, this type of intervention can be very expensive, and the need for therapy is much greater than the availability of therapists [7].

Several new, more cost-effective approaches have been made possible through other mechanisms capitalizing on communication technologies that have become increasingly widespread such as cell phones and the Internet. One study [18] found that among patients interested in some form of behavioral treatment, 92% were interested in or would consider face-to-face treatment as compared to 63% who showed interest in telephone counseling and 48% in Web-based care. The results also indicated that time constraint as a barrier to care was more predictive of interest in telephone and Internet treatments compared to face-to-face treatments. It is estimated that nearly eight in ten individuals of the US population have a cell phone [19] and about 74% of homes in America have Internet access [20]. In addition, about 40% of Americans with Internet access use it to seek information on health or health care [21]. Therefore, these alternative methods of communication have the potential to serve as vehicles for population-level interventions for many patient populations. Psychologists who embrace population health management approaches can increase their efficiency with telephone or Web-based treatments for patients who are receptive to this approach and for disorders that can be treated effectively without regular face-to-face treatment sessions.

## **Tobacco Use**

### ***The Problem***

Tobacco use is one of the world's greatest health risks [22]. Not surprisingly, it is also one of the most commonly targeted health behaviors for population health interventions [2]. Tobacco use caused 100 million deaths worldwide in the twentieth century, and it kills 5.4 million people annually [22]. Estimates project that if trends in tobacco use continue unchecked, it will cause 8 million deaths annually by the year 2030 [23]. In the USA, tobacco is the leading preventable cause of death, and it is responsible for approximately 1 of every 5 deaths, totaling 443,000 deaths

annually [24]. About 11% of these deaths are related to secondhand smoke [24]. Approximately 70% of American adult smokers indicate they want to quit smoking, but less than 5% do so successfully each year [25]. There is no safe level of tobacco use. Therefore, the potential target for population health interventions is anyone who consumes tobacco.

The most effective treatments for tobacco use are intensive interventions including eight or more sessions of individual or group behavioral counseling combined with medication [26]. Ranked in order of effect size, the most successful approaches for tobacco cessation are group behavioral therapy, use of bupropion, intensive physician advice, nicotine replacement therapy, individual counseling, and tailored self-help interventions [27]. Though these intensive treatments are effective and may double or triple the quit rates, for a variety of reasons, they are not widely used by or available to the majority of tobacco users [25]. Population health interventions, however, can help to increase the availability of tobacco cessation treatments. Of these interventions, brief primary care interventions, telephone counseling, and guided self-change programs—all of which can be supplemented by tobacco cessation medications—are likely to be the easiest to disseminate on a population level.

### *Population-Level Interventions for Tobacco Use*

One of the most basic population health approaches is the universal assessment and treatment of tobacco use in primary care settings. Although the quit rates from these brief interventions are relatively low (e.g., 5–7%), when applied to an entire population of tobacco users, the overall impact can be substantial [2]. Some of these interventions can be specifically delivered in primary care, whereas other approaches may involve referral for self-change programs delivered via books, digital video devices [28], interactive Web-based interventions [29], and telephone counseling [30]. The potential impact of brief interventions for tobacco cessation is perhaps one of the best clinical examples of the impact of population health management interventions.

Another efficient method to disseminate a tailored self-help intervention is through computer- and Internet-based programs [29]. These types of tailored programs often survey the user and provide personalized feedback and advice based on their responses [31]. Programs can be tailored based on the current level of the users' motivation to quit smoking; however, these programs tend to be more effective when used with treatment seekers who are already demonstrating motivation and readiness for change [31]. Although many Web-based interventions for tobacco cessation have been developed and marketed, very few have scientific data to support their efficacy. Though a recent meta-analysis suggests that these programs can increase smoking abstinence by 1.5 times over a control group and lead to an approximate 10% abstinence rate at a 1-year follow-up [32], previous studies have found mixed results for the effectiveness of computer- and Web-based interventions [31]. A recent review of Web-based programs concluded that several programs offered

through the Internet do not cover key components of tobacco cessation programs in enough detail and could increase the amount of interaction in their programs to make treatment more personalized [33]. Overall, it seems that Web- and computer-based interventions have the potential to be effective population-level interventions, though much more research is needed to identify the most useful components of these interventions to maximize their effectiveness.

Telephone counseling is another mechanism for disseminating tobacco cessation interventions and providing tailored feedback [28]. Telephone counseling is particularly effective as an adjunct intervention and is often used to augment guided self-change interventions [34, 35]. Telephone counseling can be proactive or reactive. Proactive programs are the ones in which the counselor contacts a patient who is already involved with a cessation program, whereas reactive counseling is available on demand whenever the patient calls. Reactive counseling, which includes programs such as quitlines or help lines, can transition into proactive counseling if the counselor later initiates contact to follow up with the caller [35].

Advances in technology and changes in consumer habits continue to present new opportunities for tobacco interventions, the latest of which is the use of the text messaging capacity of cellular phones to assist with tobacco cessation. Text messaging programs can be used in combination with a Web-based component that primarily functions to set up and initiate the text messaging service [36, 37]. As with Web- and other computer-based intervention programs, text messages can be tailored to provide individuals with personalized advice. In addition, the greater accessibility of cell phones may make text messaging programs even more useful than computer- or Web-based programs. For example, users can receive automated texts at specific times of the day when they are likely to encounter smoking-related cues [37]. They also can send texts from their cell phone whenever they are struggling with cravings, and they can instantly receive automated feedback with suggestions for coping [37]. The effectiveness of smoking cessation programs utilizing text messaging has been demonstrated through studies that have reported participant cessation rates between 28 and 42% at 6 weeks after treatment initiation [36–38]. Additional studies are needed to determine the long-term efficacy of these intervention approaches.

## **Weight Management**

### ***The Problem***

There is no question that obesity is on the rise, particularly in America. The prevalence of obesity (body mass index,  $BMI \geq 30$ ) increased from 30.5% in 1999 and 2000 to 34.3% in 2003 and 2004, while the rate of individuals classified as overweight or obese ( $BMI \geq 25$ ) increased from 64.5 to 66.3% [39]. In 2005, the World Health Organization (WHO) estimated that 1.6 billion people over the age of 15 in the global population were overweight ( $BMI \geq 25$ ) and 400 million were obese

(BMI $\geq$ 30) [40]. Global estimates project that by 2015, 2.3 billion people will be overweight and more than 700 million will be obese [39].

These escalating rates of obesity come at a high price. The cost of overweight and obesity has been estimated as US\$ 117 billion per year in direct and indirect costs [39]. Obesity has also been identified as a major risk factor for numerous chronic diseases, including cardiovascular disease, diabetes, musculoskeletal disorders, and even some cancers [40]. Likewise, higher BMI in men and women of all ages is associated with higher mortality rates [41].

Population health interventions have the potential to help alleviate the rapidly escalating weight management crisis. The primary underlying cause of obesity is simple—people consume more calories than they burn [40]; however, finding a solution is complex. Factors affecting diet and physical activity are endless, with just a few examples including increased availability of calorically dense, tasty foods, as well as modern increases in the number of sedentary jobs and sedentary methods of transportation [40]. A 2006 survey found that 62% of American adults do not engage in any vigorous activity lasting more than 10 min [39]. To reduce the rising rates of overweight and obesity, evidence-based, population health programs should be implemented to lower caloric intake and increase physical activity.

### ***Population-Level Interventions***

The most effective treatments for weight management are multisession cognitive-behavioral treatments [42]. Several behavioral treatment components have been identified as effective components of weight loss treatment, including self-monitoring, stimulus control, and cognitive restructuring [43], as well as social support, role-play, and tailored behavior instructions [44]. Though most of these interventions have traditionally been implemented through face-to-face counseling, contemporary technologies offer several other methods of implementing these interventions that may be just as effective [45, 46]. Interactive technologies, such as the telephone and Internet, increase the cost efficiency of intervention and allow for wider, more population-based dissemination [47].

For example, a meta-analysis concluded that interventions primarily consisting of telephone contact can improve diet and increase physical activity [48]. Telephone contact can be implemented by research staff, clinicians, or by automated calls, and the most effective interventions include 12 or more calls over a period of 6–12 months [48]. Phone calls are particularly useful and cost effective for providing tailored behavior instructions [49]. Specifically, helpful intervention calls might be used to provide assessment with immediate feedback, to offer advice on physical activity and diet, and to develop personal goals and plans [46, 50].

The newest version of mobile devices such as “smartphones” allow for almost unlimited possibilities for delivering and assessing population health interventions [51]. At the most basic level, modern cell phones offer text messaging services that can be used for delivering and reporting physical activity and dietary interventions.

Text messages also can be automated to provide goal reminders, such as automated messages sent at the planned time for physical activity [52]. In addition, smartphones not only allow individuals to receive tailored streaming video interventions, but they also allow patients to photograph, videotape, and audio-record various aspects of dietary-intake and physical-activity behaviors. However, much data are lacking in these areas, and cutting-edge technology does not guarantee success for such a simple (calories in; calories out) yet complex problem as weight management.

There is some research evidence to support the efficacy of Web-based programs for weight management [46, 53, 54]. Studies have shown these interactive programs to be effective in producing initial weight loss in adults [55], and preliminary evidence suggests that they may be also effective for children [56]. Some researchers have even suggested that Internet-based weight loss treatments may be as effective as face-to-face interventions [55]. The Internet is a versatile portal for providing generic education and specific suggestions, social support through virtual group bulletin boards, tailored e-mail feedback from counselors, and a space to self-monitor by logging dietary intake and physical activity [55]. Personal digital assistants, or PDAs, provide another electronic outlet for self-monitoring of diet and exercise behaviors. Although self-monitoring traditionally has been paper based, a recent study suggested that the use of a PDA to self-monitor is just as effective [57].

## **Excess Alcohol Consumption**

### ***The Problem***

Excess alcohol consumption is often described as problem drinking, heavy drinking, or at-risk drinking and is not always accompanied by alcohol dependence [58]. According to the Centers for Disease Control and Prevention [59], heavy drinking is defined as the consumption of more than two standard drinks of alcohol per day for men and more than one standard drink of alcohol per day for women. Approximately 10% of Americans will have significant problems with alcohol at some point in their lives, with men affected more often than women [60, 61]. Excess alcohol consumption is associated with an increased risk of many medical conditions such as cancer, pancreatitis, gastritis, and cirrhosis, as well as neurological and cardiovascular problems [59]. In the US, it was estimated that 1.6 million individuals were hospitalized in 2005 and more than 4 million individuals visited emergency rooms for alcohol-related conditions [59]. Each year in the US, 79,000 deaths are reported due to excessive alcohol use. This makes alcohol the third leading cause of death in the nation, after tobacco use and overweight/obesity [4, 5, 59]. About half of Americans over the age of 12 drink alcohol, 23.7% binge drink (defined as five or more drinks at one sitting), and 6.8% binge drink at least 5 days out of the month [62].

In 2009, it is estimated that 20.9 million drug- and alcohol-use disorder cases went untreated in the US [62]. Estimates from 2005 suggest that substance abuse and addiction cost the US federal, state, and local governments US\$ 467.7 billion, exceeding the costs of heart disease, cancer, and obesity [63]. In the public sector, substance abuse and addiction contribute to higher costs in areas such as health care and the criminal justice system. In the private sector, these addictions increase costs due to problems such as decreased productivity and higher insurance rates [63]. They additionally contribute unquantifiable costs to human pain and suffering in tragedies related to substance abuse, such as car accidents, homicides, suicides, rape, and domestic violence [63].

However, as compared to tobacco, there does appear to be a safe and even healthy level of alcohol consumption. There is now considerable epidemiological evidence to indicate that moderate alcohol consumption (up to two standard drinks of alcohol per day for men and up to one per day for women [59]) is actually associated with reduced health risks and total mortality as compared to abstinence from alcohol or heavy drinking. One study [64] found that alcohol abstainers had a mortality risk more than two times that of moderate drinkers. In addition, heavy drinkers had a 70% increased risk. The level of reduced mortality for abstainers compared to moderate drinkers was decreased when the investigators statistically controlled for age, gender, former problem-drinking status, existing health problems, key sociodemographic factors, and key social-behavioral factors. However, even after adjusting for all of these covariates, abstainers continued to show an increased mortality risk of 51% over moderate drinkers and 45% over heavy drinkers. These factors are important for consideration by psychologists, because the field of substance abuse often focuses on the achievement of total alcohol sobriety as a treatment goal. From a population health perspective, a common goal is to focus on reducing excess alcohol consumption for patients identified with alcohol abuse, alcohol dependence, or a health-related condition that is negatively affected by alcohol consumption. Interventions to reduce, but not necessarily eliminate, alcohol consumption are referred to as “harm reduction” treatments for alcohol problems [65].

### ***Population-Level Interventions***

Similar to tobacco cessation and weight management, the most effective treatment for alcohol dependence is intensive individual treatment, using either a cognitive-behavioral therapy, medication, or a combination of the two [61, 66]. The largest randomized controlled trial for the treatment of alcohol dependence was the Combined Pharmacotherapies and Behavioral Interventions (COMBINE) Study [66]. This study evaluated eight different combinations of the use of two medications (naltrexone, acamprosate, or both), a combined behavioral intervention (CBI), and a placebo. The CBI treatment consisted of up to 20 sessions of 50 min each and integrated aspects of cognitive behavioral therapy, 12-step facilitation, motivational interviewing, and support-system involvement external to the study. The results of



this study indicated that patients receiving medical management with naltrexone, the CBI, or both had significant reductions on drinking outcomes (approximately 80% days abstinent). Interestingly, the combination of naltrexone and the CBI did not produce better outcomes than either naltrexone or CBI alone. Unfortunately, intensive interventions such as those evaluated in the COMBINE study are not available for most individuals with problems with excess alcohol consumption.

There are, however, a variety of population-based interventions that can help decrease excessive alcohol consumption in high-risk populations. Similar to tobacco cessation, brief interventions (<1 h) incorporating motivational interviewing and motivational enhancement approaches have been demonstrated to be effective for the treatment of heavy drinking [67, 68]. A meta-analysis indicated that heavy drinkers who received a brief intervention were twice as likely to moderate their drinking 6–12 months after an intervention when compared with heavy drinkers who received no intervention [68]. Brief interventions have also been shown to result in fewer emergency room visits and hospitalization for up to 4 years after the intervention [67]. Brief intervention is a low-cost, effective preventive measure for heavy drinkers in outpatient settings.

Web-based interventions are another approach to target high-risk drinkers and alcohol-dependent individuals in large populations. While a wide range of Web-based programs are advertised, few Web sites actually offer online treatment services, and most of the alcohol treatment programs offered are not empirically based [69, 70]. Though some studies have found promising results for Web-based interventions designed to decrease alcohol consumption [65, 71], most of the programs evaluated in research clinical trials are not publically available.

Screening and brief intervention (SBI) is an example of one method to decrease excessive drinking that has been effectively adapted to the Internet [72]. SBI includes assessment tools in the screening phase, along with assessment questions and personalized feedback in the intervention portion. The assessment includes a 14-day retrospective drinking diary, self-reported weight, and perceptions of peer drinking norms [73]. Important personalized feedback consists of summaries of recent consumption, risk status, and estimates of blood-alcohol concentrations on participants' heaviest drinking days [72].

The Drinker's Check-Up (DCU) is another example of a program that decreases alcohol consumption via the Internet. Though a Windows software version of DCU was developed for therapists and clinics, a Web-based application was also developed for the general public. DCU uses brief motivational interventions [74] and can be utilized as a separate intervention or as an introduction to alcohol treatment. This program consists of integrated assessment, feedback, and decision-making modules [74]. DCU provides a complete drinking assessment and encourages the user to change his or her behaviors using the FRAMES approach (Feedback is personalized; Responsibility for changing is left with the individual; Advice to change is given appropriately; a Menu of options for changing is offered; an Empathic style is used by the therapist; and Self-efficacy is emphasized [75]). The FRAMES approach is designed for drinkers who are unsure about changing their drinking habits.

Computer-based DCU has been found to compare favorably to DCU delivered via face-to-face contact [74].

As noted through the many examples cited here, the Web- and computer-based programs are valuable tools for clinicians and their patients. Computer-based programs can create interactive dialogues, foster patient interest, and increase levels of confidentiality. Also, computer-based programs and the World Wide Web may be an effective way to offer low-cost treatment to a greater number of clients with alcohol-related problems. Research conducted to date suggests that Internet- and computer-based programs have the potential to produce significant improvement and successful results when used as a population health management intervention [69, 72, 74].

## Conclusion

The lifestyle behaviors that are the leading causes of morbidity and mortality in America—tobacco use, overweight/obesity, and alcohol use—can be significantly improved through population health management interventions. Large populations can be targeted through increasingly popular information communication methods and technological mediums, such as telephones, text messaging, and the Internet. These types of interventions have made treatment more cost-efficient by decreasing the need for face-to-face time between patients and health-care providers. Furthermore, technology-based communication has increased the availability and accessibility of interventions, especially for rural populations, while simultaneously making participation in interventions more private, even allowing for anonymity.

Several studies support the effectiveness of population-based interventions disseminated through methods alternative to traditional therapy. However, the research in this area is largely in its beginning stages, and in some areas the findings have been mixed. This is possibly due to the focus on the method of dissemination rather than treatment components. Future research in this area could work toward maximizing the effectiveness of population-based interventions by identifying the most effective treatment components that are based on empirically supported models of behavioral change.

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## Chapter 2

# A History of Clinical Psychology in Medical Settings

Mark Vander Weg and Jerry Suls

It is impossible to understand the history of clinical health psychology without first describing some developments in mainstream clinical psychology, psychiatry, and medicine in the late nineteenth and twentieth centuries. So we will start with those and then shift to health psychology and clinical health psychology, in particular. The second major section will discuss issues about generalist versus specialist training and the role of the clinical health psychologist in primary and specialist medical care as they have evolved over time.

### Roots and History of Clinical Health Psychology

#### *Clinical Psychology*

Clinical psychology received its formal start from Lightner Witmer, a psychologist at the University of Pennsylvania, who had trained with Wundt in Germany in the 1890s [1]. Witmer's initial research interests concerned individual differences in sensory and perceptual abilities, but he was also eager to use psychological principles to solve applied problems. He became interested in what is now referred to as

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The opinions expressed herein and the interpretation and reporting of these data are the responsibility of the author(s) and in no way should be seen as an official recommendation, interpretation, or policy of the National Institutes of Health, Department of Veterans Affairs, or the US Government.

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*special education*—the problems exhibited by children in school. Witmer not only created the term “clinical psychology” but also founded the first psychological clinic in the last decade of the nineteenth century at the University of Pennsylvania [2]. The clinic was established to treat children’s speech problems, sleep disturbances, behavioral problems, hyperactivity, and refusal to stay in school. Witmer instituted a routine for any child referred to the clinic by parents or teachers to be given a complete check to rule out physiological causes. If the problem appeared not to be medical in nature, Witmer’s approach was to individually communicate information to children at a level comprehensible to them so they could work on specific problems [2]. Because both learning and conditioning were still in their formative stages, Witmer’s approach was very pragmatic. He used the term “clinical” because he saw his approach as resembling medicine at that time, which involved intense observation and care of individual patients. He defined “clinical psychology” as the observational or experimental study of people to promote change. Witmer also started the first journal for this new field, *The Psychological Clinic* [1]. The word spread, and by 1914 there were 26 similar clinics in the USA [2, 3].

Although Witmer thought medicine and clinical psychology shared key features, cognitive and personality assessments were the main focus of most clinical psychologists in the first decades of the twentieth century. During World War I, two intelligence tests, *Army Alpha* and *Army Beta*, were developed by psychologists to assess recruits [4]. Serious mental distress was the domain of psychiatrists and neurologists. Of course, there is a blurry line between cognitive problems and mental disorders, so in some cases physicians and psychiatrists had contact and made referrals to clinical psychologists. After the war, testing continued to be the main preoccupation for clinical psychologists although this would change during the next war.

## ***Scientific Medicine***

What was conspicuously absent from the purview of early clinical psychologists was *physical health*, which was considered exclusively to be in medicine’s domain. Modern readers, of course, tend to think of medicine with its sophisticated tests, procedures, devices, and medications. Prior to the mid-twentieth century, however, physicians mainly relied on bedside manners, involving “empathy compassion and a nurturing feeling for the ill individual ([5], p. 10).” These were the tools that physicians had to rely on because they had few effective clinical, surgical, and pharmacological procedures. This is also why medical education in the nineteenth century mainly took the form of an apprenticeship relationship between the practicing physician and a student in training. With the advent of the cellular theory of disease, the demise of the concept of spontaneous generation, the germ theory of disease, and advances in physiology and anatomy in the late nineteenth century, medicine acquired a more substantial scientific basis, whose foundation science was microbiology.



Medicine adopted the biomedical model, which only makes provision for biological causes of illness and embraces a reductionism in which illness is derived from a single primary factor. The model is predicated on mind–body dualism (dating back to Descartes)—mind and body are separate and autonomous entities that interact minimally. In the biomedical model, psychological, social, and behavioral variables were considered to play minor roles for understanding and treating physical illness.

Scientific advances in biology, chemistry, and physiology and the biomedical model also prompted the demise of the apprenticeship teaching approach in medicine. Some didactic information about basic sciences was provided by medical schools in North America in the late nineteenth and early twentieth centuries, but these efforts failed to provide systematic or comprehensive coverage of the relevant sciences, such as organic chemistry, biology, and physiology. Motivated partly by competition with “healers” and by advances in the life sciences, the American Medical Association asked the Carnegie Foundation to study medical school education and make a report [6]. Alexander Flexner was given that task and he visited more than 150 medical schools in the USA and Canada and found the majority seriously wanting. Lecturers tended to be part time and not necessarily expert in the fields they taught, the educational curriculum was haphazard, and the content in the laboratory sciences was dated. Only a few medical schools, such as the Johns Hopkins University, had rigorous scientific curriculum and clinical training adapted from the European model of training medical doctors. The distribution and acceptance of the Flexner report had widespread effect, creating new accreditation standards and effectively closing medical schools that failed to adopt Flexner’s recommendations for a comprehensive scientific and clinical medicine curriculum [6, 7].

Positive changes resulted from the adoption of the Flexner curriculum, but with the consequence that courses were taught by experts trained in specialty subjects, such as anatomy and chemistry, and internships were completed according to specialty, such as medicine and surgery. This had the effect of providing physicians in training experiences primarily along departmental lines. Consequently, “(there was) little or no overlap or integration from one course to another ([5], p. 13).” The practitioner-specialist, rather than the generalist, tended to become the norm. Traditional bedside medicine, treating the “whole patient,” began to decline.

This tendency might have been counteracted by including content on psychological aspects of medicine. Indeed, as early as the 1910s, there were psychologists and physicians recommending such content to be added to the medical school curriculum. In fact, the famous behaviorist John B. Watson taught and published a curriculum for a course on psychology for medical students at the Johns Hopkins University [8]. However, psychology was not as advanced a scientific discipline as biology, chemistry, and physiology in the first half of the twentieth century. Psychology was not made a requirement in the medical school curriculum although there were gradually increasing roles for psychology in medical education [9].

## *Changes in Life Expectancy and Causes of Death*

During the twentieth century, life expectancy was extended, on an average, by about 30 years, which was commonly attributed to medical scientific advances. Also in 1900, death due to infectious diseases was the leading cause of death, which comprised about 30%. In the year 2000, deaths due to infectious disease comprised only 3% [10–12]. Vaccination, safer drinking water, and milk supplies, thought to be results of scientific advances, were credited with this change. However, deaths from infectious disease were starting to decline prior to the introduction of vaccination. Epidemiologists agree that antibiotics and advanced surgical procedures actually played minor roles in the increase in life expectancy. Three other factors do seem to have had a positive role—improved nutrition, sewage disposal, and healthier lifestyle (such as exercise). These changes occurred, mainly, independently of scientific research in the life sciences and medicine. Regardless of the actual evidence, modern scientific medicine, following the biomedical model, was commonly credited with increases in longevity and decline of infectious diseases.

From the 1950s through the 1960s, optimism was high among medical scientists and practitioners who perceived little reason to consider nonbiological factors as important contributors to health and illness. This was a significant departure from the bedside medicine of the nineteenth century that had explicitly or implicitly recognized psychological and social factors in determining causes and formulating treatment. Perhaps psychologists were in the best position to identify the role of nonbiological factors in physical health, but clinical psychologists served primarily to assess mental abilities.

*Psychosomatic Medicine.* In the early twentieth century, there was a discipline that was concerned about physical disorders and their psychological origins/treatment. Psychiatry was extending Freud's theories to physical conditions, leading to the development of psychosomatic medicine. Freud originally studied disorders that seemed to have no physical cause, such as hysterical blindness or paralysis. His explanation was that unconscious emotional conflicts had been converted into a physical form. Freud's followers, such as Franz Alexander and Flanders Dunbar, extended these ideas and developed psychodynamic explanations for disorders such as headache, hypertension, and asthma. In fairness, Alexander and others believed that emotional conflict made the patient susceptible to a specific physical disease process because of the "biological weakness" associated with the corresponding organ system [13]. However, in the first half of the twentieth century, psychiatry failed in its methods to identify these biological weaknesses or mediating physiological processes.

Psychosomatic medicine was dominated by psychiatrists who diagnosed and treated physical diseases that were supposedly the result of psychological conflicts. Psychodynamic approaches to physical disease mainly relied on case studies and descriptive retrospective methods. Often there was little evidence for attributing the diseases to a distinctive conflict about a particular emotion such as anger. In light of their orientation, psychiatrists in the psychosomatic field primarily relied

on Freud's talking therapy as the mode of treatment. Such treatment was popular for decades, but Freud's theory lost popularity, and so did the psychoanalytic elements of psychosomatic medicine. By the late 1960s, the psychodynamic version of psychosomatic medicine was replaced by a perspective that recognized the role of stress and personal vulnerability factors in the interaction with biological processes.

### ***Rise of Clinical Psychology in Mental Health Treatment***

World War II created a significant demand for mental health services for military personnel and veterans. The so-called neuropsychiatric patients outnumbered patients with other kinds of disorders in veterans' hospitals [14]. (As soldiers began to return from combat, psychologists started to notice symptoms of psychological trauma labeled "shell shock," eventually to be relabeled as posttraumatic stress disorder, that were best treated as soon as possible.) Because physicians (including psychiatrists) were overextended in treating bodily injuries, psychologists were called to help treat such psychological problems. To cope with the need for assessment and psychotherapy, the Veterans Administration (VA) established clinical psychology internships that were attached to psychiatric services, supported research, and sponsored training conferences (e.g., [15]). Clinical training of interns mainly concerned the interpretation of psychological tests and diagnostic interviewing. The development of behavioral treatments was still some time away. When such treatments began to emerge in the 1950s and 1960s, principles of learning and conditioning tended to dominate psychological interventions.

After World War II, the National Institute of Mental Health (NIMH) was created to promote mental health and devote support to advancing diagnostic and treatment approaches for mental illness. At the same time, the VA was providing training sites, and NIMH was providing grants for students and supporting research on mental health. It was the VA, however, that established the doctorate as the entry-level degree for clinical psychology [16]. The United States went from having no formal university programs in clinical psychology in 1946 to over half of all Ph.D.s in psychology in 1950 being awarded in clinical psychology [4].

Clinical psychologists were beginning to serve in both assessment and treatment roles, but their focus remained on behavioral and emotional disorders. Early pioneers were Guze et al. [17], who wrote about the need to consider psychological and environmental factors to understand both the causes and treatment of physical illness [17]. They drew upon Dollard and Miller's integration of learning theory, psychoanalytic thinking, and sociocultural observations [18]. Therapeutic strategies were proposed to improve the patient's "adjustive techniques" to cope with stressors and reduce the anxiety or other emotions that magnify physiological processes that may lead to infection, illness, or injury. Guze et al.'s proposal was not initially appreciated, however, "...because the apparently effective handling of complex diagnostic and therapeutic problems by twentieth century medical specialists was accompanied by a decrease in those therapeutic elements in the practice of medicine which were associated with knowing and understanding the patient ([5], p. 14)."

## *A Changing Landscape for Medicine and Psychology*

At least three parallel developments helped to create an environment much more receptive to the call for a more comprehensive medicine with a role for clinical psychology. First, there was increasing appreciation that the aforementioned decline in infectious diseases was accompanied by increases in diseases stemming from individual behavior and lifestyle (e.g., heart disease, cancer, emphysema) [19]. Changes in illness prevalence and longevity focused attention on behavior rather than on specific biological pathogens. Although vaccination could prevent most infectious diseases, there were no “magic bullets,” referring to prevention or treatment measures that “cure” a medical condition, such as cancer or heart disease. Instead, changes in lifestyle behavior, for example, physical exercise and smoking cessation, were the most viable ways to prevent disease.

Second, increasing costs, in some cases as a result of sophisticated medical procedures, technologies, and medications, were absorbing a large proportion of the nation’s financial resources [20]. As noted above, expectations about “magic bullets,” were diminishing in the context of common chronic and debilitating physical diseases. Instead, physicians increasingly had to find ways to assist patients with management of chronic conditions. Frequently, changes in behavior were becoming the focus of many programs with respect to prevention, coping, and adaptation. For example, smoking, hypertension, and serum cholesterol were the three risk factors that were the focus for the Multiple Risk Factor Intervention Trial program sponsored by the National Heart, Lung and Blood Institute [21].

Third, stress and disease were becoming major topics of interest to biobehavioral scientists and medical scientists in the 1960s and 1970s. The earlier empirical insights of Walter Cannon on “flight or fight” responses and Hans Selye’s demonstration of a general physiological reaction to noxious stimulation provided a foundation for researchers [22, 23]. The idea “in the air” was that physical and social sources of stress can increase mental and physical illness. Scholars such as Orville Brim, David Glass, David Hamburg, David Shapiro, and P. Leiderman were using earlier constructs and empirical evidence to explore the interface of social behavior and biological processes. “Interdisciplinary” was becoming the watchword. As Glass [24] observed:

...each discipline cannot ignore the conceptual and empirical advances of the others. Just as complex behavior cannot be understood in purely biological terms, mental events cannot be understood without some recourse to the relevant biological processes within the organism. And, it is true also, that relevant social environmental factors must be incorporated into any serious effort to understand behavioral and physiological outcomes (p. xvii) [24].

Glass, who played a major organizing role (besides conducting pioneering studies with Jerome E. Singer on the effects of stress and noise on human social behavior), has described some “vectors” in the 1960s and 1970s that increased the momentum for research, providing an alternative to the biomedical model [25]. First, several medical centers initiated behavioral science research and training programs in departments of psychiatry and epidemiology, often supported by private foundations

and federal agencies, such as NIMH, National Science Foundation, and other institutes of NIH (e.g., National Heart, Lung and Blood Institute and National Cancer Institute).

A second vector was financial support for research and interdisciplinary conferences. One of the first conferences, sponsored by the Office of Naval Research led to a book coedited by Leiderman and Shapiro, which was followed by conferences held at the Rockefeller University and sponsored jointly with the Russell Sage Foundation [26]. These events were unique in bringing together representatives of a wide range of disciplines, including psychiatry, psychology, sociology, economics, anthropology, ethology, nutrition, and genetics. What emerged were common themes, constructs, and evidence about associations between stress and physical and mental outcomes.

These efforts were extended by meetings of the Social Science Research Council, which obtained funding for special summer training institutes to train social scientists to combine psychosocial and biological concepts and methods in their research. Institutes were held on such topics as medical physiology, genetics, psychophysiology, and neurobiology. These experiences provided unique interdisciplinary knowledge and skills to the next generation of stress researchers.

### ***Biology Meets Behavioral and Social Science***

From the mid-1950s, psychologists, including those in the clinical subfield, began to conduct research on phenomena and practical problems extending beyond mental health concerns. For example, the Health Belief Model (HBM) was developed by Hochbaum, Kegeles, Leventhal, and Rosenstock, all psychologists in the US Public Health Service, who were trying to understand why people were not being vaccinated against tuberculosis [27, 28]. HBM became an important conceptual framework for prevention efforts and remains influential.

Successes in applying behavioral therapy to traditional mental health problems, such as phobia and obsessive–compulsive disorder, inspired behaviorally oriented clinicians to apply this approach to medically related problems, such as obesity and smoking [29]. Systematic desensitization, operant conditioning, aversive conditioning, and modeling were adapted to treat damaging health behaviors.

Neal Miller's research on the conditioning of physiological processes (i.e., visceral learning) in animals elicited substantial interest because it contradicted prior beliefs that voluntary control of fundamental physiological processes (such as heart rate and blood pressure) was impossible [30]. Soon, researchers recognized that the growing body of evidence about stress and its effects on physical function could be tied to Miller's research on visceral control and biofeedback in animals.

The key idea was that providing biofeedback—rapid accurate feedback about physiological activity, such as brain waves, heart rate, or hand temperature—to subjects might enable them to learn how to change physiological responses. For example, Schwartz, Shapiro, and colleagues demonstrated that patients provided

with rapid feedback about their blood pressure or heart rate via biofeedback could reduce their blood pressures [31]. These early successes encouraged clinical psychologists to develop interventions to test the effects of biofeedback on heart dysfunction, blood pressure, headache, and other physical disorders [32].

At the same time, Herbert Benson, a cardiologist at Harvard, was studying the effects of meditation on physiological functions. He explored the idea that meditation or relaxation may counteract the acute and perhaps the long-term effects of stress on physiology, something which may be particularly important for persons with a disorder, such as hypertension. In some of his studies, the patients' blood pressures were reduced significantly after several sessions of learning meditation [33]. (These successes led to subsequent efforts using transcendental meditation and more conventional relaxation techniques, such as controlled breathing, that had been used earlier by clinical psychologists for purely psychological problems).

Behavioral treatments, featuring biofeedback, relaxation, meditation and operant conditioning, and systematic psychological assessments were beginning to make their appearance in medical settings. One indication was the publication in 1976 of a landmark article by Schofield in the *American Psychologist* on "The role of psychology in the delivery of health care services [34]." Five years later, the American Psychological Association (APA) established a task force to collect information on the progress of health behavior research by North American psychologists.

During this same period, research showing that exposure to chronic stress made animals susceptible to physical dysfunction, such as ulcers and even death, motivated researchers to develop assessments of recent occurrence of life events and to measure illness incidence [35]. The idea was that major changes in habits and routine, such as death of a spouse or job loss, could create a physiological stress response, thereby increasing the risk of physical disease. These efforts inspired a stream of research to assess real-life stressors and their relationship with physical disease risk.

Lazarus conducted pioneering studies demonstrating how cognitive appraisals affected human emotional and psychophysiological responses to acute stressors in the laboratory [36]. A stressor appraised as threatening or harm-producing would engender an aversive physiological response, but the stress response could be short-circuited if a stressor was perceived as benign or a challenge. Lazarus also demonstrated that mental or behavioral efforts to manage the demands of stress, referred to as coping strategies (e.g., distraction, intellectualization), could reduce potential stress responses.

During the same time, Schachter, a social psychologist, was developing a theory of emotion, which, like Lazarus' theory, depended on subjective appraisal as a major component [37]. Schachter was particularly interested in identifying the circumstances under which people use the social context, rather than visceral cues to label emotions. This research on internal versus external cues would eventually lead Schachter and his students to study social and physiological determinants of obesity and smoking behavior [38, 39].

Stress-coping models inspired programs in stress management and cognitive-behavioral therapy (CBT). CBT also developed out of efforts in clinical psychology,

including Ellis's rational emotive therapy, Aaron Beck's cognitive approach, and Meichenbaum's stress inoculation approach [40–42]. Although these approaches were formulated chiefly for psychological disorders, their applicability to medical patients quickly was perceived. CBT involves a collaborative relationship between client and therapist and is based on the premise that psychological distress is largely a function of disturbances in cognitive processes. Thus, the treatment focuses on changing cognitions to produce desired changes in affect and behavior. Unlike the Freudian talking cure, CBT is time limited and focuses on specific and structured target problems. It features questioning and testing cognitions, assumptions, evaluations, and beliefs that might be unhelpful and unrealistic; gradually facing activities which may have been avoided; and trying out new ways of behaving and reacting. Relaxation and distraction techniques are also commonly included.

In the meanwhile, epidemiological research was emerging on an emotional–behavioral complex, referred to as “type A” behavior, which appeared to increase the risk of developing premature cardiac disease, independent of traditional risk factors. This construct originated with two cardiologists, Meyer Friedman and Ray Rosenman [43]. A psychological perspective was advanced by David Glass, a social psychologist, who, with his students, began a series of experimental studies documenting that type As responded more intensely to stressors and tested a theory to explain type A on the basis of learned helplessness theory [44]. This research was to provide the frame for subsequent research on the role of individual differences, such as anger and depression, in stress vulnerability, and stress resilience.

### ***Behavioral Health Zeitgeist***

In 1977, Engel published a paper entitled “The Need for a New Medical Model: A Challenge for Biomedicine” as a lead article in *Science* [45]. Engel proposed a new model, the biopsychosocial model, which recognized that illness and health were a function of three interrelated systems—biological, psychological, and social. Engel perceived that adoption of the biopsychosocial perspective would bring the “whole patient” back into the sights of medicine. Evidence was accumulating and interventions were being adopted that exemplified the biopsychosocial model and created optimism that researchers were on the right track. Initially, the term “behavioral medicine” was used to refer to this field by the physicians, psychologists, and allied professionals who were attracted to this emerging interdisciplinary field.

Matarazzo, who had coauthored the call for a “comprehensive medicine” with Guse and Saslow in the early 1950s, recognized that psychologists whose interests spanned across the many subfields of psychology could contribute to advancing the study of the etiology, prevention, and treatment of physical illness [46]. “Health psychology” was the name given to this new field. Matarazzo, who was at the newly founded Department of Medical Psychology at the Oregon Health Services University, and Stephen Weiss, who was the chief of the newly established Behavioral Medicine Branch at the NHLBI, developed a petition to the APA to establish a new

division of Health Psychology (Division 38), which was approved in 1978. Consistent with its mission, psychologists from different fields became members: social, clinical, counseling, physiological, comparative, etc. Shortly afterward, Division 38 founded a journal, *Health Psychology*, to serve as an outlet for research in this field, which first appeared in 1982 [47].

In 1978, Weiss and Schwartz convened a conference on behavioral medicine at Yale University, which brought together a group of behavioral and biomedical scientists to define this emerging field. One consequence was founding of the *Journal of Behavioral Medicine*. Those assembled at this meeting represented different kinds of training. Some researchers were educated in medicine and psychiatry and tended to identify with the field of psychosomatic medicine although putting aside its psychodynamic origins. Researchers from medicine and psychology drew from theories of learning, basic research on animal physiological psychology and human psychophysiology, and from research in social and clinical psychology. Schwartz and Weiss observed that psychosomatic medicine has traditionally emphasized etiology and pathogenesis of physical disease, whereas behavioral medicine was directly concerned with behavioral approaches to the treatment and prevention of physical disease [48, 49].

Behavioral medicine was perceived to overlap with, but was not identical to, health psychology. Researchers in behavioral medicine were interdisciplinary and tended to concentrate on direct patient evaluation and treatment (sometimes referred to as “medical psychology”); health psychologists tended to consider principles and research in mainstream psychology as their “home base.” However, in recent years, the growth of medical collaborations and interdisciplinary biobehavioral science has effectively eliminated this distinction. In the late 1960s and 1970s, another segment of investigators perceived behavioral medicine as the specific application of “behaviorism” to medicine, emphasizing operant and classical conditioning or forms of behavior therapy (emphasizing cognitive self-control procedures and social learning theory). However, just as behavior therapy has become more “cognitive” in recent decades, so has behavioral medicine.

As these fields were formed, venues were needed for conferences and conventions for like-minded researchers and interventionists. APA Division 38, of course, contributed a program of addresses, papers, and symposia to the annual American Psychological Association Annual Meeting held in August of each year. In 1978, Neal Miller, who pioneered research on biofeedback, founded the Academy of Behavioral Medicine Research to provide a yearly forum for established (senior) behavioral medicine researchers (from medicine, psychiatry, psychology, epidemiology) where ideas could be exchanged in an informal atmosphere. In the following year, psychologists and physicians who were members of the American Academy of Behavior Therapy decided to form a professional group that was specifically concerned with prevention, promotion, and treatment of physical ailments. This became the Society of Behavioral Medicine, which now also includes nurses, sociologists, and public health researchers.

By the early 1980s, the need to develop systematic graduate curricula and training standards for health psychology was perceived. Hosted by APA Division 38, the



national “Working Conference on Education and Training in Health Psychology” was held at the Arden House outside Harriman, New York, in 1983. A select group of psychologists from a wide variety of subdisciplines were invited to represent the new field and develop a curriculum. A special issue of *Health Psychology* was devoted to the proceedings of that conference. The next year, Division 38 and the Council of Health Psychology Directors established the American Board of Health Psychology (ABHP) as the credentialing body for the specialty practice of clinical health psychology [47].

By the 1980s, there was clear recognition of health psychology and its clinical specialty. The work was perceived to have made so much progress that the editors of the *Journal of Counseling and Clinical Psychology* decided to devote a special issue to “Behavioral Medicine and Clinical Health Psychology” in 1982, edited by Professor Edward Blanchard, a widely respected clinical researcher specializing in biofeedback for physical disorders [50]. Noted researchers provided surveys of state of the science and treatment on particular topics, such as smoking, obesity, headache, insomnia, and blood pressure. In 1992, Blanchard edited an update with the now “traditional topics,” and topics that emerged after the 1982 issue, such as psychoneuroimmunology, immunodeficiency syndrome (AIDS), and the role of psychology in cancer [51]. In his introduction to the 1992 Special Issue, Blanchard observed:

There now exist many controlled evaluations, across a wide array of traditionally medical disorders, of psychological therapy either as the primary therapy or as an important part of the total care of the patient. In some instances it seems established that psychological treatments are the treatment of choice. Thus, I believe that those of us in clinical and counseling psychology who treat the medically ill can be truly proud of what we have to offer. Certainly, the importance of behavior and behavior change to health care was forcefully presented in the recent Department of Health and Human Services blueprint.

In 2002, Smith, Kendall, and Keefe edited another update noting the broad “... range of topics and methodological eclecticism...black box models of connections between behavioral inputs and disease outcomes have been steadily replaced by much more specific and testable descriptions of mechanisms (lead)...to the pathophysiology of disease, and the development of approaches to evaluate the clinical significance of intervention effects in the specific context of a particular health problem or treatment setting ([52], p. 495).” In summary, clinical health psychology has emerged with a strong body of intervention strategies, evidence, and theories.

## Special Issues in Clinical Psychology in Medical Settings

### *Generalist Versus Specialized Training*

A perennial question within professional psychology pertains to relative merits of a generalist versus a more focused, or specialized, approach to training and practice. Indeed, the extent to which the field of psychology should view itself as single,

unitary discipline as opposed to a more diversified area of study containing multiple specialties and subspecialties has been debated almost from the beginning of the profession. This issue has been the source of particular discussion within clinical and counseling psychology, where several distinct areas of clinical emphasis and specialization have emerged, including health. As more and more trainees and practitioners have begun to focus their clinical practice on specific patient populations, presenting problems and settings, debate over whether such specialization is necessary and good for the profession (and the patients who are served) has continued.

When addressing the potential need for specialization, it is important to consider the variety of activities being done by those who practice in this area. Clinical psychologists in medical settings often identify themselves as clinical health psychologists to distinguish what they do from other professional psychologists. Although specific medical conditions and treatment applications are addressed in detail elsewhere in this volume, a brief review of the scope of practice of clinical health psychologists in medical settings will perhaps be beneficial for the purposes of this discussion. Based on a slight modification of Matarazzo's [46] original definition of the field, Belar [53] has described the practice of clinical health psychology as follows:

"A clinical health psychologist applies, in professional practice, the specific educational, scientific, and professional contributions of the discipline of psychology to the promotion and maintenance of health; the prevention, treatment, and rehabilitation of illness, injury, and disability; the identification of etiologic and diagnostic correlates of health, illness, and related dysfunction; and the analysis and improvement of the health care system and health policy formation" (p. 411).

Accordingly, the issues commonly addressed by clinical health psychologists include psychophysiological disorders, psychological conditions resulting from physical illness, somatic manifestations of psychological conditions, psychological symptoms associated with organic illness, physical symptoms amenable to behavioral interventions, behavioral risk factors for disease and disability, prevention of complications associated with stressful medical procedures, and problems involving health care providers and health care systems [53]. It is this primary emphasis on physical symptoms and disorders, as opposed to mental health concerns, which characterizes clinical health psychology.

In addition to the common presenting complaints and issues that are addressed in practice, several important qualifications that clinical health psychologists should possess have also been identified. Training in the biopsychosocial model of health and illness [45], commitment to the Boulder model and evidence-based practice, adequate skills to gather data and design research programs in the absence of necessary evidence, familiarity with biomedical terminology and procedures, good communication skills that enable one to work in a cross-disciplinary setting, valuing cross-cultural differences, and ability to think efficiently in ways that are both flexible and critical have all been identified as essential characteristics of effective clinical health psychologists [54]. Although several of these attributes can be just as readily applied to other areas of professional psychology, the primary focus on issues related to physical health, the ability to work in a broad range of medical

settings with other health care professionals, and the application of the biopsychosocial model as a guiding framework (as opposed to a purely psychological or psychosocial model) are key features which distinguish it from clinical psychology more broadly [55, 56].

While specialization offers the advantage of more extensive and focal expertise related to the assessment and treatment of medical problems, some have argued that it comes at the expense of the more comprehensive foundation afforded by a generalist approach. For example, the types of complaints and issues commonly addressed by clinical health psychologists rarely occur in isolation. Instead, multiple mental and physical health comorbidities tend to be the norm rather than the exception. Consequently, it is important for the clinician to have a sufficiently broad base in professional psychology to be able to treat the full range of issues that may emerge. In addition, the possibility that specialization could lead to a decreasing proportion of clinicians practicing as generalists, a development not unlike that which occurred in medicine starting in the latter part of the twentieth century, has also been noted [57, 58]. Given the unfortunate marginalization of the general medicine practitioner [57] and the fragmentation that currently characterizes contemporary health care in the United States, professional psychology should carefully consider whether it can afford to follow a similar course. Concerns have also been raised that specialization could perpetuate itself to the point where clinical health psychology becomes comprised of a growing number of increasingly narrow subdivisions (e.g., weight management psychologists, psycho-oncologists, cardiac psychologists, transplant psychologists, pain management psychologists, etc.) [59]. Such a tendency toward more finite practice also increases the risk that patients could come to be classified according to their medical problems or health behavior patterns rather than viewed as whole individuals, contributing to what Belar and Deardorff [59] have referred to as a “behavior–person dualism.”

Roberts [60] has spoken of what he refers to as an “essential tension” between the balance of unification and fragmentation in professional psychology. Although he addressed this issue in the context of developments in clinical child psychology, his comments apply equally well to health psychology. He suggested that the narrow and more focused science and practice that accompanies specialization is a natural (and necessary) consequence of advances in the field, and that it has generally had an invigorating effect on the profession. Furthermore, while it may be argued that there was once something more akin to a “single psychology,” the breadth of accumulated knowledge in the field has rendered such a perspective untenable [60]. Indeed, clinical health psychology has itself become sufficiently diverse that no single practitioner can be proficient with all types of medical problems addressed, patient populations, settings, or situations [55]. Thus, some degree of specialization has become a necessary reality. Ultimately, Roberts concluded that the tension between breadth and specialization is best addressed through the careful and balanced integration of the latter into a broad core, such that a comprehensive foundational base is supplemented by more focused expertise in a particular area.

There is perhaps no context in which the tension between a breadth (generalist) versus depth (specialist) approach has been more rigorously debated than the

establishment of guidelines for pre- and postdoctoral training. Whether specialized training should be considered necessary or sufficient for the practice of clinical health psychology was deliberated as far back as the Arden House National Working Conference on Education and Training in Health Psychology in 1983 [61], which was mentioned earlier. The consensus of conference participants was that students should receive comprehensive training in general psychology comprised of sufficient breadth and depth of resources combined with specific core requirements in health psychology [61]. That is, in order to function effectively as a specialist in clinical health psychology, one must first receive the necessary training and possess the requisite competency to practice generally as a clinical psychologist (for an alternative perspective, see, [62]). Recommendations resulting from the Arden House Conference have largely continued to guide education and training to this day [63], with contemporary doctoral programs in clinical health psychology sharing several features including common training competencies, a graduated sequence of training experiences, an emphasis on broad and general training, reliance on the biopsychosocial model, and the integration of science and practice throughout training [64].

It should be noted, however, that there is a small but growing number of doctoral programs, which Larkin [64] has described as “exclusive,” and for which training focuses entirely on preparing students to become clinical health psychologists. For these programs, all coursework and practicum activities are specifically designed to expose students to the types of issues, patient populations, and experiences they are likely to encounter as clinical health psychologists [64]. As such, little emphasis is given to providing students with generalized training in professional psychology. Whether training programs adopting an exclusive approach are as (or more) effective at preparing trainees to practice as clinical health psychologists than more traditional approaches in which specialization in health psychology is embedded in general training in clinical or counseling psychology remains to be determined.

Although arguably necessary, broad generalist training in professional psychology is itself not a sufficient foundation to practice as a clinical health psychologist. Achieving competency as a clinical health psychologist almost certainly requires both didactic and applied experiences outside of what is typically provided as part of most general clinical psychology training programs. As noted by Belar [53], there is an essential knowledge base and skills specific to clinical health psychology that must be acquired to function competently in this area. These include: the biological, cognitive–affective, social, and psychological bases of health and disease, statistics and research design in health research, psychological and health measurement, clinical health psychology assessment, intervention and consultation (including clinical practice guidelines), interdisciplinary collaboration, and ethics and professional issues, with a special focus on those specific to clinical health psychology [53]. Thus, the practice of clinical health psychology requires one to possess both a diverse range of core competencies in professional psychology as well as advanced skills and knowledge in specialized areas related to health and practicing in the health care system [64]. As such, the standard education and training to become a clinical psychologist or a nonclinical health psychologist are insufficient for practicing as a clinical health psychologist [56].

One strategy for evaluating the need for specialization is to consider the skills that are expected of someone to practice competently in a given content area. Carefully examining the essential competencies the field has chosen to require for clinical health psychology provides one means of helping to determine whether specialized training is necessary, or whether a broadly trained generalist can effectively practice in the area. In an effort to revisit the standards for graduate curricula and training in clinical health psychology, the Board of Directors of Division 38 of the APA sponsored a summit meeting in Tempe, Arizona, in March 2007.

One of the primary aims of this meeting was to identify a preliminary set of competencies for doctoral-level clinical psychologists, the recommendations for which have been summarized by France and colleagues [63]. Using the cube model of core competencies in professional psychology that was originally developed by Rodolfa et al. [65], the conference participants set out to outline what were considered to be the essential functional (applied) and foundational (knowledge-based) competencies for the discipline, including both those common to all professional-scientific psychology and those unique to clinical health psychology. Thus, consistent with guidelines established 25 years earlier at the Arden House, participants endorsed a training approach comprised of a broad, generalized core in professional psychology as a foundation, coupled with more concentrated training in health psychology.

These competencies were subsequently updated and refined at the inaugural meeting of the Council of Clinical Health Psychology Training Programs (CCHPTP) in San Antonio, Texas, in 2008 [54]. Consistent with prior consensus statements [61], the prevailing opinion among meeting participants was that training at the predoctoral level should be very broad and general, involving foundational training in the core areas of psychology [54]. The more focused and intensive applied training opportunities in assessment and intervention approaches specific to health psychology, therefore, should be introduced primarily during internship, during which clinical health psychology trainees will have the opportunity to refine their clinical and research skills and learn to function effectively within a health care setting [54, 64]. Tensions regarding generalist versus specialist training are largely resolved at the postdoctoral (and beyond) training level, as it is understood that the emphasis will be on the development of a more specialized focus on trainees' individual goals and interests at this stage of professional development [66].

In conclusion, although there are those who will argue that specialization in clinical health psychology is unnecessary and, if it comes at the expense of more generalized training in professional psychology, potentially detrimental, the prevailing opinion is that it offers considerable advantages to both patients and practitioners. Furthermore, the importance of identifying specific training guidelines and competencies for evaluating clinical health psychologists is being increasingly understood, as demonstrated by the recognition of health psychology as a clinical specialty by the American Board of Professional Psychology (ABPP) in 1991, inaugural educational summits recently convened by the leadership of Division 38 of the APA and the CCHPTP, and guidelines for lifelong competency development and self-assessment [66, 67]. Such efforts will help to ensure that practitioners receive

adequate training to function competently as clinical psychologists in the area of health, while also protecting behavioral health care consumers from those claiming expertise without the requisite education, knowledge, and experience [66].

## **Role of the Clinical Health Psychologist in Specialty Medical Care**

The past several decades have seen professional psychology gain an increasingly prominent place in health care. Recognizing the potential for psychologists to play an important role in this arena, the APA's Council of Representatives identified an expansion of psychology's role in advancing health as one of the three primary goals of the Strategic Plan adopted in 2009 ([www.apa.org/about/index.aspx](http://www.apa.org/about/index.aspx)). The recent changes have been the result of a variety of factors including a growing recognition of both the prevalence and impact of psychological disorders among the general medical population and the increasing evidence base demonstrating both the efficacy [68–70] and cost-effectiveness [71–73] of psychosocial interventions for the prevention and treatment of many common medical problems. These factors have brought about exciting new opportunities for psychologists as health care providers.

Although clinical health psychologists work in a wide range of health care locations and contexts, a useful distinction can be made based on whether one practices in primary care as opposed to settings focused on secondary or tertiary care, prevention, or rehabilitation [56]. While the services that are provided (assessment, consultation, liaison, multidisciplinary collaboration, intervention) share many similarities, there are also notable differences that distinguish the roles of the psychologist and overall approaches to care provided in these types of settings. Because the practice of clinical psychology in primary care is the focus of another chapter in this volume (Chap. 14) and is also addressed extensively in a chapter on education and training (Chap. 3), we do not cover it here. In the sections that follow, we briefly review applications for clinical health psychology in specialty care.

Whereas primary care focuses on the initial response to patients' presenting complaints, assessment of medically undifferentiated, complex problems, and continuity of care, the emphasis in specialty care is on targeted, episodic care [74]. Although psychology's presence in primary care is a relatively new development, clinical health psychologists have long been involved in providing specialty care for a variety of physical conditions. Areas in which clinical health psychologists frequently play key roles (often as part of an interdisciplinary treatment team) include cardiac rehabilitation, pain management, sleep medicine, weight management, organ transplant, eating disorders, substance use disorders, oncology, endocrinology, reproductive health, genetic testing, dialysis, and pulmonary and physical rehabilitation, to name but a few. Consequently, depending on their area of clinical focus, they may work with a variety of different specialists including nurses, obstetrician-gynecologists, surgeons, dentists, psychiatrists, anesthesiologists, oncologists, neurolo-

gists, rheumatologists, endocrinologists, pulmonologists, physical therapists, social workers, and occupational therapists, among others [55]. Services range from assessment of psychosocial contributors to physical conditions, evaluation of suitability for medical procedures, psychoeducation, strategies for improving adherence to complex medical regimens, biofeedback, and coping with chronic illness. Clinical health psychologists are also frequently involved in the delivery of evidence-based behavioral interventions to help manage a variety of conditions (e.g., chronic pain, obesity, bulimia nervosa, substance abuse and dependence, somatoform disorders, dyssomnias). In addition, they often engage in liaison activities in which they provide education to other health care providers regarding biopsychosocial factors associated with illness [75]. While many of the types of services provided are similar to those seen in primary care, clinical health psychologists working in a specialty setting tend to develop a greater depth of focal expertise related to a particular disease or patient population. As noted above, care also tends to be provided on a more episodic basis, with less emphasis on establishing and maintaining ongoing relationships with patients.

Historically, clinical health psychologists in specialty settings have been primarily involved in the provision of tertiary care to help manage and reduce the symptoms and sequelae of an illness or disorder [75]. With the growing emphasis on health promotion and preventing disease, however, clinical health psychologists have become increasingly involved in primary and secondary prevention [75]. As such, they are often involved in programs designed to modify risk factors for injury or illness. Common examples include dietary modification, physical activity promotion, and tobacco-use prevention and cessation.

Clinical health psychologists involved in specialty care may work in an independent practice setting, group practice, or institutional practice [55]. They may also be involved in health care at different system levels, providing services that target individuals, families, classrooms, work sites, or communities [75]. Consequently, the opportunities for clinical health psychologists to serve as specialist health care providers are nearly limitless with regard to setting, patient population, and disease focus.

## Conclusions

In this chapter, we presented a selective history of clinical health psychology as it evolved in the context of medicine, trends in illness and causes of death, clinical psychology, and interdisciplinary research on biological processes and behavior. The second half of the chapter discussed issues of generalist versus specialist training and the different roles that clinical health psychologists play in specialty care. The historical events bringing clinical psychologist to medical settings provide a perspective on the important theories, people, and events that have contributed to our current state of clinical practice. Being mindful of our history and the evolving role of clinical psychologists in medical settings can help us to shape our future in a way that is mutually beneficial for patients, professional psychology, and medicine.

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**Part II**  
**Professional Issues**

## Chapter 3

# Preparing the Next Generation for Integrated Care in Medical Settings: Training in Primary Care as a Foundation

Barbara A. Cubic and Abbie O. Beacham

Shifting the focus of a psychology training program to an increased emphasis on knowledge and skills to work in a variety of medical settings requires willingness to try new training paradigms. New training sites must be identified. Supervisors with experience working in medical settings must be located. Then, making it happen necessitates strong, ongoing working relationships among key players (i.e., training directors, psychologists, medical providers) and respect and commitment to interdisciplinary training among the various disciplines involved. Financial support must be obtained for trainee stipends and benefits as well as for resources needed (e.g., assessment measures, psycho-education materials, and treatment resources) and space. The final ingredient is a patient population that is open to new models of clinical service delivery. Thus, the current chapter focuses on the opportunities and challenges of training psychologists to work in medical settings. Most notably, examples are used of educational and training models within integrated care settings (subsequently referencing team-based treatment affording a patient at a minimum access to medical and psychological care concurrently) designed to prepare psychologists to operate within the patient-centered medical home (PCMH). The primary care setting is focused upon because changes in the health care system suggest that increasingly psychologists may find themselves working in primary care. Additionally, training psychologists to work effectively in this setting not only prepares them for primary care but also specialty medical settings, as training in primary care serves as a solid foundation to build on for work in the health care system in general secondary to the complexity and diversity of patient-related issues seen. Similar to the primary care physician who must be prepared for all patient presentations (knowing their limitations and when to refer for specialized care), the psychologist

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integrated into primary care must be prepared for all presentations (knowing their limitations and when to refer for specialized care). Additionally, the psychologist in primary care must be a provider to the providers and able to impact the primary care system in which they are employed. Thus, training models must equip trainees to be self-reflective and critical thinkers, aware of the ethical dilemmas that present in primary care, prepared to interact with a culturally and individually diverse group of patients and providers, able to engage in program development, invested in advocacy, and to display interprofessional professionalism in addition to clinical skills.

The main objectives of this chapter are:

1. Identifying key issues in creating a psychology workforce prepared to provide integrated services in medical settings
2. Describing attitudinal, clinical, operational, administrative, and financial barriers to training in integrated care
3. Exploring the opportunities and challenges for psychology and primary care disciplines in creating meaningful interprofessional training models

## **Integrated Care as the Wave of the Future**

### ***Stunning Statistics***

As early as 1993, primary care was labeled the “de facto mental health system” as more patients with mental and substance abuse disorders reported seeking services in primary care than from specialty mental health [1]. In 2001, a survey by the National Mental Health Association continued to support the existence of a “de facto mental health system” after demonstrating that 33% of adults without present mental health issues would turn to primary care if they developed a mental health issue [2]. In 2007, Mauer found that 54% of people with mental health issues were served in the general medical sector only [3]. These statistics are likely linked to the findings of an American Psychological Association (APA) survey indicating that 20% of adults state stigma is “a very important reason not to seek help” from a mental health professional [4]. Stigma may be especially relevant for the elderly as 71% of elderly patients assigned to integrated care engaged in treatment with a behaviorist, compared to 49% who received outside referrals [5].

Patient preference for obtaining mental health services in primary care, coupled with 60–70% of primary care physicians reporting serious difficulties accessing mental health services for their patients, [6] has resulted in physicians demonstrating increased interest in having on-site behavioral providers. In fact, access to behaviorists is seen by many as key to the PCMH implementation as the rate of access for referrals to other specialty services was over twice as high as that for specialty mental health. Individuals with serious mental illness may also be best served by the PCMH concept (especially if their PCMH is designed around their mental health needs, and primary care is integrated into their mental health treatment site). If

treated in the public mental health sector, these individuals are likely to die on average 25 years earlier than the general population, living to a mean age of 51 in contrast to age 76 in the general population and being more likely to die of heart disease (3.4 times), pneumonia and influenza (6.6 times), and other respiratory ailments (5 times) [7].

Even when specialty mental health and addiction services are easily accessible, integrated care is still indicated for primary care patients as seven of the ten leading causes of death (heart disease, cancer, stroke, respiratory disease, accidents, diabetes, and suicide) have a psychological and/or behavioral component [8]. Additionally, integrated care models for certain disadvantaged groups, e.g., persons who are homeless and injection drug users, showed a decrease in emergency and urgent care visits across 18 months from 3.8 to 0.8 visits [9].

### ***Patient-Centered Medical Home***

Integrated care has been increasingly embraced and emphasizes team-based treatment, merging of the psychosocial and medical aspects of assessment and intervention, culturally and contextually competent relationship-centered interactions, and a focus on family and community as a determinant of individual health. Perhaps, the importance of integrated care is best illustrated by the fact that it is a key component of current health care reform and is foundational to the PCMH [10]. In PCMHs, patients serve as collaborative participants in their own health and well-being through receipt of evidence-based services from a physician-led medical team that is optimally coordinated to meet the preventive, acute, and chronic needs of patients throughout their lifetimes [11]. In addition to endorsement by four major primary care physicians' professional groups (e.g., family medicine, internal medicine, pediatrics, and obstetrics/gynecology), 18 specialty health care organizations have also endorsed the seven-point Joint Principles of the PCMH [12] because this same type of collaborative involvement of patients is vital to care received in specialty medical clinics (e.g., oncology, rheumatology) and is applicable to secondary and tertiary behavioral care. However, while integrated primary care is envisioned as a model that will address a patient's immediate health care needs, to do so health care systems must address the ever-increasing complexity of interactions with patients related to increased health care knowledge, increased technology, and increased bureaucracy [13]. Further, PCMH demonstration projects raise concerns that the magnitude of change to achieve PCMH status is substantial and that the current health care workforce is not prepared to work in these new paradigms of team-based health care [13]. This is because most practicing health care professionals are accustomed to solo practices or hierarchal teams and most educational models do not focus on interprofessional training. Subsequently, it may be argued that exposure to integrated care concepts and interprofessional clinical training opportunities are a necessity for maturation of tightly integrated, on-site teamwork with unified care plans for patients to become real. This reality leads to the clear conclusion that

emphasis must be placed on how a workforce can be created that truly invests in integrated care to allow the PCMH and/or integrated care to leap from being an interesting concept to the mainstream of health care. Interprofessional training also relates to the development of the PCMH in general and specifically to incorporation of quality, accessible, evidence-based mental health services and interventions within that edifice.

## **The Case for a Paradigm Shift in Psychology to Integrated Care Training Models**

### ***Psychology Providers in the Twenty-First Century***

Psychologists trained to serve in collaborative and integrated care settings are being heralded as model “health care providers” for the twenty-first century [14, 15]. The 2009 APA Summit on the training of future psychologists emphasized it is crucial that successful components of “First-curve” (i.e., traditional) training models be retained while simultaneously developing emerging “Second-curve” models to prepare psychologists as health care providers to maintain the viability of the discipline [16]. The APA’s insights coupled with the recent emphasis on the PCMH further underscore the need for psychology’s educational models to be one step ahead of where the field is currently in order to prepare trainees for a bright future within future health care delivery systems.

Unfortunately, despite the evidence and need for integrated models of care in primary and specialty medical clinics, currently psychology’s educational models rarely incorporate training in integrated care at the didactic or clinical training level during graduate training. While opportunities for training in integrated medical settings are increasing especially at the internship and postdoctoral level, nationally, there remain insufficient prospects for training for aspiring psychologists, whether at the practicum, internship, postdoctoral, or continuing education level. Thus, while psychologists may be uniquely positioned to be part of PCMH teams, without specific training experiences in primary and integrated care, psychologists fail to understand the perspectives of primary care patients and the needs of the primary care environment [17]. These facts increase the burden on psychology training programs to create innovative models for integrated care opportunities in order to make significant contributions to the prevention and treatment of medical and mental health diseases.

### ***What Type of Training is Needed to Create Integrated Care?***

Integrated care is not simply services provided by mental health or behavioral providers relocated to primary care settings. Integrated care is a unique medical subspecialty, and for the subspecialty to thrive, organizations must have a clearly ar-

ticated model, with planning and implementation paying attention to the clinical, operational, administrative, and financial needs of the settings involved. To be successful, the providers involved must embrace the model, electronic health records that enhance collaboration must be in place, and the treatment plans must be data and outcome driven. Thus, the foundational and functional competencies required of psychologists to function effectively in integrated care, are consistently described as building on and then expanding from those needed for clinical psychologists and health psychologists. Chapter 14 provides more details regarding the state of the art for the field in regard to the development of competencies in integrated care.

Psychologists who function in integrated models of care must adapt to physician-driven environments, culture, and work flow, as well as be knowledgeable of and contributing to medical education and the improvement of health care in practice. Furthermore, while psychologists with interests in providing services in health care settings are in a distinctive position to partner with primary care because of their ability to provide a wide range of brief, empirically based interventions that are rendered in a pragmatic, here-and-now oriented, focused, and finite manner, they must accept that many other mental health and behavioral providers will compete with them for inclusion. Subsequently, psychology's future in integrated care will largely be determined by the discipline's ability to foster knowledge, skills, and attitudes during education and training within psychology trainees that allow them to create vital, noncompetitive, integrated care relationships.

## **Shifts in Training: Opportunities and Challenges**

### ***How do you Integrate Integrated Care into a Training Program in a General Manner?***

Realistically, most psychology training programs, especially those not already offering health psychology tracks, cannot make a radical shift to training in integrated care or emphasis, especially since a number of trainees will still chose to enter specialty mental health care. However, recent trends in the health care field behoove all psychology training programs to introduce trainees to the concepts, culture, patient characteristics, provider characteristics, and unique challenges of psychological service delivery of integrated health care and to provide advanced educational experiences for those individuals who have an interest in working in primary and specialty medical settings.

A logical progression for training programs to add integrated care training into their curriculums and clinical training would be to first build on the clinical service delivery models of interdisciplinary medical and behavioral collaboration described in the literature [18] and to determine which, if any, of these models may be achievable given current or easily added resources. These existing interdisciplinary models are on a continuum from coordinated services to true integrated care.



Coordinated care refers to the exchange of information regarding mutual patients between a behavioral and primary care or specialty medical provider. Similar to a traditional mental health model, coordinated care reflects a separation of service delivery; however, an exchange of information is offered to enhance the patient's overall health care. In colocated practices, psychologists and primary care or specialty medical providers are housed in the same setting but referrals to the psychologist often result in traditional psychological services (e.g., 1-h-long individual therapy sessions and traditional psychological assessments). Location serves as an advantage for referral facilitation, but true integrated care is not provided. Collaborative care, whether through collocation or separate offices, focuses on fostering an ongoing communicative relationship between a psychologist and primary care or specialty medical provider to allow for shared decision making longitudinally while treatment is offered autonomously by both providers. On the far end of the continuum is integrated care where primary care or specialty medical and behavioral providers (as well as other disciplines, e.g., pharmacy, nutrition) provide patient care as a united team addressing the full spectrum of the patient's biopsychosocial needs. The reader is directed to Chap. 14 for further discussion.

Next, training programs need to review their educational model, goals, and objectives to insure that they are creating appropriately trained professional psychologists as "health service providers" who can assess and treat mental illness, while also being able to demonstrate their competence and expertise in behavioral and psychosocial treatments of chronic diseases, system-based practices, collaborative relationships with health care providers, health promotion, and disease prevention. Although there is some opinion that training in integrated care may be considered specialty training and therefore, more appropriately developed at the postdoctoral level, we contend that in fact, primary and specialty integrated care skill development should be considered a core competency and developed early. While initially it might appear that doctoral programs with specialty tracks in health psychology and/or behavioral medicine would be easily adapted to prepare trainees for integrated care, this is not always the case. Preparedness for integrated care requires on-site interdisciplinary training in dealing with behavioral issues in health care for psychologists and physicians within the design of primary and specialty medical visits (e.g., fast pace, time constraints, variety of presenting problems). Thus, general health psychology programs must remain aware that the knowledge, skills, and attitudes for a psychologist to partner in some specialty areas of medicine (e.g., cardiac rehabilitation, neurology) may differ markedly from those needed to partner with generalists in integrated care.

Third, training programs need to develop a mechanism for the creation of integrated training opportunities (i.e., the simultaneous training of psychology with other primary care disciplines) at the doctoral and advanced level (i.e., practica, internship, residency) that creates an understanding of the different backgrounds, values, professional models, and ideologies of various disciplines. And, the program needs to insure that the supervision provided during these experiences can be delivered by psychologists who are experienced in working in these primary and specialty care settings which may mean reaching out to adjunct or community faculty.

And, last but not least, training programs need to design research opportunities in integrated care (e.g., dissertations) as translation of the large psychology, behavioral medicine, health psychology, and primary care psychology efficacy literature into effectiveness in real-world studies is needed. The need is underscored by the National Institute of Health's continuing shift towards translational science (e.g., Centers for Translational Science Awards) providing further opportunities for psychology trainees to participate in interdisciplinary research and dissemination of best practices and best practice models [19, 20]. It is also important to note that the primary care settings that trainees would serve in offer rich opportunities for integrating research into clinical practice, program development experience, and quality improvement initiatives.

### ***What Specific Shifts in Education and Training are Needed?***

*Shift in Nature of Competencies.* Over the last decade, psychology graduate, internship, and fellowship training programs have shifted to competency-based education as have other health care disciplines. These shifts have increased the emphasis on trainee performance and away from the structure of training. To create a competent integrated care, psychology workforce emphasis must remain on the foundational competencies applicable to all psychologists of reflective practice, self-assessment, scientific knowledge and methods, relationships, individual and cultural diversity, and ethical and legal standards/policy issues and then expand to the development of specific competencies. France et al. (2008) provide a description of how to adapt these foundational competencies to make them more closely suited to health care psychologists [21] and these have been, I further refined to make them specific to integrated care. For example, psychologists in integrated care need to understand the ethical and legal standards of a primary care health system context in order to address issues around confidentiality, allocation of health care resources, and informed consent regarding health care services and procedures. Additional guidance regarding competency goals for integrated care psychologists can also be found in the recommendations of the APA's Interorganizational Work Group on Competencies for Primary Care Psychology Practice [22] which articulates competencies in understanding the biological components of health, illness and disease, and the interaction between biology and behavior; how learning, memory, perception, and cognition can influence health; ways emotions and motivation can influence health; how social and cultural factors affect health problems, access to health care, and adhering to treatment regimens; and how to assess cognitive, affective, behavior, social, and psychological reactions for all common conditions seen in primary care [23]. For more details about competencies and training in medical settings in general and integrated care refer to Chaps. 4 and 14.

As models of training in integrated care are developed, the educational and clinical activities need to be individualized to fit with the varying backgrounds, aptitudes, abilities, and styles of learning of trainees. Accountability across trainees, faculty, program directors, and institutions to insure incremental learning

(i.e., benchmarks) is necessary and when feasible, achievement of integrated care competencies should be developed from real-world experiences and fostered by trainees' self-assessment. Additionally, the diversity of skills that an integrated care psychologist will need means trainees must be afforded opportunities to develop and enhance functional competencies across the assessment, intervention, consultation, research, and supervision-training and management-administration domains as they apply to integrated care settings.

*Shift in Content Areas.* In many ways, psychology trainees who wish to pursue a career in integrated care need to unlearn many aspects of what they are learning or have learned about provision of traditional psychology services. Key components of training for psychologists to provide integrated care may contradict with traditional psychology training including contemporary training approaches to prepare health psychologists. Possible areas of stark contrast are highlighted in Table 3.1. Additionally, several content areas (see Table 3.2) must be integrated into the graduate and internship curriculum to provide the trainee with the confidence and skills to effectively work with primary care providers and primary care patients who have quite different needs and perspectives than psychologists (see Table 3.3, adapted from Bluestein and Cubic (2009) for a synopsis of differences).

A way of introducing the content needed for integrated care into an organizational scheme that existing traditional psychology faculty and psychology trainees can relate to is to discuss the topic within the Four-Quadrant Model, a conceptual system-wide framework for health and mental health services developed by the National Council for Community Behavioral Healthcare [24]. The Four-Quadrant Model divides the general treatment population into four groups based on their behavioral and physical health risks and status as illustrated in Fig. 3.1. Present integrated care within the context of this model helps existing faculty and trainees see that integrated care conceptually is for all patient populations with the role and services delivered by the psychologist varying depending on the setting and patient population and thus underscores that integrated care does not replace or compete with specialty mental health, but enhances it. This realization can allow existing faculty to see training in integrated care as a population-based approach and helps them determine the set(s) of skills trainees will need to work within each of the quadrants. The model also allows trainees in clinical practica and on internships to sort out where services for different individuals should be obtained.

*Shift in Perspective.* Stated simply, psychology trainees will likely thrive in the integrated care model if they adopt the motto "When in Rome do as the Romans Do." In other words, trainees need to recognize that it is their job to learn the language and style of primary care not the responsibility of primary care providers or primary care patients to adapt to psychology. The importance of interdisciplinary coordination must be understood and trainees need to prepare to make themselves easily accessible (e.g., have a system for easy contact, welcome interruptions). Despite being novices, trainees must also perceive themselves as having expertise in interpersonal interactions based on their understanding of behavioral principles and human interactions in order to utilize their skills to facilitate the team process.

**Table 3.1** Comparison of issues in training for traditional psychologists, health psychologists with a specialty focus, and integrated care psychologists

Area	Traditional psychology service delivery	Specialized health psychology service delivery	Integrated care service delivery
Knowledge of primary care	Most supervised training has been in mental health settings; limited knowledge of medical terminology, medical culture, and needs of medical patients	Supervised training in medical settings often in specialized area (e.g., rehabilitation medicine, cardiac medicine); has cursory knowledge of PC through referrals; general knowledge of medical terminology, culture of specialized medical setting and needs of specialized medical patients	Supervised training in various medical settings which includes time in primary care; general knowledge of medical terminology, primary care culture, and diverse needs of the diverse primary care patient population
Confidentiality	Operates within the specialized mental health setting and shares information with psychiatric treatment team; confidentiality typically prioritized over interdisciplinary collaboration with physicians; information released to physician generally only when requested by patient	Operates within the specialized setting and shares information with specialized treatment team; patient informed that team communicates about patient care to facilitate treatment; psychological information generally not released to PCP (except possibly as part of a team summary)	Operates within the primary care setting longitudinally; patient informed that psychologist and PCP and treatment team will communicate about patient care to facilitate treatment; psychological information released when it is relevant to patient care
Interdisciplinary coordination	Opportunities to work on interdisciplinary mental health teams lead by psychiatrists; experiences with other disciplines usually limited to other mental health professionals (e.g., social workers) and nurses	Experience with interdisciplinary teams with same specialized focus interest as the health psychologist; depending on structure of the team psychologist may have an egalitarian relationship with others, be a consultant or be viewed as a physician extender	Experiences with interdisciplinary primary care teams; egalitarian relationships with primary care physicians, nurses, and allied health professionals (with recognition that PCPs are the leaders for PCMHs)
Documentation	Progress notes written for mental health setting; with psychological jargon; reports are generally detailed and lengthy to cover developmental and lengthy to cover developmental history, current presentation, test findings, and treatment plan; when EHR in use, the notes are generally in separate sections that does not allow for physician access	Progress notes follow medical model (e.g., SOAP format); reports are generally detailed and lengthy to cover developmental history, current presentation, test findings, and treatment plans directed towards both patient's mental and physical health care needs; when EHR in use, the notes are placed in a section team can access or if in a specialty section a summary is also placed in general record	Progress notes follow medical model (e.g., SOAP format); brief reports (preferably a few paragraphs) that focus primarily on conclusions and recommendations; psychological jargon avoided; when EHR in use, notes are incorporated into the primary care record (with special safeguards only given to highly sensitive information)

Table 3.1 (continued)

Area	Traditional psychology service delivery	Specialized health psychology service delivery	Integrated care service delivery
Efficiency	Treatment is generally offered in 1-h units across multiple sessions; psychological assessments may occur over several hours or days and final reports may not be available for several days or weeks; therapy sessions and psychological assessments are generally done in a private office setting and not interrupted	Treatment may be offered in a traditional manner or in brief units of time depending on setting and patient needs; psychological assessments are generally comprehensive and lengthy and final reports may not be available for several days or weeks; therapy and assessment may be done in an office setting, at bedside, or in a medical clinic	Brief interventions (often 15 min or less); focus is on specific issue at hand; heavily relies on adapting empirically supported techniques from CBT, IPT, and psychoeducation; Therapy and assessment generally done in examination room or at bedside
Skill set	Demonstrate functional competencies as they relate to mental health issues; often develop areas of expertise in a specific area of mental health (e.g., eating disorders), psychological assessment (e.g., neuropsychology), or a form of mental health treatment (e.g., CBT); relies on psychological interventions combined with community resources	Demonstrate functional competencies as they apply to general health psychology; often develop areas of expertise with a specialized medical population; focus primarily on comorbid psychological disorders connected with the medical condition patient is experiencing and the behavioral factors impacting adherence to treatment	Demonstrate functional competencies as they apply to integrated care which requires a diversity of skills; manage majority of presenting problems at PC office; reserve specialty referrals for specialized situations; carry a diverse toolbox of assessment and treatment resources; heavy reliance on community resources (e.g., AA, support groups)
Patient population	Develop general expertise with patients with mental disorders; often develop a specific expertise with a demographic population (e.g., child psychology) or mental health diagnostic group (e.g., eating disorders); receive referrals as specialists	Often develop expertise with a specialized medical population(s) (e.g., patients with chronic pain) and serve as main psychological resource for this patient group(s)	Develop skills to treat the diverse patient population seen in PC with a diverse set of medical and psychological needs; may or may not have an area of specialization
Mode of communication with physicians	Limited communication which is generally through provision of reports	Oral communication through participation with the treatment team; written communication in EHR	Daily communication as on-site with PCP; written communication in EHR

*CBT* cognitive-behavioral therapy, *EHR* electronic health record, *IPT* interpersonal therapy, *PC* primary care, *PCP* primary care physician, *PCMH* patient-centered medical home, *SOAP* Subjective, Objective, Assessment, Plan, *AA* Alcoholics Anonymous

**Table 3.2** Recommended areas of key training to prepare psychologists for integrated care

1	Awareness of the culture of primary care
2	Knowledge about common medical illnesses
3	Chronic disease management
4	Factors to enhance behavioral adherence to treatment regimens
5	Medical terminology/jargon
6	Psychopharmacology
7	Presentation of mental health issues in primary care
8	Brief psychological screening techniques for common cognitive, mental, and physical disorders seen in primary care
9	Brief, evidence-based interventions for individuals, families, and group
10	System-based practice
11	Staff development
12	Practice-based quality improvement
13	Program development
14	Advocacy

To build trainee confidence in making the transition to operating in primary care and to assist them in avoiding intimidation, they must learn basic medical terminology, have role models that can demonstrate the unique skills psychology can offer in a primary care setting, be taught how to provide practical advice, and have a sense of humor. Trainees must understand the concept of a treatment team and explain to patients that primary care treatment teams share information across providers, offering full disclosure to the patient about what will and will not be shared. Furthermore, despite what the trainee has learned about the rules of confidentiality in specialty mental health, trainees must recognize the dilemmas created by secrets between health and mental health care providers and learn to differentiate between what needs to be shared versus what is private (i.e., distinguish relevant information to patient care in a direct manner), and use written consents in specific circumstance as a safeguard. As there is considerable variability in the manner and degree to which integrated care practices interpret and comply with state and federal laws related to the confidentiality of mental health records, especially substance use and abuse, practitioners in integrated care settings need to assure that trainees are taught about confidentiality dilemmas in a manner within their confidentiality practices.

Primary care settings treat diverse patients across the life span who present with diverse health and mental health concerns. Additionally, primary care providers treat patients longitudinally so issues are addressed according to immediacy with the understanding that over time, less pressing problems can be addressed. Psychology trainees must be taught how to adapt to this approach. Thus, a diversity of skills is needed and trainees must be provided with experiences with a toolbox of assessment measures, treatment tools, and referral resources. For example, graduate psychology students should be able to utilize a portfolio of assessment measures designed for or easily adapted to primary care practices (e.g., Patient Health Questionnaire, PHQ-2 and PHQ-9, Beck Depression Inventory-Primary Care; Geriatric Depression Scale, Mini-Mental State Examination; Montreal Cognitive Assessment (MoCA). Repeatable Battery of Neuropsychological Deficits, R-Bands, Conner's)

**Table 3.3** Converging perspectives of primary care patients, primary care providers, and psychologists completing training as usual (TAU) and suggested perspective for psychologists to provide integrated care (IC)

Primary Care Patients	Primary Care Providers	Psychologists (TAU)	Psychologists (IC)
<ul style="list-style-type: none"> <li>• Reflect the Population in Terms of Diversity and Diverse Needs</li> <li>• Present with Multiple Medical and Psychological Needs</li> <li>• See PCP Generally When Symptomatic</li> <li>• Expect a Brief Visit</li> <li>• Favor Pharmacological Interventions</li> <li>• Struggle to Alter Behavioral Issues Contributing</li> </ul>	<ul style="list-style-type: none"> <li>• Have Large Caseloads with Diverse Concerns</li> <li>• Treat Complex Cases</li> <li>• Need to Prioritize What to Address at Each Visit</li> <li>• Are Ultimately Accountable for Care Provided by Extenders</li> <li>• Endure Intense Time Pressures</li> <li>• Assume Ownership of Patient’s Care</li> <li>• Need Coordination of Care</li> <li>• Assume an Exchange of Information</li> </ul>	<ul style="list-style-type: none"> <li>• Treat a Small Number of Patients (usually in a specialized area)</li> <li>• Give Confidentiality Utmost Importance Over Coordination of Care</li> <li>• Operate Largely in Context of Ongoing Relationships with Patients</li> <li>• Expect to Complete In Dept Assessments</li> <li>• Offer Interventions</li> </ul>	<ul style="list-style-type: none"> <li>• Treat Diverse Patients with Diverse Issues</li> <li>• View Treatment as a Team Process</li> <li>• Share Information with PCPs</li> <li>• Conduct Brief Assessments</li> <li>• Use Empirically Based Interventions (modified to be offered in brief encounters)</li> <li>• Integrate Services</li> </ul>

**Table 3.3** (continued)

<p>to Health Concerns</p> <ul style="list-style-type: none"> <li>• Are Not Expecting Psychological Advice and Interventions Unless Specifically Requesting It</li> <li>• View Referral to Mental Health as Stigmatizing</li> </ul>	<ul style="list-style-type: none"> <li>• Feel Underequipped to Handle Mental Health Issues and Behavioral Aspects of Health Care</li> <li>• Welcome Practical Support from Mental Health Professionals</li> </ul>	<p>in Units of Time (i.e. generally hourly visits)</p> <ul style="list-style-type: none"> <li>• Expect Patients to Engage in Extensive Courses of Treatment</li> <li>• Provide Solicited Psychological Advice to Patient or Patient’s Advocate</li> </ul>	<p>Seamlessly into Health Care Visit to Avoid Stigmatization Issues</p>
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PCP primary care physician



**Fig. 3.1** A diagram of the general characteristics of the patient population within each of the four quadrants from the four-quadrant model from the National Council for Community Behavioral Healthcare

and therapeutic techniques (e.g., educating a patient about the cognitive model of depression and teaching them to do a dysfunctional thought record, a relaxation script, motivational interviewing to encourage a patient to attend Alcoholics Anonymous, review pointers with parents for helping their children with ADHD, imparting sleep hygiene information). Trainees must also learn the value of sharing refer-



ral and psychoeducational information (e.g., index of local health and mental health care services, listing of support groups, Internet website addresses for common issues such as bereavement, cancer, cardiovascular disease, depression, diabetes, and domestic violence) with primary care providers and be taught techniques for knowing when to share resources with patients (e.g., understanding stages of change) and ways of increasing the likelihood that patients will access these resources (e.g., motivational interviewing).

*Shifts in Role.* The services provided by psychology trainees during clinical practica, internship, and fellowships while on integrated care rotations will be diverse. Trainees are best served by being forewarned about and prepared for the fact that they will serve as clinicians, consultants, and educators during their integrated care experiences. Role models versed in working in integrated care settings are needed to demonstrate to the trainees how to conduct each of their roles. It is crucial that these role models not lapse into demonstrating only traditional service delivery models (e.g., “sacred 50-min h”). The most common roles that trainees need to be prepared for are described below. A more elaborate listing and synopsis of the roles that psychologists play in integrated care can be found in the Air Force Primary Behavioral Health Care Services Practice Manual 2.0, (2011) [25]. The percentage of time each service will be provided depends on the quadrant(s) most of the patient population fits in and the unique needs of the integrated care environment where the rotations are offered (e.g., academic primary care clinic, federally qualified health center).

**Screenings** (at 10–12 min) occur during the primary care visit to determine need for mental health or substance abuse care or behavioral intervention to enhance medical outcomes and are often co-conducted with primary care provider.

**Brief Assessments/Interventions** (at 30 min) are generally conducted following the primary care provider’s interaction with the patient at a primary care visit to allow for diagnostic clarification, problem solving, goal setting, and treatment planning with the intent of providing recommendations to the patient and provider that are feasible to implement within the scope of primary care.

**Brief Follow-up(s)** (at 15–30 min; usually no more than 4–6 appointments) are scheduled to co-occur with or immediately following the patient’s primary care visit to review the patient’s progress, provide therapeutic guidance, and to reinforce changes made.

**Consultations of Complex Cases** (at 15–20 min) are mainly applicable to patients in Quadrant 4 and the visits are structured to provide the primary care provider with additional support in maintaining a patient’s adaptive functioning or offered to patients on a leave of absence from duties with an emphasis on return to duties.

**Individual Therapy Appointments** (at 30 min; 8–12 appointments) are scheduled generally separate from the primary care visits and offered to a select number of patients who likely will gain from a brief course of treatment, are highly motivated, and would likely not avail themselves of services outside of the primary care environment if referred. These sessions are offered generally to address common issues that result in high health care costs, such as treating depression, improving compliance with a chronic medical condition, and/or motivating a patient to make lifestyle changes to improve health.

**Psychoeducational Groups** (at 45–90 min; 6–8 appointments) are generally held in the primary care clinic’s conference room spaces with a target audience of varying sizes depending on the topic discussed. The focus is generally on education and skills building and may be provided by a leader or coleaders representing psychology and medical health care, and the audience likely includes both patients and family members.

**Telephone/Telemedicine Consultations** are planned, scheduled intervention contacts or follow-ups with patients that are conducted by the psychology trainee via telephone or telemedicine.

**Urgent Consultations** are usually initiated by the primary care provider, either by phone or face to face, generally in an emergency situation (e.g., suicidal patient) requiring immediate or short-term response by the psychology trainee.

**Referral for Psychiatric Consultation** should be available (e.g., through a Department of Psychiatry and Behavioral Sciences if the training is in an academic health center (AHC) or through a private practice if the training is in community practices). Ideally, psychiatry resident(s) or attending(s) will be available in the primary care clinics to further integrate care. The psychology trainee’s role in regard to this referral is to assist the primary care provider in determining which cases requiring psychotropic medications can be managed in integrated care versus requiring specialty care.

**Provider to the Provider** activities, in addition to those described of a clinical nature, can include provision of education to primary care providers regarding appropriate referrals to the psychology trainee; didactics on mental health, substance abuse, and behavioral topics; workshops to address systems issues or provider concerns (e.g., work pressures, interpersonal conflicts); and team-building events and curbside consultation.

*Shifts in Pace.* Because efficiency is necessary in primary care, early in their training primary care resident physicians are allowed ample time to assess complicated cases but ultimately as their training continues, visits are shortened usually to 15 min or less. In keeping with this model of training, psychology practicum students should be allowed to adapt to the primary care culture and to provide assessments and interventions in timeframes that meet their level of training (e.g., 1-h appointments initially). However, over time the amount of time allocated to a patient appointment should be shortened with the goal that on completion of internship, psychology trainees will be able to assess, diagnose, and treat presenting problems quickly (e.g., 15 min or less except in complicated cases). To expedite the interactions, trainees need to be taught how to identify themselves to patients as psychologists (in training) in a way that does not lead to the patient feeling stigmatized by primarily describing their role and purpose for interacting with them rather than overemphasizing their profession (e.g., “I’m Dr. Cubic, a clinical psychologist, working with Dr. Bluestein and I’m here to review some ideas with you about how to manage your pain”). Trainees must also have role models who demonstrate how to stick to the issue at hand and to use primarily psychoeducational, motivational interviewing, cognitive behavioral, interpersonal and supportive approaches as their empirical basis because these interventions are strongest in primary care settings.

*Shifts in Ideas about Collaborative Communication.* Lastly, trainees in integrated care must learn that primary care providers need useful, immediate documentation. Subsequently, primary care providers are not impressed with reports that describe theories or provide lengthy details or specific test scores. Rather, as primary care providers are responsible for the diverse health care needs of their patients and must review numerous laboratories, test findings, and notes from other providers, documentation that highlights final conclusions and recommendations in succinct, carefully crafted 1–2-paragraph descriptions that are accessible to them in the electronic health record is needed. In the event that the psychology trainee has completed a more detailed evaluation on a complicated case, the reports should still be a limited number of pages and emphasize the history of present illness (1–2 paragraphs), prior history (only most relevant), behavioral observations (Quick MSE), test results (without jargon), diagnostic impressions (generally, Axis I and II are sufficient), and most importantly, case recommendations (which are often placed at the front of the note for ease of access).

For example, most health care professionals are acquainted with a Subjective, Objective, Assessment, Plan (SOAP) note and psychologists in medical settings need to be prepared to write in this format to be consistent with other health care providers. Or even better, to use an APSO note as initially described by Cubic (2010), in an electronic health record where the assessment and plan are described first followed by the subjective and objective data supporting it. The APSO note helps the health care team identify quickly what is being recommended by the behaviorist.

## **Attitudinal, Clinical, Operational, Administrative, and Financial Barriers**

Oftentimes, psychology has been accused of adding more expectations of their trainees without removing any previously taught areas of knowledge that have become outdated. Thus, it is not recommended that training programs simply try to incorporate information and clinical experiences regarding integrated care into current graduate school or internship curriculums as specialty tracks or in addition to current demands. Rather, it is recommended that training programs focus on introducing key constructs of integrated care when they fit well with content aimed at developing the overall foundational competencies in psychology early on (e.g., evidenced-based treatment approaches, globalization, interprofessional professionalism).

It is also recognized that when new training models are implemented, the existing culture for the training program, faculty, trainees, and their patient base must also change. Understandably, there are also numerous barriers to shifting towards incorporating more integrated care training into graduate, internship, and fellowship models that must be addressed and some of the most notable are briefly discussed below:

*Resistance from Faculty.* It is not uncommon for traditionally trained psychology colleagues to have misconceptions about integrated care and psychology's role

within primary care. Although the field is increasingly recognizing the importance of psychologists being part of integrated care models as evidenced by the formation of a Primary Care Coordinating Group within Division 38 (Health Psychology) in APA, the field is only now starting to understand and define how training in these settings should occur. For example, in February of 2011, the first author of this chapter was asked to serve as chair for a Primary Care Training Task Force (PCTTF) for APA and recommendations were available to the Board of Educational Affairs (BEA) in October of 2011. One important goal of this group was to help offset the myth in many training programs that the types of interventions offered in integrated care (e.g., brief problem focused assessments and interventions) do not provide trainees with real opportunities to provide the types of clinical services psychologists should conduct.

*Funding.* Long-term stability of interprofessional training programs will require more creative allocation of funds dedicated towards graduate medical education in hospitals and advocacy that leads to reimbursement for integrated care.

*Resistance from Patients and Trainees.* To address this, psychology trainees must be taught how to introduce themselves as “behavioral specialists” and focus on treatments that are present oriented and provide practical ways to cope with stress, distress, and medical issues (for more specifics regarding areas of training to create this change, refer to Blustein and Cubic, 2009). Primary care providers and residents have to be introduced to the psychology trainees, given ideas about how the trainees can be of value to them and their patients, and provided education about a variety of mental health topics. Psychology faculty must buy in to the importance of psychology being part of health care and ways that participating in integrated care experiences will benefit their trainees.

*Resistance to a New Model.* Being treated by a dyad of providers (i.e., a primary care resident and a psychology trainee) is a novel concept to most patients as well as to most providers. Patients and providers both can display resistance initially due to misconceptions about the intent and benefits of integrated care. Therefore, a gradual introduction of the model into the primary care settings will be necessary.

*Resistance to Completing Evaluation Measures.* The types of psychological services provided in any setting should be based on data. Thus, it would be ideal if psychology graduate students had opportunities to develop dissertation projects in primary care. However, collecting empirical data from primary care providers and patients may be challenging due to the competing demands for time.

## **Training in Integrated Care at the Predoctoral Level**

To a lesser or greater degree, most psychology graduate programs offer training opportunities in the application of behavioral principles to medical issues and health care environments. In fact, Division 38 of the APA estimates that 40–50 programs offer a health psychology or behavioral medicine concentration/track [26]. This list is an estimate and not all inclusive as some programs offering health psychology training are not listed in this resource. Nonetheless, while the

number of programs that offer training in primary care psychology or integrated care is unknown, generally if primary care psychology is available, it is embedded into a health psychology track often accounting for a minor portion of the educational offering. This is in contrast to the recommendations made by Talen, Fraser, and Cauley as early as 2002 advising graduate programs to place primary care psychology into the generalist training received by all doctoral psychology students [27]. Also concerning is the fact that when doctoral programs do offer coursework in health psychology or behavioral medicine, rarely are there placements available for practicum in medical settings and even less so in integrated care environments.

Functioning successfully in an integrated care setting requires more than knowledge and the ability to provide psychological assessment, consultation, and intervention. Skills in interdisciplinary collaboration are necessary that go beyond developing relationships with medical patients and primary care providers. In integrated care, health care psychologists must also form positive interprofessional interactions with nurses, allied health professionals, and behavioral providers other than psychologists (e.g., social workers) and support staff [28]. Unfortunately, some authors [29] have expressed concerns that traditional psychology doctoral training may in fact socialize psychologists into a competitive stance with other disciplines.

Over the last decade, much has been written about meeting these emerging needs in AHCs and in primary care clinics [14, 15, 23, 29–31]. In order to meet the increasing demand of predoctoral psychology trainees, internship training directors are forthcoming regarding their need to recruit interns who already have some training and exposure to primary care models of service delivery. What was once a skill set thought to be developed during or after internship is now one that many experts agree needs to be introduced earlier in clinical training [14, 15, 26, 29]. To accomplish these training goals, the paradigm shift may need to occur as an extension of generalist training at the predoctoral level [16]. Primary care psychology training recommendations have been clearly delineated to include: biological, cognitive, affective, behavioral, developmental, and sociocultural aspects of health and wellness; health policy and health care systems; clinical assessment and intervention with common primary care conditions; and ethical issues in primary care [23].

### ***Can Trainees Adapt to Primary Care Models Early in Predoctoral Training?***

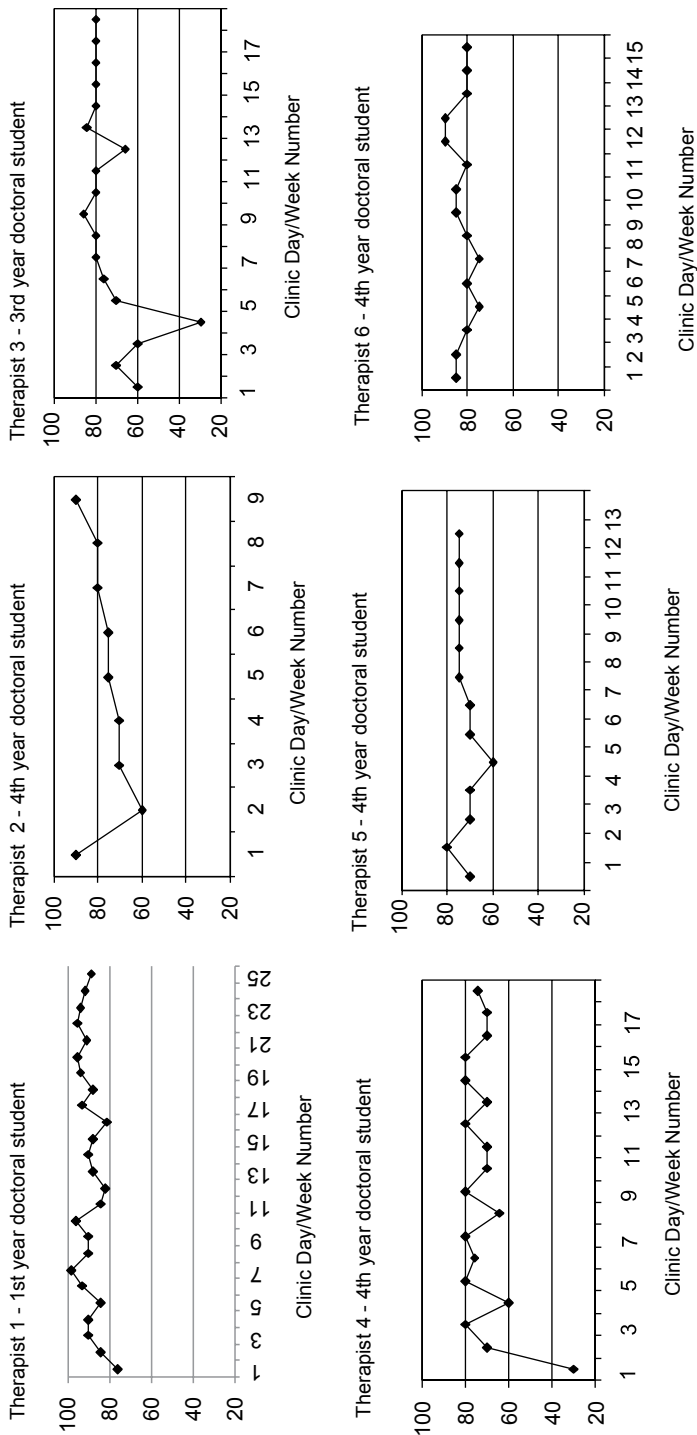
Directors of Clinical Training (DCTs) and planners of curriculum and clinical practica encounter numerous challenges in balancing developmentally sequenced needs of trainees across all levels. In fact, all may not agree that primary care clinical skills can be successfully taught so early in the training of professional psychologists [27]. As in all areas of psychology, regardless of opinions, decisions about when and how integrated care can be taught should be data driven.

In the course of an integrated care training practicum, subjective ratings of clinical psychology doctoral students were collected over an 11-month period [32] (see Fig. 3.2). Doctoral students served as behavioral health consultants (BHCs) in five urban, medically underserved primary care health clinics. On average, student BHCs were in clinics 8–10 h per week. None of the students had previous integrated care clinical experience, and they differed widely in amount of clinical training and contact hours, with one student having no previous clinical experience at all. Other students ranged from 2 to 5 years of previous clinical practicum experience. Notably, only one of the students had any formal coursework/training in behavioral and cognitive behavioral therapy interventions. Each of the students had previously completed at least two graduate level health psychology courses, and all students participated in a 3-day training workshop including didactics in integrated care models, assessment, treatment, and “real-time” role play prior to beginning practicum placements.

In accordance with social cognitive theory, [33] it was hypothesized that self-efficacy regarding students’ perceived ability to perform necessary tasks in an integrated care model would be a sound predictor of students’ actual performance in integrated care clinics. At the conclusion of each clinic day, student BHCs completed a subjective rating of self-efficacy ( $0 = \text{“Not at all confident”}$  to  $100 = \text{“Extremely confident”}$ ) regarding their perception of performance of activities consistent with the integrated care model as reviewed in program practicum training and defined by Strosahl [31] and Robinson [34]. Student BHC self-efficacy ratings were analyzed sequentially to identify trends and cycles [35, 36] and are presented in Fig. 3.2. Taken together, the students’ early rating data probably represent an expected “warm-up” period or learning curve as new environments and demands are encountered. Downward trends in self-efficacy tended to co-occur with student therapists’ open-ended comments referencing a particularly complex patient presentation or feeling as though optimal clinical outcomes were not achieved. Objective data, such as time per session (15–30 min sessions) and number of follow-up sessions (average 2–4 sessions), suggested that beyond the initial “warm-up” learning curve period, the students were able to consistently adapt to the integrated care model. Notably, there did not seem to be any difference in 2nd- versus 3rd- or 4th-year students in their ability to “catch on” to the model. Anecdotally, students who had been trained primarily in models of long-term psychodynamic oriented therapies (4th-year students) reported more difficulty adapting to such a brief, fast-paced model. These results underscore the need to track training process and outcome data as the “Second curve” of the training of professional psychologists emerges [37].

### ***Models of Primary Care Training in Predoctoral Curriculum***

Frequently, in predoctoral training programs, the degree to which trainees have access to clinical practicum experiences in integrated care is contingent upon availability of financial and personnel resources. There are a number of ways in which programs might consider including integrated care psychology training in the



**Fig. 3.2** Therapist-subjective self-efficacy ratings on clinic day/week in primary care clinic practicum

curriculum and/or clinical practicum sequence. It may be helpful for the reader to evaluate possible models in terms of match to their own program structure and the following evaluation criteria: (1) logistics (i.e., ease of implementation, cost, and necessary resources), (2) clinical competencies addressed (knowledge, skills, attitudes) and (3) the degree to which higher level integration skills may be developed [38, 39]. In the following sections, three models previously implemented by the second author and colleagues are presented along with the respective advantages and disadvantages.

*Model I: Inclusion of Primary Care Psychology Topics and Training in Existing Program Curriculum and/or Didactic Structure.* When clinical practicum opportunities in primary care settings are unavailable, training recommendations can be met through inclusion of topics in existing curriculum and/or didactic sessions. In the Health Psychology Emphasis Area in the School of Professional Psychology at Spalding University in Louisville, KY, USA, the curriculum structure included a sequence of three doctoral-level Health Psychology courses (Health Care Systems, Introduction to Health Psychology/Behavioral Medicine, and Advanced Clinical Health Psychology). The program course structure allowed for the infusion of knowledge, skills, and attitudes across this curriculum. The knowledge and attitude components of integrated care were included as curriculum topics in each of the three courses. The skill acquisition and integration across levels of training in this model were addressed through assignment of applied projects in the Advanced Clinical Health Psychology course, in which students were tasked with adapting applied clinical programming assignments to both specialty clinic settings with traditionally formatted length assessment and interventions, as well as brief, integrated care format. In the absence of this breadth and number of courses addressing specific Health Psychology topics, similar content may be covered through seminar and/or regular didactic case presentations and other formats.

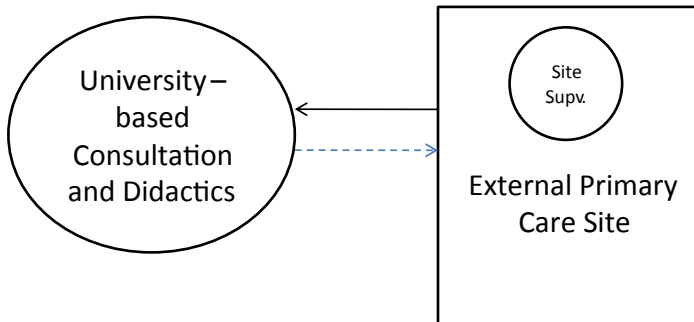
*Model Advantages:* Logistic advantages include ease of inclusion in the existing curriculum or didactic structure. The knowledge and attitude domains are readily covered in this model. Implementation of this model does not necessitate hiring of additional faculty resources or may be accomplished through guest presenters or seminar format.

*Model Disadvantages:* Although this model readily supports knowledge and attitude levels of competency, it can fall short in developing requisite integrated care skills. Graduate students who are trained in traditional models of psychological service delivery may have difficulty executing brief assessment and interventions utilizing only role play or laboratory-based experiential learning. Higher level of ability to integrate knowledge, skills, and attitudes may also be lacking in this model. Finally, existing faculty may not have the level of expertise necessary to facilitate effective integrated care training [40].

*Model II: External Primary Care Practicum Site with External Site Supervisor (Fig. 3.3).* In this model, students are assigned to external sites and have site supervision with persons who are employees of the facility but who may not be part of the doctoral program faculty. In an application of this model at Spalding University,



## Model II – External Practicum and Supervision



*NOTE:* - - > Denotes degree to which university-based consultation input or didactic information is bi-directional is variable

**Fig. 3.3** External or supplementary practicum placement at external site with external site supervision

two sequential cohorts of six students were placed at area primary care clinics for a period of 11 months. The students served as BHCs in five urban, federally designated medically underserved primary care health clinics. All of the students participated in a 3-day training workshop including didactics in integrated care models, assessment and treatment, and “real-time” role play prior to beginning integrated care placements. In an effort to facilitate supervised supervision among more advanced students, the students from the first integrated care practicum cohort assisted in the “real-time” role play and training of the second cohort. On average, BHCs were in clinics 8–10 h per week and reported 8–17 patient/medical provider contacts per day. Each of the students carried a patient caseload for brief intervention (range 2–6 sessions) and received regular on-site supervision from behavioral health consulting staff employed by the primary care health centers. In addition, students attended a weekly 3-h vertical clinical team group supervision, consultation, and didactic session conducted by the doctoral program faculty member. It is noteworthy that the training program during the second student cohort was supported by a state-based foundation grant initiative.

*Model Advantages:* Logistic advantages include ready access to existing primary care venues. Site supervision in this model was part of a collaborative project and was supported financially by external grant funding. Faculty time for university-based supervision was likewise supported by external funding sources. The knowledge, skills, and attitude domains, as well as higher levels of integration, were easily woven into this structure.

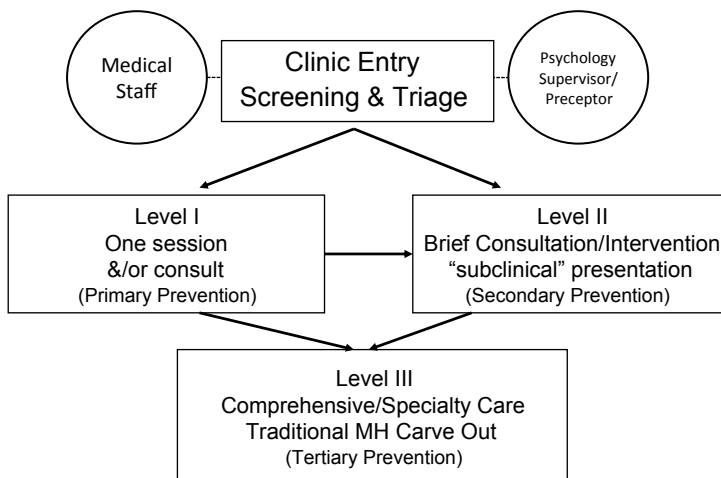
*Model Disadvantages:* If not supported by adequate funding and other resources, this model can present numerous logistic disadvantages. For example, reliance on external supervision can require financial support to offset supervisor time during which they are not engaged in billable activities. Similarly, program faculty may be

pressed to either buy out of courses, develop a new course or adjust their agreed-upon workload to accommodate university-based consultation and adjunctive training in this model. With respect to training objectives and competencies, external supervisors may be trained in different disciplines or models of psychology training that may or may not parallel the training model or philosophies of the students' program. Additionally, trainees may receive didactic training for competencies in integrated care models, but clinics may function solely in a colocated model of service delivery with more traditional session length, supervision, and administrative structure. Finally, ASPPB Practicum Guidelines [39] stress the importance of a commitment to training in practicum training sites. External supervisors in busy primary care settings may encounter competing demands relative to clinical productivity versus training mission activities.

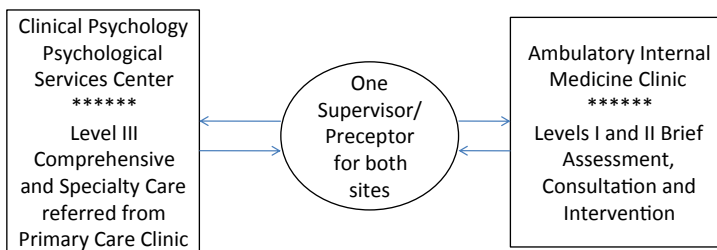
*Model III: A Partnership between a University-affiliated Medical Residency Primary Care Training Clinic and a Clinical Psychology Doctoral Program* A third model for predoctoral programs to consider is one in which a psychology faculty member serves as a preceptor/medical team member in both the primary care clinic and the department-affiliated psychology training clinic. This example model structure mirrors a stepped care model providing levels of intervention across primary, secondary, and tertiary levels of need [38]. One example of this model was implemented in the University of Louisville Graduate Psychology Education (GPE) program as a predoctoral integrated primary behavioral health care training program. It was a collaborative project between the departments of Internal Medicine and Psychological and Brain Sciences supported by Health Resources and Services Administration GPE funding [42, 43]. In this model, the two departments (Internal Medicine and Clinical Psychology) and training programs shared training objectives grounded in competency-based education [44]. The service delivery model was based on a stepped care model with three levels of assessment, consultation, and intervention (Figs. 3.4 and 3.5). Levels I and II (brief assessment, consultation, and intervention) were executed on site, in the primary care clinic. Patients identified as best served via level III comprehensive or specialty care were referred to the psychology department doctoral training clinic, Psychological Services Center. Supervision for psychology graduate students was provided across levels of service delivery by the same supervisor. Graduate students received real-time collaborative supervision in the primary care clinic, wherein the supervisor was a part of the medical team in a preceptor role. Students were encouraged to adapt to a primary health care culture, [34] competencies, and an abbreviated integrated care session structure [31]. Additionally, in order to foster seamless continuity of care, level III referrals were often seen for ongoing treatment by the same students and with the same supervisor. On average, each doctoral student was in the primary care clinic 4–8 h per week, carried a 2–4-h-per-week level III patient load, and attended weekly 3-h vertical team group supervision. Students in this model were also actively involved in the delivery of case and didactic presentations and primary care-based clinical research. For more detailed information specific to the University of Louisville program, the reader is referred to Newton et al. 2006.

### Stepped Care model approach

Adapted from *MedPlus Behavioral Medicine Consultant Model*, Pruitt et al. (1998)



**Fig. 3.4** Model III: Example of stepped care model with psychology faculty preceptor in primary care. (Adapted from *MedPlus Behavioral Medicine Consultant Model*, [41])



**Fig. 3.5** Model III: Seamless continuity of care model with one supervisor in both clinical psychology psychological services center and primary care clinic

*Model Advantages:* In this model, there is continuity in supervision across all stepped care levels. The supervision format across models of training and service delivery (i.e., traditional vs. integrated care) is demonstrated and modeled for trainees. Consistent with training recommendations, [15, 16, 23, 29, 44] both trainees and supervisors are members of the multidisciplinary team and involved in an interdisciplinary training model. Supervisor and trainees are able to readily monitor the degree to which the team is adhering to the integrated model. Vertical teams also support implementation of “supervision of supervision” [38] as trainees move through the program. In many respects, models of this nature may represent a “gold standard” in both integrated care training and enhancing knowledge, skills, attitudes, and advanced integration skills among psychology trainees.

*Model Disadvantages:* In terms of logistic concerns, this model is time and resource intensive. Faculty expertise and ability to both perform and supervise within the integrated care model are crucial. The partnering integrated care site must demonstrate a commitment to the inclusion and training of psychology trainees as a part of the overall training and service delivery mission. The introduction and integration of psychology within a busy primary care clinic may be viewed as an additional barrier to medical care and training among medical staff and faculty. Obtaining high levels of partner buy-in may be difficult for programs that do not have a health science training center affiliation or external partnership. The reader should refer back to earlier sections of this chapter that delineate the most likely of these barriers.

## **Integrated Care Training at the Internship Level**

In contrast to graduate programs, many internship and postdoctoral fellowships, especially those housed in academic health centers (AHCs), offer some type of training in primary care settings. According to Blount, [15] a review of the Association of Postdoctoral and Internship Centers (APPIC) online directory showed that 93 APA-accredited internships offer a major primary care rotation and 16 APA-accredited postdoctoral fellowships offer a specialty area in primary care. Unfortunately, what is not known is how much exposure to integrated care these trainees receive. As described earlier, training in primary care settings ranges from coordinated care to colocated practices to collaborative care to integrated care. It is not uncommon, therefore, for a trainee in a primary care setting to provide traditional mental health services, not integrated care.

### ***Allowing a Program to Evolve Towards Integrated Care***

If an internship program would like to develop rotations in PCMHs, the type of care (i.e., coordinated, colocated, collaborative, integrated care) that can realistically be provided in available primary care settings warrants significant consideration. Additionally, the program must also focus on identifying and developing key relationships (e.g., medical director of the primary care clinic(s), primary care residency director(s)) that will enhance quality of services patients receive and the training experiences of all trainees affected.

The history of training psychology interns in primary care settings at Eastern Virginia Medical School (EVMS) demonstrates how an internship can learn from its challenges and develop rotations in integrated care. The EVMS Clinical Psychology Internship program has evolved through three phases of training in integrated care by the first author and colleagues, and each phase is presented along with the respective advantages and disadvantages as these phases are the likely scenarios

most internship directors would need to ponder in order to add integrated care training to their programs.

### **Phase I: Co-Located Practice**

In 1995, the Department of Family and Community Medicine at EVMS funded one FTE psychology internship position for 2 years to place an intern at Ghent Family Practice (GFP) in a model of colocation to enhance patient services and residency education. The decision was made through negotiations between the departmental chairs of psychiatry and behavioral sciences and family and community medicine to enhance relationships between the departments and to fill a void in behavioral education noted during the residency program's accreditation process. EVMS offers 6-month rotations; thus, this funding allowed four psychology interns to be trained at GFP over the 2-year time frame. Supervision was provided by two psychologists with faculty appointments in the Department of Family and Community Medicine, and funding for the supervision was covered by the family medicine department. The funding for both the interns and the supervisors was discontinued when a collocated practice did not appear to meet the needs of the residency training program.

*Main Phase Advantage(s):* The collocated practice between the psychology internship and GFP introduced the faculty and trainees to the mutual benefits of collaborating in patient care. The collocated practice also increased access to care for GFP patients with mental health needs. The four psychology interns who participated in the training received exposure to a diverse patient population and developed peer relationships with many of the residents, which enhanced their understanding of primary care physicians' training and perspectives.

*Main Phase Disadvantages:* The most notable disadvantage of this approach was that the collocated practice required that the behaviorists previously assigned to the education and training of family medicine residents shift time and effort to the supervision of the psychology intern(s) without tangible value added to the education of the GFP residents. Thus, GFP returned to hiring a behaviorist dedicated only to the training of its residents, and funding was no longer available to support the lines. Additionally, the model did not provide the psychology intern(s) with a unique training opportunity of how psychology could operate effectively in primary care as the collocated model resulted in the provision of traditional psychological service delivery.

### **Phase II: Collaborative Practice**

In 2002, through Health Resources and Services Administration (HRSA) GPE funding, the concept of training psychology interns with family medicine residents at EVMS was resurrected by the first author, but the model was altered based on the research of Kirk Strosahl, Patricia Robinson, Nicholas Cummings, William O'Donohue, and Susan McDaniel. Funding received from the HRSA GPE grant

was dedicated primarily to trainee stipends and fringe benefits with some allocation of resources to cover faculty time for supervision. This grant was predicated on the premise that it was vital for psychology interns to have supervised training in primary care as a prerequisite to offering integrated care (for more details, regarding this project see Leventhal et al. 2004 [45]) and continued for 3 years. The model converted to training two psychology interns (out of a program of 6–8 interns) in primary care settings a year side by side with family medicine attending physicians and residents. Real-time supervision by the clinical psychology supervisor was provided during rounds and through the precepting office used by the physicians. Family medicine residents and interns were encouraged to work as a team and as dyads and to create individualized educational plans regarding the integration of behavioral sciences and primary care medicine. The resident(s) and psychology intern(s) were trained to reinforce one another's treatment efforts to enhance patient compliance. The training sites used provided services to a high percentage of minority patients, e.g., over half of the patients seen were minorities (largely African American). Objective measures of the types of clinical encounters psychology trainees were experiencing and the degree of effectiveness of and satisfaction with the interprofessional training model were obtained (see Tables 3.4 and 3.5, for details).

*Main Phase Advantages:* The number of family medicine residents positively impacted by the program was substantial (approximately 18 residents per year) and the provider satisfaction (both faculty and family medicine residents) was high. Access to mental health services for patients was improved. Psychology interns had in-depth training in integrated care. The presence of a psychology supervisor in the preceptor role and in preceptor space was another clear advantage for training of and modeling for interns. Additionally, the “real-time” supervision provided is in line with the anticipation that this type of supervision will be the wave of the future in how supervision is delivered for psychologist serving as health care providers.

*Main Phase Disadvantages:* The phase only allowed a small number of psychology interns (two per year) to receive training in integrated care. Given the small percentage of interns participating on integrated care rotations, the amount of content on primary care psychology that could be infused into the didactic training was limited.

### **Phase III: Integrated Primary Care**

Due to the success of the 2002 HRSA GPE grant project, in 2007 another 3 year grant in 2010 entitled *Creating an Integrated Care Workforce through Inter-Professional Education*. GPE grant was awarded to the first author for a project entitled *Enhancing Patient Care by Collaboratively Training Psychologists and Primary Care Providers*. These new training projects were crafted to redesign and enhance the internship's training model further to make training opportunities available in primary care psychology for all of the psychology interns accepted into the psychology internship program and to expose a larger number of family medicine residents to the role psychologists can play in primary care by training the psychologists with-

**Table 3.4** Sample of a tracking method for psychology trainees to use for clinical encounters in primary care settings. ((Psychology interns) Performance reports of psychosocial encounters Name: \_\_\_\_\_)

Date seen	Setting (please circle)	Patient's initials	Age	Sex (please circle)	Ethnicity (please circle)	SES (please circle)	Psychosocial issue or diagnosis (please circle)	Treatment recommended (please circle)
	Inpatient rounds			M	White	Low	Depression Anxiety	None
	Family medicine clinic			F	Black	Middle	ETOH Abuse Drug abuse	Pharmacotherapy (by PCP)
	Nursing home				Asian	High	Abuse ASD/PTSD	Brief counseling
	Specialty clinic				Hispanic		Somatization ADHD	Individual therapy
					Native American		Eating D/O Sleep D/O	Group therapy
					Other		Marital Px Family Px	Family therapy
							Work Px Personality D/O	Marital therapy
							Cognitive impairment	Biofeedback
							Child Behavioral Px	Brief cognitive assessment
							Medical issue _____	Psychological assessment
							Other _____	Consultation with Other professional
								Referral to Community services
								Referral to MH Professional
								Other _____

SES socioeconomic status, ETOH ethanol, ASD acute stress disorder, PTSD posttraumatic stress disorder, ADHD attention deficit hyperactivity disorder, D/O disorder, Px prognosis, behavioral, with, MH mental health

**Table 3.5** Sample of an outcome measure to determine impact of adding psychology interns to training sites with primary care residents

**Feedback Survey**  
**Regarding Placement of Psychology Interns within the Family Practice Each Time It Occurs Settings**

\_\_\_\_\_ Resident \_\_\_ Faculty \_\_\_ Other \_\_\_\_\_

Name or Last 4 digits of your SS# (Please Mark One)  
 (Describe)

**Please use the following scale to rate each statement.**

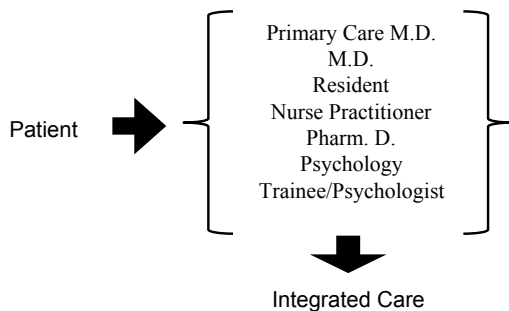
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
<b>Strongly Disagree</b>	<b>Somewhat Disagree</b>	<b>Somewhat Agree</b>	<b>Strongly Agree</b>

- \_\_\_\_\_ 1. The presence of psychology residents at the family practice each time it occurs has lead to an increased emphasis on psychosocial issues overall.
- \_\_\_\_\_ 2. Working with psychology residents has enhanced my comfort in treating psychosocial problems.
- \_\_\_\_\_ 3. When psychology residents are present I am more likely to investigate psychosocial problems with my patients.
- \_\_\_\_\_ 4. Psychology residents have had no impact on the way I deal with psychosocial issues with patients.
- \_\_\_\_\_ 5. The presence of psychology residents has encouraged me to consider both organic and psychosocial problems in patient care concurrently.
- \_\_\_\_\_ 6. If a psychology resident is present I am more likely to routinely investigate psychosocial issues myself.
- \_\_\_\_\_ 7. The presence of psychology residents has significantly enhanced the training at the family practice each time it occurs residency program.
- \_\_\_\_\_ 8. I would be less likely to consult with a psychology resident about a patient’s psychosocial issues if they were not in the family practice each time it occurs settings.
- \_\_\_\_\_ 9. I view the psychology resident as an important personal resource in maintaining my emotional well being.
- \_\_\_\_\_ 10. Having psychology residents present has enhanced the care received by patients at the family practice each time it occurs.

in two family practice residencies. Funding received from the HRSA GPE grants were dedicated to faculty support or supervision of trainees, faculty development, and creation of an infrastructure for integrated care, not only to trainee stipends and fringe benefits. The main goal of the second project was to ultimately insure that all



## Sr. Consultation Clinic



**Fig. 3.6** Model of a senior care consultation clinic in a primary care practice

of the interns had exposure to family medicine preceptors and primary care patients. To accomplish this, all psychology interns were required to participate in minor rotations in primary care mental health, participate in didactics in primary care psychology, and teach a behaviorally oriented didactic to family medicine residents.

The project also allowed the competencies of 30 family medicine residents to be enhanced, especially as pertained to interpersonal and communication skills, compassionate patient care, mental health and substance abuse knowledge, professionalism, and cultural diversity. As in the previous grant, the primary care patients served received treatments collaboratively designed by psychology interns and family medicine residents under the supervision of a licensed clinical psychologist and a family medicine preceptor. Additionally, continuing education workshops were made available to all psychology internship faculty on the topics of primary care psychology, motivational interviewing, and PCMHs, and continuing education workshops were made available to all family medicine and psychology faculty on cultural diversity.

The graphic in Fig. 3.6 shows the composition of the Senior Care Consultation Clinic, one of the minor rotations, to illustrate the composition of a typical integrated care consultation team. This team operates within GFP and allows geriatric patients to present at the primary care clinic with their families and get their medical and mental health needs addressed simultaneously creating a more efficient and less stigmatized process for the elderly. All patients are seen by all members of the team and an interdisciplinary decision-making approach is used. Assessing clients for the possibility of geriatric depression or dementia is a common service that the psychologist(s) or psychology trainees provide. Psychology trainees also commonly work with the families to help them deal with caretaker burnout and difficult decisions that must be made regarding placement in assisted living or nursing home facilities and death and dying concerns.

*Main Phase Advantage:* This model had all of the advantages of phase II and changed the philosophy of the internship program and its commitment to integrated care as all faculty and trainees had some exposure to integrated care and its con-

cepts. The model is also one that is sustainable without grant funding as most internships prefer interns to have minor experiences, and thus exposure to integrated care (both didactic and clinical service delivery) is achievable in most situations even if new funding is not available. Additionally, as all family medicine residency programs are required to have behavioral training for residents, it is likely that behavioral providers will be available as role models (even if not psychologists) without the cost of additional funding.

*Main Phase Disadvantage:* Considerable funding was needed for faculty development to obtain the shift in philosophy and to insure that all training sites had the resources needed for the trainees to operate effectively.

### ***Faculty Development***

Psychology faculty in training programs must have their own skills, competencies, and insights to prepare trainees to offer integrated care through interdisciplinary training. Unfortunately, many clinical psychologists have steered away from providing services in primary care settings as behavioral health historically has had difficulty generating sufficient income in these settings to cover overhead costs [46]. The special authorizations and billing processes needed to obtain reimbursement for services provided by psychology in primary care settings due to insurance requirements, especially when mental health services are carved out or two services cannot be billed on the same date, have historically created confusion and disincentives for primary care providers who want to offer integrated care. Thus, to expand training to integrated care, a psychology internship will need to provide continuing education opportunities for teaching faculty and supervisors on how to create best practice models for competency-based curriculums and outcome measurement in integrated care.

When psychologists well versed in integrated care are not already available within a psychology internship, multiple methods of providing continuing education offerings for faculty are available [44]. Two major consultants offering on-site training for entire faculties are CareIntegra ([www.CareIntegra.com](http://www.CareIntegra.com)) and Mountainview Consulting ([www.behavioral-health-integration.com](http://www.behavioral-health-integration.com)); however, without significant funding, these options may not be viable. A second way to approach faculty development would be to have supervisors who will have a main supervisory role, but have limited personal training in integrated care, enroll in advanced training through a certificate or postdoctoral training program; a list of such programs is available at [www.integratedprimarycare.com/training](http://www.integratedprimarycare.com/training). While the training is considerably more cost effective, participation in such programs does require multiple trips to a few distance learning sites which creates associated travel expenses.

If a program decides to use both existing resources and some consultant services to create training in integrated care, at a minimum, faculty and staff need to receive training in interdisciplinary team skills, psychosocial issues most relevant

to primary care, motivational interviewing, medical compliance barriers, and multicultural diversity. Interprofessional competencies should focus on values clarification, methods of constructive disagreement, understanding diverse models of professional behavior, and an appreciation of group process. Such didactics and other group training experiences should supplement the standard seminars and training opportunities already available to faculty and staff.

## Summary and Recommendations for the Future

A psychology workforce that can address behavioral aspects of health care and the reality that most patients seek their mental health treatment in primary care is vital to the advancement of the discipline. More opportunities for psychology trainees to complete practicum, internships, and postdoctoral fellowships in primary care settings need to be developed. These educational opportunities need to pay close attention to developing experiences that create shared values and common goals between primary care providers and psychologists needed for trainee internalization of integrated care precepts. This type of training can also serve as a foundation for individuals who want to continue to practice in specialty mental health areas or specialty medical settings (by enhancing their communication and coordination skills with their patient's primary care medical providers).

To begin to meet these goals, the field needs to assess the current state of integrated care training in psychology, create a comprehensive strategic plan for education and training to prepare psychologists for integrated primary care across a number of settings (family medicine clinics, pediatric clinics, etc.), and complete a workforce analysis so the proper number of psychologists needed in this area are trained.

This strategic plan for training needs to be broad enough to retain the key educational and training components that lead to a high-quality, traditionally trained clinical/counseling/health psychologist, while simultaneously training psychologists to:

1. Work in a variety of integrated health care settings
2. Provide evidence-based care in a variety of modalities (most notably, brief assessments and interventions) most relevant to integrated care settings
3. Gain working knowledge of psychopharmacology, medical terminology, and medical disorders
4. Thoroughly comprehend the interplay between behavior and health
5. Identify when individuals should be referred for more intensive behavioral or traditional mental health treatments
6. Conceptualize psychology's role in the larger health care system (including interprofessional professionalism so that trainees maintain respect for other disciplines)
7. Understand the complex ethical issues that arise in medical settings
8. Demonstrate respect for the individual and cultural diversity of patients treated within primary care settings

Recommendations for meeting these goals might include:

1. Innovative ways to educate and train psychologists regarding (physical and mental) health promotion, disease prevention, and management of chronic disease across the life span across the course of educating a psychologist
2. Ways to educate the public and other health care disciplines about how psychology fits into integrated care
3. A plan for promoting research regarding and application related to how psychological knowledge can be applied to enhance health care settings, decrease health disparities, and lead to health and wellness (both physical and mental)
4. Advocacy for the inclusion of psychology in integrated care related and other health care reform policies (to include, but not be limited to, reimbursement issues)

Strategies to meet these goals might include:

1. Mentoring programs that enhance the ability of current educators to prepare trainees for integrated care opportunities
2. Building on collaborations with other disciplines invested in integrated care
3. Provisions for developing competencies and competency-based evaluation tools that can be effectively and efficiently implemented (which might include toolboxes)
4. Dissemination of strong educational and training models and practices (i.e., ones that allow for bidirectional primary and behavioral health-integrated practice and insure that trainees are well versed in concepts related to wellness and disease)
5. Employing innovative, user-friendly, and cost-effective technologies to enhance learning
6. Research opportunities/funding sources that allow for investigating comparisons between behavioral and psychosocial interventions for the prevention and treatment of specific health conditions, medical and psychosocial interventions, integrated systems of care, and health interventions across the life span and across diverse individuals and cultures
7. Creation of an environment that fosters attitudinal change for learning, especially as it pertains to getting psychologists to broaden their view of psychology (i.e., creates the paradigm shift needed)
8. Developing a workforce that operates optimally in an integrated system of care as evidenced by improvements in patients' health outcomes and status
9. Retraining current psychologists interested in transitioning to integrated care
10. Developing leaders—representing clinical, financial, operational, and educational spheres—with exposure to, and experience in, integrated models of care
11. Identification and support of leaders who can convey the vision for the value of integrated care
12. Inspiring health care systems to operationalize principles and practices associated with integrated systems of care

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# Chapter 4

## Core Competencies for Psychologists: How to Succeed in Medical Settings

Anne C. Dobbmeyer and Anderson B. Rowan

### Core Competencies: How to Succeed in Medical Settings

Over the last decade, the field of professional psychology has made advances in specifying and elaborating on the core competencies and associated behavioral benchmarks required to function effectively and ethically as professional psychologists. Further refinement of professional competencies has been undertaken within specialty areas of professional psychology, including the specialty of clinical health psychology. Clear competencies and associated benchmarks provide essential guidance for training programs, supervisors, students, and psychologists wishing to expand their scope of practice. With the growing interest in incorporating psychology into a variety of medical settings, and the movement of clinical psychologists, many of whom have not had specialty fellowship training in clinical health psychology, into roles and positions within medical settings, the issues surrounding professional competencies for psychological practice in medical settings remain important. The current chapter aims to present a brief overview of the professional psychology competency literature, with a particular emphasis on additional competencies specific to clinical health psychology. Several competency areas not previously described in the literature will be proposed. Finally, core competencies for psychologists in medical settings will be illustrated using two detailed applied case examples. Core competencies essential for integration into medical settings and gaining acceptance and credibility as part of a medical team are highlighted.

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## Overview of Core Competencies

The professional psychology competencies literature includes a developmental perspective, framing competencies across levels of training from practicum student through lifelong learning. This chapter centers predominately on core competencies for those psychologists just entering practice in medical settings. This may include psychologists who have recently completed their internship, or more seasoned psychologists moving into medical settings for the first time. It does not address specific competency benchmarks desired across all developmental levels (e.g., practicum, internship, etc.). Furthermore, the chapter does not focus heavily on competencies essential for practice in integrated primary care settings (discussed more completely in Chap. 14), but rather more broadly on work within other specialty medical clinics.

### *The Competency Cube Model and Professional Psychology*

The most widely cited recent model of professional competencies in psychology is the three-dimensional “cube” model for competency development, developed out of a 2002 work group examining “Specialties and Proficiencies of Professional Psychology.” [1] In this model, Rodolfa et al. [1] propose a multidimensional approach to understanding the construct of competency. The three-dimensional cube model includes six foundational competency domains, six functional competency domains, and five stages of professional development in professional psychology. The domains are interrelated and developmental. According to this model, foundational competency domains represent the knowledge, skills and attitudes, and values that form the basic, underlying building blocks for the work done by psychologists. Foundational competency areas include the following six domains: reflective practice and self-assessment; scientific knowledge and methods and relationships; ethical-legal standards and policy issues; individual and cultural diversity; and interdisciplinary systems. Functional competency areas build from and integrate with the foundational competencies into the specific, day-to-day functions accomplished by professional psychologists. The six functional competency domains include assessment-diagnosis-case conceptualization, intervention, consultation, research-evaluation, supervision-teaching, and management-administration. Finally, the cube model maintains that the standards for achieving competencies change over time, based on the stage of professional development, from graduate education, internship, postdoctoral supervision, and fellowship, to continuing lifelong competency. This landmark publication, although proposing the levels or stages of development, did not delineate specific competency benchmarks for each competency domain.

Since the introduction of the cube model in 2005, [1] others have expanded on this competency model for professional psychology. Notably, the Assessment of Competency Benchmarks Work Group, convened by the American Psychological Association (APA), elaborated further on the cube model in defining and measuring competence in professional psychology [2]. The members of the work group

retained the 12 competency domains (functional and foundational), but in the third dimension restricted its focus to three of the five previously identified developmental levels: readiness for practicum, readiness for internship, and readiness for entry into practice. They determined that delineating competency benchmarks for entry into graduate school and for lifelong learning, while important, was beyond the scope of their current endeavor. This publication markedly expands and elaborates on the original competency cube model by operationally defining essential components of each competency at each of the three developmental levels, and by providing behavioral anchors or benchmarks and assessment methods that reflect each competency.

An example may help clarify. One of the foundational competencies, “relationships,” defined as “capacity to relate effectively and meaningfully with individuals, groups, and/or communities,” (p. 18) is further broken down into four essential components: interpersonal relationships, affective skills, intradisciplinary relationships, and expressive skills. Looking deeper at one of these areas, intradisciplinary relationships yields descriptions of behaviors or benchmarks that would be expected at the practicum level (e.g., “demonstrates respectful and collegial interactions with those who have different professional models or perspectives than own”), internship level (e.g., “adheres to ethical standards and institutional policies and procedures”), and entry-level practice (e.g., “adheres to ethical standards and institutional policies and procedures” and “participates in local and national professional organizations”) (p. 20). Methods for evaluating capacities are also included for each developmental stage, and include such strategies as self-evaluation, client evaluation, and supervisory evaluation [2].

Thus, the Assessment of Competency Benchmarks Work Group [2] provided a much greater degree of specificity regarding behavioral anchors or benchmarks valuable for evaluating the extent to which trainees, at different points in their development, demonstrate each of the specific foundational and functional competencies in the three-dimensional competency cube model. Further discussions among work group members, as well as input from relevant constituency groups and public comment, led to additional modifications and an expanded model [3]. The broadened model included one new foundational competency (professionalism) and two new functional competencies (teaching and advocacy), each with their own operationally defined essential components and behavioral anchors/benchmarks. Additionally, the authors revised some of the essential components of competencies and included new behavioral anchors in many places. Returning to the previous example of the “relationships” foundational competency, the expanded model includes such behavioral anchors as “listens and is empathic with others” (practicum level); “demonstrates respectful and collegial interactions with those who have different professional models of professions” and “involved in departmental, institutional, or professional activities or governance” (internship level); “effectively negotiates conflictual, difficult, and complex relationships, including those with individuals and groups that differ significantly from oneself” and “maintains satisfactory interpersonal relationships with clients, peers, faculty, allied professionals, and the public” (p. S12) [3].

**Table 4.1** Foundational competencies unique to clinical health psychology [4]

Foundational competency domain	Clinical health psychology foundational competency
Reflective practice/self-assessment	Engage in reflective self-assessment regarding the dynamic knowledge base and skill set necessary for working with individuals and families with physical health concerns, with an awareness of their place in a larger social and relational context and health systems
Individual and cultural diversity	Access and evaluate the best available biopsychosocial evidence relevant to the practice of clinical health psychology, taking into consideration...relevant individual and culturally based differences
Interdisciplinary systems	Demonstrate an awareness of the unique nature of interdisciplinary collaboration in health care and the importance of patient–practitioner relationships
Ethical and legal standards	Understand the particular ethical-legal standards involved in the health care system

### *The Competency Cube Model and Clinical Health Psychology*

Advances in the delineation of competencies within professional psychology continued with recent elaboration of competencies within several specialty areas, including clinical health psychology. This developed out of the recognition that while there exist many commonalities with generalist practice, significant differences do remain in knowledge, skills, and attitudes necessary to function well as a psychologist in medical settings. In 2007, Division 38 (Health Psychology) of the APA sponsored a summit meeting to identify the competencies expected of an entry-level clinical health psychologist. Summit participants delineated these unique foundational and functional competencies, again using the competency cube model as the underlying framework [4]. The developmental dimension of the model was restricted to one level, focused on competencies expected at the completion of doctoral training (entry-level practice). The authors identified and described four additional foundational competencies unique to practice as a clinical health psychologist. These are summarized in Table 4.1. Finally, the authors confirmed the relevance of clinical health psychology of the core functional competencies outlined previously [1–3]: assessment, intervention, consultation, research, supervision-training, and management-administration. They further delineated knowledge-based competencies and applied competencies for each of these core areas, tailoring them to the specialty of clinical health psychology.

An example may help illustrate the nature of the additional competencies specific to the field of clinical health psychology. New, health psychology-specific competencies falling in the domain of “supervision-training” included the following, for example: “The entry-level clinical health psychologist will have knowledge of the role of other health care professionals (e.g., medical students, nurses, social workers) in the treatment of an individual and/or within an interdisciplinary health

care team” and “The entry-level clinical health psychologist will be able to provide effective instruction and supervision in psychology both to psychology trainees and across disciplines and across levels of training” (p. 579) [4]. The latter competency clearly moves beyond the teaching and supervision competencies desired in professional psychologists [3] by its inclusion of effective teaching and supervision of trainees outside the discipline of psychology.

### ***Competencies for Psychologists in Medical Settings***

Clearly, not every psychologist practicing in a medical setting identifies as a specialist in clinical health psychology. Clinical psychologists without specialty training in health psychology may find themselves working in hospital-based outpatient mental health clinics, involved with medical specialties to provide assistance with weight management or bariatric assessment, implementing tobacco cessation interventions in a primary-care clinic, assessing and treating cancer patients through an oncology department, or working within a cardiac rehabilitation program to address biopsychosocial aspects in post-myocardial infarction patients, among other activities. Clinical psychologists desiring to succeed in medical settings should be familiar with the foundational and functional competencies for entry-level practice as a clinical health psychologist elaborated by France et al. [4] and aspire to achieve the competencies essential for success in his or her specific roles. The competencies needed for success, if working full time in a specialty medical unit (e.g., cancer care center), would likely differ from a psychologist consulting part time or on a limited basis (e.g., teaching a class as part of a diabetes management program and periodically consulting on a few cases). Thus, psychologists in medical settings should focus particularly on those competencies that directly relate to the type of work undertaken. For example, mastering competencies within the assessment and intervention domains may be particularly crucial for success in a position involving direct patient care within a specialty weight management or cardiac care clinic. Other roles, such as that of a consultation-liaison psychologist to inpatient medical wards, would warrant close attention to the clinical health psychology consultation competencies. Clinical psychologists finding themselves in academic medical centers with a greater emphasis on research activity may need to develop clinical health psychology research competencies for success in their settings.

France et al. [4] acknowledge that their delineation of competencies for entry-level practice as a clinical health psychologist would benefit from further development. They note that additional input from practitioners to refine this set of competencies would be of value, particularly in clarifying existing competencies and in identifying new ones. One goal of the current chapter, therefore, is to describe additional competencies and elaborate on existing competencies needing clarification. A second goal is to illustrate select competencies through detailed applied clinical examples showing how these competencies can appear in several different medical settings and contexts. We hope this will illuminate and flesh out the competencies described previously in the literature.

**Table 4.2** Expanded competencies for psychologists in medical settings

Assessment	Psychologists in medical settings will have knowledge of psychological assessment measures specific to medical conditions. Psychologists in medical settings will understand the impact of medical symptoms and medications on standard psychological assessment measures developed and normed with nonmedical populations
Advocacy	Psychologists in medical settings will effectively advocate for patients' needs, and for appropriate psychological services to be available to medical patients
Teaching	Psychologists in medical settings will effectively educate and train medical professionals from diverse disciplines in a biopsychosocial understanding of illness and in conceptualizing patients functionally rather than dualistically
Professionalism	Psychologists in medical settings will pursue continuing education to increase knowledge and skill in topics related to health psychology. Psychologists in medical settings will demonstrate appropriate distress tolerance for working with patient populations in which physical disease, disability, or terminal illness are prevalent features

### *Expanded Competencies for Psychologists in Medical Settings*

The competency literature described above clearly identifies a broad range of core competencies for professional psychologists, as well as for clinical health psychologists. A close review does reveal, however, some gaps in the delineation of core knowledge and skill competencies for clinical psychologists in medical settings. These areas are summarized below and included in Table 4.2.

*Assessment.* First, in the area of assessment, entry-level psychologists in medical settings need to have knowledge of assessment measures specific to the medical condition being treated. Numerous measures have been developed and normed for specific medical conditions. For example, a psychologist working with patients in a pain management program would benefit from the knowledge of psychological measures relevant to chronic pain (e.g., measures assessing pain affect, quality, experience; pain beliefs; pain coping strategies). The existing clinical health psychology competency literature includes a competency related to selecting and administering assessment tools appropriate for an individual's physical illness; however, this competency is listed under "intervention" rather than "assessment". [4] The need for competency in using psychological instruments related to specific health conditions also appears to go beyond the knowledge-based assessment competencies described in the literature, [4] which emphasizes knowledge of biological assessment, psychological assessment, and social-environmental assessment strategies relevant to individuals and systems. Including the phrase "and their medical conditions" would broaden this competency appropriately.

Second, also in the area of assessment, psychologists working in medical settings need knowledge and skill in interpreting psychological measures developed and normed with psychiatric patients, but being used with medical patients. Some

standard psychological assessment instruments can give skewed results when used with medical patients due to the presence of physical symptoms from the underlying medical disorders or from medications used to treat the medical problem. It would be important for psychologists to be aware, for example, that patients taking corticosteroids for multiple sclerosis or asthma might endorse symptoms of nervousness and insomnia (side effects of medication) on psychological assessment instruments, leading to score elevations in anxiety scales. Similarly, individuals with lowered activity levels related to obesity, chronic pain, and physical deconditioning might elevate items related to fatigue, energy, and lack of interest on a depression measure. Awareness of the potential for invalid or skewed results when using measures normed on nonmedical populations is therefore another core assessment competency for psychologists in medical settings.

**Advocacy.** As discussed earlier, the identified core competencies for professional psychology include competencies focused on advocacy [3]. However, competencies in advocacy knowledge and skills are not clearly identified for the specialty of clinical health psychology [4]. Clearly, though, psychologists working in medical settings should demonstrate an ability to advocate for patients' needs, for example, advocating for psychological resources to be provided to medical patients. This often requires skills in "marketing" psychological services through educating medical providers on how psychologists can help medical patients.

**Teaching.** Within the area of supervision and training, France et al. [4] proposed that the "entry-level clinical health psychologist will be able to...provide effective instruction and supervision in psychology both to psychology trainees and across disciplines and across levels of training" (p. 579). To function optimally in medical settings, psychologists must have solid skills in teaching medical providers about the psychosocial aspects of health and disease. Given the importance of this skill for increasing medical providers' understanding of the role of psychologists with medical patients, and hence for increasing referrals and utilization of a psychologists, we believe there should be a more detailed delineation of teaching competencies for psychologists in medical settings. Specifically, psychologists in medical settings should be able to effectively educate and train medical professionals from other disciplines about the biopsychosocial understanding of illness and in conceptualizing patients functionally rather than dualistically. Such teaching might occur in formal settings such as medical Grand Rounds or in-service training, or informally through "curbside" discussions.

**Professionalism.** Several aspects of competencies related to professionalism deserve greater clarification and delineation. In addition to aspects described in the existing competency literature, psychologists working in medical settings should demonstrate appropriate professionalism through actions such as pursuing continuing education opportunities focused on health psychology-related topics, attending conferences to network and build relationships with other psychologists in medical settings (and/or clinical health psychologists). Psychologists in medical settings should also strive to develop appropriate distress tolerance for working in settings and with patient populations in which physical disease, disability, or terminal ill-

ness are prevalent features (e.g., bone-marrow transplant units, dialysis units, cancer care centers, etc.).

**Interprofessionalism.** The attitudes and skills needed to function optimally in medical settings clearly include appropriate interaction and collaboration across a variety of medical disciplines. This concept is recognized in the existing health psychology competency literature through the inclusion of several consultation competencies that bear on interprofessionalism [4]. These include knowledge of professional roles and expectations for medical consultation, an understanding of differences in policies and procedures in different medical settings, and an ability to communicate effectively with individuals from various disciplines.

The concept of interprofessionalism, however, goes beyond that of these consultative skills. Interprofessionality involves “the process by which professionals reflect on and develop ways of practicing that provides an integrated and cohesive answer to the needs of the client/family/population...[I]t involves continuous interaction and knowledge sharing between professionals, organized to solve or explore a variety of education and care issues all while seeking to optimize the patient’s participation...Interprofessionality requires a paradigm shift, since interprofessional practice has unique characteristics in terms of values, codes of conduct, and ways of working” (p. 9) [5].

Several health care disciplines recently developed educational initiatives and core competencies for interprofessional collaborative practice, both within the USA and worldwide. The osteopathic medicine literature, the Association of Schools of Public Health, the Association of American Medical Colleges, the Accreditation Council on Graduate Medical Education, the Commission on Dental Accreditation, the American Association of Colleges of Pharmacy, and the Accreditation Council for Pharmacy Accreditation have all formally identified and recognized the need for strong interprofessional collaborative practice skills [6]. This has occurred through discipline-specific policy statements, accreditation standards, or formulation of core competencies. This focus on interprofessional education and collaborative practice by individual professions has not yet been seen to the same degree within the field of professional psychology.

In addition to individual disciplines moving forward with promoting competencies in interprofessional education and practice, we are also now seeing discussion and collaboration across disciplines around this issue. A recent expert panel report delineated a number of core competencies in interprofessional collaborative practice. This panel included representation from the national organizations of nursing, osteopathic medicine, pharmacy, dentistry, public health specialists, and physicians [6]. Psychology is notably absent.

This document, the *Core Competencies for Interprofessional Collaborative Practice: Report of an Expert Panel*, [6] outlines four broad interprofessional competency domains: values/ethics for interprofessional practice, roles/responsibilities, interprofessional communication, and teams/teamwork. Within each of these domains, the contributors delineated multiple specific role/responsibility competencies. To illustrate the nature of the competencies, one from each domain is excerpted below; the interested reader is referred to the source document for additional detail.

- “Manage ethical dilemmas specific to interprofessional patient/population-centered care situations.” (Values/ethics for interprofessional practice; p. 19).
- “Engage diverse health care professionals who complement one’s own professional expertise, as well as associated resources, to develop strategies to meet specific patient care needs.” (Roles/responsibilities competency; p. 21).
- “Organize and communicate information with patients, families, and health care team members in a form that is understandable, avoiding discipline-specific terminology when possible.” (Interprofessional communication competency; p. 23).
- “Engage self and others to constructively manage disagreements about values, roles, goals, and actions that arise among health care professionals and with patients and families.” (Teams and teamwork competency; p. 25) [6].

Health care professionals practicing in medical settings clearly need to engage in effective interactions across disciplines, function well on interdisciplinary teams, and appropriately manage ethical dilemmas, roles, and responsibilities within the context of interprofessional work. Such interprofessional collaborative practice competencies seem crucial not just for other health care disciplines but also for psychologists in medical settings as well.

## Core Competencies Case Examples

The remainder of the chapter details two case examples drawn from different medical settings to illustrate and elaborate on many of the core competencies for psychologists in medical settings described above. Our hope is that through these descriptive examples, psychologists entering practice in medical settings will have a more thorough understanding of the expected competencies that underlie effective clinical, consultative, and educational practice in diverse medical settings. The first case example involves a psychologist’s part-time work with a diabetes management program (DMP) in a large medical center; the second focuses on establishment of a full-time health psychology service within a large medical center.

### *Example 1: Diabetes Management Program*

The first case example details the involvement of a psychologist in a multidisciplinary DMP housed within the endocrinology service of a large medical center serving approximately 38,000 military medical beneficiaries (active duty, retired military and family members). In the last year, approximately 350 individuals with either type 2 diabetes or with prediabetes completed the 12-hour DMP intervention. During this period, the DMP had nearly 1,500 group encounters with referred patients. The program outcomes include an average reduction in glycated hemoglobin levels (HbA1c) in individuals with diabetes by nearly 1% (0.85%). This reduction



is notable, in that the literature considers a 0.5 point reduction in HbA1c clinically meaningful, and each 1-point drop corresponds to a 37% reduction in the risks of complication from diabetes [7, 8].

The DMP structure and curriculum are determined by a multidisciplinary team consisting of an endocrinologist, certified diabetes educators (CDEs; nurses at this facility), a registered dietician (RD), an exercise physiologist or physical therapist, and a clinical health psychologist (with approximately 0.20 Full Time Equivalen devoted to DMP). The program primarily provides diabetes management education and intervention in a group format, although individual appointments within any of the involved specialty areas are available as needed. The curriculum includes the following core components: overview of diabetes, healthy eating, carbohydrate counting, goal setting and behavior change (two-part series led by psychologist), dining out, managing special occasions, home glucose monitoring, physical exercise (two-part series), preventing complications, foot care, "sick day" care, overview of additional available resources, and relapse prevention/maintenance of progress (led by psychologist) provided over a span of 3 months.

The DMP had utilized behavioral health resources prior to the involvement of the current psychologist. The CDEs periodically referred patients with diabetes to an outpatient mental health clinic in the medical center if there were concerns about mental health problems (such as depression or anxiety) interfering with diabetes management. A psychologist also taught one class on behavioral goal setting as part of the DMP. This more peripheral program involvement has shifted over time to the present, in which the psychologist has an expanded role, becoming an integral member of the DMP team responsible for shaping the direction and curriculum of the program; increasing the course content related to behavioral health topics; providing education and consultation to other involved medical providers (e.g., motivational interviewing for dieticians, etc.); improving referral processes among the DMP, integrated behavioral health in primary care, and specialty health psychology services; and collaborating across disciplines on several grant-funded diabetes research projects.

A good part of the psychologist's successful integration into the DMP resulted from demonstrating to other DMP health professionals an understanding of biopsychosocial factors relevant to diabetes management. Credibility was enhanced through showing understanding not only of the psychosocial aspects of diabetes management but also a working knowledge of key biological aspects. For example, being familiar with biological assessment strategies (such as testing of HbA1c and blood glucose levels) and biological interventions (various types of medications for diabetes), as well as relevant psychosocial factors impacting diabetes management (e.g., relationship between depression and poorer glycemic control, impact of stress on blood glucose levels) and strategies for increasing adherence to behavioral recommendations for diabetes management (e.g., changes in diet, physical activity, alcohol use, etc.) enhanced the psychologist's credibility in the eyes of other health professionals. These behaviors are consistent with knowledge-based and applied health psychology assessment and intervention competencies (e.g., understanding biological assessment and treatment strategies, biopsychosocial factors related to

adherence to medical care, and empirically supported treatment interventions appropriate to the target medical population) [4].

Becoming a valued member of the DMP team not only developed through establishment of credibility and competence but also through interprofessional collaborative practice skills. Competencies in interprofessional communication and teamwork have been essential throughout the development and ongoing modifications of the DMP. Challenges to effective communication arose not only from logistical reasons (e.g., psychologist not housed in endocrinology clinic but in another area of the hospital) but also from differences across disciplines. To overcome the problems posed by less frequent opportunities for face-to-face communication, the psychologist and other DMP team members established regular meetings complemented by frequent electronic communication. Additionally, the psychologist increased the use of unscheduled, brief visits to the endocrinology and nutritional medicine clinics to discuss issues and questions face to face when possible. This proved particularly invaluable when resolving conflicts related to roles and responsibilities in the DMP. Additionally, the psychologist found that making a concerted effort to minimize the use of psychological jargon (for example, specific psychiatric diagnostic terminology and behavioral/learning theory language) improved interprofessional communication. This use of straightforward language, combined with clearly defining any discipline-specific terminology used (e.g., stages of readiness for change), helped demystify the work done by the psychologist and made key concepts more accessible to all DMP providers. These behaviors align closely with interprofessional competencies in communication and teamwork [6].

With a foundation of credibility, and behaviors facilitating effective communication and teamwork, the psychologist established herself as a key member of the DMP team, leading to increased opportunity to shape the structure and content of the program. Knowledge of the literature on learning, behavior change, and effective goal setting for diabetes (knowledge-based intervention competencies) [4] suggested several ways in which the DMP might be modified to improve outcomes. On a basic structural level, patients initially had been offered their choice of attending the program through several shorter (2–3 hour) classes spread over several months, or in a longer (full day, followed by half day several months later) format. Although many patients chose the “marathon” class format for its convenience, the psychologist and other DMP team members identified differential outcomes in the two formats, consistent with what the literature on learning would predict. As a result, the “marathon” class option was discontinued in favor of spaced learning over time. Additionally, the psychologist provided consultative recommendations regarding the approach to behavioral goal setting used in the program. Although the psychologist used an evidence-based goal-setting approach within the behavioral curriculum, this approach to goal setting occurred towards the middle of the DMP intervention, after patients had already been asked to make numerous dietary and physical activity changes by the CDEs and RDs. As a result of sharing evidence-based information about behavior change and goal setting to the other team members, the order of modules was revised (moving goal setting with the psychologist earlier), and the forms and language used throughout the DMP were modified to

emphasize focusing on one-to-two attainable, specific, measurable behavioral goals at a time. Additionally, providers from the other disciplines adapted their own approaches, such as incorporating a focus on use of rewards to help motivate behavior change. These actions reflect applied intervention and consultation competencies involving translating and communicating relevant scientific findings related to consultation questions, and conducting empirically supported treatment in the context of an interdisciplinary team [4].

The DMP psychologist's professional activities also included supervision and training activities, both within the profession of psychology (supervising predoctoral psychology interns on a health psychology rotation) and across professions (teaching and training members of other health care professions on the DMP team). As part of psychology interns' professional training in health psychology and in diabetes specifically, the psychologist provided sequential, developmental training experiences to increase their ability to effectively assess and intervene with patients having diabetes. Training began with a didactic presentation, assigned readings, and discussion on biopsychosocial management of diabetes, as well as the structure and content of the DMP. The interns then observed the psychologist leading the DMP psychoeducational groups, prior to having the opportunity to lead the groups themselves, under the direct observation of the psychologist. Once interns demonstrated competency in leading the group, they led it independently (under supervision). This "see one, do one" approach of graduated independence allowed interns to learn through observation, modeling, and immediate feedback from the psychologist directly observing their work, and was consistent with the supervision competency of "providing effective instruction and supervision in psychology...to psychology trainees...across levels of training" (p. 579) [4].

Beyond providing interns with the opportunity to master the content and process of the DMP psychoeducational groups, however, the psychologist strove to enhance interns' professional identity, by understanding the unique aspects that psychology contributes to management of a disease like diabetes, as well as recognizing the contributions of other involved professions (e.g., endocrinology, nursing, nutritional medicine) and the appropriate limits of psychological practice with this medical population. Towards this end, interns observed not only the DMP groups led by the psychologist but also several core DMP classes taught by other health professionals. This expanded their knowledge about diabetes and diabetes management beyond that obtained in the required readings and didactics, but perhaps more importantly, also highlighted the unique skill sets and roles of other professionals on the health care team. Additionally, interns accompanied the psychologist to DMP-planning meetings to observe and participate in a multidisciplinary team in which the psychologist could model assertion of professional autonomy, as well as respect for the autonomy of other professions. These training experiences reflect core competencies in applied supervision and training, particularly "demonstrat(ing) awareness of and appreciation for the unique knowledge base, skill sets, roles in the health care team, and limitations and boundaries of the professions that provide services to the population being treated," "train(ing) students to assert their professional autonomy

and identity,” and “encourag(ing) behavior that appropriately respects the professional autonomy of other professions” (p. 579) [4].

When working in medical settings, psychologists often discover opportunities to enhance the skills of professionals from other health care disciplines, as well. In the context of working with the DMP, one of the RDs discussed with the psychologist her struggle to effectively triage patients with diabetes and obesity to appropriate weight management resources. She voiced frustration regarding the initial no-show rates for many patients referred to the medical center’s more intensive programs (such as the DMP, or a 12-week behavioral weight management program offered to patients with prediabetes, diabetes, or obesity). This opened an opportunity for the psychologist to provide training to nutritional medicine staff on assessing stages of readiness for change, and to assist in modifying one of their existing assessment tools to include several items for assessing readiness for eating- and exercise-related behavior changes and screening items for other psychological symptoms. This tool provided the nutritional medicine staff assistance in triaging patients into the appropriate level of care, based on readiness and on other comorbid psychological factors (e.g., binge eating, depression). The psychologist also trained staff in basic motivational interviewing methods that could be used in individual and group settings, worked with them to develop referral algorithms based on readiness for change, and provided concrete information about how to access the myriad of available behavioral health options, including brief behavioral health consultation in primary care clinics specifically to enhance readiness to change health-related behaviors. These activities highlight the supervision-training competency of providing “effective instruction and supervision in psychology... across disciplines and across levels of training,” (p. 579), as well as the consultation competencies of being able to “communicate about and cultivate mutual understandings about problems among individuals from diverse disciplines” and “translate and communicate relevant scientific findings as they bear on the medical consultation-liaison questions” (p. 578) [4].

One area of potential conflict when psychologists work in medical settings involves navigating the sometimes hazy line between disciplines when working with a shared population and problem area. An unclear understanding of where one’s own competencies end, and where the competencies of a team member from another discipline begin, can lead to significant conflict between providers from different disciplines. One knowledge-based consultation competency, having an awareness of the limits of one’s professional knowledge and expertise within the context of a medical consultation, [4] assists psychologists in remaining in the appropriate “lane.” It is not uncommon for patients in the DMP to ask the psychologist questions requiring detailed knowledge of blood glucose control or dietary recommendations. Knowing the limits of one’s professional expertise, restricting practice to an appropriate professional role, and pulling in the appropriate health professional to answer questions illustrate this aspect of consultation competency.

Program evaluation competencies have also been pertinent in the psychologist’s involvement with DMP. Although physical outcome data (e.g., change in body mass index, BMI, decrease in A1c levels) had long been collected and reviewed

by program staff, little systematic effort had been made to measure or use behavior change outcomes. Such information can provide a useful window into understanding identified trends in the physical or medical outcomes. For example, if A1c levels or BMI levels do not decrease to the expected degree, knowledge from behavior change data (e.g., trends in physical activity or in implementing behavioral strategies such as consistently using a food diary or decreasing carbohydrate or calorie intake) may increase the understanding of the physical outcome results and suggest areas for program modification. Consultation from the psychologist led to changes in how the program collected and used self-report data regarding behavior change and achievement of personalized behavior change goals, consistent with the health psychology management-administration competency of developing “clinical health psychology services and to *evaluate their effectiveness* and their quality” (emphasis added, p. 579) [4]. Through systematic evaluation of outcome data, the psychologist and other DMP staff regularly identified areas for improvement and change. One recent example included recognition that prediabetic outcomes were lower than desired, leading to modification in the format of the DMP for prediabetics (establishing separate classes for prediabetic individuals, rather than including them in the classes for diabetics) as well as content (increasing the behavioral health component related to goal setting, behavior change, and relapse prevention by 50%). Evaluation of outcomes since these changes is underway.

Finally, involvement with the DMP has offered the psychologist an opportunity to make use of and further develop research-related competencies. The health psychology competency literature delineates several knowledge-based and applied research competencies, including knowledge of “strengths and potential pitfalls of role relationships that characterize interdisciplinary collaborative research” and “legal-ethical issues relating to interdisciplinary research,” (p. 578) [4] both of which have proven essential in collaborative DMP research. Over the course of the last year, the psychologist served as a member of an interdisciplinary research team focused on diabetes research. In this time period, the research team submitted three research grant proposals for intramural funding; two of the three were awarded funds. An additional protocol is currently under development. The psychologist’s role on the research team has included writing grants, assisting with research design and identification of appropriate measures, preparing materials for Institutional Review Board (IRB) submission, reviewing proposal drafts, and budgeting. Navigating role relationships has involved negotiating role responsibilities of various involved parties (e.g., endocrinologist, CDE, dietician, psychologist), each of whom brings valued skill sets, different amounts of available time to devote to research, and skill deficits in particular areas. One example involved a research protocol with a primary focus on evaluating the impact of a behavioral health intervention (motivational enhancement) on prediabetes outcomes. Although the psychologist performed the primary grant writing for this project, knowing and using the strengths of other team members proved essential. The endocrinologist provided needed input on outcome measures related to laboratory tests, and the CDE and dietician on personnel and budget needs. Commitment of team members is critical in research implementation, so positive working relationships and clear lines of communication are essential.

A second example involved a grant authored by the endocrinologist. The psychologist provided consultation regarding research design and measurement, particularly in assisting with selection of an appropriate instrument to assess psychological outcomes. Discussion around legal and ethical issues ensued, to ensure that psychological assessment instruments would be interpreted by a qualified individual, and that plans were in place to address any concerning mental health responses obtained during the course of the study.

This example of the DMP illustrates how a psychologist's success with even a single program or project in a medical setting depends on possessing multiple competencies. In this case, the development, implementation, and evaluation of this multidisciplinary treatment program required the psychologist to draw on competencies in assessment, intervention, interprofessional communication and teamwork, consultation, supervision and training, and program evaluation.

### ***Example 2: Establishing a Clinical Health Psychology Service***

The second example details the creation of a full-time behavioral clinic focusing on addressing biopsychosocial factors affecting medical conditions or health-compromising behaviors in a major medical center. The processes involved in initiating psychological services focused on improving health care in a large medical center may be relevant for both clinical psychologists and specialist clinical health psychologists expanding full-time practice in a variety of medical settings.

The medical center was the largest overseas Department of Defense (DoD) medical treatment facility with 180 beds and more than 2,000 personnel. The hospital's mission was to provide comprehensive health care services for US Soldiers, Sailors, Airmen, and Marines needing higher-level care throughout Europe, Southwest Asia, and Africa. In this case, the behavioral health leadership of the institution had recognized the value that a clinical health psychologist could provide to the clinical care of their patients and successfully advocated for the general clinical psychologist position to be changed to a clinical health psychologist. Of note, in the DoD, the Services have psychologists with specialization in clinical health psychology; however, in civilian settings generalists with appropriate training and experience may be used to provide such services. The new psychologist was the only provider for the DoD in this region with training and experience in health psychology and had to build the clinical services from the "ground up."

This initial recognition of the potential value of psychology services, specifically targeting medical patients, provided the initial credibility with leadership that the incoming psychologist wanted to build on rapidly upon arrival. Additionally, since this would be a consultation/referral-based service, he recognized it would also be critical to quickly establish credibility with potential referring providers, as well as their recognition of the benefits to their patients of psychological services for medical conditions or health-related behaviors. Thus, the psychologist worked to develop plans and resources prior to arrival through identifying high cost and

complex patients commonly seen at the medical center. Additionally, he decided that an important way to further develop credibility with leadership was to demonstrate efficiency and effectiveness of clinical services and to have a robust service developed very quickly. Therefore, resources were developed and collected prior to arrival, including interview forms, clinical documentation templates, patient educational handouts, clinical outcome measures, draft clinic brochures, and predetermined methods for calculating cost benefits. Additionally, once the high cost and complex conditions were identified, the psychologist ensured he had an in-depth knowledge of current medical practices as well as the research on psychological treatments and biopsychosocial factors affecting conditions for which he lacked previous training. Further, methods to deliver behavioral treatments for various medical conditions in the most efficient means were studied.

Training opportunities will vary across individuals, but it is important that psychologists pursuing opportunities to work in medical settings obtain sufficient training to adequately prepare themselves to provide the planned services. In his case, the foundation behind this preparation occurred partly through a clinical health psychology rotation during internship, followed by 2 years of practice as a general psychologist in which he also sought out opportunities to work with medical patients. He subsequently completed a 1-year postdoctoral fellowship in clinical health psychology from which he was moving to this new position. The fellowship employed a scientist-practitioner model that focused on utilizing empirically based decision making, critical thinking, and technical skills. Specifically, the program emphasized training in skills to maximize the efficacy of health care delivery through consideration and use of behavioral and psychological treatments and included training in conducting behavioral analysis for health-compromising behaviors and conducting individually tailored or group programs of cognitive-behavioral treatment. Furthermore, the fellowship equipped him with an extensive array of experience working in different settings and with a variety of medical conditions or health-related behaviors. More specifically, he obtained experience on (a) several interdisciplinary teams (Chronic Pain Management Program with physical medicine and physical therapy, Temporomandibular Disorders Treatment Program with dentistry; Chronic Obstructive Pulmonary Disease Rehabilitation Program with pulmonology); (b) consultation and associated assessments/interventions (sleep center, bone marrow transplant service, renal dialysis, neurology, internal medicine and numerous other outpatient and inpatient services); and (c) health promotion interventions (smoking cessation, weight management, etc.). As a fellow, he was also responsible for training and supervising predoctoral psychology interns during their clinical health psychology rotation. Finally, during internship and the fellowship, the psychologist had recognized the value of enhancing efficiency of care delivery and obtained training in group and home-based modalities. As a scientist practitioner, he had also collaborated on several research studies, including a meta-analysis of home-based treatments for headaches [9]. Thus, the above-referenced preparations consisted of fine tuning, enhancing and tailoring previously developed skills and resources, and applying them to the target conditions at the new hospital. This training and advanced preparation align with the foundational competencies of reflective practice

self-assessment, use of scientific knowledge and methods, relationships, and interdisciplinary systems, as well as the breadth of functional competencies in assessment, intervention, consultation, supervision training, and some components of research competencies [4, 6].

As soon as he was established in the facility, he began marketing services by going around to the specialty services and introducing himself and the new service briefly to the providers and giving them a stack of brochures to provide patients when referring. Particular emphasis was placed on the benefits of psychological services for conditions commonly seen in their services (e.g., migraine headaches to the neurologist; chronic pain conditions to the physical rehabilitation provider; diabetes to the internist and endocrinologist; headaches, insomnia and gastrointestinal (GI) disorders to the primary care providers, etc.). A more in-depth talk on the new services was arranged for the first professional staff meeting after arrival. This 10-minute talk emphasized the empirical support for behavioral treatment and the practical benefits of referral (e.g., assistance managing their complex and challenging cases and high utilizers of care). A short while after meeting providers, the psychologist contacted the senior clinician in each clinical service and offered to do an in-service for their staff on a topic thought to be beneficial from their perspective (i.e., fill a gap of knowledge for them) and the psychologist's (i.e., enhance a biopsychosocial understanding of a condition and promote awareness of the potential benefits of referral). These efforts to develop and market the program align with the management and administration competency of knowing appropriate methods to develop a practice [4].

Most of the initial referrals were the cases that had been frustrating the referring provider, either due to lack of progress in spite of provision of treatments that would typically be successful or due to challenging interpersonal issues between the provider and patient. A thorough biopsychosocial functional analysis focused around the referral question(s) was conducted using clinical interview, psychometric instruments specific to medically related behaviors (e.g., Multidimensional Pain Inventory [10] for chronic pain) and physical and psychological records/results reviewed to determine specific impacts of the condition, factors contributing to symptoms, treatment goals, and empirically based interventions tailored to the needs of the patient based on the functional analysis. Beyond typical ethical and legal considerations, given that many of the patients were active duty military members, the psychologist needed to consider whether there were requirements to disclose information to command regarding potential for psychological symptoms impacting fitness for duty or other military-related issues beyond any limitations already identified by the referring provider (Note: patients are informed of this reporting requirement as part of the initial informed consent process). While this particular ethical/legal issue is unique to such settings as military treatment facilities, providers working in medical settings need to become familiar with unique issues relevant to their settings. These research-based, biopsychosocial evaluation procedures illustrate the knowledge-based competencies of knowing relevant psychological, biological, and social/environmental assessment strategies unique to the individual, medical condition, and system, as well as applied assessment competencies such as inde-



pendently evaluating the problem using empirically supported assessment methods, conducting a comprehensive biopsychosocial interview and evaluation of objective biological and psychosocial findings related to a physical health problem and demonstrating awareness of ethical and legal ramifications [4].

In the first few months of this practice, in addition to the normal desire to provide the highest quality care, the psychologist viewed these cases as opportunities to demonstrate to referring providers the benefits of this new service. It was important for there to be some sort of noticeable benefit to the referring provider through improvement in the patient's condition, reduced frustration in providing care to the patient, etc. One key element to ensure such benefits were noticed was communication with the referring provider. Such communication is also central to ensuring quality of care through effective coordination of care. The referred patients were seen promptly, and the verbal feedback that focused on a brief conceptualization and recommendations was provided in 1 to 2 days. A more in-depth written consultation response was placed in the medical record and sent to the referring provider within a week to provide detailed documentation of the evaluation, conceptualization, and treatment recommendations. The patients were also provided feedback in layman's terms at the conclusion of the evaluation, and a copy of the final report was offered to them with an opportunity to review and ask the psychologist any questions. Subsequent updates were given to the referring provider on patient progress at reasonable intervals for cases that required prolonged services (e.g., more than 4 months) and upon termination of care, either on the successful outcome or on problems encountered, which contributed to the lack of success. While the psychologist was able to assist many patients in making marked symptom or functional improvements, even in cases in which minimal or no change occurred, referring providers found the feedback helpful in giving them a clearer understanding of the complexity of their difficult patients, enabling them to have increased empathy and improved awareness of other approaches that they might employ to better manage these patients. All communication with the medical provider intentionally employed minimal psychological jargon and tended to be focused on the relations between specific behaviors and medical outcomes. These behaviors were consistent with the interprofessional communication competencies [6]. In sum, after initial marketing efforts, the best marketing was providing effective treatment and feedback on their patients, prompting referrals of other patients, including less complex ones, resulting in even better outcomes for many of their patients.

Through the development of relationships with other health care providers and demonstration of the benefits of involving a psychologist in the health care of patients, discussions about developing multidisciplinary programs began to occur. The collection of outcome data in a database and calculations of cost savings enabled the psychologist to report tangible impacts to leadership and to include this data in in-service trainings and marketing materials to patients and providers. For example, the Physical Medicine and Rehabilitation (PMR) Clinic noted a large number of fibromyalgia (FMS) patients, which led to the creation of a standard psycho-educational class led conjointly by the psychologist and physiatrist, which was provided to all new FMS referrals to the PMR Clinic. The class reduced redundancy across

clinical services and improved efficiency by providing educational interventions to several patients at once rather than individually. Additionally, provision of a class enabled some sense of normalization and social support for this group of patients. Many FMS patients who attended the class reported this aspect of the group as very helpful, especially given many of them had found the medical system unsupportive due to the perceived negative reactions of their health care providers regarding the legitimacy or organic origins of their symptoms. The class employed empirically based chronic pain management strategies with all FMS patients as well as education from the physician about the hypothesized physiology of FMS and associated research support. This structure also reduced the stigma as well as any perceived implication that the provider believed the FMS was of psychological origin associated with being individually referred to a psychological service. Additionally, it allowed all FMS patients to have established working relations with the psychologist and to be educated on the normalcy of psychological factors affecting pain management and the benefits of working with a psychologist. In addition to calculating cost savings through increased efficiency, critiques of the program were obtained from participants, providing feedback on perceived benefits of the program and knowledge gained.

Similarly, the dietician was seeking to develop a more effective weight management program. Collaboration with the psychologist resulted in the recommendation to employ the LEARN program [11] based on the empirical evidence for its effectiveness. Additionally, the delivery of the program was modified based on factors in the literature that predict sustained weight loss in an effort to increase long-term benefits. For example, sustained exercise was a predictor of maintenance of weight loss; thus, physical therapy was brought into the collaboration to enhance exercise interventions beyond the LEARN materials. Low-intensity, enjoyable exercise and lifestyle exercise were the main focus due to evidence that such exercise methods themselves are more likely to be sustained after the intervention is completed. Also, based on research showing continued contact beyond the conclusion of the initial program was a predictor of success, patients were encouraged to continue attending the LEARN sessions at least once a month upon completion. Weight loss was tracked across the program to evaluate the program's effectiveness and to enable referral for further evaluation and intervention of participants not making progress.

Other programs that were created included the initiation of home-based treatment for headaches, decreasing patient visits and provider time by 66% with no change in treatment benefits; incorporation of the psychologist into a stuttering program conducted by the speech pathologist and a tinnitus management program conducted by the audiologist; and inclusion of a psychological assessment protocol in the Persian Gulf Illness Evaluation Program. The behaviors evident in implementing these multidisciplinary programs align with applied intervention competencies such as utilizing evidence-based practice and incorporating the latest research, implementing empirically supported treatments appropriate to the target population, and conducting empirically supported treatments in the context of an interdisciplinary team, as well as the management-administration competency of developing services and evaluating their effectiveness and quality [4].

Finally, due to a desire to contribute to training and the need to increase capacity to meet the increasing number of referrals, several training-related initiatives were established. First, a practicum placement agreement was developed with a local masters program in counseling psychology. Practicum students were trained in two focused clinical areas that were high-volume referrals and that were well suited to practicum-level skills once specific training was provided in the techniques. Specifically, a student worked 10 hour per week in the clinic for a 1-year rotation. The student was trained in cognitive-behavioral treatment for headaches and insomnia as well as the medical conditions themselves, medical and military culture, and communicating with medical providers. The psychologist conducted initial evaluations and if the case was determined to be suited to the practicum student's level of training, the case was assigned to the student. A face-to-face supervision for 1 hour per week and a review of 100% of clinical documentation were provided by the psychologist.

Second, the psychologist developed a therapist and patient manual for relaxation training. The mental health technician assigned to the clinic was then trained in the delivery of the relaxation intervention and supervised in its delivery. Initially, the technician was observed by the psychologist, but once the psychologist verified proficiency she was permitted to conduct the intervention without direct observation. Additionally, in order to promote autonomy in supervision, she was encouraged and given guidance on ways to modify the relaxation training materials and to adapt the training to fit her personality and style or the needs of individual patients. Patients who would benefit from relaxation training and who would not be receiving this training through involvement in another program were scheduled with the technician. This treatment was normally provided over four 1-hour individual sessions, and the supervision time across the four sessions usually totaled about 1 hour. Thus, for each patient trained in relaxation by the technician, 3 hours of provider time were saved, which could be used to serve other patients. Given the frequency with which this intervention is employed in medical settings, this initiative, along with the practicum program, significantly increased the capacity of this sole psychologist to meet the growing demand.

Finally, to enhance training of other psychologists in the region, the psychologist pursued APA continuing education sponsorship to enable local and regional training for psychologists to obtain APA-approved continuing education units (CEUs) in support of psychologist licensure requirements. Running this program provided opportunities to develop relationships with other psychologists in the region, enabling the psychologist to become both a referral and consultation resource to psychologists not trained in clinical health psychology. Additionally, it further solidified credibility with leadership by reducing the need to pay travel expenses for psychologists to return to the USA to obtain CEUs. Finally, in response to the offer to conduct in-services for medical providers and the development of relationships with them, the psychologist was frequently asked to conduct training on psychological issues related to medical conditions commonly seen in various medical services and to attend trainings on medically related topics. These trainings enabled the psychologist to both recognize and value contributions and perspectives of the medical

team while also enhancing their understanding of the interaction of psychological, physical, and environmental factors. The development of the practicum program, APA CEU sponsorship, and medical clinic in-services, along with training and supervising the technician, are consistent with supervision and training competencies such as providing effective instruction and supervision in psychology, both to psychology trainees and across disciplines and across levels of training and training students to assert their professional autonomy and identity [4].

## Conclusion

Psychologists seeking to expand practice into medical settings face challenges in adapting existing skills and developing new knowledge and skills to effectively evaluate and treat patients with a range of medical problems or problematic health behaviors. The competency literature for professional psychology, as well as for clinical health psychology, provides substantial guidance and may be used for self-evaluation, as well as for formal evaluation, by supervisors to determine a psychologist's readiness to move into a medical setting. This chapter provided additional elaboration on competencies essential for psychologists' success in medical settings, through delineation of additional competencies as well as through detailed case examples demonstrating the complex set of skills, crossing the domains of assessment, intervention, supervision, teaching, program evaluation, consultation, research, professionalism, and interprofessionalism, among others. It is hoped that these concrete descriptions will aid psychologists in understanding the competencies essential for success in medical settings, identifying areas of relative weakness, and evaluating their own readiness to practice in medical settings. This essential process of self-evaluation, relative to an objective standard, can assist psychologists in appropriately seeking out tailored training and supervision to improve the quality of their practice and their ultimate success in practicing within a medical setting.

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# Chapter 5

## Ethics and the Law

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### Introduction

Strong health care rests within a foundation of respect and humanity. When people seek health care, not only do they seek the wisdom and knowledge of providers but they also seek a professional connection that makes them feel comfortable. They make sometimes difficult decisions based on the information they are given as it applies to their individual situation and to their family, community, and cultural context. They do so privately, within a network of confidentiality. The work of health care providers is guided by ethical principles, broader philosophical principles, and relevant legislation. Recent legislation, and updates to that legislation, in the form of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), Public Law 104–191, also known as the Kennedy–Kassebaum Act, were drafted to protect privacy in the electronic era. It contains prongs designed to improve efficiency of health care delivery, to standardize electronic data interchange, to protect confidentiality and security of health data, and to protect the confidentiality and integrity of individually identifiable health care information. Ethical principles do not carry

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the weight of the law, but they are applied within professions and they traditionally have been used as touchstones to provide a lens through which professional conduct may be examined, measured, debated, modified, and improved. Philosophical principles reflect higher-order constructs, beliefs, approaches to individuals and work, and values within work. This chapter aims to integrate these three approaches to professional conduct as they apply to clinical health psychology in medical centers. In the ever-evolving ethical and legal contours of health care, the bases for shaping the interface between professionals and consumers lie in the law, ethics codes, and philosophical notions of what constitutes professionalism. Within each of these sources, it is possible to enrich dialogue on the impact of a professional's conduct on the individual patient, the community of consumers (the public), public perceptions of the profession of clinical health psychology, and the community of clinical health psychology providers.

## Ethical Principles and Resources

The basic benchmarks and norms about appropriateness of conduct within a profession are set forth in ethical principles [25]. Some of these basic notions date back to the first written ethics code, the Code of Hammurabi (*Codex Hammurabi*), created ca. 1790 BCE in ancient Babylon [33], and containing 282 laws, each no more than a sentence or two [21]. Psychologists are guided by the *Ethical Principles of Psychology and Code of Conduct* [3]. Because of the diversity of practice within the field of psychology, divisions or joint task forces sometimes develop specialty guidelines that are meant to further guide practice. See, for example, the *Record Keeping Guidelines* [7], the *APA Statement on Services by Telephone, Teleconferencing, and Internet* [1], the *Guidelines on Multicultural Proficiency for Psychologists* [4], the *Guidelines for Psychological Practice with Older Adults* [6], and the *Criteria for Evaluating Treatment Guidelines* [2]. Whereas ethical principles are mandatory, guidelines for practice are aspirational and they are designed to facilitate competent and appropriate practice within a defined area. Embedded in ethical principles and guidelines is an expectation that providers have a substantial understanding of the issues of relevance to their work [5].

Psychologists prepare for practice through formal and informal education and training, attending specialized continuing education workshops, seeking consultation, reading relevant scientific literature, and referring to ethical principles and guidelines for practice. Training in the comprehension and implementation of ethical principles begins in graduate school and continues as a career-long pursuit. Ethical principles and practice guidelines are intended to facilitate the development of the psychologist and the profession to assure a consistently high quality of research and practice. These sources are not meant to be exhaustive. Although meant to be comprehensive, no set of principles or guidelines could possibly anticipate the expanse of ethical dilemmas or research and practice settings that might be faced by individuals. In some cases, federal and state statutes may supersede standards

and guidelines [6]. Psychologists are trained to be aware that potential conflicts sometimes arise between the law, the ethics of the profession, and guidelines for practice. Although legal, ethical, and guideline resources provide useful strategies and approaches to ethical practice, there are a host of complex concerns faced by providers and sometimes unique to particular settings [13]. The *Ethical Principles of Psychology and Code of Conduct* [3] was written broadly for applicability to the varied roles of psychologists. Most members of ethical bodies in medical centers try to minimize the potential for ethical complexity by anticipating possible permutations of ethical questions, establishing internal standards and procedures, providing mechanisms for consultation, and carefully considering the impact of practice on the populations served by the medical center [13, 16].

The practitioner in a medical setting should be familiar with internal standards, ethical principles relevant to their profession, and relevant federal and state legislation written to guide practice. The most recent examples of each of these domains include the HIPAA, Public Law 104–191; the American Psychological Association’s *Ethical Principles of Psychology and Code of Conduct* [3]; relevant specialty guidelines for practice; and internal standards and regulations for the medical center. Fundamental ethical issues include determining who the patient or consumer of services is, the role of the psychologist, informed consent, confidentiality and privilege, standards of record keeping in medical centers, professional responsibility, professional competence and specialization, and practicing in a manner that appropriately satisfies legal standards. Legal and ethical issues in medical centers may sometimes differ from those in other clinical settings. Unique legal and/or ethical concerns may arise when research and practice are combined, because electronic or paper records are accessible to multiple providers, when medical records departments develop internal standards for the routine distribution of clinical notes to referring physicians, and because multiple professions contribute information with varying degrees of sensitivity to medical charts.

## ***Ethical Principles***

Ethical principles are mandatory and binding and they carry an enforcement mechanism through regulatory ethics bodies of state, provincial, and territorial associations and through national associations such as the American Psychological Association. Although traditionally judicial in their structure, there is a growing trend among state psychological associations to shift the judicial functions of ethics committees to educative and consultative structures. The most recent version of the *Ethical Principles of Psychologists and Code of Conduct* was published in 2002 (there were nine previous versions). They provide enforceable standards for the conduct of psychologists. They are used by the American Psychological Association, state and provincial psychology boards, courts, and other public bodies to enforce the standards of professional conduct relevant to the practice of psychology. Compliance with or violations of ethical principles is not isomorphic with legal liability, but rules based on the ethical principles may be admissible as evidence in



civil and criminal proceedings for some legal matters [13, 30]. The ethical issues that are unique to medical centers cover a spectrum of concerns that are contained in the *Ethical Principles*, but in some cases issues may be more comprehensive than or different from those addressed by the ethical principles of the profession. Psychologists are obligated to seek training and guidance in anticipation of ethical concerns that are unique to their settings and specialties [30]. The introduction of the ethics code states that psychologists must meet the standard of conduct established by the *Ethical Principles of Psychologists and Code of Conduct* [3] if that standard is higher than required by law. If there is conflict between the ethical principles and the requirements of the law, then the psychologist is required to take steps to resolve the conflict in a responsible manner. If an ethical concern arises that is addressed neither by the law nor the ethical principles, the psychologist is obliged to consider other professional materials (such as practice guidelines or relevant scientific articles), to seek consultation, and to consider his or her own conscience [3].

### ***Professional and Specialty Guidelines***

The term *guidelines* refers to pronouncements, statements, or declarations recommending specific professional endeavors or conduct for psychologists [5]. They are intended to be neither mandatory nor exhaustive, and they are sometimes applicable only to specific areas of practice. They are intended to supplement but not supersede sound reasoning and judgment of psychologists [6]. Guidelines usually are developed by national task forces (e.g., the Committee on Professional Practice and Standards, American Psychological Association). They tend to evolve over time and they are based on existing empirically validated practice and scientific literature relevant to a specific domain of practice [13]. They address knowledge and research relevant to the domain of practice, clinical issues relevant to the domain of practice, assessment, intervention, consultation, other service provision, and education and training. Because of the relative complexity of some areas of practice, guidelines are designed to elucidate those complexities and to offer procedures and methods that promote competent and effective practice. They are intended to assist psychologists and to facilitate practice rather than to restrict or exclude psychologists from specialized practice. They recognize that some psychologists will seek specialization by entering into more extensive training or earning formally recognized proficiency or certification [5–6].

### ***Biomedical Ethics and Principles***

Although ethical principles are distinct from moral or philosophical principles, their implementation exists in the context of both explicit and implicit higher-order principles that are drawn from constructs or beliefs about how individuals are expected to relate to one another. Interwoven within any implementation of ethical principles

or codes, practice guidelines, and legislative requirements to protect patients' rights are philosophical or moral principles and rationales [10]. Legislative requirements or ethical principles may specify particular courses of action, but the rationale behind the legislation or ethical principles, as well as the form the implementation takes, reflects higher-order principles. To offer an illustration, people in health care roles frequently face difficult undertakings. Examples include how to tell patients they have serious health problems, how to include relevant individuals in treatment decision-making processes while honoring patient autonomy, how far to extend helpfulness or beneficence in the administration of treatment, multiple views of the helpfulness of medicine and psychology, and how to do no harm in the course of treatment decisions and treatment provision [22]. One can act in a legally correct or ethically appropriate manner as a provider, but still assume a great deal of latitude in choosing the tone and an approach to recommending a particular course of treatment or a menu of treatment options.

Examples of principles that support the actions of treating professional and their interactions with patients include the concepts of patient autonomy, paternalism, nonmaleficence, beneficence, respect, veracity, fidelity, and justice. Examples of rules or doctrines that emanate from those principles include informed consent, the right to refuse treatment, proxy decision makers, analyses of what constitute optional and relatively obligatory (e.g., some immunization) forms of treatment, and risk/benefit analyses [10]. Philosophical principles have been used to describe the bases of differing approaches to care and treatment. Differing approaches lie at the root of dilemmas that arise when patients are faced with complex decisions about health care [31]. Although decisions take place in the context of a scientific context involving evidence-based treatments, to learn that a treatment is based on evidence is only one dimension of the complexities faced by patients. Dilemmas arise when one can appeal to moral or philosophical considerations for taking different courses of action. Judgments about what ought to be done in particular situations are justified by explicit or implicit rules governing behavior. Those rules are justified, whether manifestly or not, by underlying philosophical or moral principles that ultimately weave their way into ethical theories and standards [10]. A judgment expresses a decision or conclusion made by a patient about a particular action proposed or taken by a doctor or treatment team. Rules underlying judgments state that actions of a certain kind are indicated (or contraindicated) because they reflect the right course of action. Principles are more general and fundamental than rules, and they serve as the foundation or justification of the rules. For example, the philosophical or moral principle of respect supports the rule, "It is wrong to lie to patients" [10]. Theories are bodies of principles and rules that are systematically related. The most commonly recognized philosophical theories relevant to health care ethics and decision making are deontological (relatively paternalistic and rule based) and utilitarian (relatively individualistic and situational). Broad scientific, metaphysical, or religious beliefs often underlie the interpretations of situations in which patients and treatment providers must act [31]. Disputes over actions and policies often involve quite complex disagreements about factual beliefs, moral or philosophical rules, and moral or philosophical principles [10].

Ethical scholars make a distinction between the relevance and the adequacy of the reasons justifying the actions of patients and doctors. General normative ethics is a field of inquiry that attempts to answer the question of which actions are worthy of acceptance and for what reasons [10]. Professional ethical principles or codes grow from these questions and answers. They represent articulated statements of professional roles, obligations, and actions. Professional principles and codes operate best when they are internally consistent and coherent [22]. Comprehensive principles without major gaps are preferred, but either overly broad or overly detailed principles can be problematic [10, 26]. Patients and psychologists or physicians participate in daily decision making and judgments, and in reasoning through or identifying rationales for their recommendations or choices. Ethical theories and standards build on, systematize, and critique these daily ordinary communications [10, 22].

## **Positive Approaches to Ethics and Standards of Practice**

Clinical health psychologists have a long history of building upon the strengths of patients. Treatment providers must consider the illness in the fullness of its complexity while not losing sight of the aim of catalyzing change [31]. The aim of positive approaches to ethics and standards of practice is to focus not only on repairing the worst things in life and disease but also on building the best qualities in the context of treatment. Patient well-being and satisfaction emanate from effective treatment, but there are multiple dimensions to any treatment that include not only the technical administration of treatment but also standards that emanate from constructs of optimism, hope, and faith. At the individual level, positive approaches to putting ethics and standards into practice can be drawn from individual capacities for empathy, courage, interpersonal skills, aesthetic sensibilities, perseverance, originality, future mindedness, talent, and wisdom [35]. At a group or institutional level, these capacities translate into professional concepts of citizenship, responsibility, nurturance, altruism, civility, moderation, tolerance, and work ethic [18, 36]. Psychologists, like other health care providers, must work to stay focused on the positive goals of the profession. There has been a heavy emphasis on empirically validated treatments for mental illness and various forms of individual suffering. More positive approaches utilize these approaches but they also emphasize individual strength and resilience. Treatment does not focus solely on ameliorating the illness but upon human behavior in all its complexity and upon enhancing the strengths of the individual [35].

Clinical health psychologists have been on the forefront of a shift in the emphasis of treatment of illness to a broader model of treatment, consultation, and prevention. Strategies and techniques for enhancing the quality of patient's lives are not just treatment focused, but educational, relational, social, and political [28]. Although regulations and manuals designed to illustrate the implementation of standards, codes, and guidelines focus on task-oriented and illness-focused strategies, it takes individual, group, and agency creativity to address the broader spectrum of

patient needs [16, 20]. A collaborative approach best serves these goals. There is an ongoing tension, however, between the legal and ethical duties of treatment providers to protect patients from the consequences of their decision, and the legal and ethical duties to include patients as partners and collaborators in decision making and treatment participation [17, 39].

### ***Primary Goals of Providers***

Training in ethics is a significant component of clinical health psychology curriculum [37]. There are issues that are fundamental to the proper execution of ethical and legal standards in clinical health psychology. They include but are not limited to competence, collaboration, intervention, consent, benefits, diversity, self-monitoring, and standards of practice [37]. Experiences of health and illness are subjective, but the assumptions embedded in large systems of care sometimes place unintentional pressure on patients and treatment providers to potentially perpetuate an objectification and depersonalization experienced by many consumers of health care [14]. One of the goals of ethical and legal standards of care is to promote the human element of health care. These goals stand juxtaposed to organizational goals of productivity and efficiency. Recognizing the potential conflicts among these goals is one of the necessary steps of facing the complexities of practice in medical centers. In the daily work life of the psychologist, it is useful to begin with a reminder of the fundamentals of ethical practice.

In the context of clinical health psychology in medical settings, ethicists recommend that the psychologist should stay within his or her area of competence as determined by the psychologist's education, training, and experience. Psychologists should seek appropriate collaboration with other psychologists and with other medical professionals. Psychologists should be aware of both the direct and indirect consequences of experimental or research procedures and interventions used in clinical research trials. Explicit and detailed informed consent is necessary in both clinical and applied research contexts. Risks and benefits should be included in informed consent documents and explanations. Possible value conflicts should be explored when a diversity of perspectives exists. Understanding those conflicts begins with self-examination of the psychologist's own health-seeking and utilization behaviors [37]. Health psychology constitutes a large domain of research and practice that center upon predicting health- and illness-related behavior and managing and changing those behaviors through the application of scientific theories and the implementation of empirically validated treatment and consultation [14]. Treatment models of risk behavior, disease, pain, and attitudes toward death sometimes fall short of fully encapsulating the subjective dimensions of these phenomena. Dealing with significant and traumatizing serious and painful illnesses, people sometimes find themselves examining their own behavior from a novel but nonetheless stressful perspective. Patients may be busy exploring the implications of life, illness, and death for their lives, while treatment providers may be focused on the technical steps necessary to begin treatment or palliative care [14, 27].

## ***Responsibilities and Obligations of Providers***

Providers are required to treat patients regardless of the reasons for their illnesses and without reference to who they are as individuals [17]. While remaining focused on respect for patients, beneficence, and patient autonomy, providers in medical centers offer state-of-the-art treatment for advanced and serious illness. They face a delicate balance between the technical and human aspects of care [27]. Responsibilities and obligations of providers typically center upon informed consent, effective communication of all components of the relevant information, assessment of the patient's competence for treatment decision making, patient autonomy in deciding for themselves the course of their treatment or whether to be treated at all, persuading patients of a reasonable course of action without coercing them, and abiding by the decision that the patient makes while preserving their confidentiality [17]. Modern medicine presents countless new technologies and treatment choices to patients, increasing the complexity and difficulty of health care decisions. The clinical health psychologist's role may be central or supportive in these decision-making processes. The first step faced by the treatment team in optimizing decision making is to define whether the goals of care are: curative therapies, supportive or maintenance therapies, a focus on prolonging life, or palliative care without concern for disease-modifying interventions. Although these goals may be relatively clear in late-stage disease, withholding or withdrawing treatment in the early phase of an incurable disease is a more complicated decision-making process. Providers and patients consider the prognosis and related uncertainty, possible treatment options, personal values and goals, the patient's subjective values and hopes, and the dynamic nature of decisions that may change rapidly and may sometimes be contradictory [27]. Systems of cure and systems of care in modern medicine are not dichotomous and may overlap considerably. In reality, numerous goals are possible, and it is sometimes possible to pursue more than one. The psychologist's role may span discussions of avoidance of premature death, maintenance or improvements in function, relief of suffering, maintenance of quality of life, control, and preparation for death [27, 34]. Treatment teams often turn to the proportionality principle, which states that a treatment is ethically mandatory to the degree that the benefits are likely to outweigh the burdens upon or risks to the patient. Identifying the appropriate treatment goals and avoiding futile treatments are overriding goals in medicine and in psychology [27].

The doctrine of informed consent is rooted in the legal right to self-determination and the ethical and philosophical principle of autonomy. Decisions about treatment are made in a collaborative manner between the patient and the treatment provider, and informed consent is obtained before the treatment may be administered. The patient is provided with relevant information in the form of a disclosure, so that he or she may make a well-considered decision and express consent (or decide not to consent). The information that is provided to the patient must be understood and it must be sufficient in breadth and depth for the patient to make the best decision

possible under the current circumstances and in light of the current and most up-to-date knowledge and technology available in the relevant field of inquiry [26–27]. Disclosure includes information about the nature and purpose of the proposed treatment or procedures, its risks and benefits, and any available alternatives [27]. To be valid, consent to treatment must be granted by a competent patient or his or her designated decision-making proxy. Determination of competence to grant informed consent begins with a clinical inquiry, but it sometimes culminates in a legal venue in which a judge is asked to determine the competence of the patient to make informed decisions or to grant that decision-making authority to another individual who then exercises it in the form of substituted judgment [19, 27]. Advance directives are oral or written instructions specifying the wishes of a person for future treatment, in case future incapacity precludes the patient's decision-making capacity at the time that the decision is relevant. Withholding takes place when a treatment is not provided, and withdrawing treatment is defined as ending treatment that has no demonstrated effectiveness. These procedures are relevant when it is no longer reasonable or beneficial to provide aggressive treatments or interventions. These terms are often used in situations in which a serious and terminal illness is reaching the phase of culmination. Examples include ventilator support, hemodialysis, extension of chemotherapy, artificial hydration, nutrition, and other therapies that may prolong life beyond expectations or delay death [27]. The relevance to clinical health psychology is seen in the support and accompaniment that patients might desire as they face difficult and complex decisions. At another level, however, the clinical health psychologist might work with the patient to help him or her sort through the relative level of presence or withdrawal of support and accompaniment desired from family members and friends, or the development, transitions, and malleability of the patient's day-to-day preferences in their desired level of support. Support, even when well intended, may be a source of comfort or stress depending upon the patient's state of mind and the capacity of the person providing support to do so in a manner that is helpful and relevant to the patient's concerns. People with serious illness face psychological, social, and spiritual issues with a heightened awareness and their reactions can be quite complicated intrapsychically and interpersonally [29]. The psychologist serves and supports the roles of determining the need for and providing interventions relevant to the patient's mental state, subjective experience of illness, vulnerability, pain, acceptance and denial, disavowal, and use or rejection of other support resources such as family members, friends, and support groups [34, 37].

The ethical and philosophical or moral framework of clinical health psychology serves as a backdrop to the work, and it also highlights the complexity of the work. Recent legislative initiatives have included fairly straightforward goals of streamlining some of the more tedious or mundane aspects of the work. Juxtaposed with these rather straightforward goals was the more human element of granting patients easier access to their own medical records and giving them well-defined information about what constitutes personally identifiable health care information and how they may exert control over the release of their medical records. We turn now to a description of recent legislation relevant to clinical health psychology practice in medical centers.

## **Legal and Record-Keeping Requirements in Medical Settings**

The foregoing analysis provided an illustration of the distinct but interlinked nature of moral and philosophical principles and ethical principles. Ethical principles also are distinct from legal requirements, codified in state and federal legislation, but ethical principles or standards sometimes overlap with legislative initiatives in their intent (and vice versa). Each of the three domains of moral/philosophical principles, ethical principles, and legal requirements provides the bases for institutional internal policies and regulations that are designed to fine-tune those requirements to fit the institution's health care goals and objectives [34]. Each community of providers takes on a distinct community identity or set of identities. Although ethical and legal requirements are standardized in written or codified form, their proper implementation may take many forms, depending upon the range of services that are provided by an institution. Even within institutions, there may be different requirements for different providers due to varying risk–benefit considerations in medical decision making and treatment provision [19].

For some ethical principles and legal regulations, it is possible to distill the complications of both sets of requirements into fairly straightforward internal regulations. Credentialing requirements is one example. Before the psychologist is appointed to a staff position, there is an administrative review of the psychologist's educational and clinical preparation for practice, and his or her credentials. The review of the psychologist's credentials is intended to document their preparedness for the range of patients they will treat, the extent of their clinical privileges, and the scope of their practice within the medical center. Privileges may be limited or extensive, depending upon the psychologist's intended role, educational background, clinical training, and areas of expertise. Medical center bylaws, policies, and procedures define what is meant by hospital privileges, the scope of practice definitions, the description of the structure of professional staff organizations and committees, medical record-keeping requirements, quality improvement expectations, human resource rules, admission and discharge practices, emergency and disaster preparedness plans, and voting rights of attending staff members [34]. Local applications of relevant legislation are reflected in medical center policies and procedures. How an agency implements legislative requirements depends on the size and complexity of the practice or institution.

Other internal standards drawn from legislative requirements are less straightforward because of their broad reach. The most recent and most notable example is the HIPAA, Public Law 104–191. In this section, we will describe how HIPAA serves as an example of the sometimes interwoven nature of ethical and legal requirements, especially those related to confidentiality and privacy of communications. HIPAA compliance is essential to psychological practice because the health care industry is fast moving toward electronic transactions. HIPAA helps protect patients, it reflects sound business practice, compliance is a matter of law, and following HIPAA specifications can help providers avoid potential risks. The Privacy and Security Rules have quickly come to reflect the prevailing standard of care [9].

## HIPAA and Other Relevant Federal Legislation

The HIPAA, Public Law 104–191, was passed on August 2, 1996, and it was signed into federal law on August 21, 1996. The act amends the Internal Revenue Code of 1986. It contains four sections: Title I: Health care access, portability, and renewability; Title II: Preventing health care fraud and abuse, administrative simplification, medical liability reform; Title III: Tax-related health provisions; and Title IV: Application and enforcement of group health plan requirements. The general goals of HIPAA are to improve health care portability and continuity of health insurance coverage (i.e., to protect Americans who were previously ill from losing their health insurance after changing jobs or residences), to streamline health insurance claims through the adoption of consistent standards for transmitting uniform electronic health care claims, and to reduce waste and fraud in the health insurance and health care industries [8, 16]. The Centers for Medicare and Medicaid Services in the Department of Health and Human Services is responsible for the implementation and the provision of HIPAA, and the Office of Civil Rights has responsibility for enforcement. Title II, Section F, of HIPAA, Administrative Simplification, is the pivotal section that generated the high level of scrutiny and activity surrounding the act. Because of the provisions of the Administrative Simplification, the health care industry virtually revamped many of its administrative and financial systems, and enhanced the security of business offices and computer systems in order to ensure the confidentiality and privacy of protected health care information [11, 16]. The Administrative Simplification provisions were designed to eliminate administrative costs, to standardize the format of electronic data interchange of certain types of health care administrative and financial transactions, to safeguard the security and confidentiality of health care information, to set standard codes for diagnoses and procedures, to set unique health identifiers for employers and providers, to set unique health identifiers for individuals and health plans, to codify civil penalties for compliance failures, and to codify criminal penalties for wrongful disclosure of individually identifiable health information [16]. The privacy rule of HIPAA addresses the application of policies, procedures, and business service agreements designed to control access to and use of patient information. The security rule addresses the institution's physical infrastructure. Examples include access to offices, files, and computers containing secure and private communications. It addresses mechanisms for assuring the maintenance of confidentiality of patient information [8].

Protecting confidential patient information is a familiar standard for psychologists. Liability for releasing certain kinds of information without proper authorization or consent already exists under state and federal laws, and it is supported by relevant ethical principles. Before HIPAA, psychologists already were required to seek patient authorization or consent to the release of confidential information for all purposes, including treatment and billing goals. HIPAA reinforced or added to existing legislative and ethical principles by requiring the use of specific documents designated as consents and authorizations, and by explicitly listing the necessary elements that must be contained in consent and authorization forms [32]. HIPAA consent refers to permission to release protected information for the purpose of



treatment, payment, and other health care activities such as utilization review, peer review, continuity of care, and quality assurance. Patients must provide consent in writing and they may revoke consent in writing. Authorization is required for all other disclosures that are made for purposes other than treatment, payment, or other health care activities. An example of an authorization is when a patient requests that records be released to a third party such as an attorney or a school [32]. Examples of explicit information include a specific definition of the information to be used or disclosed, to whom the information will be disclosed, the purpose of the disclosure, an expiration date, the right to revoke the authorization, and the right not to authorize the disclosure [8]. Authorizations must be in writing and in specific terms, and they may be revoked in writing [32]. Neither consent nor authorization is required for protected health information when it is required by law, by a health oversight agency, by a coroner or medical examiner identification/cause of death purposes or other duties authorized by law or state pre-emption, by the military or Veterans Affairs for national security purposes, to avert a serious threat to the health or safety of a person or the public, to satisfy Workers' Compensation laws, to protect victims of abuse and neglect as provided by statute, and to protect victims of domestic violence as provided by statute [8].

HIPAA Privacy and Security Rules are triggered when a psychologist or an entity acting on behalf of the psychologist transmits electronic information (Internet, extranet, private networks, computer-generated faxes) in connection with health care claims, health care eligibility and payment, coordination of benefits, inquiries regarding subscriber enrollment information in a health plan, health care claim status, subscriber coverage eligibility to receive services, health plan premium payments, referral certifications and authorizations, reports of injury for workers' compensation claims, and any extraction of relevant information from the medical records to demonstrate the rationale for service provision and subsequent claims [9, 11]. The privacy rule applies to health care providers, health plans, and health care clearing houses. The type of information protected by the act includes health information, whether oral or in recorded form, created or used by health care professionals or health care entities; individually identifiable health information; information that relates to the past, present, or future physical and/or mental health condition of an individual; the provision of health care to an individual; and the past, present, or future payment for the provision of health care to an individual or that identifies the individual or that could be reasonably used to identify the individual [8]. Prior to treatment or other interventions, psychologists must obtain patient consent prior to using protected health information for treatment, payment, or other health care operations. The generalized consent form used for HIPAA purposes differs from and is not a substitute for informed consent forms that are obtained prior to the initiation of treatment. When protected health information is disclosed, the privacy rule requires that the psychologist disclose only the minimum amount of information necessary to conduct the billing or insurance activity of relevance [8].

## State Privilege Statutes

State statutes and regulations offering less privacy protection are superceded by the HIPAA privacy rules, except for some notable exceptions. In state statutes across the 50 states, one finds requirements for the reporting of child abuse and injury, certain diseases for public health surveillance, and births and deaths. State law provides for health plans to report information relevant to business management and financial audits, licensure of facilities, and evaluation or monitoring of facilities. The government sanctioned requests for information to prevent fraud or abuse related to health care, to satisfy reporting requirements for health care delivery statistics or costs, to serve a compelling emergent public health or safety need as provided by state statutes or regulations, and to ensure appropriate state regulation of the health insurance industry. State privacy or privilege statutes in some states may be more stringent than HIPAA, in which instance the state law would supercede HIPAA [8]. For example, in states with privilege statutes, if called to testify or provide documents for a legal review, one must first assert privilege on behalf of the patient and then await a judicial determination as to whether privilege pertains or is waived [13]. It would be up to the individual providers to determine if their state privilege statute is more or less stringent than HIPAA requirements. Relevant information is often found on the state board of psychology Web sites and in their dissemination of relevant data. Under HIPAA, personal health information may be disclosed for research for a limited set of circumstances, such as de-identified information, in the setting of an approved waiver from an institutional review board, or for deceased individuals [8].

## How HIPAA and State Statutes Differ from Ethical Principles

HIPAA applies only to practices using electronic transactions relevant to health plan and payment functions. A psychologist in solo or group practice who accepts no insurance would find most portions of HIPAA inapplicable. Another psychologist in a solo or group practice who bills by mail and conducts authorizations by telephone may not find it relevant now, but would need to be prepared for the possibility of future electronic transmission requirements by HIPAA. A third psychologist in a solo or group practice who routinely uses electronic transition for payment and billing activities would be considered a “covered entity” by HIPAA regulations. Yet another psychologist who uses e-mail for office functions unrelated to payment and billing activities would find HIPAA applicable in limited circumstances. HIPAA is triggered primarily by electronic transition of payment and billing activities. There are many nuances to the regulations, however, and it is best to consult a variety of resources and colleagues before concluding that it is inapplicable. HIPAA reflects a

balancing between confidentiality of patient records and the practicalities of billing and insurance concerns. It actually facilitates rather than protects disclosure as it applies to billing and insurance purposes [11]. The disclosure elements of HIPAA do have their limitations. HIPAA did not alter the applicability of privilege where state statutes provide for it, or the applicability of ethical principles. The traditional duties of informed consent and psychologist–patient confidentiality require psychologists and physicians to keep information private unless a patient signs a release of information form. There are certain well-known exceptions related to emergencies, mandated reporting requirements, and public safety concerns. In other words, HIPAA does not create a minimum standard for psychologists and physicians. It is a supplement to already existing ethical and legal standards [9, 11].

## **Medical Center Internal Policies and Regulations**

In response to HIPAA regulations, institutions have developed internal standards that specify procedures for establishing and terminating a user’s access to electronic patient health information, preserving patient confidentiality in the setting of periods of computer session inactivity, employee violations and related sanctions for unauthorized viewing of medical records irrelevant to their practice or for allowing other individuals unauthorized access to their computers or passwords, preventing security violations, containing and correcting security violations, regularly reviewing records of information system activity, network firewalls and routers, security access controls, remote access infrastructures and authentication, encryption software, Internet and wireless security, repair and maintenance of hardware, and anti-virus software. Institutions need specific policies for introducing new hires to and deleting terminated employees from electronic medical record access, security of data provided to outsourced individuals and contractors with access to protected health information, institution-wide security program plans, and a variety of other computer hardware and software management issues. The impact on the individual clinical health psychologist or other providers is, at a minimum, a set of specific internal standards for accessing medical records, viewing records, refraining from viewing records irrelevant to practice, and closing records upon departure.

## **Clinic Notes**

Clinic notes are distinct from psychotherapy notes. Clinic notes record assessment data, observations, and consultations to physicians, but do not contain sensitive psychotherapy data. They appear in the general medical record, according to the HIPAA record-keeping standards. This standard was already in place in many institutions. The narrow exception criteria relevant to psychotherapy notes are described below. At the outset of patient consultation, it is best to discuss the rules of privacy

and confidentiality, as they apply to the particular practices of clinical health psychologists or other psychological specialties in medical centers. The discussion might include how e-mails, calls to the receptionist, note-taking, clinical notes, and psychotherapy notes are handled in the practice. Patient consent is needed to discuss treatment or to release clinical notes to primary- or specialty-care clinicians outside the institution. Clinic notes subject to disclosure should be limited to relevant treatment or consultation data. All required and relevant information must be documented in the medical record. Minors must be informed of the psychologist's obligations to the minor's parents or guardians. Know in advance to whom to direct confidentiality questions, disclosure questions, and HIPAA questions. According to HIPAA regulations, every institution must appoint a designated HIPAA officer. Local and national organizations also provide HIPAA guidance for members [11].

## Psychotherapy Notes

HIPAA recognizes that some information in the course of psychological or psychiatric treatment should always remain private and makes a specific exception to patient direct access to psychotherapy notes. The notes cannot be released for treatment, payment, or health care operations without specific patient consent. Psychotherapy notes, however, are narrowly defined as having three key features. They (a) document or analyze the content of conversations (b) during private, group, or family sessions, and (c) are separated from the rest of the individual's medical record [11]. Even if they are kept in a separate psychotherapy record, notes that include information properly regarded as part of the medical records (medications prescribed, test results, treatment plans, diagnoses, prognoses, and clinical progress) are still considered part of the medical record and therefore not protected by the psychotherapy exception. Psychotherapy notes, though part of the exception, may not be protected from other formal requests such as subpoenas or court orders in the context of litigation [8, 11]. There is no prohibition on the release of psychotherapy notes to patients, but it is wise for clinicians to develop policies regarding their release to patients so that the conditions of release are given reasonable foresight. HIPAA has had an unintentional, though possibly enhancing, effect on the principle of patient autonomy by encouraging active patient participation in care, patient review of treatment progress, and documentation that does not fall in the narrow exception criteria; but, internal policies may be needed to define or fine-tune the best practice relevant to information that does fit into the narrow exception criteria [11]. Mental health professionals retain a duty to their patients to do no harm to the physical or mental well-being of patients through careless entries into a medical record. In a post-HIPAA era in which patients have broad access to their medical charts, the duty has not changed, but the likelihood of patient review has increased in frequency. The narrow exception criteria do afford special status to sensitive information, but record-keeping practices must reflect the narrowness of the criteria and avoid fragmentation of the record [11].

## Electronic Medical Records

One of the results of HIPAA regulations has been a structural change in the access of other fields of medicine to psychiatry and psychology clinic notes (not psychotherapy notes), and vice versa. In the past, the mental health record was often separated and treated differently from the general medical records. Medical providers needed a separate consent to view psychiatric records, and patient access to psychiatric records was relatively limited. HIPAA eliminated the distinction by allowing mental health information not covered by the narrow exception criteria to be shared with other treatment clinicians within the same institution without a specific consent requirement [11]. Electronic records introduce a significant advantage, particularly in large institutions, to access to data relevant to clinical health psychology encounters. Written background, consultative, or treatment information by other professionals that, in the past, was slowly gathered by psychologists from a paper record is now quickly available in electronic form.

Electronic medical records are being used increasingly for the potential advantages of their durability, confidentiality, accessibility, and efficiency. They have addressed some limitations of paper records in work flow, improved quality of patient care and safety, decreased medical errors, and access to the medical records by multiple providers at the same time and anywhere or at anytime within a network. Electronic medical records have paved the way for clinical health psychologists to use electronically enhanced means to keep track of behavioral data relevant to disease, such as monitoring patient access and utilization of therapeutic and preventive health services that may affect illness outcomes [41]. Access to some information is available to credentialed providers on their private computers via virtual private networks or VPNs, making the electronic medical records, or portions of it, portable in some instances. To comply with HIPAA, internal medical center standards usually require that computers must be encrypted if they are to be used to access data via VPNs.

The adjustment to the electronic medical record was not without its ups and downs for most providers, but studies have shown that individuals who use electronic medical records, relative to those using paper records, are more likely to find the records up to date, find the records more accessible, and report greater satisfaction with electronic medical records. Increased duration of use was related to greater satisfaction with electronic medical records relative to paper records. The benefits included increased access to relevant information from multiple providers, the ability to search the system for relevant records, improved quality of patient records, and improved quality of documentation. Records were viewed as accessible, modifiable, timely, and of satisfactory quality. There were no differences in perceptions of quality of care delivery when providers using electronic records were compared to those using paper records. In some cases, electronic medical record systems were associated with a more efficient use of time, improved management of illness, and improved preventive care [23]. Electronic medical records carry the potential to mitigate delays in diagnoses and treatment provision, to facilitate monitoring of

duration of follow-up, and to facilitate monitoring missed appointments and providing support for transportation or other issues that may be impeding patient access to desired health care [41].

## **Clinical Health Psychology Practice in Medical Centers**

Clinical health psychology is a field in which providers seek to apply the contributions of psychology to the understanding of health and illness. They seek to integrate biomedical information about health and illness with current psychological knowledge. Psychologists provide consultation on how biology, behavior, culture and ethnicity, and social context influence health and illness. They work alongside other medical professionals in a variety of settings. The most common theme within the work is that health and illness are products of a combination of biological characteristics, genetic predispositions, lifestyle, stress and coping strategies, health beliefs, cultural influences, family influences, and social influences. Clinical health psychologists work toward promoting prevention strategies, and they investigate the effects of illness on psychological well-being. Because their role is often consultative, the ethical contours of their work sometimes take place within a relatively broad context.

## **Individual Confidentiality and Networks of Confidentiality**

Patient confidentiality in the context of a medical center exists within a network of confidentiality rather than a dyad confidentiality offered by an individual provider toward an individual patient [40]. With increased accessibility of medical records, it is possible for a clinical health psychologist to quickly review a patient's neurology records, ophthalmology records, and surgical records before providing consultation. Although that same access was possible using a paper record, access is more efficient and more easily accessible with electronic medical records. In addition to relying upon the patient to be a historian about his or her health history, the health records of patients can be quickly reviewed, and interview questions can query relevant topics. Although the clinical health psychologist quickly has access to relevant data, the information must be treated with appropriate respect and sensitivity to the patient's concerns. Information must not be dispensed to anyone outside the network of confidentiality without the patient's permission. In the new world of electronic medical record keeping, it is advisable to remind the patient that others responsible for their care within the institution will have ready access to the clinic notes of the clinical health psychologist (and the clinical health psychologist will have access to the clinic notes of other providers). HIPAA regulations and internal standards disallow providers from viewing the records of any patient not in their care, but they have ready access to the records of all patients and may quickly

access the records of their own patients. Networks within the institution may be small or large depending upon how many providers are responsible for a patient's health care. When records are to be sent outside the institution, a release must be obtained [41].

### *The Medical Center as a Community of Providers*

HIPAA regulations affect how clinicians may access existing health information and how to handle identifiable information created as a result of clinical activities. It applies not only to records but also to conversations among providers. When a team of providers discusses a patient, it is required that they do so in a private venue such as an office with a closed door. Records or conversations should be limited to identified patients. When families are seen together, records for one family member must respect the privacy of other family members. Joint records are not permitted. When a team of clinical providers produces a joint document on an individual patient, there should be appropriate coordination of records and meetings so that all members of the team appropriately adhere to record-keeping requirements. The notice of privacy relevant to HIPAA is applicable to all team members as individual providers and not to the team as a whole. The complications and permutations of releases, restrictions on uses and disclosures of health care information, and revocations of releases must be anticipated for team reports. Report-preparation provisions must anticipate the possible revocation of release for one team member but not other team members. If a team report is prepared and a release is revoked for one member of the team and not the other members, there must be a mechanism for releasing only those portions of the report that the patient has agreed to release [38].

Clinical health psychologists work in a community of providers, usually in a team model but sometimes somewhat more individually. Behavioral medicine, education, behavior change, and work-related health initiatives are common foci in clinical health psychology. The duty of confidentiality remains relevant, but it is likely to be handled differently than traditional psychotherapy. Team models of treatment require an acknowledgment at the outset, in verbal and paper form, that the members of the team will be in communication with one another. If there is cross-consultation with other professionals in the same institution, the patient must be informed of who will be included in the network of confidentiality and they must be in agreement with cross-consultation. If there are sensitive data that the patient prefers to keep private, there must be provisions for preserving that sensitivity. When patient care utilizes family and community support services, the limitations to confidentiality must be stated in advance of care. Services must be appropriately contractual, confidentiality and the limits thereof must be communicated effectively, and the psychologist must remain within the bounds of his or her competence. Patients have the right to view and request a copy of their mental health records (except those that fall within the exception provision), and they have a right to request that corrections be made to incorrectly recorded data [24, 38].

## ***Professionalism***

Professionalism is central to sustaining the public's trust in the integrity of health care providers. It reflects the essence of the provider–patient relationship. Academic institutions are beginning to recognize that emphasis is needed on strengthening the resolve of providers to sustain their commitments to the ethics of professionalism. Professionalism is a component of the competence of providers and it begins with selection processes, instruction, role modeling in learning environments, and student feedback specific to professionalism. Professionalism reflects a set of skills, some of which are easily defined and quantified, and others of which are a bit amorphous and individual. Society explicitly and implicitly assumes that health care providers ought to be trustworthy in their pursuit of their professional goals and that they should be served by the public interest in the integrity of the health care professions. Professionalism reflects the means by which individual providers fulfill their profession's contract with society, and they include qualities such as altruism, respect, honesty, integrity, dutifulness, honor, excellence, and accountability [12].

There is growing concern about professionalism within medical centers due to increasingly relaxed views of individual and family privacy at a societal level, and due to changing standards of manners and civility. Professionalism, from an ethical and legal standpoint, centers upon the need to apply ethical and legal standards in the context of ever-evolving roles and responsibilities of psychologists within constantly shifting moral, cultural, economic, political, and legal contours. Trends of current relevance include the advent of Internet-mediated research and supervision sites, electronic telemedicine, the use of electronic media for the dissemination of research literature and health information, increased sensitivity to the research and treatment needs of disadvantaged populations, and the ebb and flow between paternalistic and autonomy-based attitudes and regulations relevant to informed consent and patient privacy.

## ***Community Parameters for Individual Patients***

Whether the treatment community consists of individual providers within the medical center, a network of providers, the inclusion of family members or other social partners in treatment, group treatment modalities, or electronic communities, attention must be given to patient views of the sensitivity of their health care information. Patients have varying attitudes about the sensitivity of their health care information. What is personally embarrassing to one patient may seem relatively innocuous to another. To determine the patient's level of comfort with the sharing of information within the medical community, it is important to specify in advance the advantages of collaborative communication between providers, to determine any reservations the patient might have about those collaborations, and to determine what information they might view as sensitive regardless of whether it is classified as such by treatment providers [26].



Couples, families, or groups of clients seen together can promote a patient's sense of belonging within the context of a network of supportive individuals or those going through the same illnesses. It also raises the possibility of conflicting interests. There may be competing medical, social, and political interests within the network or hierarchy of individuals involved either centrally or peripherally in an individual patient's care. In the context of group treatment, patients may not experience the same degree of benefit from treatment, support may be seen by some patients as intrusiveness, and patients may not share the same understanding of group confidentiality. By focusing on the welfare and best interests of the most vulnerable parties in the social community, legitimate professional duty is made more clear and it enhances the likelihood of a good outcome [24, 40]. Similar dynamics may apply to treatment teams. A team of providers may be responsible for the well-being of patients but individual members of those teams may have different priorities. Team structure, size, form, and role composition must be clearly delineated and coordinated. Teams of providers must communicate well in order to appropriately address the patients' needs and provide effective service coordination.

Clinical health psychologists typically provide services in the context of a team of providers that focus on particular categories of illnesses, disabilities, or services. Team size may affect patient outcomes in a bimodal manner. Too few or too many providers can yield problems in meeting the team's treatment objectives. Responsibilities must be divided according to professional competencies, with due attention given to limiting the potential for dual roles or spreading responsibilities too broadly. Effective teams tend to be moderately sized, include patient perspectives, include family perspectives when relevant, and take advantage of the positive influence of key players. Consultations and interventions are optimized when they take place within a planned sequence of interventions and when they take advantage of a patient's readiness to incorporate advice and suggestions. Coordinated reporting of information is optimized when both verbal and written communication of data are planned in advance. Information that is communicated in writing must correspond to that which has been communicated verbally. Cogency is important both within teams and across other consultations so that the most critical information is effectively gleaned by those who will use the information at a later time in the patient's treatment course [40]. The readership should be considered, and both written documents and verbal exchanges should be communicated in a tone that is appropriately respectful of patients as consumers of health care [13].

### ***Communicating with Individuals and Families***

The question of allowing family members to participate in or be present during critical or other care of patients, whether during emergency or routine procedures, is a question that revolves around basic values more than treatment outcomes [19]. The presence of family members can help orient patients coming out of anesthesia, give courage to patients who must endure pain, and give treatment providers a better understanding of the patient as a person enduring illness. The question of the value

of the presence of a family member becomes more complicated when health care providers are faced with potentially stressful procedures (to the patients, the family members, and the providers). The benefits of having a family member present in these circumstances is difficult to predict, calculate, or compare due to different attitudes toward emergent treatment, unpredictable vicarious trauma reactions of family members, and a host of other potential complications. Attitudes toward the presence or exclusion of family members have their basis in theoretical views of whether the individual patient is the only appropriate focus of care (and that this focus ought not be distracted by family members or violations in confidentiality and privacy), or whether the socially embedded nature of existence is the norm and that family members may have curative influences and they will and properly may influence individual choices [15]. Health care providers never really know what kind of relationships any given patient has with his or her family members, whether the family members might wield too much influence or improper kinds of influence, and whether the patient might decide or behave differently if family members remain peripheral to the decision-making processes [15]. It is appropriate to view the patient as an individual who lives in a web of relationships with family members and community members, but the individual's preference for unitary or family-supported decisions must be discerned to the best degree possible and respected when possible.

### ***Communication with Patients via Electronic Means***

Modern microelectronics have made possible the provision of clinical health psychology services via e-mail, Internet chat rooms, Web sites, and interactive audio and video technology. The nature and terms of how the clinical health psychologist relates to patients are changed significantly in these media. Consent forms must be modified to anticipate the potential permutations of communications via these media. The geographic expanse of consultations must be considered in light of licensing regulations and prohibitions against practice across jurisdictions. Relevant consumer information must be posted on professional Web sites. Providers must consider a myriad of new contractual issues and related liability components. Providers must consider to what extent it is appropriate to provide services via these media. There is little research to date that is relevant to the quality of therapeutic alliances formed via electronic exchanges or how they compare to in vivo alliances. Caution is in order as providers make ethical and service delivery adaptations to these media. There is potential for therapeutic value as well as the potential challenges to the adequacy of treatment and consultation [24].

The use of new technologies has created innovations and opportunities for the provision of psychological services that move beyond the in vivo dyad. For example, behavioral telehealth is one of the fastest growing dimensions of telehealth. Psychologists who wish to expand the scope of their practice to techniques or technologies that are new to them are ethically bound to undertake relevant education, training, and consultation to reach the necessary qualifications established by

the field. The ethical competence standard of the American Psychological Association's ethical principles [3] addresses the utilization of technologies and emerging technologies in practice. Psychologists must take reasonable steps to ensure the competence and safety of their work in new or emerging areas of practice. Emerging areas of practice must draw upon sound and established scientific or professional knowledge in the discipline of psychology. Steps must be taken to ensure that e-mail or Internet-mediated consultations are undertaken in a manner that preserves the competence of the provider's work and the confidentiality of the patient's concerns. The obligation of informed consent applies to Internet services. Psychologists who provide Internet-based assessments or e-therapy must ensure that the individual who provided consent is in fact the individual utilizing the services. The age and legal status of service recipients must be verified, and there must be provisions for individuals with impaired consent capacities. Fees, third-party involvement, confidentiality (and limits to confidentiality), and the implications of HIPAA must be addressed. Formal consultative services provided by e-mail must anticipate confidentiality concerns, lack of immediacy, and the limited range of therapeutic services available through this medium. When sensitive information is transmitted, it is advisable to use encrypted data transmission, password-protected data storage, and firewall techniques [24, 34].

## Teaching Hospitals

### *Teaching, Supervision, and Observation*

Within teaching hospitals, it is customary to inform patients when their care includes interventions or procedures delivered by interns, residents, or fellows. It is customary to inform them of who has supervisory responsibility over the trainees. Internal medical center regulations and insurance regulations require that the attending physician or psychologist meet individually with the patient rather than supervising the trainees from a distance. Under HIPAA, patients must be informed of a myriad of nuanced ways in which their health care information will be used. Patient authorization is needed for a variety of activities, from the mundane to the formal. Examples include appointment reminders, offering treatment alternatives, consultations about health-related benefits and services, fund-raising activities, patient directories, and marketing. Teaching and clinical supervision is no exception. Patients must be informed when trainees are part of the treatment team. Student observers must be cleared by administrative procedures. Even people who serve as hospital volunteers are subject to HIPAA regulations. Patient permission is needed for the inclusion of student observers, trainees, consultants, other teachers, or any other individuals who might be in a training/trainee role. If a patient's case is to be used to illustrate a teaching point, the patient's permission must be secured and all identifying information must be removed [38].

Ethics education shapes relevant attitudes and values of students who will become the next generation of clinicians and researchers working with persons with

serious physical and mental illnesses. Ethics and professionalism preparation heightens the sensitivity and facilitates appropriate professional attitudes, and it strengthens the skills of future clinicians and researchers in preserving, enhancing, and fostering a humanistic view of treatment and research. Case-based, experiential, and small-group learning experiences are particularly valuable in ethics education. In research ethics, considerable debate persists about participant motivations, participant understanding of research goals, the perceived vulnerability of physically or mentally ill research participants, capacities for independent decision making, and appropriate levels of professionalism among researchers (Roberts et al. 2007).

### ***Research and publication***

The legal component of research is seen in the higher standards introduced by HIPAA for researchers. Researchers that provide health care to individuals in clinical trials are directly covered as health care providers. Researchers who access existing protected health information from medical records or computer databases must comply with the HIPAA Privacy Rule because they operate in medical centers that are “covered entities.” They are obliged to protect the privacy of individually identified health care information used or released for research. From a clinical investigator’s perspective, HIPAA affects how researchers access health information and how they handle identifiable information created as a result of clinical research activities. In addition to informed consent requirements, investigators must obtain an authorization, with more detailed information, in order to use and release identified protected health information for research. The criteria used by Institutional Review Boards to waive the authorization and informed consent for medical record or database reviews are much more stringent than before HIPAA went into effect. Investigators must provide more detailed information on protocol applications about the use, disclosure, and necessity of accessing protected health information. HIPAA requires that the hospital, and investigators using hospital records, track any individually identified information that is released for research when waivers of authorization are granted. The purpose of tracking is to provide patients, upon their request, with a list of how the information about them was released for research or other nontreatment purposes without their knowledge. A “business associate” agreement may be needed if organizations collaborate on research [38].

### **Summary**

Clinical health psychologists are committed to improving the condition of individuals, organizations, and society through the application of scientific theories and research to people’s behavior and their understanding of themselves and others. Clinical health psychologists respect the autonomy of patients in their roles of granting informed consent, using judgment and reasoning to make health care decisions,

forming opinions or perspectives on health and illness, coping with illness, and participating in research. The work of clinical health psychologists is guided by ethical principles, standards of practice, medical center regulations, and relevant legislation. In the implementation of these sources of guidance, it is possible to discern higher-order moral or philosophical principles that are interwoven throughout the sources of guidance and the work itself. Although each of these mechanisms carry with them the ingredients for healthy scientific debate about appropriate practice, and although they may sometimes offer conflicting guidance, they provide a wealth of common standards upon which clinical health psychologists base their professional and scientific endeavors. These mechanisms have a common goal of protecting the welfare of individuals and groups seeking health care.

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# Chapter 6

## Evidence-Based Practice: Concepts and Techniques for Translating Research into Practice

Barbara B. Walker, Charlotte Collins and Hope C. Mowery

### Evidence-Based Practice

Consider the following scenario:

Ms. Smith is a 45-year-old woman who comes to you for help with depression. You perform a comprehensive biopsychosocial evaluation, formulate the case, and diagnose her with major depressive disorder. You learned in graduate school that cognitive-behavioral therapy (CBT) is an effective treatment for major depressive disorder and you have used it successfully with similar patients in the past. As a result, you decide to begin treating Ms. Smith with CBT.

Is this “evidence-based practice in psychology” (EBPP)? Recent surveys indicate that most graduate students and faculty in clinical psychology programs [1, 2] believe it is because the clinician chose to deliver an “empirically supported treatment” (EST). Psychologists familiar with the newer view of “evidence-based practice” (EBP) adopted by the American Psychological Association (APA) in 2005 [3], however, would argue that although the above scenario contains elements of EBPP, it is missing some key components. Thus, ESTs are a part of EBP, but they are not synonymous with it. Applying an EST represents just one part of a larger, more comprehensive paradigm termed “evidence-based practice” which has now been formally adopted by every major health care profession including psychology.

The purpose of this chapter is to introduce readers to this paradigm by describing EBP and highlighting the critical components missing from the scenario above. With the growing emphasis on the importance of integrating research into practice,

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practitioners need techniques for doing so, and researchers need ways to ensure that their research findings are used by evidence-based practitioners. EBP provides tools for both. In the next section, we trace the development of EBP and discuss current conceptualizations of the process. We then provide an introduction to the five steps in doing EBP and discuss some novel resources and tools that are particularly useful for psychologists working in medical settings. Using a case illustration, we then describe how we applied EBP to a patient in a “real-world” clinical setting. Because EBP relies heavily on practice-based evidence, in the last section we turn our attention to the role psychologists can play in generating and synthesizing evidence that will ultimately help answer the questions that practitioners pose.

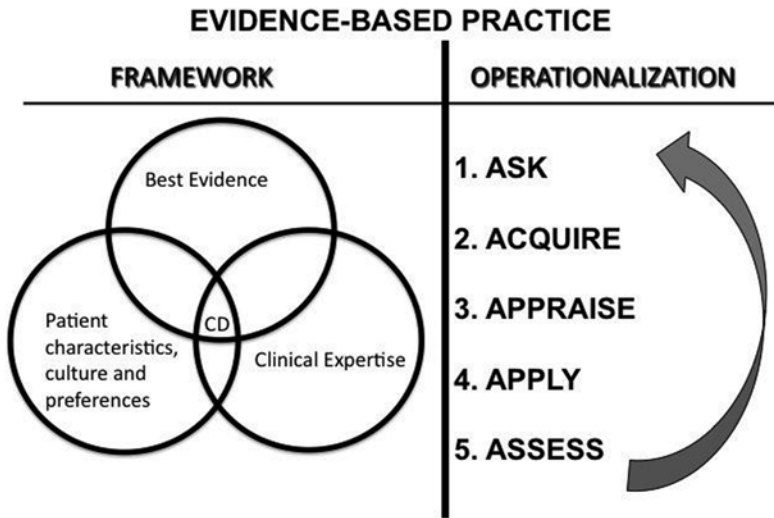
### ***The Evolution of “Evidence-Based Practice” in Psychology***

Very few terms elicit a stronger emotional reaction among psychologists today than the term “EBP”. Practitioners often express concern that it means others can dictate what they must do with their patients in order to be reimbursed. Researchers often express concern that it gives practitioners permission to ignore the research and rely solely on their opinion (i.e., their “clinical expertise”) to make clinical decisions. These concerns, along with the host of others that have arisen in recent years [4], emanate from ones’ definition of “EBP,” and this definition has been a source of much confusion.

To understand the confusion, it is helpful to examine the evolution of the term “EBP.” Over the past 15 years, almost every health care profession has sought to develop more formal processes for incorporating research into practice, and progress has occurred in different ways at different times among the various professions [5]. Within psychology, the APA commissioned a task force in 1995 [3] to develop a rigorous set of criteria for evaluating treatment outcome research in psychology and to use these criteria to establish a set of “empirically supported treatments” (ESTs) for specific disorders. This task force identified treatments that have since been widely disseminated and taught in graduate psychology programs across the country [6, 7]. Among many psychologists, “EBP” became synonymous with using ESTs.

During the same time period that ESTs were being developed within psychology, David Sackett and his colleagues in the field of medicine at McMaster University were integrating research into practice from a very different vantage point. Rather than focusing on which treatments were likely to be effective for the *average* patient with a particular disorder, they focused on developing a system to help clinicians care for an *individual* patient. Specifically, they set out to develop a process and set of tools to help clinicians make decisions about a particular patient based upon the best available evidence. This ultimately led them to define “evidence-based medicine” (EBM) as “. . .the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of *individual patients (italics ours)*. The practice of evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research [8, 9].”





**Fig. 6.1** The framework and five steps associated with EBP. The clinical decision (*CD*) lies at the intersection of the three spheres and the EBP process is comprised of five steps

From its initial inception, this conceptual model of EBM was tied to a skill set. Specifically, Sackett and his colleagues developed a five-step process (Ask, Acquire, Appraise, Apply, Assess) for making clinical decisions regarding an individual patient [8]. Thus, as illustrated in Fig. 6.1, EBM is not only a conceptual framework; it is also a behavioral prescription for how to integrate research into practice. The relative significance of these behavioral skills is evident when one examines the content of the most recent edition of their book entitled *Evidence-Based Medicine: How to Practice and Teach EBM* [9] which is now required learning for most medical students across the country. A mere 4% of the pages in the book is devoted to the framework whereas more than 70% is devoted to the specific skills one needs to become competent at *doing* EBM [10].

As ESTs were being disseminated in psychology and EBM was taking hold in the field of medicine, other health care professions were also working toward defining some type of “EBP.” By 2005, the Institute of Medicine [11], along with every major health care profession, had formally adopted some definition of “EBP” as policy. Most organizations adopted definitions very similar to the one originally proposed by David Sackett and his colleagues. Within psychology, the APA established an evidence-based task force in 2005 and later adopted a policy of EBPP, defining it as “...the integration of the best available research with clinical expertise in the context of patient characteristics, culture, and preferences [3, 12].” This policy statement represented a significant paradigm shift in the field of psychology; rather than standing alone, the ESTs became part of a much broader approach requiring practitioners to integrate the best, most up-to-date research evidence with clinical expertise and patient characteristics.

Despite the intense controversy it sparked [13], our view is that this policy represented significant progress. First, it aligned psychology with other major health care professions in its definition of “EBP” which is critical for collaborative efforts in health care. Second, the policy has already advanced our understanding of EBP; it served as the impetus for psychologists to begin clarifying the domains of clinical expertise and patient characteristics, both of which have received limited attention in other fields. Specifically, the APA defined “clinical expertise” in terms of eight different competencies and articulated how psychologists could acquire them. It also expanded patient preferences to include “patient characteristics, values, and context,” and listed a wide range of factors that need to be considered (e.g., gender, socioeconomic status, religious beliefs, cultural values, readiness to change, etc.).

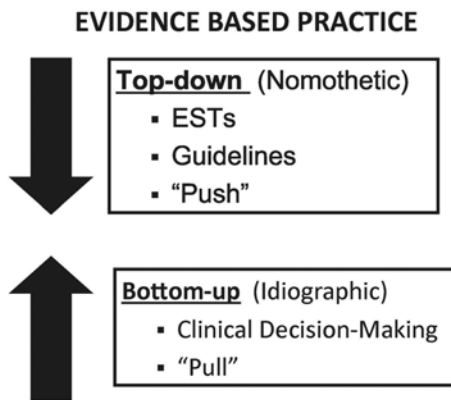
Interestingly, however, the skill set that has played such a predominant role in medicine, nursing, and other allied health fields was notably absent from the APA policy statement. Neither the APA policy statement nor several books that appeared shortly thereafter in psychology about “EBP” [13] detailed the five-step process that began playing a prominent role in other health care fields. As a result, psychologists have been exposed to the conceptual model far more than they have been exposed to the skills associated with EBP.

This, along with the fact that almost all the books and website tutorials at the time focused exclusively on medical questions, provided impetus for the Office of Behavioral and Social Sciences Research to fund a transdisciplinary group whose mission was to develop web-based training materials in evidence-based *behavioral* practice (EBBP). The group, led by Bonnie Spring, Ph.D. at Northwestern University, hosts a website designed to train social and behavioral scientists in EBP ([www.ebbp.org](http://www.ebbp.org)). In addition to this website, Norcross and his colleagues [14] published the only book of which we are aware that provides mental and behavioral health practitioners with detailed instructions on how to *do* EBP. This book, along with the tutorials on the [www.ebbp.org](http://www.ebbp.org) website, is an invaluable resource for psychologists who want to learn how to do EBP.

## **Defining Evidence-Based Practice**

With its deep roots in research, it followed naturally that psychology would focus on a nomothetic or “top down” approach to integrating research into practice. Specifically, the focus was on identifying treatments that are likely to be effective for most patients with a particular problem. EBM, however, emerged as an idiographic or “bottom up” approach, focusing on finding and using the best research to answer questions about an individual patient. Given that psychologists are likely to be trained extensively in research whereas physicians are trained primarily to provide patient care, the fact that the two fields took different approaches is not surprising. It is also not surprising that confusion arose almost immediately and persists to this day, in part as a result of perceived differences between these two approaches.

**Fig. 6.2** In EBP, nomothetic and idiographic approaches are complementary and are both taken into consideration



In our view, not only are these two approaches complementary, they are synergistic as well. We propose they be conceptualized as illustrated in Fig. 6.2: two sides of the same process that are both actively engaged in “push–pull.” Research evidence needs to be “pushed” out by those generating research (using the nomothetic approach) and “pulled” in by practitioners looking for the evidence that they need to apply to an individual patient (idiographic approach). Using this scheme, one could speculate that clinical outcomes are maximized when the nomothetic “push” is appropriately combined with the ideographic “pull.”

To summarize, practitioners need a structure and appropriate techniques for integrating research into practice, and researchers need ways to ensure that their research findings are used by evidence-based practitioners. EBP provides tools for both. In the next section, we focus on the practitioner by describing the five steps involved in doing EBP and some novel resources and tools that are particularly useful for psychologists working in medical settings. We will then illustrate how we applied these steps to a patient in a “real-world” clinical setting.

## The Five Steps in Doing EBP

### *Step 1: Formulating Questions*

In one study of physicians in a teaching setting, five clinical questions were raised for every patient discussed [15] and there is little reason to believe that it would differ significantly in psychological settings. Not only do clinicians generate a multitude of questions after each patient visit, questions routinely arise from patients as well. Given the wide range of health-related information now available on the Internet, patients enter treatment armed with much more information than in the past. It is not uncommon, for example, for patients to ask if a particular “alternative treatment” might be as or more effective than the traditional one. Many patients are well informed by accessing the Internet, but others are regrettably misinformed.

Psychologists have an ethical and professional obligation to help patients make decisions based on the best scientific evidence we have to date.

This process begins with formulating “well-built” questions. Using the specific format outlined in EBP is critical not only because questions guide the search for evidence but because they also determine what type of evidence to seek and where to find it. As has been described in more detail elsewhere [10, 16], it is often helpful to visualize clinical scenarios as one might visualize a photograph or a painting. Similar to what one sees in a photograph or painting, questions can arise in both the foreground and background. In EBP, *background questions* ask about a general setting or context, whereas *foreground questions* ask about an individual case within that context. Although clinicians practicing EBP are trained to generate both background and foreground questions, the relative proportion of each often varies depending upon the clinician’s familiarity with a particular disorder. Beginning students, for example, pose more background than foreground questions, whereas experienced clinicians pose more foreground than background questions [9].

Background questions usually begin with words such as *who*, *what*, *where*, *how*, or *is*, and are followed by a condition or situation. Treatment (i.e., effectiveness) questions are the most common type asked, but background questions about diagnosis, prognosis, etiology, harm, and cost-effectiveness are also important. Considering the scenario presented earlier, one background question might be: What are the most effective treatments for major depressive disorder? Another might be: What is the prognosis for a middle-aged woman experiencing her first episode of major depressive disorder?

Questions about harm are far more common in medicine than in psychology. The wrong drug or the wrong surgery holds enormous potential for doing harm. In psychology, however, there is often an implicit assumption that psychological interventions either help or have no effect; they have little potential for harm. This assumption is untrue, however, particularly for psychologists working in medical settings. In addition to specific psychological interventions that have been found to be harmful [17], specific components of treatments could potentially be harmful to a particular type of patient. In the opening scenario, for instance, if we knew our patient had a history of trauma, could relaxation training prove to be harmful in any way? If she had a history of cardiac disease, could certain forms of exercise be harmful?

To answer this type of question about a specific patient, we need to generate a foreground question, and foreground questions are also structured using a very specific format. Although modifications have been proposed [14, 18, 19], the most commonly used format is known as PICO. The PICO acronym refers to the population or patient group (P), intervention (I), comparison group (C), and outcome measures (O). With regard to our concern about harm mentioned above, we could ask:

**Population:** In a middle-aged woman with major depressive disorder and a history of trauma

**Intervention:** is there any evidence that relaxation training

**Comparison:** compared to no relaxation training

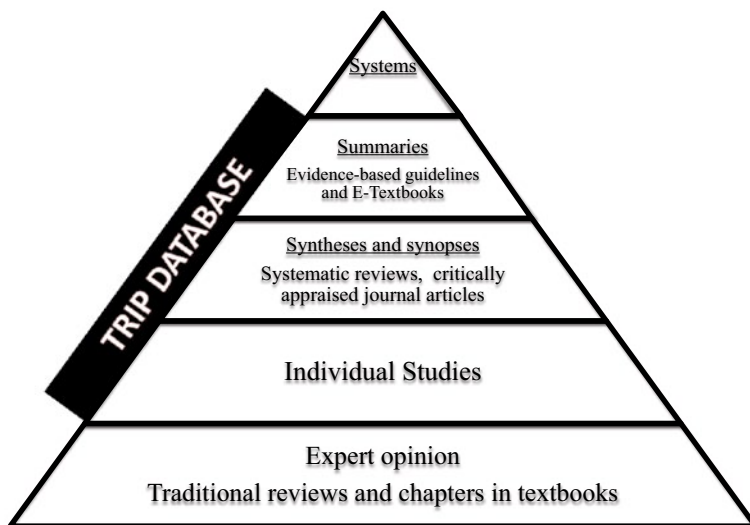
**Outcome:** could result in worsening of depressive symptoms or emergence of symptoms of PTSD?

It is easy to imagine that in a significant proportion of cases, there is no good evidence to answer a specific foreground question. As a result, some clinicians might become convinced that searching was not worth their time. Nothing could be further from the truth. Knowing that the answer to a particular question is unknown is extremely important in EBP. First, equipped with the knowledge that there is no good evidence to answer the question, the clinician is on firm ground making clinical decisions based upon his or her clinical expertise and the patient's characteristics and preferences. Second, storing these important, unanswered questions in a database and disseminating them can increase the probability that the questions can be answered in the future. This is already being done to some extent by organizations that host CATBANKS, which are databases that contain CATS, an acronym for Critically Appraised Topics. Among other institutions, the University of Michigan (<http://www.med.umich.edu/pediatrics/ebm/Cat.htm>), the University of Western Sydney (<http://www.otcats.com/>), and the University of North Carolina (<http://med.unc.edu/medicine/edursrc!/catlist.htm>) currently host online CATBANKS on their websites and The Centre for Evidence-Based Medicine at Oxford in the UK provides a free CATMAKER on their website (see <http://www.cebm.net/index.aspx?o=1216>). Unfortunately, the vast majority of CATS available to date focus on medical questions; there are few dedicated to questions in the social and behavioral sciences. Hopefully, this will change as EBP becomes more fully integrated in education and training in psychology.

### *Step 2: Searching for the Best Evidence*

**What is the best evidence?** Most psychologists have been trained to search the scientific literature for research purposes, the goal of which is to find and review all of the relevant articles within a relatively narrow field of interest. An EBP clinician, however, has a very different goal; EBP clinicians need practical, efficient methods of finding the best evidence quickly and easily. Unlike the researcher, they are not concerned about missing papers that are peripheral to their question; they need the one or two papers that directly answer their specific question. As a result, the first goal of searching in EBP is to determine whether or not the evidence relevant to a specific clinical question has already been located, appraised, and synthesized. If someone has already assembled the relevant studies and critically appraised them in an attempt to answer the question, the clinician need only find that particular source.

To find that source quickly and efficiently requires an understanding of how evidence is organized in EBP. Since all evidence is not equal, a "hierarchy of evidence" has emerged which is usually portrayed as a pyramid with the highest level of EBP resources at the top and clinician opinion at the bottom. Although the details of the structure of these pyramids have been debated in the literature [4, 13, 20], Fig. 6.3 illustrates the levels that have been generally agreed upon and are



**Fig. 6.3** General schematic of the hierarchy of evidence in EBP

particularly relevant for health psychologists. The pyramid has been the shape of choice because each level in the pyramid represents integration and/or synthesis of the information below it; as such, as one moves up each level on the pyramid, one finds fewer and fewer resources that integrate more and more high-quality evidence. Thus, as we will later illustrate, practitioners typically begin their search at the top of the pyramid and work their way down.

As illustrated in Fig. 6.3, information based on opinion is at the base. Above that are individual studies that vary widely in design type and quality. Because of this variability, a new body of literature has emerged in EBP that is often referred to as syntheses and/or synopses. These papers synthesize the highest-quality primary literature in different ways; the most noteworthy are specialized reviews called *systematic reviews*. Most psychologists are familiar with traditional reviews where authors search the literature and generate conclusions based on their findings. Unlike these traditional reviews, systematic reviews follow highly specific, predetermined methods for capturing the evidence, appraising it, and synthesizing it in a manner that is easily accessible to clinicians. They focus on a clear, clinically relevant question and end with a statement about the “clinical bottom line.” Systematic reviews apply the same scientific rigor to the review process that is applied in primary research and are designed to avoid the biases that can occur in traditional reviews. Traditional reviews, for example, often rely exclusively upon findings that have been published in English. This approach can bias the conclusions of the review since negative findings are more likely to appear in (1) non-English than English journals and (2) unpublished than published studies [21, 22]. In contrast, systematic reviews attempt to locate *all* relevant articles in order to minimize bias. Unlike

traditional reviews, an explicit goal of systematic reviews is that their results be replicable. In short, systematic reviews are performed to answer a specific clinical question using strict predetermined rules for capturing the evidence, appraising it, extracting the data, synthesizing it, and disseminating it in a manner that is easily accessible to clinicians.

Above syntheses and synopses are summaries. Summaries synthesize results of the lower levels and are extraordinarily useful to practitioners. Evidence-based guidelines are summaries which are usually based on systematic reviews of the literature (see, the National Institute for Clinical Evidence (NICE) guidelines <http://guidance.nice.org.uk/> for excellent examples). Also notable are online, evidence-based textbooks. Two of the very best of these, *Clinical Evidence* (<http://clinicalevidence.bmj.com/ceweb/index.jsp>) and *UpToDate* (<http://uptodate.com/index>), extract the highest-level, most up-to-date evidence and publish chapters on a wide range of health topics. These two online texts require institution subscriptions, but there are other evidence-based summaries that do not; these are best found using TRIP, an acronym for Turning Research into Practice (<http://www.tripdatabase.com/>), which is a search engine based in the UK that is designed to help clinicians quickly find answers to their clinical questions using the best available evidence. The TRIP database is a powerful tool for EBP practitioners that is further described in the next section and highlighted in the case illustration that follows.

“Systems” rest at the very top of the pyramid. In EBP, these refer to decision support tools that are integrated into computerized systems and/or electronic medical records that enable clinicians to link directly to the information they need at the point of service. These systems are in their infancy and are just beginning to be developed within medicine, and have already been the subject of at least one systematic review [23]. To our knowledge, with the exception of a few reports focusing on depression [24, 25], these types of systems have not yet been pursued within the behavioral and social sciences. We include it here to emphasize that this level is likely to become increasingly important in the future, and it is important that data from the social and behavioral sciences be incorporated into these systems. With health care reform and the growing emphasis on a patient-centered medical home (<http://www.medicalhomeinfo.org/joint%20Statement.pdf>), it is likely that these efforts will intensify in coming years.

**How to find the evidence** As mentioned earlier, EBP clinicians must first determine what type of evidence would best answer their question(s). Having done so, one strategy is to begin by searching TRIP, a free search engine that is designed to find evidence-based primary research, syntheses, synopses, and summaries from around the globe. TRIP is extremely easy to use; one simply enters the search term(s) and the database displays evidence-based synopses, syntheses, and summaries along with the relevant evidence-based primary literature. Guidelines can be filtered by country of origin, and the primary literature can also be filtered for those focusing only on therapy, diagnosis, etiology, and/or prognosis.

There are advantages and disadvantages for using TRIP. The main advantages are that it offers free public access to the highest-quality evidence-based literature and it is user-friendly. It also has a unique feature that allows the user to set the specific level of evidence for articles displayed. One disadvantage, however, is that it is difficult to do a narrow, focused search in TRIP; as a result, searches can be inexact and inefficient. Another disadvantage is that TRIP may not contain the information one needs; although it will display only evidence-based information, evidence-based information exists that will not necessarily be displayed in TRIP. Thus, although TRIP is an extremely useful resource, it is one of many and should not be relied upon exclusively.

Another strategy for finding answers to questions is to search each level of the hierarchy separately, which allows the user to perform more specific, efficient searches than those done by TRIP. To maximize efficiency, EBP practitioners are advised to start at the top of the pyramid and work their way downward to find the most synthesized information available. Background questions are often best answered by summaries, for instance, so practitioners with access to online evidence-based textbooks would be well advised to begin by searching those. They might also search evidence-based guidelines using the National Guideline Clearinghouse (<http://www.guideline.gov/>). It is important to note, however, that because not all guidelines in the Clearinghouse are evidence-based, a “Detailed Search” must be performed in order to filter for evidence-based guidelines. In addition, it is important to recognize that EBP is evolving rapidly, and some evidence-based guidelines are not yet indexed in the National Guideline Clearinghouse. To find the most recent evidence-based guidelines, we have often found it helpful to enter “evidence-based guidelines for...” into Google or Google Scholar.

There are many questions that cannot be answered by summaries or are best answered by evidence at a lower level. In these cases, practitioners search for a high-quality systematic review to answer the question. Systematic reviews can be found using several strategies. One is to search the Cochrane Library [26] which is the premier resource for up-to-date, evidence-based systematic reviews on the effectiveness of health care interventions. It is part of the Cochrane Collaboration, a worldwide network of librarians, patients, health care professionals, and laypersons who work together to create and maintain an updated library of the highest-quality systematic reviews in health care. Its two major products, the Cochrane Database of Systematic Reviews (CSDR) and the Database of Abstracts of Reviews of Effects (DARE), are considered by most health care professionals to be among the very best resources available for practicing EBP [9, 27]. The Cochrane Library provides summaries of their systematic reviews on their public website (insert website here) and complete detailed reviews to institutions with subscriptions.

Whereas summaries, syntheses, and synopses are often the best resources for answering background questions, they are often insufficient for foreground questions. For these, it is often necessary to search the primary literature. Answers to foreground questions asked by psychologists are most likely to be contained within PsycINFO (the APA’s database focusing on social and behavioral sciences) and/or Medline (the National Library of Medicine’s premier database focusing on health



and medicine). Searching PsycINFO and Medline for the purposes of EBP requires a specialized set of skills that vary depending upon several factors related to the person doing the searching and the systems they are using to access the databases. Because of this, it is advisable to consult with a librarian in your own system about searching individual databases. There are, however, a few basic concepts that are common across systems, and these are important to understand before consulting with a librarian.

1. *Databases need to be distinguished from the interfaces to the databases:* It is important to understand that Medline is not the same as PubMed, and PsycINFO is not the same as EBSCO. Both Medline and PsycINFO are bibliographic databases, which means that they contain references to articles and perhaps some other information about them (e.g., summaries and links), but typically do not contain the full articles. The full articles are delivered via interfaces to (or vendors of) the databases. For example, PubMed is the main open access interface to Medline; it is not the database itself. Ovid is a very expensive interface to Medline that is usually available only through institutional subscriptions. As one might expect, highly specific Medline searches are much easier to perform using Ovid than using PubMed. PubMed does, however, offer a relatively new link called “clinical queries” which allows one to search specifically for systematic reviews and other high-quality evidence-based literature. Similarly, EBSCO and CSA Illumina are commonly used interfaces to (i.e., vendors of) PsycINFO. The distinction between databases and interfaces or vendors is important because each vendor uses a different method of searching and filtering for evidence-based information, but the user should understand that the underlying database remains the same.
2. *Medline and PsycINFO do not contain the same information:* Although there is overlap between articles referenced in Medline and those in PsycINFO, there are many articles that are unique to both, so it is critical that psychologists search at least these two databases when doing evidence-based searches. Perhaps even more importantly, psychologists need to be aware that PsycINFO does not currently link to the Cochrane Library, which means that if one searches only PsycINFO, one will miss all the systematic reviews contained in the Cochrane Database. Psychologists should familiarize themselves with other large health care databases as well; answers to nutrition questions, for instance, are most likely to be found in CINAHL (the premier nursing database), and at times it is important to search EMBASE as well, which is the European equivalent to Medline.
3. *EBP searches require combining and filtering datasets using controlled vocabulary:* Regardless of the interface or the database, there are some common principles for doing EBP searches. Librarians have developed empirically supported strategies for conducting EBP searches in Medline or PsycINFO, for example, which include taking the following into consideration regardless of the interface or database that is used [28].

- A. *Select terms from the controlled vocabulary list:* According to librarians who specialize in EBP, failure to use the controlled vocabulary is the most common cause of difficulty in retrieving a manageable number of highly relevant articles. To illustrate this point, consider the following: A practitioner is interested in learning more about acupuncture as a treatment and types the word “acupuncture” into a search box. A typical interface will display all the articles that contain the word “acupuncture.” It will display reports about the history of acupuncture, it will display articles that claim their data are unrelated to acupuncture, and it will display articles about acupuncture as a treatment. It will not display articles about “acupressure” as a treatment. Given this example, it is easy to see how searches based on keywords will retrieve many irrelevant articles and fail to retrieve many that are highly relevant. Efficient EBP searching requires a method that links articles to concepts rather than specific words, and that is precisely the purpose of the controlled vocabulary.

When articles are entered into databases, librarians code different concepts associated with each article using standard terms that are referred to as the controlled vocabulary. In our example above, entering the controlled vocabulary term “acupuncture therapy” in Medline would yield only articles on acupuncture as a therapy regardless of whether the article referred to the method as acupuncture, acupressure, or electroacupuncture. In Medline, controlled vocabulary terms are called MeSH terms (Medical Subject Headings) and can be found in the online MeSH database [29]. In PsycINFO, these terms are called descriptors and can be found in the Thesaurus available online or purchased from APA directly [30].

- B. *Use truncation for keywords if needed:* Another technique for expanding a search to include papers that use different terms for the same concept is to truncate keywords. Each interface has a symbol one can use to truncate a keyword, which means to search for any word beginning with the specified letters. Using the example above, entering acup\$ (\$ is the truncation symbol in this case) as a keyword in Medline will include articles that include the words acupuncture and acupressure. Entering behav\$ will include all articles that contain the words behavior, behaviour, behaviorally, behaviorism, etc.
- C. *Filter for the appropriate level and type of evidence-based papers:* Each interface includes specialized techniques to filter for different levels of evidence (e.g., summaries, syntheses, etc.), different types of papers at various levels (e.g., systematic reviews, evidence-based guidelines, etc.), and different types of study designs (e.g., randomized controlled trials, cohort studies, etc.). Exactly how this process is executed differs depending upon both the database and the interface. One excellent example of an evidence-based filter is the one that was developed for searching Medline using PubMed. When doing PubMed searches, there is a list of “PubMed Tools” which includes “Clinical Queries.” This link allows users to filter searches by study types (e.g., etiology, diagnosis, therapy, prognosis, etc.) and for systematic reviews. Readers are encouraged to complete an easily accessible online tutorial that

was designed specifically for social and behavioral scientists (<http://www.ebbp.org>) and/or consult a librarian within their system.

### *Step 3: Appraising the Evidence*

As discussed above, EBP practitioners are taught techniques for searching for the “best available evidence” by first searching for high-quality synthesized research, and then moving down the evidence hierarchy. At times, the “best evidence” will be a summary, a systematic review, or an evidence-based guideline addressing the specific question; at other times, the “best evidence” may be a meta-analysis, one or more randomized controlled trials, a qualitative report, or a single case study. Regardless of what type of evidence is found, the practitioner is then faced with the task of appraising it.

Critical appraisal has received a great deal of attention within the field of medicine, particularly since its incorporation into the curriculum at most major medical schools. Although the details are beyond the scope of this chapter, it is worth mentioning some general characteristics of critical appraisal that are particularly relevant to health psychologists. First, critical appraisal is essentially a process whereby practitioners answer three specific questions:

1. How valid are the results of the study?
2. What were the results of the study?
3. How applicable are these results to my particular patient?

To help practitioners in this endeavor, checklists have been published for practitioners in mental health and addictions [14] and worksheets have been developed by the Centre for Evidence Based Medicine for therapy, harm, prognosis, and diagnosis questions (<http://www.cebm.net>). Although the checklists and worksheets vary for each type of question, validity is related to study methodology (e.g., randomization, blinding, bias, etc.) and is ascertained first because if the study is not valid, the data are not likely to be useful. It is also worth noting that studies are not rated either “valid” or “invalid” in EBP; their “truthfulness” exists on a continuum since every study has limitations. Once it has been determined that the evidence is “valid enough” to go further, the practitioner examines the results and their applicability to their patient. Clinicians need to ask, for instance, if their particular patient is different enough from the patients studied in the literature to conclude that the study is not generalizable.

Much has been published on this topic which is beyond the scope of this chapter, but to date the most comprehensive resource is the series of Users’ Guides to the Medical Literature which were published both online by JAMA (<http://www.shef.ac.uk/scharr/ir/userg.html>) and more recently compiled in a volume edited by Gordon Guyatt and his colleagues [31]. For psychologists, excellent resources include the tutorial on critical appraisal on the website [www.ebbp.org](http://www.ebbp.org) which focuses on appraising controlled trials, time series designs, and systematic reviews, and the chapter on appraisal in Norcross et al. [14].

#### *Step 4: Applying the Evidence*

After locating, appraising, and synthesizing the evidence, the clinician conceptualizes the case within the broader (three-circle) framework of EBP. In this framework, clinical decision making takes place at the intersection of three spheres which represent (1) the best research evidence, (2) clinical expertise, and (3) the patient's characteristics, values, and context. As mentioned earlier, the policy statement endorsed by the APA defines the *best research evidence* as "evidence based on systematic reviews, reasonable effect sizes, statistical and clinical significance, and a body of supporting evidence [3]." *Clinical expertise* "develops from clinical and scientific training, theoretical understanding, experience, self-reflection, knowledge of current research, and continuing education and training [3]." Clinical expertise is used to identify each patient's unique health status and diagnosis, and to integrate the scientific evidence with the clinical context. *Patient characteristics, values, and context* refer to the preferences, values, strengths, weaknesses, personality, socio-cultural factors, and expectations that each patient brings to a clinical encounter, as well as the clinical setting itself [3].

One of the major misconceptions about EBP is that these three spheres are integrated all at one time. If this were true, then it would be easy for a clinician to weigh their clinical expertise more heavily than the research evidence. As Norcross [14] has pointed out, there is a specific order to be followed, and the first step in applying the evidence is to gather and organize the research evidence. After that is done, the practitioner asks himself or herself if their particular patient is different enough from those in the research to warrant deviating from the research. Further, using their clinical expertise, they discuss these findings with the patient who plays a key role in decision making. In EBP, clinical decisions are "made in collaboration with the patient, based on the best clinically relevant evidence, and with consideration for the probable costs, benefits, and available resources and options [3]."

#### *Step 5: Assessing the Outcome*

While the importance of this step is often underestimated, assessing the outcome of a delivered intervention is particularly critical. As shown in Fig. 6.1, EBP is an iterative process that requires measuring outcomes and asking new questions as appropriate. EBP clinicians are obliged to decide on a set of outcome measures and as outcomes are assessed, ask more clinically important questions, and repeat the EBP process.

#### *Integrating the Five Steps Using a Case Example*

Thus far, we have described the history and development of EBP and defined EBP as both a conceptual framework and a specific set of behavioral steps one can take to *do* EBP. Understanding EBP from a theoretical perspective, however, is not sufficient. It is important to see how it can be applied in real practice settings. In the next section, we provide a case illustration to give readers a glimpse of how we applied EBP with a patient in a real-world clinical setting.

## Case Illustration

*Our patient<sup>1</sup> is a 39-year-old woman weighing more than 500 lbs (BMI = 73) with co-morbid conditions of diabetes and hypertension. Her primary care physician referred her to Geisinger Medical Center's National Center of Excellence for Bariatric Surgery where the physician recommended a gastric bypass and referred her to us for a required presurgical psychological evaluation. During this evaluation, she indicated that she was motivated to improve her health, but she was uncertain if surgery was the right answer for her. She admitted to fears about having surgery and asked if there were other options available to her. Her clear preference was to lose weight without surgery. Since one of the clinicians had little experience as yet in the area of obesity, she generated several background questions. Three of them were as follows:*

What is (are) the most effective treatment(s) for super obesity to date?

Is bariatric surgery more effective than other more conservative treatments?

What are the risks and benefits of bariatric surgery in a person who is super obese?

To locate the evidence to answer these questions, we first turned to the online resource described earlier called UpToDate to search for broader summaries, which are at the top level of the “hierarchy of evidence.” We entered the terms “morbid obesity” and “treatment” into the search box and found two relevant summaries: “Overview of therapy for obesity in adults [32],” and “Surgical management of severe obesity [33].” In addition, links to evidence-based guidelines from the American Gastroenterological Association were included in the first chapter. Continuing down the “hierarchy of evidence” to syntheses, we then searched the TRIP database for evidence-based guidelines and systematic reviews by entering the term “morbid obesity”<sup>2</sup> into the search box. Search results in TRIP can be filtered easily by the type of results returned (e.g., systematic reviews, guidelines, core primary research, etc.). We initially filtered the results for our background questions by limiting to systematic reviews. A brief glimpse through these titles revealed a recently updated Cochrane review on surgery for obesity [34]. In addition, we performed an advanced search on the National Guidelines Clearinghouse and found the most recent clinical practice guidelines for perioperative nutritional, metabolic, and nonsurgical support of bariatric surgery patients [35]. Finally, we appraised the evidence we found in order to answer our background questions and summarize our conclusions below:

1. What is (are) the most effective treatment(s) for super obesity to date?

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<sup>1</sup> This case is based upon a patient seen by Drs. Collins and Mowery; details have been changed to protect the identity of the patient. At the time the patient was seen, Dr. Mowery was a psychology intern and Dr. Collins was her clinical supervisor.

<sup>2</sup> Although the surgical literature has adopted the term “super obese” for those with a body mass index (BMI) more than 50, we used the term “morbid” rather than “super” in our searches to be consistent with the controlled vocabulary of the resources we searched.

1. There is strong evidence that bariatric surgery results in greater weight loss, and maintenance of weight loss, than conventional treatments for the morbidly and super obese [33, 34].
  2. There is also strong evidence that bariatric surgery results in resolution or improvement of obesity-related diseases, such as diabetes and hypertension, where resolution is defined as ability to discontinue related medications and, in the case of diabetes, maintain blood glucose levels within a normal range, reductions in HbA<sub>1C</sub>, and fasting glucose levels.<sup>35</sup>
  3. There is some moderate evidence that bariatric surgery results in overall improved quality of life [34].
2. Is bariatric surgery more effective than other more conservative treatments?
1. For morbidly and super obese patients, bariatric surgery results in significantly greater improvements in measures related to weight and diabetic control than patients who received either behavioral or drug treatments [33, 34].
  2. Bariatric surgery is effective for the super obese patients for whom nonsurgical treatments have been ineffective [33, 35].
3. What are the benefits and risks of bariatric surgery in a person who is super obese?
1. Benefits include loss of excess weight (greater than with conventional strategies), reduced body mass index (BMI), improved quality of life, and improvement of obesity-related comorbidities, such as diabetes, hypertension, obstructive sleep apnea, and gastroesophageal reflux disorder. The percentages of patients whose conditions improve enough to discontinue medications are generally more than 50% [33, 34].
  2. Risks include death (less than 1%) and surgical complications (approximately 20%), such as a hernia, infection, obstruction, pulmonary embolism, or anastomotic leak [33].

**Visit 2** *After reviewing the evidence and having conversations with the rest of the bariatric surgery team, we met with the patient again to discuss the options. The purpose of this meeting was to share the evidence we had found and engage in collaborative decision making with regard to a plan. We shared with her that the evidence pointed to the fact that surgery would be best and that for her, the risks outweighed the benefits. She reported that it had been very hard in the past for her to change her eating patterns based on “childhood messages” she received about food. She had already tried dietary counseling and had been unable to stay on a 1,200–1,500 calorie plan. This, combined with the evidence we discussed with her, led to her decision that it would make most sense to go ahead with surgery. She told us that the medical providers indicated that she should have a gastric bypass. At that point, we began working with her to prepare for a bypass surgery by giving her instructions on the necessary behavioral changes (e.g., chewing food thoroughly, eating slowly, separating eating and drinking).*

**Visit 3** *We did not hear from her until 2 months later when she returned feeling very discouraged and having gained weight. She had experienced little success changing her eating behaviors. She became tearful and indicated that she had been unable to lose weight because it would “only bring her closer to bypass surgery.” For the first time, she revealed that having bypass surgery was against her spiritual beliefs. She wondered whether she could have the lap-band surgery, which was also done at our center, as this option would not alter the body God gave her. While she preferred lap-band surgery, the medical providers had strongly recommended she have a gastric bypass. She stated that if she were convinced that bypass surgery was clearly superior with fewer risks, she could go ahead with the surgery.*

This patient’s strong preference for a lap-band procedure raised a more detailed question specific to her situation. We needed to know how effective lap-band surgery is compared to bypass surgery in a super obese patient such as ours. In addition to speaking with the medical team about this, we posed the following foreground question:

- P: For a patient with super obesity (a BMI=73) along with diabetes and hypertension,  
I: is there evidence that gastric bypass is more effective  
C: than the lap-band procedure (in)  
O: promoting long-term weight loss and/or lowering blood sugar and/or blood pressure?

In order to answer this foreground question, we turned to Medline using Ovid, which is one of the most efficient interfaces when searching for evidence to answer the more specific questions. We searched using the MeSH terms, “obesity, morbid” and “gastric bypass” and lap\$ as a keyword. Results were then limited to English and EBM reviews. We found a recent systematic review comparing the two procedures [36] a prospective, randomized trial with 5-year results [37], and two meta-analyses on bariatric surgeries [38, 39]. We also found a 2-year prospective study examining predictors of success in patients who have the lap-band procedure [40]. Finally, we appraised the evidence. We discovered the following:

- Gastric bypass patients lose significantly higher percentage of excess body weight than lap-band patients at 1 year after surgery [36].
- Gastric bypass patients have significantly lower weights, lower BMIs, and greater percentages of body weight loss than lap-band patients at 5 years after surgery [37].
- Weight loss failure, defined as BMI > 35, was significantly higher in lap-band patients than gastric bypass patients at 5 years after surgery [37].
- Resolution or improvement of obesity-related conditions such as diabetes and hypertension is significantly higher for gastric bypass than lap-band patients [36].
- Super-obese patients (BMI > 50) are more than five times less likely to succeed in losing weight with the lap band than patients with severe obesity (BMI between 40 and 49) [40].
- Lap band is NOT recommended for patients with a BMI of 50 or higher [40].

In addition to searching for the answer to our foreground question in Medline, we consulted with the rest of the bariatric surgery team. The medical providers explained that laparoscopic procedures are more difficult than open procedures on patients with lots of fatty tissue surrounding the organs.

**Visit 4** *The purpose of this visit was to help her make a decision. She began by reiterating that she would prefer a lap-band procedure because she did not want to interfere with the body given to her by her Lord. We asked how she felt about hearing what we discovered from a scientific perspective, and she was willing to listen. At that point, we explained to her that studies to date have clearly shown that gastric bypass is much more likely than lap-band surgery to result in her losing weight and maintaining that weight loss. In addition, we explained that bypass surgery would also be far more likely to lead to improvements in her diabetes and hypertension. She listened intently, was clearly disappointed, and remained ambivalent. She understood the reasons for the bypass, but she was also strongly committed to her religious convictions. During the rest of session, we used motivational interviewing [41–43] to help her resolve her ambivalence about having the bypass surgery. Toward the end of the session, she was leaning more toward having the surgery, but remained ambivalent. As a result, our plan is to continue meeting her regularly to help her lose weight using behavioral strategies, help her manage her mood, her diabetes and her hypertension, and to continue to help her make decisions about her health care. Throughout the treatment, we will track her BMI, quality of life, blood pressure, blood sugar, and HbA<sub>1C</sub> levels.*

One may reasonably wonder why we chose this case to illustrate EBP given that the patient did not choose the course of action supported by the scientific evidence. The truth is that we chose this case for that very reason: It illustrates a critically important aspect of EBP that is often ignored. In EBP, practitioners are obligated to find, appraise, and present the highest-level scientific evidence to the patient for the purpose of *engaging the patient in joint decision making*. Thus, EBP does not involve telling patients what they “should” do. It is a process designed to help them take the science, along with a multitude of other factors, into consideration when making decisions. For practitioners, it involves being aware of and respecting the fact that patients choose what information they do and do not share with us and, as a result, their decisions may not make sense to us at times. Ultimately, however, EBP begins and ends with each patient; they make their own choices. As illustrated in the case above, motivational interviewing is a necessary skill for this step of EBP; practitioners who are not proficient in this would benefit by receiving training. There are also some new clinical decision-making tools that can also be useful in the process.

### ***Psychologists as Research Generators and Synthesizers***

Thus far, we have focused on EBP from the perspective of practitioners learning to “pull” in the information they need. Many writers and speakers have correctly asserted that “to have more evidence-based practice, we need more practice-based



evidence.” Thus, psychologists can play a significant role in the “push” of EBP at every level of the pyramid shown in Fig. 6.2. With regard to individual studies, there is no doubt that psychologists will continue to make important contributions regarding empirically supported treatments. It will become increasingly important, however, for psychologists to ensure from the start that their studies will be included in future systematic reviews and summaries. To date, the majority of primary studies published are usually excluded from systematic reviews for a variety of reasons. Research psychologists need to be aware of the reasons for exclusion in their specific topic area, and rigidly follow the accepted standards for reporting so their work will later be included in higher-level publications such as syntheses and summaries. There are several useful resources that articulate these standards—see, especially the APA standards for reporting research in psychology [44], the Quality of Reporting of Meta-analysis (termed QUOROM) [45], and the Consolidated Standards of Reporting Trials (termed CONSORT) [46].

Moving up the pyramid in Fig. 6.2, another important role psychologists can play is in synthesizing existing evidence and performing systematic reviews. As described earlier, systematic reviews offer an invaluable contribution to the literature because health care providers, consumers, researchers, and policy makers are inundated with unmanageable amounts of information. The details of each step are beyond the scope of this chapter; those who want to learn more are referred to other resources such as the *Cochrane Handbook for Systematic Reviews of Interventions* (available at [www.cochrane-handbook.org](http://www.cochrane-handbook.org)) and the Evidence-Based Behavioral Practice systematic review training module ([www.ebbp.org](http://www.ebbp.org)).

Critical appraisal of individual studies is yet another area in which psychologists can become involved. The Center for Reviews and Dissemination currently operates the DARE whose mission is to identify and appraise systematic reviews on the effects of health interventions around the world. Each systematic review is independently assessed by raters, and those that meet criteria are then published as abstracts in the DARE database. These abstracts include a description of the methods, results, and conclusions along with a critical assessment of the review’s validity and reliability written by health researchers with expertise in systematic reviews. DARE currently includes 15,000 abstracts of systematic reviews; more detailed information on how to write abstracts for DARE can be found on their website (<http://www.crd.york.ac.uk/crdweb/>).

Of particular interest to psychologists is *Evidence-Based Mental Health*, an on-line multidisciplinary journal published quarterly by the *British Medical Journal* (<http://ebmh.bmj.com>), that operates in a manner similar to DARE. They search an extensive range of international medical journals, identify the highest-quality studies, and ask clinicians to assess their relevance and present the best, most relevant studies in succinct abstracts. These evidence-based abstracts are organized into categories that include areas very familiar to psychologists: treatment, diagnosis, etiology, prognosis, and health care economics. This journal also includes qualitative research which is rare among evidence-based journals. Each abstract is accompanied by an expert commentary regarding its clinical application. Psychologists have been vastly underrepresented among the clinicians that have been involved to

date. One excellent way to become familiar with this unique publication is to arrange for the table of contents to be sent to you directly each quarter (<http://ebmh.bmj.com/cgi/alerts/etoc>).

At the level of summaries, the APA has just begun an initiative to create evidence-based guidelines, and psychologists have the opportunity to become involved in this endeavor over the next several years. There are also opportunities for psychologists to contribute to some of the most commonly used evidence-based summary resources (e.g., UpToDate and Clinical Evidence) that include a variety of psychological topics. Finally, given their extensive training in areas such as informatics, cognitive science, neuroscience, and social science, many psychologists are uniquely qualified to make significant contributions to developing the very top level of EBP by designing systems that will ultimately enable evidence-based practitioners to provide better health care for their patients.

## Concluding Remarks

Few would argue with the fact that translating research into practice is a daunting task. Practitioners need practical, efficient methods for locating the best research evidence, appraising it, integrating it with clinical information, and helping their patients make the best possible health care decisions. In this chapter, we illustrated how EBP can prove useful in this process. Like any new skill, however, learning EBP takes time and effort, and this represents a significant challenge for busy practitioners. Is it worth the effort? One reason to consider it as worthwhile is that research evidence is continually being updated, and new treatments are constantly being developed and tested. It seems reasonable to hypothesize that EBP has the potential to improve clinical outcomes, and this now needs to be tested in psychological settings. Furthermore, as the scientific evidence for behavioral health treatments continues to evolve, practicing psychologists are ethically bound to update their knowledge. One of the major strengths of EBP is that it provides a set of skills for lifelong learning.

On the other hand, few recent topics have elicited more controversy in the field of psychology than the question of what constitutes the best evidence and how it should be used to inform clinical decisions. Not surprisingly, EBP has been a source of lively debate among psychologists [13]. In spite of the controversy, there is general agreement that EBP presents both opportunities and challenges for the field. With regard to challenges, the techniques and infrastructure that have been developed for EBP emerged in the field of medicine and may not directly translate to the behavioral sciences. Consequently, although there are many resources and tutorials available for learning EBP [47–49], we are aware of only two that are oriented toward the behavioral and social sciences [18]. In addition, many clinicians lack an affordable, easy way to access full-text research articles, and this is a serious barrier to practicing EBP. Another challenge for psychologists is that PsycINFO does not currently index the major databases that contain systematic reviews. As such, the

highest level of EBP evidence is not accessible via the resource used most often by clinical psychologists. Moreover, although EBP has become an integral part of the curriculum in many medical schools and nursing programs around the country, it is just starting to be integrated into graduate programs in clinical psychology. In spite of these challenges, EBP presents exciting opportunities for psychologists. Although much work is needed to adapt this approach for use in psychological settings, it is not too soon for scientists and practitioners in psychology to engage in an active dialogue about EBP [50]. Additionally, it is not too soon for psychologists to begin applying EBP in clinical settings and become involved in writing critical appraisals, collaborating on systematic reviews and online evidence-based summaries, and devising new systems for the future. In this chapter, we illustrated just a few of the many techniques available in EBP for developing an evidence-based treatment plan for a patient suffering from super obesity. Although still in its infancy and much work lies ahead, EBP has the potential to improve standards of care by bridging the gap between science and practice, arguably a fundamental goal for all health care providers.

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**Part III**  
**Practice Issues**

# Chapter 7

## Marketing Health Psychology

Steven M. Tovian

### Introduction

Professional services are not products, and marketing professional services is not simply product marketing. A product is tangible, something you can see and touch. A service, by contrast, is intangible. Clinical psychologists in health care organizations provide professional services to patients, health care providers (i.e., physicians, nurses, and other health care professionals), and other systems within the health care organization.

A formal definition of marketing involves the analysis, planning, implementation, and control of carefully formulated programs designed to bring about voluntary exchanges of values for purposes of achieving organizational objectives [32]. In psychological practices, the values exchanged are often professional services for an appropriate fee. Marketing relies heavily on designing the products and services of a practice in terms of the target market needs and desires as well as on using effective pricing, communication, and distribution to inform, motivate, and serve the intended markets. Psychologists' professional core competencies and skills, as enumerated by the American Psychological Association (APA) Practice Directorate [2], include relationship building, research, assessment, problem solving, facilitating change, expertise in behavior, program design and evaluation, and

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You can't see them—so how do you sell them? That's the problem with services. (H. Beckwith 1997, p. xiii)

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communication skills. Practitioners can use these very same core skills to help build, manage, and market their practices. Essentially, marketing is what psychologists do best—building relationships and influencing change.

Marketing may be seen as communicating one's skills and services to potential patients, health care providers, and health care organizations. Marketing involves a process by which a clinical psychologist or group of clinical psychologists in a medical setting, for example, systematically determines the needs of potential patients and potential consumers and subsequently develop a plan to meet those needs. Marketing involves making sure potential consumers and customers are aware of such services [1].

Marketing is an attitude. It is a way of thinking about the role of clinical psychology in a health care center and the needs of the health care setting that leads to opportunities that will provide the best match between skills, interests, and the needs of others. A marketing attitude means that you, your group, or your program in clinical psychology is always looking for appropriate ways to assist patients and health care professionals, and always being alert to new information that can be translated into meaningful services [1]. For example, if it is learned that a considerable number of postsurgery cardiac patients at your medical center do not continue to take their medications or remain noncompliant with recommended lifestyle changes, you, as a clinical psychologist, or members of your clinical psychology program may consider evidence-based services that could be developed to help reduce the incidence of negative outcomes among these cardiac patients in the medical center.

Marketing is about commitment and persistence and about a willingness to promote. It is the process of educating others, and very importantly, it is about planning. Marketing requires careful thought regarding: the goals and purposes of practice of clinical psychology in a specific health care setting; the skills, knowledge, and competencies brought into such a practice; and the external barriers to success such as the potential competition, perhaps seeking the same goals in the health care setting [29].

Rabasca [22] pointed out that psychologists have traditionally eschewed anything to do with business, marketing, or merchandising their services. What was once viewed skeptically as an unethical and unsavory tactic involving selling and profit is now being seen as a legitimate opportunity to educate or serve the public. Business planning and marketing provide an opportunity and methodology to educate consumers and policy makers, allow patients in need to get assistance with medical conditions, and ethically and professionally build the practice of clinical health psychology. In addition, many professionals equate marketing with public relations or selling. Although some elements of both may be present in marketing, they are more often activities performed to reach a specific marketing goal [33]. However, the enormous and complex changes in health care delivery as a response to much needed quality assurance and cost-containment reform indicate *all* professional psychologists, including clinical health psychologists, need to develop innovative evidence-based models of health care delivery and then learn to market these models to patients and other all other consumers involved in health care.



**Table 7.1** The marketing process. (Adapted from [1])

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Analyzing market needs and opportunities
Selecting marketing targets
Developing market strategies
Developing a market plan
Implementing and the marketing plan
Evaluating the market plan

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## The Marketing Process

There are six basic steps to the marketing management process: analyzing market opportunities, selecting marketing targets, developing market strategies, developing a market plan, implementing the market plan, and evaluating the market plan [1]. The steps involved in the marketing process are listed in Table 7.1.

### *Analyzing Market Opportunities*

Analyzing marketing opportunities begins with gathering information about the internal and external marketing environments. A clinical psychology program can assess its internal environment by examining its capabilities, strengths, weaknesses, financial status, and information systems in the context of personal and professional terms. A program may assess the external environment, including demographics (potential referral sources, patient population, age, diagnostic mix), economics (budget constraints, income distribution, income from grant and clinical services), and political trends within the medical setting. Clinical psychologists should examine general health care trends in the community as part of their external environment and to aid in planning marketing efforts. For a more detailed discussion on the marketing process, the reader is advised to consult texts by the American Psychological Practice Directorate [1], Beckwith [4], and Kerin, Hartl, and Rudelius [15].

One of the biggest marketing challenges is trying to understand potential referral sources or consumers. A clinical psychology program might examine how cultural, social, personal, and psychological factors affect consumer or patient behavior.

For example, consumers go through four steps in the decision-making process: problem recognition, information search, evaluation of alternatives, and purchase decision [15]. Understanding the markets in a community and medical setting may provide insights as to what unique services you or your clinical psychology program may provide [18].

### *Selecting Target Markets*

Selecting target markets, the second step in marketing planning, involves forecasting the attractiveness of various markets and dividing them into segments to make the marketing effort most effective. A clinical psychology program can estimate

demand by using a variety of methods to determine which market segment might be the most efficacious to enter. The most popular method is by assessing the needs of potential referral sources and consumers. A program often evaluates market segments in an effort to determine which would be best to target. One evaluation tool is to examine a factor that can determine the long-term attractiveness of a market in a medical center, that of competition or perceived overlap of services from other departments or programs. There are several patterns that programs can use to select target markets: single segment (e.g., individual patient consultation and intervention), multi-segment (e.g., family and individual patient intervention), product specialization (e.g., assessment and testing, biofeedback), market specialization (e.g., adult oncology patients), and full market coverage including all patients and all services [1]. Attempt to quantify the potential demand for your or your program's services. In other words, what is the share of the market for clinical psychology services in the medical setting that you can realistically expect to obtain? It is easy to overestimate success, so carefully consider health care demographics, assets, and constraints within the medical setting, and any assets you may have to gain referrals. A situational analysis will enable you or your program to evaluate whether services originally contemplated to offer is the right one for the market chosen. The practice or services envisioned within a community or health care setting must mesh well with the market you have chosen and the services you provide. The market must be not only the right one in the health care system but also the right one for you and your program [18].

### ***Marketing Strategy and Marketing Mix***

A marketing strategy requires determination of long-range objectives to allow a psychology practice or program to focus its efforts. Differentiation is designing a practice's or programs' service offerings to create a distinct impression in the potential referral source or consumer's mind. Some clinical psychology programs in a medical setting go through a life cycle that requires different marketing strategies at different stages [1].

Four distinct roles exist for a practice or program: market leader, market challenger, market follower, and niche player. The market leader is the practice or program with the largest market share in any relevant market. Typically, a market leader attempts to expand the total market demand, defend the market share, and expand the market share. A market challenger attempts to challenge and become the market leader while a market follower may attempt to mimic the market leader's services, distribution, or promotion while slightly differentiating themselves from the market leader. Finally, a niche player refers to a program or practice that specializes in market segments not covered by market leaders. Organizations with a total market share can be very successful using a niche strategy [1]. An example might be a psychology practice that focuses on the Medicaid population.

A clinical psychology program's or practice's marketing strategy is determined by its strategic goals, while its marketing mix consists of the four Ps (Table 7.2):

**Table 7.2** Service goals in marketing strategies. (Adapted from [1])

Product/Service
Identification of services
What services are offered?
Pricing
What will the services cost?
Promotion
Why should a referral source choose your services?
Place or distribution
Where and how are your services offered?

product/service, pricing, promotion, and place (distribution). There are several unique issues associated with marketing clinical psychology services: intangibility (location, environment, communication), inseparability (psychologist–patient or psychologist–health care professional interaction), variability (which staff delivers what intervention to inpatients or outpatients), and perishability that often involve improving the match between supply and demand [1]. One way for a program to differentiate itself is to deliver services that are of higher quality in terms of reliability, responsiveness, assurance, and empathy [32].

### ***Professional Image***

Patients and other referral sources decide to obtain or purchase a particular service that will meet their needs and standards of quality. Like a “brand,” a strong professional image for your practice or program communicates a promise of quality, value, and reliability. Professional image can set you and your program apart from competitors by making patients and referral sources aware of you and your program’s unique strengths so you and your services are seen as the preferred choice. Like a brand, professional image reflects the way others think and feel about your practice and services. For more information about image and branding in marketing professional services, readers are referred to Beckwith [4].

Branding has both physical and psychological dimensions that relate to defining a professional image. Physical elements include distinctive graphic elements often seen in promotional materials such as brochures and medical setting websites. Consider working with the marketing department of your health care organization or a design consultant to create a look and feel that is best suited to your practice and program within the medical setting and patients in the community. Psychologically, your professional image as a clinical psychologist affects the way others perceive your practice or program, the value of the services you provide, and the type of patients who utilize your services. These factors can influence whether or not you or your program receive referrals in a medical setting.

Purposefully define your image as a clinical psychologist into statements that serve as an anchor to focus any promotional materials. An effective statement, for example, should reflect your or your program’s mission and values, leverage your strengths, and address the needs of your target market. The main purpose of a

**Table 7.3** Key factors in developing a professional image

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Define your or your clinical psychology program image
Distinguish how your program and services are unique
Communicate consistently over both time and communication vehicles
Evaluate, revise, and monitor results and efforts with the following questions:
How do people perceive your practice or program in clinical psychology?
How aware of your practice or program are potential clients, patients, and referral sources?
How well do others understand the ways you differentiate your practice or program?
Are the aspects that set you or your program apart valuable to patients and referral sources?
How visible is your practice or program in the medical setting, health care organization, or community?
Are competitors duplicating the unique characteristics of your or your program's professional image?

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professional image is to communicate the way in which your practice and program is unique. Claiming that your services as a clinical psychologist are “high quality” is simply not enough to set you or your program apart. Choose an aspect of your practice or program that differs from competitors, cannot be easily duplicated, and that patients and health care professionals value. For example, if you provide family therapy for cancer patients and have well-established relationships with the oncologists in your medical setting, strive for and emphasize your ability to work collaboratively with the entire oncology treatment team to help families through the process. In addition, do not try to communicate that you or your program can be everything to everybody. Emphasize what you do best and deliver it consistently. Support service delivery, if necessary, with documented evidence of training, supervision, and professional experience. The professional image conveys your strengths and provides prospective referral sources and patients with a better understanding of the circumstances in which your services are appropriate and desirable. Once you have defined your or your program's professional image and considered how to differentiate your or your program services, the next step involves creating a communication plan. Identify each of your target audiences (e.g., patients, referral sources like physicians, colleagues, payers), the communication vehicles you have that reach each audience, and the purpose of each communication. Consider how to communicate your professional image in a way that tailors the message to each audience and purpose while maintaining a consistent message. Repeat the same, simple, and focused message year to year in all promotional materials. The effects of marketing are cumulative, so consistency is crucial. Table 7.3 summarizes some key factors involved in developing a professional image.

### ***Implementing Marketing Plans***

The promotional tools that programs can use to communicate their clinical health service offerings include public relations, educational—didactic, and personal contacts with perspective referral sources, direct marketing to patients. The six steps

involved in developing an effective communication or promotional strategy are: identifying the target audience, determining the communication objective, designing the message, selecting communication channels, budget allocation, and deciding on the promotional mix. Again, the public relations department found in medical settings and academic health centers are invaluable resources for marketing assistance. Establishing a good, close working relationship between a clinical psychology program and a medical center public relations department, for example, can be a salient factor for any practice or program success. But remember, the most important elements in marketing are your own ideas, strengths, and vision. A consultant can help articulate your message, but the fundamentals must come from you.

Several important additional communication methods used to communicate clinical psychology professional services and image include making personal contacts with referral sources in the medical setting, giving presentations at case conferences or grand rounds at relevant medical departments, teaching seminars to medical residents and fellows at your academic health center, offering speeches and presentations at local community organizations and both relevant and targeted self-help groups on health psychology issues, increasing visibility through contributions to your medical setting online website or patient magazine, writing consumer-oriented clinical health psychology articles for local newspapers, or becoming a reliable source of health psychology insights for local reporters in print, radio, television [18].

### ***Evaluation of Marketing Efforts***

Monitor or track the results of all marketing efforts and adjust your approach as needed. There are several different methods to monitor or track results. Such methods range from less formal means, such as talking with colleagues and health care professionals who refer patients to you and your program, to more formal means, such as patient satisfaction surveys. Market segmentation, for example, involves dividing referral patterns into distinct groups of potential patients with common characteristics allows you or your program's marketing efforts on segments that are most likely to respond to your marketing communications, seek your services, and benefit most from them. Market share analysis, for example, reveals how well a practice or program is performing relative to its competitors. To be most effective, market share analysis should evaluate a practice or program's performance against that of its closest competitors in size, service, location, and other relevant factors in the medical center [2].

Yenney [32] outlined several important parameters involved in assessing outcome and effectiveness of marketing efforts. These parameters, for example, can include the number of patients, diagnosis, referral source (e.g., medical departments, individual physicians, insurance organizations), type of assessment technique utilized (psychological inventories), type of intervention, inpatient and outpatient location, the average number of sessions per diagnosis and intervention, and payor mix. If possible, for each diagnosis, compute the average cost per case. Such data can be used to assist budgeting and demonstrate the cost-effectiveness of professional services.

Revenue analysis can assist in evaluating patient fees compared to program revenue goals. Organize and review these data on a regular basis. If more than 20% of referrals, for example, come from one source, make sure you are actively working to build and maintain this source. You might also consider diversifying your referral sources to protect yourself from any major changes that could adversely affect revenues.

### ***Customer Satisfaction Tracking***

Customer satisfaction tracking is a qualitative control measure that is extremely important in the management and marketing success of a practice or program in clinical psychology services. Given the highly personal and interactive nature of these services, customer satisfaction is a necessary qualitative measure that can assist in practice or program growth (i.e., attracting new patients, increasing new referral sources, increasing client retention and loyalty) as well as means to provide early warnings of impending changes in market shares [3]. Practices and programs should develop systems and measures to monitor the attitudes and satisfaction levels of patients and referral sources. This conduit for feedback should be viewed as a constructive part of any practice program. The reader may wish to review Yenney [32] for some examples of practice analysis forms.

### ***Ethical and Social Responsibilities***

Practices and programs in clinical psychology need to ultimately evaluate whether they are practicing ethical and socially responsible marketing. A practice or program's business success is ultimately tied to the adoption and implementation of high standards business and marketing conduct. By assessing the quality of a practice or program's performance along ethical and social responsibility guidelines [8], marketing efforts are most likely to follow the same high standards of action.

### ***Summary***

Marketing professional services involves communicating and building relationships with potential clients and referral sources. It requires a basic understanding of approaches that generally produce positive results, and those that do not. The APA Practice Directorate [1] offers some practical guidelines that are summarized as steps to consider and steps to avoid. They are listed in Table 7.4. Steps to consider include: getting marketing materials whether they be business cards, websites, brochures, etc. in front of perspective referral sources and, literally, in their hands; marketing services in terms that potential clients, patients, and referral sources can understand; being brief and succinct in explaining the value of services offered; focusing on the benefits of services provided; identifying unique professional

**Table 7.4** Marketing guidelines to “consider” and those to “avoid” (Adapted from [1])

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Attempt to...
Place marketing materials before or in the grasp of potential referral sources
Market services using terms that potential clients and referral sources understand
Be brief and succinct in explaining the values of services provided
Focus on the benefits of the services offered
Identify your or your groups' unique professional strengths and expertise
Build relationships with all, other health professionals who interact with patients in the target market
Observe and learn how clinical psychologists in other markets and medical settings market services
Measure the effectiveness of marketing efforts
Avoid...
Basing marketing efforts on untested assumptions
Becoming irrelevant to ongoing referral sources
Assuming “expert” status in marketing
Stopping marketing efforts
Excluding marketing costs in your or your program's budget
Offering services that referral sources and patients do not value

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strengths and expertise; building relationships with other professionals who interact with patients in your target market—for example, nurses, nurse practitioners, physical therapists, speech therapists, occupational therapists, physician assistants, dieticians in medical settings: observing how clinical psychologists in other markets and medical settings, even competitors, market similar services; measuring the effectiveness of marketing efforts and track results by talking to referral sources; and becoming an “expert” in marketing. Learn to use the services already established in the marketing or public relations department in the medical setting. Steps to avoid include: avoid making marketing efforts on untested assumptions. Instead, use marketing or public relation departments in the medical setting to know your client base and target base; avoid becoming irrelevant. Monitor the environment in the medical setting, the surrounding communities served, and important professional trends. Identify professional competencies that will become increasingly important and develop related skills; learn to use the services already established in the marketing or public relations department in the medical setting; and avoid stopping marketing efforts. Marketing is an ongoing investment that requires constant review over time by you as an individual practitioner, your clinical psychology program, division, or department in the medical setting; avoid shortchanging marketing efforts in your budget whether you are an individual practitioner, within a program, division, or department in a medical setting; and avoid offering services that clients and referral sources do not value. Patients and referral sources will eventually not use irrelevant services even if these services are well marketed.

The National Register of Health Services Providers in Psychology [18] summarize additional key points to market a practice or program. These points, which may be adapted for a medical setting or health care organization, may involve: developing quality materials to support outreach efforts to potential referral sources

(i.e., business cards, websites, brochures, letters of introduction); being active in establishing relationships with other professionals (i.e., spending time in physician's outpatient offices consulting with staff and patients, accompanying physicians and residents during inpatient rounds, giving grand rounds presentations to medical departments, joining medical center committees, giving talks in the community and to medical self-help organizations, contributing regularly to local newspaper columns on health issues and to medical center publications typically produced by the medical center public relations department); building and tracking referral networks (i.e., build data bases to track referral sources and patterns as well as patient demographics, formal expressions of gratitude to referral sources, refer to other health care professionals as appropriate as they may refer to you or your program in return, maintain contact with your referral sources and professional network); distinguishing yourself as well as your program and emphasizing what makes you a clinical psychologist (i.e., emphasize those areas of expertise based on training, continuing education, research, and clinical experience to referral sources, assess customer satisfaction and outcomes through validated questionnaires, and obtain board certification).

## **Increasing Referrals from Other Professionals**

In the current market place in medical settings, good clinical skills and solid credentials are necessary, but not sufficient, to create and maintain a successful practice or programs in clinical psychology. Clinical psychologists must also be competent in their professional relationships and activities. There is a recognized spectrum of professional titles, or specialties, for the scope of activities undertaken by psychologists in medical settings and in working with medical patients including clinical psychology, clinical health psychology, neuropsychology, rehabilitation psychology, primary care psychology, pediatric psychology, geriatric psychology, and integrative medicine. In practice, psychologists have functioned as practitioners and carried out research in medical settings for many years. For example, many have seen primary care for clinical psychologists as a relatively new endeavor "even though psychologists have functioned as de facto primary care providers for a sizable part of our history" ([19], p. 3). Similarly, the APA changed its bylaws to include "health" in its mission in 2001 stating that APA's mission is now "to advance psychology as a science and profession, and as a means of promoting health and human welfare" ([14], p. 5). Clearly, psychologists have been involved in medical care for many, many years even while many practitioners are seeking to expand their practices into this realm today. Belar et al. [7] offer those practitioners a model of self-study that can be used "to assess their readiness to provide services to patients with physical health problems" (p. 136). Understanding and practicing the "politics of competence" [28] can be instrumental in sustaining or helping to grow a substantial presence in the medical setting.

Rozenky [24] outlines initial considerations necessary for practice in the medical setting which include assuring ethical and competent expansion of practice,



understanding the Health Insurance Portability and Accountability Act (HIPAA) and the management of protected health information, record keeping and hospital practice, interdisciplinary communication, credentialing and privileging for medical setting practice, competence to practice, and thorough understanding of the medical setting organization and bylaws. In addition, Robinson and Baker [23] offer important considerations for obtaining medical staff privileging professional appointments in medical settings. The authors recommend: learning and understanding the culture and rules of the medical setting. If you are practicing outside the medical setting and wish to apply for staff privileges to a given medical setting, become familiar with programs and services already established within the existing Psychology Department or Psychology Division. Obtain medical staff privileges via the existing Psychology Department or Division and not through separate individual medical departments which may reflect your practice niche; and as a means to market, make yourself known by attending medical staff meetings and join medical center committees relevant to both your expertise (i.e., pain management committee) and those relevant to the visibility and advancement of the field of clinical psychology (i.e., promotions and tenure committee).

### ***Interdisciplinary Collaboration***

The development of collaborative practice in the medical setting with physicians and other allied health professionals requires patience, perseverance, and good marketing skills. Clinical psychologists should use those marketing strategies that emphasize their expertise as well as inquire about the needs of physicians and their staff as means to insure practice growth. Essentially, along with patients, physicians should be viewed as the primary customers of the clinical psychologists' services [10]. Clinical psychologists need to decide the specific services they are competent, trained, and skilled to offer. Then, they need to identify the key personnel in larger medical practices and departments who need to be contacted. They can also develop methods to educate and inform physicians about their profession, their respective competencies, and of the need and value of the services they offer. Clinical psychologists should apply for professional staff privileges at the medical setting and volunteer to give lectures and grand round presentations to relevant medical departments consistent with their training, experience, and expertise [30]. They can also volunteer to provide smaller office seminars, perhaps at lunch, on salient issues that affect physicians' practice (i.e., management of the high utilizing, somaticizing patient in a primary care practice). Consider advantages and disadvantages of spending time with physicians in their offices and seeing patients there. Psychologists in primary care have demonstrated the value in not waiting for patients to come to their offices but seeing patients in the physician's suite [9]. Psychologists must also consider advantages and disadvantages of participating in managed health care panels. Primary care physicians often serve as "gatekeepers" for such plans, and collaborative work can be facilitated when the psychologist is a member of the same panel as the referring physician.

## ***Nature of Referrals***

In ambulatory settings, psychological services are often geographically separated from medical-surgical services, even in large health care systems. This can be a barrier to integrated care and can hinder patient follow-through with referrals as well as interprofessional collaboration in practice and research. Psychologists in primary care specialties like family medicine and pediatrics provide services where psychologists can practice on-site, often in joint sessions with physicians. McDaniel [16] describes five levels of practice-location based on the proximity the psychologist practices with the primary care physician. The levels range from collaboration from a distance, typical of most independent practitioners in separate offices from the referring physician; collaboration on-site with regular meetings to discuss referrals or problem areas; to collaboration in joint sessions with the physicians as needed. The decision by the psychologist to remain on-site in the physician's office depends upon many factors including the physician's permission and practice style, patient permission and confidentiality, and financial considerations and scheduling, to name a few. Psychologists working in primary care settings have found substantial success with on-site collaborative practice models [13]. Creativity and flexibility in being available for referrals is an important marketing technique to establish a successful practice or program.

## ***Developing the Relationship***

Successful collaborative relationships between health care professionals such as physicians and psychologists depend on the very interpersonal skills that are similar to those psychologists use with patients to facilitate psychotherapy. These same skills, as discussed earlier in this chapter, can be used to build, manage, and market programs [3]. Good, inclusive communication is a crucial element to coordinated care. The psychologist should clarify what information the physician expects them to provide about the patient, and they should specify what information they would need from the physician. Psychologists should have an empathetic understanding of the physicians' worldview as well as an understanding of how the physician may approach patient care differently from psychologists. The psychologist needs to have tolerance for their position on a health care team that is often hierarchical. Psychologists also should avoid overidentifying with the profession of medicine or undermining a preexisting treatment plan. This can be an issue with regard to psychotropic medication in primary care, for example. Psychologists who may be skeptical of the efficacy and use of psychotropic medication must be careful not to undermine the patient's motivation to follow through with the medication. In such a situation, a discussion with the primary care physician is warranted. Psychologists should avoid triangulation with the patient if they disagree with the physician on the treatment plan [12]. Never compete for who cares more about the patient. Collaboration is key and will benefit both professionals and patients.

Psychologists will also want to develop good working relationships with the physician's ambulatory staff, which can include nurses, nurse practitioners, physician's assistants, rotating residents (if the physician is on staff at an academic health center), practice managers, secretaries, and even office billing and coding clerks.

### ***Differing Physician Styles***

Primary care physicians (i.e., family medicine, internists, pediatricians) attempt to meet the broad health care needs of their patients, whereas specialty tertiary care physicians (i.e., cardiologists, oncologists, endocrinologists, surgeons) provide in-depth care for selected patients who meet certain diagnostic and treatment criteria. Psychologists would do well to understand the culture of the organization where the physicians practice (i.e., large medical group practices, boutique medicine practices) as well as those specific techniques and procedures needed to function. Psychologists may ask new referral sources whether they prefer written or telephone feedback about their referrals. They should educate physicians about referral criteria in a manner that is neither defensive nor arrogant. Psychologists may need to be willing to expand their expertise via additional training and/or supervision to meet selected patient needs of a particular physician or group practice [20]. Responding to the needs of referral resources is essential in marketing efforts.

### ***Communication Parameters***

It is crucial that psychologists are precise in both verbal and written communications with physicians. Physicians, like most health care professionals are pressed for time. The psychologist may only have a very brief time window of opportunity to make a verbally salient point about a patient. Written consultation reports should be brief, concise, and void of lengthy narratives, which all too often the harried physician will never read. Reports should offer specific and practical recommendations that are relevant to the patient's presenting problem(s) as well as plans for follow-up. The psychologists should use terms that are easily understood in verbal and written communications. Never try to "dazzle" the physician and the interdisciplinary health care team with your theoretical sophistication. The psychologist may need to avoid using mental health terminology that can be misunderstood by the interdisciplinary health care team. For example, health care professionals may not always correctly understand the term "borderline personality".

If possible, psychologists should make attempts to schedule regular times with referring physicians and their relevant staff to discuss referrals. Such meetings are also excellent opportunities for the psychologist to make presentations about psychological issues in patient care. Finally, psychologists must protect patient confidentiality, as physicians are not often accustomed to the different confidentiality obligations followed by psychologists by laws and ethical standards. It is imperative to address all necessary privacy concerns with patients prior to releasing

**Table 7.5** Effective communication parameters with health care professionals. (Adapted from [30])

Be aware of different physician styles and needs
Protect patient confidentiality
Avoid jargon
Be brief and concise in written and verbal communications
Schedule regular meetings with health care team when possible
Keep the physician in the communication “loop”

confidential information or discussing this information with the collaborating physician. In an effort to provide integrative, seamless, high-quality outpatient care, appropriate documentation and recommendations need to be in the patient’s chart without revealing unnecessary sensitive information [27]. Recommendations for effective communications are summarized in Table 7.5.

### *Additional Necessary Skills*

Psychologists who are integrated into ambulatory health care settings will need additional specific skills to adapt to that setting and optimize success. Several of these skills are summarized in Table 7.6.

Psychologists should avoid lengthy assessment measures and reports typically used in mental health settings. To be useful to physicians and medical patients, the psychologist would be wise to use brief assessment measures (see [5, 11]) targeted to biopsychosocial domains with norms from medical populations. Broad, closed-ended questions should be used to cover general areas such as anxiety and depression in initial assessment. Referral for more in-depth assessments, such as neuropsychological assessment, can be made at a later time or part of longer-term recommendations. Traditional 50-min psychotherapy sessions may not be relevant or even possible in ambulatory health care settings. The Current Procedural Terminology (CPT) codes for psychology assessment and interventions with medical diagnosis are coded in 15-min intervals or *units*. In ambulatory health care settings, consultations, assessments, and interventions do always fit into 50-min segments as with traditional psychotherapy. Be comfortable with brief episodic and continuous care often seen in a primary care model that is quite different from the thorough “treat everything in one course of therapy” approach [11]. When engaging in consultation with medical patients, for example, psychologists should expect periodic cancellations because of illness or treatment side effects (i.e., an oncology patient cancels an appointment secondary to low platelet count from chemotherapy). Psychologists must often make conclusions and recommendations based upon limited and diverse sets of data from several biopsychosocial domains. Avoid unsupported, nonevidence-based conclusions or treating all patients the same without regard to individual differences (i.e., not all diabetic patients are alike as not all depressed patients are alike). The psychologist should be knowledgeable about the best indicators, key factors, risk factors, and predictors of a particular disorder or problem area. Flexibility in the delivery of diagnostic and treatment services is important.

**Table 7.6** Additional necessary skills for successful collaboration. (Adapted from [30])

Focused assessments
Time and session efficiency
Decisive decision making with diverse and limited data
Knowledge of evidence-based practices
Flexibility in delivery of services
Enhancing patient motivation for change
Understanding medical conditions, procedures, and medications
Obtaining ABPP <sup>a</sup> board certification

<sup>a</sup> American Board of Professional Psychology

The psychologist should be prepared to expand clinical services to different settings (i.e., inpatient milieu when following a chronically ill patient) or to different targets (i.e., the patient and his/her family). Also, the psychologist should be prepared to provide educational, didactic services to patients, families, and health care staff. They should not neglect opportunities to influence public policy and participate in the political process on behalf of patients, medical conditions, and our profession.

Psychologists in collaborative health care settings should understand models for attitude and behavior change (i.e., [21]) and motivational interviewing [17] that often appeal to the action-oriented results favored by physicians in health care. Within primary care, for example, problems involving weight control, substance abuse, exercise, smoking cessation, and adherence to medical regimens are often amenable to these aforementioned approaches to behavior and attitude change [10].

Working in a primary or tertiary medical setting requires knowledge of medical terminology, a basic understanding of common diseases and their treatments, and a familiarity with medications. The establishment of a well-selected reference library is essential for maintaining this knowledge. This library should include medical dictionaries, texts, medication handbooks, and access to reliable Internet sites.

Board certification, as administered by the American Board of Professional Psychology (ABPP), is intended to serve the public and the profession of psychology by recognizing education, training, experience, and competence in specialty areas of professional psychology. Belar and Jeffrey [6] have proposed that board certification be the standard for all practicing psychologists as it is in the medical profession. Physicians readily identify with the need for and importance of board certification. Psychologists would be wise to follow this direction and obtain ABPP board certification in their designated specialty.

### ***Future Challenges***

Through effective marketing, the field of clinical psychology can plan wisely for the future or be victims of that very same future. The challenges imposed by new health care reforms and technology are clearly defined—provide the most effective medically and psychologically necessary services at the lowest possible cost.

Financial accountability will be paramount in any new evolving health care system. The competitive pressures from the health care market place demand accountability and require a science-based model of behavioral health care delivery [26].

Clinical psychology must be more active at promoting services at numerous levels. For example, the field must market to consumers by developing media relationships and make grassroots efforts by becoming more involved in medical self-help chapters and organizations. Clinical psychologists must deal directly with benefit administrators of large corporations and market the value of clinical psychology services (e.g., decreased medical utilization with behavioral health interventions). Finally, psychologists must use marketing skills on a political level and become more active in educating politicians and the makers of public policy about the important contributions psychologists can make in promoting health, well-being, and cost-effectiveness. The scientist-practitioner model of training for health psychologists is well suited to develop an accountable, data-based model of behavioral care in medical settings. Using effective marketing techniques to communicate our field's unique contribution to health care and, in essence, help shape our future is far better than having others impose their mandates and solutions upon our profession [29, 31].

## ***Summary***

When asked what are the three most important aspects of marketing and developing a collaborative relationship with physicians in ambulatory and inpatient settings, one could answer, "build the relationship, build the relationship, and build the relationship." There are very few professionals who possess more knowledge about relationship enhancement than psychologists. With changes in the health care system and increases in scientific knowledge base, our profession can anticipate expansion of psychological practice across the spectrum of health problems. Collaboration with physicians offers many challenges and opportunities for psychologists who remain faithful to the scientist-practitioner model in psychology. Physicians need us, we need physicians, and patients need us both [16].

## **Conclusions**

This chapter has outlined the steps involved in marketing professional services in clinical psychology. These steps in the marketing process have been defined and described. One specific aspect of the marketing process, that is, increasing referrals from other professionals, has also been described in detail.

Today's clinical psychologist must learn to apply standard business principles to their practices and programs without sacrificing their clinical and ethical integrity. Responses to the multiple and complex problems inherent in our nation's health care delivery system will have a direct impact on the future practice of clinical

psychologists in medical settings [26]. The market place will reshape health care delivery systems and challenge health care professionals to provide high-quality services at a competitive costs. Psychologists must consider how their practices will fare in this new health care environment. The clinical psychology practice of the future will most likely be larger, more efficient, more business oriented while still quality conscious, better connected to primary and tertiary medical communities, and more vertically and horizontally integrated into health care.

Above all, clinical psychologists will need to acquire more expertise in the art and science of doing business. Marketing is the key to fulfilling the goals of any practice or program in clinical psychology. Strategies for marketing may vary, but the targets are simple: new patients, new referral sources, and placing clinical psychology securely in the public lexicon of health care. To market effectively it is necessary to find out what our customers need and want and then demonstrate that you can fulfill that need in independent practice, medical settings, and medical home environments [26]. Tracking the quality and value of clinical psychology practice and programs are essential to effective marketing efforts, as well as for professional viability and survival.

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## Chapter 8

# Balancing Value and Cost

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Behavioral conditions such as depression, anxiety and substance use disorders, stress and adjustment disorders, and lifestyle habits such as smoking, overeating, and lack of exercise all contribute to worse outcomes and higher costs for patients with chronic medical conditions [1, 2]. Patients with comorbid medical and behavioral conditions are seen mostly in primary care settings where the behavioral conditions that contribute to adverse health outcomes are largely undetected or, when diagnosed, are offered inadequate treatment that does not meet evidence-based practice guidelines [3]. There is a long-standing and growing body of evidence that targeted, focused behavioral interventions delivered in primary care settings can improve both health outcomes and reduce excessive medical costs for patients with chronic medical conditions and patterns of high utilization of health care services [4].

The lack of integration of behavioral and medical health care and the consequences of poor health outcome and excess health care costs have led to calls for integrated care as a key component of health care reform. First, national advocacy groups are actively lobbying for implementation of the patient-centered medical home (PCMH). The Patient-Centered Primary Care Collaborative was formed in 2006, and in 2009 its membership included 500 large employers, insurers,

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consumer groups, and doctors [5]. The American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, and American Osteopathic Association released Joint Principles of the Patient-Centered Medical Home [6]. Second, the government is actively involved in promoting health care reform in an effort to improve quality and decrease escalating costs of care. The outline of health care reform presented by President Barack Obama promotes improved access to prevention and disease management programs [7]. Third, employers are becoming increasingly aware of the adverse impact of chronic medical and behavioral conditions on workforce productivity, and they are searching for health promotion and disease management programs in an effort to reign in the increasing costs of lost productivity and disability [8].

The push of integrated behavioral primary care has created an opportunity for psychologists to demonstrate they can provide great value to the health care system by providing behavioral interventions that both improve clinical outcome and decrease excess utilization of medical services and related high costs of care. However, taking advantage of this opportunity will require a true “makeover” and retooling of the psychologists’ professional role, clinical skills, and view of treatment [9]. In addition to evidence based interventions with demonstrated efficacy in randomized controlled trials and effectiveness in clinical trials, *efficiency* is critical (written communication, N. Cummings, August 2009). Efficient interventions are population based in order to identify patients who are high cost, and require fewer and less costly resources to deliver. Cost–benefit analysis directly compares the cost of treatment with the monetary value of the resulting outcomes [10]. For example, assuming equivalent outcomes, an eight-session group treatment for [12] depressed patients is far more efficient than for each of those patients to receive individual therapy for 8 weeks. This chapter will delineate the key components of primary care-based behavioral interventions that have demonstrated cost savings. In order to understand the opportunity for adding value by demonstrating cost savings, one must first understand the impact of behavioral conditions on health care utilization and cost.

## **The role of behavioral health in total health care costs**

The economic burden of chronic diseases in the USA is a growing problem with more than 125 million individuals having at least one chronic condition in 2000, a projected 157 million by 2020, and 50% of these individuals having more than one condition [11]. Increases in chronic conditions are attributed to medical advances that enable those with chronic conditions to live longer, increased screening and diagnosis of chronic conditions, and the aging of Americans [12]. Treatment of chronic conditions accounts for 78% of health care spending, 76% of all hospital admissions, 88% of all prescriptions filled, and 72% of physician visits [12]. The costs of chronic care fall upon private, employer-based insurance, government programs, and individual insurance premiums paid out of pocket. In 2007,

employers spent an average of US \$ 3,785 and US \$ 8,824 for single and family plans, respectively, above employee contributions [13]. There is increased recognition that in addition to direct medical costs, the financial impact of chronic illness on employers includes decreased work productivity. Employee productivity consists of both time away from work, such as absenteeism and disability, as well as reduced performance while on the job, known as presenteeism. The costs associated with decreased productivity and absenteeism due to illness are three times more costly than the medical costs of care [14–18]. Employees with chronic health conditions have higher medical costs and these conditions result in increased absenteeism and presenteeism [15, 16, 19–22].

There is a significant overlap between behavioral conditions and chronic medical illness. The top 10% of complex chronic patients utilize the majority of health care services and more than half of these patients have comorbid behavioral disorders [23]. The health care cost of patients with comorbid behavioral conditions is twice the cost of patients with medical conditions without behavioral conditions [1]. Depression, anxiety, and somatization, each with prevalence rates of about 10%, and alcohol abuse, with prevalence rates of 26%, are the most frequent behavioral disorders in primary care [24–28] and are present in 25–40% of patients seen in primary care [29]. Studies show that patients with comorbid medical and behavioral conditions have greater morbidity associated with the medical illness, increased health care utilization and poorer functional health status [30–44].

## **Inadequate Quality of Behavioral Care in Primary Care**

It is well documented that the majority of patients with behavioral problems seen in primary care settings do not receive evidence-based care for their conditions. Myette [45] summarized a number of factors that lead to a quality of care gap between usual care and evidence-based management of chronic conditions for depression. These include:

- Patient reluctance to seek treatment due to stigma and other barriers
- Failure to detect and diagnose depression in patients who do seek treatment
- Insufficient dosage and duration of psychopharmacological interventions
- Failure to recommend evidence-based psychotherapy
- Limited access to behavioral health specialty clinicians
- Lack of regular monitoring and relapse prevention
- Failure to integrate medical and behavioral care
- Underutilization of allied health professionals to assist physicians
- Failure to provide education to patients and their families and promote condition self-management
- Failure to use community resources and support

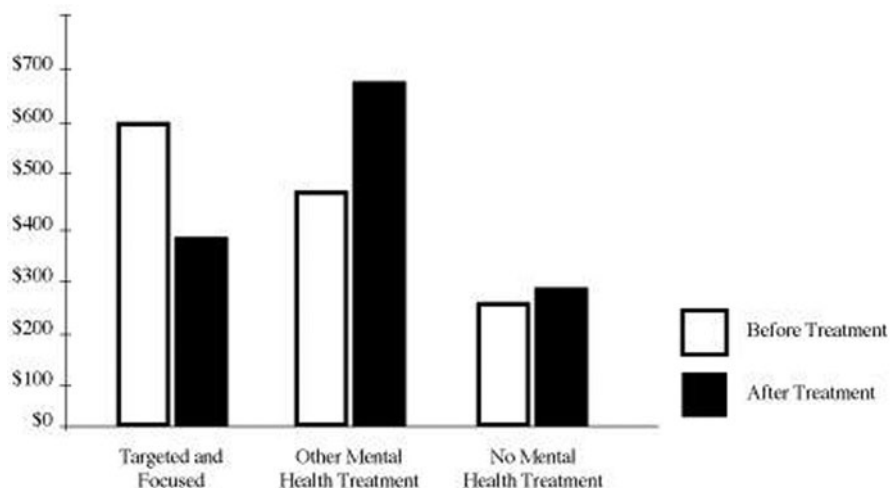
## Physical Symptoms Mask Behavioral Conditions

It is estimated that between 60 and 70% of primary care medical visits are for physical complaints and symptoms that result in no medical diagnosis [46]. One study found that of 70% of such visits, 35% were for anxiety, mood, and somatization; 35% were for stress and adjustment problems; and the remaining 30% were for medical conditions. Even after 10 years of follow-up, no organic conditions were identified to explain the somatization [47]. Patients with behavioral conditions may focus on physical symptoms because they represent real, acceptable reasons for a visit to a primary care provider (PCP) [48]. Patients suffering from comorbid chronic medical and behavioral conditions amplify physical symptoms and may not realize that these symptoms represent diagnosable behavioral disorders [49–54]. These patients often do not receive an accurate behavioral diagnosis at the time of their initial PCP visit [55]. Between 50 and 80% of patients with anxiety and depression initially present with symptoms such as headaches, chest pain, fatigue, and exacerbation of chronic medical conditions, and these may distract physicians from identifying underlying behavioral conditions [48, 55, 56]. Depression, anxiety, and somatization share substantial commonalities in underlying physical symptoms [57] that may also contribute to difficulty in physician diagnoses of these behavioral conditions.

## Review of the Evidence

Several lines of evidence demonstrate that focused, targeted behavioral interventions can lead to medical cost savings in primary care. First, the classic work of Nicholas Cummings on medical cost offset demonstrates the consistent cost savings associated with focused interventions in primary care settings. Second, there has been increased focus on behavioral interventions for somatizers, a population that is characterized by high utilization of medical services. Third, emerging models of population-based, stepped care approaches called collaborative care for depression have demonstrated cost savings. Fourth, behavioral interventions for substance use disorder have demonstrated medical cost offset, and brief substance abuse interventions designed for primary care have demonstrated good outcomes. Fifth, the use of antidepressant medications presents opportunities for cost savings either through interventions to improve adherence or to use stepped care approaches in which behavioral rather than pharmacological treatment is considered as an initial step in treatment.

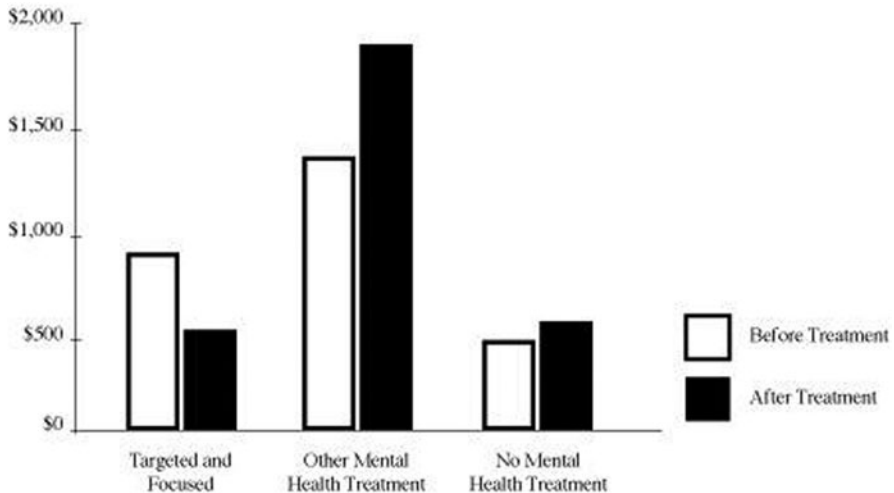
*Medical Cost Offset and Cost Savings* The term “medical cost offset” was first used by Nicholas Cummings and associates in research at Kaiser Permanente [58, 59] to describe how a program of focused, targeted behavioral interventions delivered in an innovative delivery system later called the Biodyne model led to reductions in medical cost that were greater than or offset the cost of delivering the behavioral intervention. These findings were replicated in the Hawaii Project I that has been



**Fig. 8.1** Non-chronic group. Average medical utilization in constant dollars for the Hawaii Project non-chronic group for the year before (*white column*) for those receiving targeted and focused treatment, or other mental health treatment in the private practice community, and no mental health treatment, and for the year after (black columns) for each treatment condition. (Cummings et al. 1993)

extensively reported [60, 61]. The study population included both 36,000 Medicaid recipients and 90,000 federal employees who were randomly assigned to experimental and control groups and were classified as: (1) psychological stress with no medical comorbidity, (2) behavioral and medical comorbidity (asthma, diabetes, emphysema and other airway blockages, hypertension, ischemia, and rheumatoid arthritis and fibromyalgia), and (3) primarily substance abuse. The experimental group received behavioral care from Biodyne centers using specially trained psychologists using a combination of focused individual sessions, behavioral and medical group treatment, and outreach for high utilizers of primary care services. The control group patients were seen in specialty behavioral care.

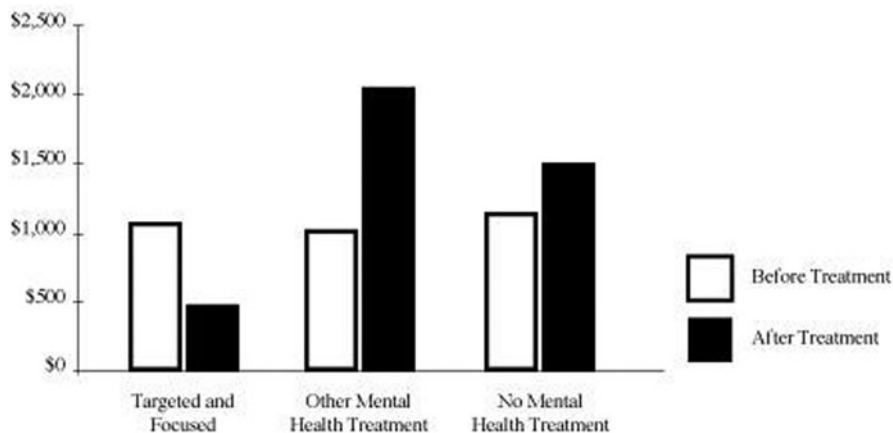
Two principal findings were established: (1) the experimental group resulted in medical cost offset with savings in millions of dollars in medical care and (2) traditional specialty behavioral care delivered in conventional settings *increased* medical costs [60, 61]. The experimental non-chronic, psychological distress group resulted in annual per patient savings of more than US \$ 200, while the control group had a nearly US \$ 200 increase in medical costs (Fig. 8.1). The chronic disease experimental group showed a savings of nearly US \$ 350 per year, while those in the control group showed increased medical costs of more than US \$ 500 per patient annually (Fig. 8.2). For substance abuse, the experimental group showed a US \$ 700 savings while the control group resulted in a US \$ 900 increase, a US \$ 1,600 differential per patient [60, 61] (Fig. 8.3).



**Fig. 8.2** Chronically ill group. Average medical utilization in constant dollars for the Hawaii Project chronically ill group for the year before (*white column*) for those receiving targeted and focused treatment, other mental health treatment in the private practice community, and no mental health treatment, and for the year after (*black columns*) for each treatment condition. (Cummings et al. 1993)

A review of the medical cost offset [4] found that in 90% of studies reviewed behavioral interventions resulted in decreased medical utilization. In addition, (1) an average 15.7% reduction in treatment conditions versus a 12.7% increase in controls; (2) cost savings in the range of 20–30%; (3) in about one third of the studies, significant cost savings even after the cost of the behavioral intervention was subtracted from the savings; (4) behavioral medicine interventions performed better than psychotherapeutic approaches; and (5) the type of professional (e.g., psychologist, social worker) was not significant in producing cost offset.

*Somatization or Medically Unexplained Symptoms* Somatization is defined by Cummings [58, 59] as the manifestation of stress and distress into physical symptoms in the absence of medical etiology or the exacerbation of disease by psychological factors. This term is not equivalent to the diagnosis of somatoform disorder [62]. Somatizers have health care costs 6–14 times the US average [63]; high rates of functional impairment, disability, productivity, and relationship problems result in significant costs to employers in lost productivity [63, 64]. The underlying psychosocial stress and psychological distress are often overlooked [65–68]. Physicians test or treat for medical disease leading to unnecessary laboratory testing and consultation, increased cost of care and high iatrogenic complication rates due to treatments for suspected but absent organic disease [69–72]. The majority of somatizers refuse to seek services outside of primary care with some reporting as few as 10% completing referral [73–75]. Conversely, 81% of somatizers will accept behavioral interventions in primary care settings [76].



**Fig. 8.3** Substance abuse group. Average medical utilization in constant dollars for the Hawaii Project substance abuse group for the year before (*white column*) for those receiving targeted and focused treatment other mental health treatment in the private practice community, and for the year after (*black columns*) for each treatment condition. (Cummings et al. 1993)

The Cummings Hawaii project [60, 61] was the first to demonstrate that a systematic treatment program for somatizers results in cost savings. The model will be described in detail below. A number of other studies have demonstrated similar cost savings. A behavioral medicine group therapy program resulted in improved functioning, decreased symptoms, and decreased cost of care [77]. An intervention based on sending a consultation letter to primary care physicians with treatment recommendations for somatizers resulted in improved physical functioning and a net 21% reduction in health care charges 1 year post intervention [78]. A study using a biopsychosocial intervention resulted in reduced consultant visits, emergency room visits, hospital days, and reduced mortality for the intervention compared to a control group [79]. Other studies utilizing cognitive-behavioral treatment for somatizers have demonstrated significant clinical improvements but not cost savings [80–82].

*Depression* According to the World Health Organization, depression is the third leading cause of disability worldwide [83, 84]. Depression often manifests in patients presenting with physical symptoms and contributes to poor disease control [48]. Between 50 and 80% of patients with depression present with physical symptoms such as headaches, fatigue, pain, and weakness [19]. Patients with chronic medical illness have a higher prevalence of depression than patients without chronic illness, and depression is associated with poor medical outcomes [85]. A meta-analysis reported a significant correlation between depression and complications of diabetes [86]. A study of patients with diabetes showed that those with depression compared to those with diabetes only had poorer adherence to diet, exercise, smoking cessation, and more lapses in taking oral hypoglycemia, antihypertensive, and lipid-lowering medications [87].

Patients with depression incur two times the health care costs of matched patients without depression [88] with medical costs increased in outpatient primary care, medical specialty and behavioral care, hospital-based care, emergency department, laboratory testing, and radiographic imaging [89]. Total health care costs are 50–100% greater for outpatients with depression than those without and these increased costs are predominantly due to higher utilization of medical services than solely due to increased costs for behavioral health services [90–92]. Improvement in depression is associated with decreased medical care utilization [93, 94]. Depression is among the most costly of all health problems for employers in terms of lost productivity [95, 96]. Compared with nondepressed individuals those with depression have more unemployment, absences, and at-work performance deficits [97]. The costs of depression in terms of losses in workplace productivity, increased absenteeism, and presenteeism are greater than the associated direct medical costs. A review of studies found the annual average cost per case of depression was US \$ 1,000–2,500 for medical costs but US \$ 2,000–3,700 for total morbidity [98].

*Collaborative Care for Depression* The collaborative care model of depression is a population-based, stepped care approach designed to improve detection, diagnosis, patient education, and provision of evidence-based care via collaboration between the patient, primary care physician, and ancillary health care providers [99]. A key component of the model is a dedicated case manager, typically a nurse or social worker, to engage the patient as an active partner in treatment. The case manager closely tracks the treatment outcome and helps the patient learn the skills to self-manage depression. Often lifestyle changes such as exercise, diet, and medication adherence are incorporated into treatment. The stepped care model is based on the acknowledgment that: (1) different patients require different levels of care, (2) the most appropriate level of care is based on closely monitoring outcomes, and (3) that moving from lower to more intensive levels of care based on patient response can increase the effectiveness of care while lowering overall costs [100]. The case manager will use measures such as the Patient Health Questionnaire (PHQ-9) [101] to evaluate baseline severity and repeat administrations over the course of the program to monitor progress. Patients with low illness severity may initially receive educational materials, guided self-help exercise, and referral to self-help groups. More intensive treatments may range from brief interventions in the primary care site, such as group treatment programs, to referral to a specialty behavioral health provider for psychotherapy or psychopharmacological intervention. A hallmark of the collaborative care model is that the care manager is typically colocated in the primary care office to assist with the coordination of care and transformation of the health care system consistent with the Chronic Care Model [102]. However, other approaches to collaborative care have used remote case managers who rely on telephonic outreach and management [103].

A meta-analysis [104] of collaborative care for depression reported a twofold increase in antidepressant medication adherence at 6 months and evidence of enhanced depressive and functional outcomes that lasted 2–5 years compared to usual treatment. Cost-effectiveness research shows that the collaborative care model costs between US \$ 125 and US \$ 500 more per year in direct medical costs [105]. How-



ever, recent studies show evidence for cost savings for collaborative care with depression and medically comorbid conditions. Two studies used nurse collaborative care interventions for patients with diabetes and major depression and dysthymia [106, 107]. Cost-effectiveness analysis showed that the increased costs of the behavioral interventions were offset by a larger savings in medical costs for more than 2 years [106, 107]. Two additional studies of collaborative care for primary care patients with panic disorder, most patients with comorbid depression, showed similar results [108, 109]. Both studies showed improved quality of care compared to usual care in clinical outcomes and cost-effectiveness analysis showed that the cost of the interventions was offset by larger savings in medical costs for more than 1 year [108, 109].

*Substance Abuse* A large body of research indicates that integrating treatment for alcohol problems in primary care or general medical settings can result in reduced alcohol use, improved health outcomes, and more comprehensive care [110–114]. Excessive drinking contributes to social, medical, and behavioral problems; injury; and death [115, 116]. The majority of these consequences are a result of excessive drinkers, as opposed to the smaller percentage of patients who meet the criteria for alcohol dependence [117]. A number of studies showed that substance abuse treatment results in medical cost offset of patients with substance use disorders, who are high utilizers of health care services compared to other patients [118–122].

Excessive drinking is prevalent in primary care and is underdiagnosed [123]. In order to better meet the needs of this population, screening and brief intervention programs have been implemented. These interventions typically include feedback on alcohol use, identification of harmful consequences and high-risk situations, motivational enhancement and coping strategies, and a treatment plan to reduce drinking. Meta-analysis show that these interventions result in decreased alcohol use compared to control groups for 1 year or more after interventions [124].

*Antidepressant Medication Treatment Costs and Potential Cost Savings* The predominant approach to depression in primary care is antidepressant medications [125]. Yet research shows that most patients who initiate antidepressant treatment receive dosages lower than recommended evidence-based guidelines [126]. Between one quarter and one-third of patients discontinue medications within 1 month of treatment initiation and about one half discontinue within 3 months [127–129]. A study by Weilburg and associates based on a large sample of HMO patients [130] concluded that a majority (51 %) of patients prescribed antidepressants received inadequate medication treatment defined as never receiving at least a minimum likely effective dosage. Other research has shown that medication treatment that fails to meet minimum standards is unlikely to produce optimal outcomes [131, 132]. The costs of medications for these patients with inadequate treatment trials represented 15 % of total antidepressant costs in the Weilberg study, or US \$ 2.4 million of the total US \$ 15.6 million spent on antidepressants. The recommendations in this study and others often call for improved PCP training in dosage guidelines and improved PCP instructions to patients on continuation of antidepressant medications. In this case, behavioral interventions designed to improve medication adherence such as collaborative care for depression have proven effective [45].

However, another approach to antidepressant medication cost savings is to apply stepped care, tailored interventions using evidence-based decision rules in which antidepressant medication is not automatically the first or only step in treatment. First, research comparing antidepressant versus psychotherapy treatment for depression has found that both are effective and that each has its own merits [133]. Second, there is evidence that many patients, when given a choice, prefer psychotherapy over antidepressant treatment [134]. Third, a major reason for medication discontinuation is side effects. One study [135] reported that 86% of patients reported at least one side effect and 55% reported two or more, the most common being sexual dysfunction and drowsiness (17% each). They also noted that while most side effects occurred in the first 2 weeks, the majority of patients were still experiencing the same side effect [75–105] months after initiation, mostly blurred vision (85%) and sexual dysfunction (83%) [135]. The study also found that physicians underestimated the occurrence of side effects and tended to underrate how bothersome the side effects were to their patients [135]. Given the comparable effectiveness of medication and psychotherapy, patient preference for psychotherapy in many cases, and the significant problem of discontinuation due to side effects, the increased use of behavioral interventions as an alternative to medication only in primary care seems strongly indicated.

## Assessment

A comprehensive and feasible approach to assessment is necessary to document the value of psychotherapy in generating cost savings. A comprehensive approach is needed to measure clinical outcomes, workplace productivity, and utilization and cost of health care services pre- and post-intervention. A feasible approach is based on the use of brief self-report questionnaires, ideally incorporating computerized scoring, reporting, and tracking of results. In addition, systematic patient follow-up is a component of effective collaborative care and recent advances in outcomes management demonstrate that the routine review of clinical outcomes leads to improved outcome, retention, and efficiency. Finally, emerging research demonstrates that computerized and Internet-based programs can effectively be used by patients to improve clinical outcomes and result in significant savings in clinician's time.

*Cost-Effectiveness Ratio* The Biodyne model measures behavioral provider performance based on clinical effectiveness and cost efficiency. The criterion for effectiveness is reduction in patient medical and surgical service utilization from the start of treatment compared to a full year's utilization in a 1-year period prior to the start of treatment. Efficiency is measured based on the number of weighted sessions per treatment episode [136]. For example, individual sessions are counted based on the number of minutes of contact, whereas a 2 hour group session with one therapist and eight patients is weighted one-fourth of an hour per patient. The

cost-effectiveness ratio is the average number of medical services for 1 year prior to the start of treatment divided by the average medical utilization in the year after treatment initiation plus the number of weighted behavioral treatment sessions for that group of patients [136].

*Somatization* Somatization is typically measured with the Patient Health Questionnaire somatic symptom module (PHQ-15) [137]. The PHQ-15 is a patient self-administered questionnaire designed to measure 15 somatic symptoms clusters that account for more than 90% of physical complaints in outpatient settings and most of the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV) somatization disorder symptoms [137]. As a self-report questionnaire, the PHQ-15 cannot distinguish between medically explained and unexplained symptoms but several lines of research support the validity of this measure such as a high correlation between PHQ-15 scores and clinician-rated somatoform disorder [137, 138], and high correlation between the PHQ-15 and functional impairment, disability and health care utilization [139].

*Depression* Depression is typically measured with the Patient Health Questionnaire depression module, the PHQ-9 [140, 141]. The PHQ-9 has been shown to be a responsive and reliable measure of depression treatment outcome [142]. Each PHQ-9 item corresponds to *DSM-IV* Criterion A symptoms for major depressive disorder [143]. Research supports the PHQ-9 as superior to other depression self-report measures compared to standard interview diagnoses of major depression [144, 145].

*Alcohol Abuse* The most commonly used screening measure for alcohol abuse in primary care settings is the Alcohol Use Disorder Identification Test (AUDIT). [146]. The AUDIT was designed specifically for primary care settings and has 92% sensitivity and 92% specificity for identifying harmful alcohol use [147].

*Workplace Productivity* Workplace productivity can be measured with the Work Limitations Questionnaire (WLQ) [148] that has been used extensively in populations with depression. The WLQ measures four dimensions of work task performance common to a wide variety of jobs, is sensitive to the effects of behavioral and medical conditions related to treatment, and is related to employment productivity. The WLQ addresses the impact of behavioral and physical symptoms on four dimensions: time management, physical job duties, mental and interpersonal job tasks, and workload output. The WLQ has been validated for use in depression studies and a short-form version is widely used for large-scale population-based health assessments [149, 150].

*Outcomes Management Systems* Research has demonstrated that the systematic collection and review of patient outcomes feedback by clinicians during the course of behavioral treatment has positive effects on treatment outcome [151]. These systems are based on using a large outcomes data base to predict the trajectory of change and using this to project individual patient recovery. Examples of these measures include the Outcome Questionnaire-45 (OQ-45) [152] and the Partners for Change Outcome Management System (PCOMS) using the Outcome Rating

Scale (ORS) and Session Rating Scale (SRS) [153]. The key premise of these systems is that reviewing outcomes in real time allows the clinician to adjust the treatment plan for patients who are deteriorating or not making expected progress in treatment. A series of studies by Lambert using the OQ-45 showed that outcomes feedback (vs. no feedback) yielded an effect size of 0.40, deterioration rates decreasing from 21 to 13%, and clinically significant change increasing from 21 to 35% [154]. In addition, and critical for this chapter, feedback resulted in more cost-effective delivery of services. The majority of patient making expected progress attended significantly fewer sessions in the outcomes feedback versus no feedback condition, whereas the minority of patients at risk for deterioration attended more sessions, resulting in a net decrease in utilization [154]. Research on the PCOMS demonstrated that outcomes and treatment alliance feedback resulted in a significant improvement in clinical effectiveness with the overall effect size increasing from 0.37 at baseline to 0.79 at completion, and demonstrated improved treatment retention [153]. These measures are available at low or no cost to clinicians and for a reasonable fee are available in an Internet-based, real-time automated scoring and reporting package.

*Computer and Internet Behavior Change Resources* The use of computer and Internet-based behavior change tools as an adjunct to behavioral treatment is growing at an exponential rate in behavioral health [155]. Three examples that are most likely to increase the value of the behavioral clinician in primary care will be described here. First, a multitude of health information websites are available at no cost for patients and can serve as an excellent source of patient education materials. For example, WebMD ([www.webmd.com](http://www.webmd.com)) has detailed information on a wide range of medical and behavioral conditions that include educational information, self-assessment tools, and self-help exercises. Patients can create a free account and sign up to receive tailored messages for specific conditions on a regular basis. These web-based resources provide an excellent means of supporting patient condition self-management and also offer increased efficiency for behavioral clinicians by saving time that might otherwise take up time during in-person sessions.

Second, there is a proliferation of computer or Internet-based behavioral treatment programs based on cognitive-behavioral therapy (CBT) [156]. These programs offer patients modules for self-assessment and self-monitoring, cognitive restructuring, symptom management, and other common components of CBT. These programs are now integrated on a population basis in Europe and Australia. In England and Australia, each family physician has unlimited access to these programs to refer their patient to, literally a behavioral prescription from primary care [156]. Research had demonstrated that these programs are more effective than treatment as usual and as effective as in-person treatment for behavioral disorders such as generalized anxiety [157], panic disorder [158], depression and substance abuse [159], and posttraumatic stress disorder (PTSD) [160]. It is especially notable that meta-analyses have demonstrated that these computer-based CBT programs result in savings of 50–80% in clinician time [156, 161]. It is important to note that a critical component of these tools is the facilitation by a clinician with the patient to

explain, support, and follow up on patient use of the programs. Without this support, patients are highly unlikely to initiate these programs, or if they do initiate, they quickly discontinue use resulting in very high attrition [156].

Third, a new generation of behavior change computer programs based on “expert systems” [162] are emerging as a tool to help patients work develop an individually tailored approach to managing common behavioral and lifestyle problems, such as depression or overeating. An example of an expert system is the work of Prochaska et al. [163] and associates offered by their company ProChange Behavior Systems ([www.prochange.com](http://www.prochange.com)). Specific behavioral interventions are generated based on complex algorithms using decision rules designed to match the most appropriate treatment to the patient illness severity, motivation for treatment, and readiness for change. These web-based expert systems are based on theories of behavior change that serve as a template for developing algorithms that help determine software decision rules. The ProChange products are based on the Transtheoretical Model (TTM) key components: stages of change, processes of change, decision balance, self-efficacy, and temptation [163]. The ProChange expert system is designed to use patient self-assessments on these dimensions to develop individually tailored behavior change interventions. Stage-based, self-help manuals are provided to individuals to guide their behavior change efforts between interventions [163]. Patients complete these assessments at monthly intervals and receive individually tailored feedback and recommendations tied to the workbook. These approaches have demonstrated significant improvement for many behavioral conditions, including diet, exercise, stress, and depression. [163]

In summary, the assessment model for psychologists to effectively demonstrate cost savings must include, at minimum, pre- and post-intervention health service utilization. Measuring work productivity is necessary to document cost savings from the employer perspective. Screening measures will help identify patients for population-based treatment and document pre- and posttreatment changes. Screening and outcome measures will ideally be computer and Internet based for patient and clinician convenience. Similarly, the use of Internet-based psychotherapy and behavior change programs will contribute to improved outcome, efficiency, and a source of program evaluation data. Fortunately, factors such as decreased cost of technology, availability of affordable measures, and increased use of electronic medical records within health systems make this assessment model feasible.

## **In Practice**

The recent literature review and recommendations on guidelines for the effective practice of integrated behavioral care [164] (Canadian Collaborative Mental Health Initiative) concluded that:

1. Collaborative relationships between behavioral and medical providers require significant preparation, time, and supportive administrative structure.

2. System-level collaboration requires similar planning and must address staff buy-in, institutional leadership, policy and procedures, and performance management.
3. Colocation is important for both providers and patients. Providers who have not interacted in person are less likely to engage in collaborative care [165, 166]. Offering patients behavioral care in primary care produces greater engagement of patients [167, 168]. This appears especially to be the case for substance abuse treatment in primary care based on research that patients in integrated settings have significantly better outcomes and those with poorer health benefit the most [169, 170].
4. Systematic follow-up by a clinician using formal assessment of patient outcome is associated with positive clinical outcomes. This includes a mechanism to alter treatment when the patient is not responded as expected, such as a stepped care approach [171–175].
5. Collaborative interventions should focus on behavioral interventions, not just medication adherence. While improving medication adherence has strong face validity, the meta-analysis found no clear relationship between medication adherence and clinical outcome [174, 176–180].
6. Patient choice about treatment modality is an important factor in treatment engagement. Research shows that when given a choice, 26–66% of primary care patients with major depression would prefer to be treated with psychotherapy rather than medication [134]. Two studies gave patients a choice between medication and psychotherapy and a third used psychotherapy as one of the randomized options and the popularity of psychotherapy was confirmed [165, 181] and sustained quality of life was found for psychotherapy but not medication [182].

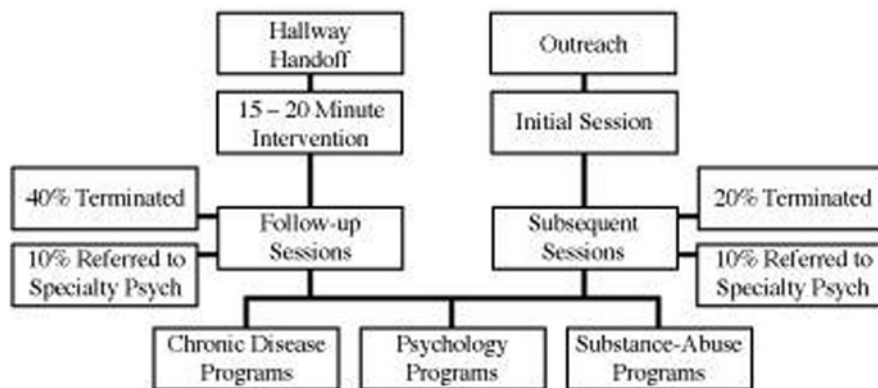
These conclusions are consistent with the research on behavioral interventions in primary care associated with cost savings. In this section, detailed examples of the Biodyne model for somatizers and collaborative care for depression will be reviewed to serve as an example of the components of care necessary for achieving cost savings in practice.

*The Biodyne Model* The Biodyne behavioral intervention for somatizers in primary care is based on an outreach program designed to balance the need to engage the somatizer in treatment while avoiding challenging the patient's belief in the physical nature of his or her problems [183]. Patient identification for outreach is based on the 15% of highest utilizers based on the frequency of physician visit, as opposed to total health care costs. This is because the highest cost cases are often related to expensive serious medical conditions whereas the somatizer is characterized by frequent visits without medical etiology. The following principles are critical for successful outreach: (1) outreach is preferred over direct referrals from the PCP since it is difficult for the physician to recognize somatizers given their focus on real physical symptoms; (2) physician buy-in is essential and achieved by treating physicians respectfully and results in no patient complaints; (3) the behavioral provider should be a member of the PCP medical system in order to communicate and coordinate care consistent with HIPAA and related privacy and confidentiality laws; (4) direct phone calls are highly effective provided that the behavioral

provider identifies himself as calling from the PCP's office. This differentiates the call from telemarketing or health plan or related company calls; (5) it is important not to challenge the patients' conception of his illness [183]. Somatizers welcome additional health services, especially if not threatening. Cummings notes the statement "Anyone that is having as much illness as you are having must be upset and depressed about it. Perhaps we can help you with that" ([183], p. 53); (6) the majority of outreach patients make an appointment during the first call, while others require a second or third call. About 85% of the targeted patients will attend the sessions, with about 10% refusing and 5% resisting making an appointment while not refusing. Cummings reports successfully engaging most of this 5% by sending an outreach nurse to conduct a home visit; (7) the behavioral provider colocated in the PCP's office can avoid telephone outreach for patients who are making a regular visit to their PCP by having the PCP walk her down the hall to the awaiting behavioral provider, a process termed the "hallway handoff" ([183], p. 53; Fig. 8.4).

The delivery system for somatizers is based upon the availability of a comprehensive set of focused, targeted, and evidence-based primary care behavioral interventions. In effect, these are individual disease and population-based interventions with a focus on behavioral interventions. The hallway handoff sequence results in a 20–30-min appointment and most patients returning for one or two additional appointments to reach sufficient resolution as evidenced by patient satisfactions and subsequent reductions in medical visits. This is the typical sequence for about 40% of the patients, with 50% of the remaining referred to individual or group primary care behavioral treatments. The remaining 10% represent serious and persistent mental illness referred to specialty behavioral care [183]. For somatizers who enter the delivery system via the outreach program, most will be seen for an individual appointment within 1 or 2 months while 90% will be seen within 6 months. Following one or two individual appointments, 20% of these patients will have resolved the underlying cause for somatization and complete treatment. The majority are referred to the appropriate primary care behavioral group intervention [183].

The Biodyne model of individual and group behavioral interventions has been described in detail [184, 185] and will be summarized briefly here. The behavioral clinician's time in the primary care setting consists of: 25% individual appointments, 50% in group disease and population programs, and 25% in group psychotherapy. The group disease programs include: asthma, diabetes, emphysema, hypertension, ischemia, and rheumatoid arthritis and fibromyalgia. The psychotherapy groups include phobias, bereavement, borderline personality disorder, depression, schizophrenia, anxiety and panic, and obsessive-compulsive disorder (OCD)/perfectionism. The four addictive groups include pre-addiction, addiction, ACOA, and obesity [183]. The group culture greatly facilitates treatment progress. Each group program is based on: (1) treatment of the behavioral and medical aspects of each condition, (2) facilitating patient self-management of chronic aspects of their illness, and (3) prevention of relapse or worsening of outcomes due to poor condition self-management. The Biodyne group protocols share common characteristics that are interchangeable between specific groups [183]:



**Fig. 8.4** Patient flow in halfway handoff and somatizer outreach. In the integrated primary care setting halfway handoffs and somatizer outreach complement each other, resulting in 90% of the patients being seen in the primary care setting

1. Patient education.
2. Pain management.
3. Relaxation techniques and stress management.
4. A support system to address social isolation and a buddy system.
5. A self-evaluation component in which the patient learns to self-monitor biomedical and behavioral indicators.
6. Homework is assigned for each session
7. Treatment of depression that accompanies most conditions emphasizes psychosocial determinants of depression and behavioral interventions rather than traditional focus on antidepressant medications and adherence as the key to treatment.
8. Incorporating principles of self-efficacy [186] and learned helplessness [187] to improve confidence and mastery.
9. A sense of coherence to help patients with chronic medical and behavioral conditions make sense of their circumstances and life [188].
10. Exercise as an essential component of every protocol to reduce depression, increase self-efficacy, and promote active coping and mastery.
11. Modular formatting of these components enables each group protocol to serve different populations with similar treatment needs by inserting or substituting modules.

The key components of the Biodyne model are consistent with the primary care integration guidelines outlined earlier [164]. One key area that has differentiated the Biodyne model is a strong reliance on behavioral interventions for mood and anxiety disorders rather than psychopharmacology as a first-line approach. It is interesting to see collaborative care depression move in this direction with the inclusion of behavioral interventions rather than a primary focus on medication adherence. The other key differentiator of Biodyne is the use of decision rules to refer patients



to a wide range of group interventions for medical and behavioral conditions. The availability of such a wide range of interventions and reliance on modular group treatment programs that can be tailored to the specific population are keys to the efficiency of the model that contribute to cost savings.

The Biodyne model has continued to be incorporated into both practice settings and graduate education programs. The clinical model has been integrated into many integrated primary care programs in the military and Veterans Administration. The model has been incorporated into both doctoral programs at the University of Nevada, Reno, and Arizona State University. Recent publications have continued to include the Biodyne model under the umbrella of integrated behavioral care [189, 190]. The evolution of the model is documented in the Healthcare Utilization and Cost Series of the Cummings Foundation for Behavioral Health [191–195]. It is likely that with the increased emphasis in health care reform on behavioral integrative care as a solution to quality and cost of care in primary care, the model will receive increased attention.

*Collaborative Care for Depression* The Improving Mood: Promoting Access to Collaborative Treatment (IMPACT) program has reported on the long-term effects on total health care costs of the program for late-life depression compared with usual care [196]. Patients were identified by depression screening or referral by the PCP. The IMPACT intervention is a 1-year stepped collaborative care program delivered by a nurse or psychologist care manager colocated in the primary care clinic. The care manager completed an initial evaluation and provided education about antidepressant medication and psychotherapy treatment options. Patients were offered a choice of antidepressant medication or psychotherapy using a problem-solving treatment for primary care, a six to eight session psychotherapy program designed for primary care patients [197–199]. The care manager participated in weekly supervision with a PCP with geriatric expertise and a psychiatrist to monitor patient progress and adjust care based on stepped care algorithms [200]. The algorithm-guided intervention intensity and contact frequency from acute and continuation to relapse prevention phases during the 12-month treatment program. The care manager followed up with patients every 2 weeks during acute phase and monthly during the continuation phase. At the end of the 12-month program the care managers completed a relapse prevention plan with the patients, who continued in usual care from that point forward. Outcome measures included claims data from two participating health plans and included costs for all inpatient and outpatient services, and prescription medications [196]. The costs of providing the IMPACT intervention was based on detailed records of all patient contacts (in person and by phone), mean salary, and benefit costs of care managers plus 30% overhead to account for space and administrative support, the cost of supervision from PCPs and psychiatrists at each site plus overhead costs, and the costs of intervention materials [201]. Intervention patients had a 4-year mean total health care cost of US \$ 29,422 compared to usual care patient costs of US \$ 32,785. The intervention group had lower health care costs on every cost category (inpatient, outpatient behavioral health, medical, and pharmacy) than usual care patients [196]. This study is also notable in offering

patients a choice between evidence-based antidepressant or problem-solving psychotherapy and reflects a shift from a focus primarily on medication adherence to increased focus on behavioral interventions such as behavioral activation and problem-solving therapy.

*Population-Based Collaborative Care for Depression and Work Productivity Outcomes* A study of collaborative care for depression used workplace productivity measures in order to evaluate cost-effectiveness based on changes in workplace productivity [202]. Patient identification consisted of a two-step process. Phase 1 was completion of a health risk assessment to screen chronic conditions, psychological distress, and work performance. Patients with positive depression screen scores were contacted by letter and telephone to complete a phase 2 interview-assessing depression using the Quick Inventory of Depression Symptoms Self-Report (QIDS-SR) [203, 204] and the World Health Organization Health and Productivity Questionnaire (HPQ) [205]. The intervention was telephonic and designed to assess need for treatment, facilitate referral to specialty behavioral care for therapy and/or antidepressant medication, and monitor treatment adherence, and for patients who declined in-person treatment, a structured telephonic psychotherapy program. Patients assigned to the treatment condition were contacted by phone by a licensed master's level mental health case manager and completed the PHQ-9 [101], prior treatment history, and motivation for treatment. Patients were followed up with regular phone contacts for ongoing assessment. Patients with significant depression severity were referred to in-person psychotherapy and medication evaluation. Patients who declined referrals were provided a brief motivational intervention and received continued follow-up contacts by the case manager.

Patients who experienced significant depressive symptoms after 2 months and declined in-person treatment were offered a structured eight-session cognitive-behavioral psychotherapy program with weekly telephone sessions of 30–40 min using the workbook. A cognitive-behavioral-based workbook designed to facilitate condition self-management was mailed to each patient [206]. Telephonic sessions included ongoing assessment of motivation and motivational interviewing; behavioral activation designed to increase pleasant and rewarding activities; identifying, challenging, and distancing from negative cognitions [207, 208]; and developing a personalized condition self-management plan covering medication adherence. Follow-up sessions were scheduled every 4–8 weeks to monitor and support progress. Patients who accepted in-person treatment were also followed up by case managers who provided ongoing assessment of depressive symptoms, treatment adherence, and barriers to treatment. Feedback was provided to providers and a United Behavioral Health psychiatrist was available for consultation. For patients receiving only one mode of treatment, a second was added if significant depression continued after 2 months [202].

The results of the study combining data across 6- and 12-month assessments demonstrated that the intervention group had significantly lower QIDS depression scores at 6 and 12 months. The proportion of patients in the intervention group compared to the control group showed significant symptom improvement (30.9 vs. 21.6%) and achieving recovery (26.7 vs. 17.7%) at 12 months. The scores on the summary scores of hours worked were significantly higher for the intervention than

usual care group, with workers in the intervention group having an average of 2 more hours per week than usual care, equivalent to an annualized effect of more than 2 weeks of work. A formal return on investment analysis was not possible in this study due to nonavailability of additional information on duration of improvements, disability payments, and overall health care expenditures. However, the annualized savings in additional hours worked of US \$ 1,800 among intervention patients retaining their job are significantly greater than the US \$ 100–400 outreach and care management interventions [202]. This study presents an excellent example of a population-based intervention that demonstrated improved clinical outcome and workplace productivity using brief self-report measures. The initial cost-effectiveness data indicate an average savings of US \$ 1,400 per employee based on the highest cost of the intervention, US \$ 400. The population-based model in this study would also be practical for high-utilizer outreach and is a demonstration of effective intervention delivered completely by telephone.

## Summary

There is clear evidence that behavioral clinicians can introduce value into health care systems by delivering targeted, focused behavioral interventions in primary care that result in cost savings and medical cost offset. The effective ingredients of medical cost offset first identified by Cummings five decades ago receive continued support in more recent studies. First, the interventions must be not only effective but also efficient. Brief interventions and group treatment are effective and less costly than treatment as usual. In addition, approaches that delegate the tasks of in-person psychotherapy to activities the patient can perform outside of the treatment setting in their own home, such as computer and Internet behavior change tools, contribute substantially to efficiency with savings of 50–80% in therapist time. Second, the program must be colocated in order to leverage patient trust, lack of stigma, and convenience. Third, the program must incorporate population-based interventions that identify and outreach high utilizers and successfully invite them to engage in treatment. Fourth, a comprehensive array of interventions that are applied in step-wise fashion based on evidence-based decision rules is necessary. For example, the Biodyne model of medical and behavioral treatment groups with interchangeable components can be tailored to the individual needs of each patient and still delivered in an efficient manner.

In terms of patient populations, the somatizers are the most likely to demonstrate significant cost savings. Somatization accounts for 10–15% of the US \$ 1.4-trillion health care budget, or US \$ 140–210 billion annually [62]. Evidence for medical cost offset for substance abuse and effectiveness of the brief interventions in primary care also make this group a key group for demonstrating cost savings. Evidence is emerging that depression and anxiety can result in cost savings and documenting the cost savings in terms of workplace productivity for these groups is associated with substantial cost savings to the employer. Finally, it is likely that offering

behavioral instead of psychopharmacologic treatment based on evidence-based decision rules can result in substantial cost savings. Research to date has compared effectiveness for medication versus traditional psychotherapy but has not included more efficient psychotherapy model comparisons.

In order to demonstrate cost-benefit, the psychologist must measure, analyze, and report on the clinical and cost outcomes of care. The most critical measure from the perspective of payers in health care is reduced utilization and cost of care that require claims or medical record data. The next most important measure is workplace productivity due to the recent emphasis on quantifying the cost of lost productivity. Employers and health plans are actively searching for behavioral interventions that will improve productivity and decrease these costs. Third, condition-specific questionnaires such as the PHQ-9 for depression and PHQ-15 for somatization are useful for both screening and ongoing assessment. Outcomes management systems have demonstrated improved outcome and cost-effectiveness in specialty behavioral care settings and may show similar benefits in primary care settings. Advances in and decreased costs of computer technology, combined with the steady movement to electronic medical records, mean that clinicians will be able to integrate a completely electronic suite of assessment and outcomes management tools that will further contribute to increased efficiency and greater ease of collecting and reporting on clinical, productivity, and utilization/cost of care variables.

The good news is that the psychologist has access to: the evidence to provide targeted, focused behavioral interventions that lead to medical cost savings or cost offset; the assessment tools to document the value dimension of behavioral health in medical settings; and an expanding array of computer, Internet-based behavior change technologies that will further improve efficiency and add to cost savings. The downside is that the components of integrated behavioral care that are increasingly recognized as most critical to success: colocation in primary care, being a part of the medical system, brief and focused interventions, a case manager role using population-based stepped care interventions, Internet behavior change tools, and business entrepreneur skills are exactly the types of activities that the majority of psychologists avoid or are openly hostile towards [209]. The clinical skills that lead to proficiency in traditional specialty behavioral care settings with a focus on the 50-min hour in the privacy of a remote office are not the same skills required to be as successful as a behavioral PCP. In the past, as new behavioral health opportunities emerged, psychologists stood at the sidelines as other professionals responded to meet marketplace needs. Nurses and now social workers are predominant in the burgeoning disease management industry and nurses have focused on the management skills necessary for leadership positions in hospitals and clinics [209]. Nursing programs now are integrating specialty behavioral care into their curriculums. At this time, the government, health plans, employers, and medical health care professionals have aligned to endorse integrated behavioral care. It is likely that clinicians who enter primary care settings and proceed to demonstrate cost savings and medical cost offset will become highly valued and rewarded in the twenty-first-century health care system. It will be interesting to see whether or not psychology as a profession takes advantage of this opportunity.

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# Chapter 9

## The Practice of Psychology in Medical Settings: Financially Sustainable Models

Daniel Bruns, Rodger Kessler and Brent Van Dorsten

*I've got all the money I'll ever need, if I die by four o'clock.*

—Henny Youngman

### Background

It is a tacit assumption of the psychological profession that psychological services have value, and that psychologists should be paid for what they do. The unfortunate reality though is that for psychologists, getting reimbursed for services performed was never especially easy and is especially complex in medical settings. If psychologists are to have financially sustainable practices in medical settings, however, a number of economic matters need to be addressed.

At the time of this writing, we are in an era of health care reform, and practice models are changing. New practice constructs such as Patient-Centered Medical Homes (PCMHs), certification systems, integrated care, accountable care organizations, and others, too numerous to mention, are appearing on a regular basis. Given the intensity of the ongoing debates about health care, it seems likely that the reconceptualization of health care will remain an ongoing process. What is clear is this: At this time, the USA has no national public policy specifying a financial model for the provision of mental health, substance abuse, and health behavior services. Beyond that, in this national conversation, terms such as “health psychology” and “behavioral medicine” are rarely even mentioned. While there is a national mental

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health budget, mental health is being brought into the medical home, and the future of separately allocated mental health funds is uncertain.

At the present time, there are a number of interdisciplinary medical settings where no attempt is made to bill for psychological services. This model, sometimes referred to as the “leveraging time model,” [1] assumes that patients with behavioral aspects to their medical conditions can be cared for more efficiently by referring them internally to behavioral medicine specialists (BMSs). By allowing the physician to off-load complex patients to BMSs who are better trained in dealing with behavioral problems but earn less, the physician is able to see more patients. This approach assumes that by thus “leveraging” the physician’s time, the increased physician productivity will pay for the BMS services. However, this model is not sustainable for two reasons. First of all, by not billing for psychological services for medical patients, under the leveraging time model psychological services have no economic value. In the business world, services with no monetary value are the first ones to be cut. Secondly, given the growing financial pressures in medical settings, there is considerable risk that physicians will come to see this model as financially parasitic, and resist paying for services that BMS professionals should be billing for themselves.

There have been some attempts in the literature to address the range of methods that can be used when seeking reimbursement for psychological services provided to medical patients [2], in integrated primary care settings [3], or the business of psychology generally [4]. However, to the best of our knowledge, nothing has been published about the range of financial models for these services being used in governmental and private sectors. If psychologists are to remain a financially viable type of health care provider, they will need to understand issues much broader than clinical practice, and be active in areas well beyond the scope of patient care.

This chapter will address four key areas: (1) understanding payer models and reimbursement dilemmas, (2) possible solutions, (3) problems that arise from the application of the biopsychosocial model to practice, and (4) emerging trends.

## Understanding Payer Models

To many in the field, payer policies often seem devoid of logic, baffling, and unalterable. In many cases though, what appears to be shortsighted thinking and ineffective policies may actually be due to a lack of education, bureaucratic entanglements, or contractual barriers. It is a mistake to assume that these barriers can never be overcome, though. To do so, however, it is necessary to understand the nature of medical payer systems.

There are markedly different types of payer systems. For example, Medicare, the Veterans Administration, Medicaid, many health maintenance organizations, and, in most cases, Workers Compensation are single-payer systems. In single-payer systems, psychologists, physicians, and physical therapists all send their bills to



the same payer. In contrast, most private insurance plans are two-payer systems and separate services provided by physicians and mental health professionals into separate payer plans. Two-payer plans place the practice of psychology in medical settings in a unique and complex financial situation.

## The Impact of Carve Outs

Over the past 15–20 years in the USA, private medical insurance policies have rarely covered psychological services. Instead, private commercial insurance plans contractually “carve out” coverage for psychological services and allocate them to a mental health/substance abuse payer. This payer then manages all claims for mental health services. The “mental health carve out” insurance plan generally has a separate panel of mental health and substance abuse providers and will reimburse panel members for specified mental health services. These services generally require a *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)*<sup>1</sup> psychiatric diagnosis [5] and the use of specific psychiatric Current Procedural Terminology (CPT) [6] codes. In contrast, the medical plan covers the medical panel, medical diagnoses, and medical procedure codes such as the Evaluation and Management (E&M) codes for medical office visits. This system works well when psychologists are providing psychological treatments for psychological disorders. However, when psychologists perform behavioral medicine services for medical patients who have no psychiatric diagnosis, or when no psychiatric diagnosis is being treated, reimbursement becomes much more problematic.

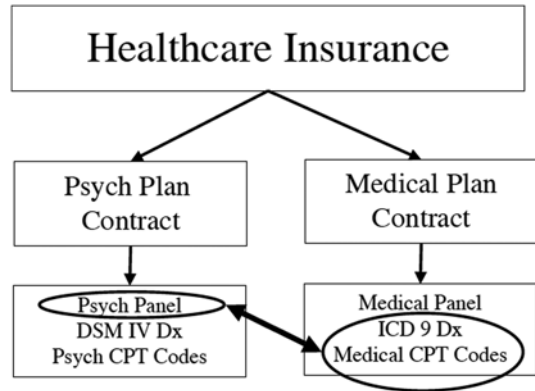
It is important for psychologists to be aware that often even if a medical payer understands the utility of psychology services for medical patients, this payer may still be obligated by contract to have the mental health payer reimburse services performed by psychologists. In an attempt to address this problem, the American Medical Association created new procedure codes called the Health and Behavior (H&B) codes in 2002 [3].

The H&B codes were created to be a means for psychologists to bill for behavioral services provided to patients for the treatment of medical diagnoses. For example, if a diabetic patient was having difficulty with making the dietary behavior changes necessary to manage their health condition, a psychologist could use the H&B codes to bill for psychological treatments intended to help the patient to adhere to the prescribed diet. In this case, while psychological services would be

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<sup>1</sup> Note that at the time of this writing, the DSM 5 has now been published, but has yet to be implemented by most payers. However, in the United States, the Health Insurance Portability and Accountability Act (HIPAA) has now mandated the use of ICD-10 for diagnostic coding for all services beginning in October of 2015. Since the DSM 5 differs markedly from both the ICD-10 and the beta version of ICD-11 on many of the diagnoses that health psychologists are likely to use, it is not clear how relevant the DSM 5 will be to the practice of health psychology. At the time of this writing, it appears that payers may continue to utilize the DSM IV codes until October of 2015, at which time the ICD-10 codes and definitions will be adopted.

**Fig. 9.1** H&B code reimbursement in one- and two-payer systems. (©2012 by Bruns and Disorbio. Used with permission)



performed to change eating or exercise habits, no primary psychological diagnosis would be present. While the H&B codes were intended to solve the financial problem involved with psychologists work in medical settings, their implementation in the field has been problematic.

Most of what has been written about the H&B codes have been written from the standpoint of Medicare reimbursement. Although it took a few years, at the time of this writing Medicare has been routinely reimbursing H&B services in almost all areas of the country [7]. As previously noted, Medicare, and in most states Medicaid, are single-payer systems, in which all treatment fees, whether medical or psychological, are reimbursed by one payer. Within single-payer systems, H&B reimbursement is less problematic, and for Medicare the problems are largely solved.

In contrast, the private sector is dominated by two-payer systems, where reimbursement policies are governed by contractual relationships between payers. These two-payer systems have created major challenges to the reimbursement of the H&B code services and, more broadly, to health psychology services in general, as private payer systems have responded to H&B services in idiosyncratic ways.

Although the contractual relationships between insurance payers sound like a very arcane topic, it ends up having major ramifications for the reimbursement of H&B services. Unfortunately, the H&B codes by their nature are often incompatible with payer contractual obligations created by mental health carve-out contracts (Fig. 9.1). This is because an H&B code service allows a traditional mental health professional, such as a psychologist, to provide psychology services for patients who have a medical condition, but no psychiatric diagnosis. This creates a dilemma for the two insurance payers with the medical payer, potentially covering this service since contractually it is responsible for covering *medical conditions*, versus the mental health payer, potentially responsible for the payment of this service since contractually it is responsible for reimbursing the services of *psychologists* both saying the other payer should be responsible. Thus, from the medical payer perspective, although a medical diagnosis such as diabetes falls under its contractual obligation, the medical payer does not have psychologists on its panel, and may in fact be prohibited contractually from placing psychologists on the panel. In contrast, the

mental health payer will have psychologists and other mental health professionals on their panel of providers. However, contractually, they are often forbidden from reimbursing services for nonpsychiatric conditions. Thus, neither payer is able to reimburse the claim.

As a result, even when the medical payer would like to pay for H&B services, they may be contractually constrained from doing so. For example, a number of medical payers require presurgical psychological evaluations for procedures such as spinal cord stimulation or bariatric surgery [8, 9]. However, even if medical payers require these services, and may be willing to pay for them, they are prevented from doing so as they have no psychologists on their panel.

So, why don't psychologists simply join the medical panels? With the exception of neuropsychology, medical panels have often excluded psychologists from membership, due to strong opposition by some groups of physicians. Consequently, in many cases, forces in the medical marketplace have decided that the mental health carve-out payer is responsible to reimburse H&B services, creating an unusual Catch-22: Some mental health payers will reimburse for H&B services only when a psychiatric diagnosis is assigned, which according to the CPT is a logical impossibility.

## Barriers to H&B Reimbursement

As noted above, the primary market barrier to H&B reimbursement in the private sector is a contractual one having to do with mental health carve-outs—leaving the medical payer with a difficult conundrum. On one hand, nearly all private medical payers list H&B procedure codes as covered benefits. Further, in the case of presurgical psychological evaluations, these payers sometimes even *require* these services. However, given the contractual problems resulting from mental health carve-outs, these same payer systems may not be able to reimburse a psychologist for the very services that they require, when there is only a medical diagnosis and no psychological diagnosis. Ironically, all the professionals allowed on many medical panels are in one way or another prohibited from providing H&B services that psychologists perform, such as presurgical psychological evaluations. Thus, although these contractual conundrums represent a significant barrier to H&B reimbursement, they leave the medical payers in the difficult position of having promised something to patients that they are contractually unable to deliver.

A second barrier to reimbursement for H&B codes is a result of a lack of information and acceptance. Medical payers are typically not accustomed to having mental health caregivers perform behavioral health services, and they may not even be aware of what these services are. Furthermore, at the time of this writing some payers appear to have actively resisted the inclusion of psychology on their medical panels.

A third problem has to do with a clash of professional interests and rivalry. When physicians and nurses hear that psychologists or social workers would like to be

on the medical panel, there may be a pushback. Having psychologists treat medical patients could be construed by physicians as psychologists becoming another competitor.

A fourth barrier is that in settings such as integrated primary care centers, the carve-out conundrum makes reimbursement for patient services much more complex. For any patient receiving integrated care, both the medical insurance and the mental health insurance may have to be billed, making billing doubly complicated. This problem remains, however, as long as carve-out contracts stipulate that the payer that reimburses behavioral medicine services is determined by the profession of the provider, not the diagnosis of the patient.

Fifth, for reasons that are not entirely clear, over the years the H&B codes have been limited by the addition of “exclusions.” The term “exclusion” here refers to an amendment to a medical procedure that limits its use. For example, at the time of this writing, a clinic cannot bill the H&B codes on the same day that they bill E&M codes for medical caregivers, as this is regarded as a duplicate service. This is difficult to understand, as the services offered by psychologists are quite different than those offered by physicians. Unfortunately, this exclusion greatly complicates billing for integrated primary care services. In contrast, psychotherapy codes can be billed for on the same day as E&M codes. Another exclusion is that while through the use of the H&B codes a psychologist can treat almost any International Classification of Diseases, Ninth Revision (ICD-9) condition, the H&B codes cannot be used for the treatment of primary obesity. However, H&B codes can be used for treating obesity when the obesity appears within the context of another treatable condition, such as diabetes or heart disease.

Sixth, even if there is no contractual issue, and there is agreement for psychology to bill the medical payer, a very practical problem is that at the time of this writing many health plan computer systems could not accept claims unless it was a service performed by an authorized *medical* provider (as opposed to a mental health provider), and was for the treatment of an ICD-9 medical diagnosis. One of the authors (RK) has had the experience of an enlightened chief executive officer of a commercial insurance company say that the company would like to have psychologists in medical settings bill medical services, but, unfortunately, the expense of revising the computer software system to allow this was prohibitive.

Lastly, there are more general barriers to the financial sustainability of psychology in medical settings that are only indirectly related to reimbursement. One of these has to do with the formulas for productivity that are adopted without adequate knowledge of the details of the psychological profession. In some cases, physician productivity formulas may be adapted for use with psychology, even though these professions are quite different. For example, in some cases these productivity standards may be based on face-to-face time with patients, rather than billable hours. However, a unique role of psychologists is conducting psychological and neuropsychological testing. When using these procedure codes, time spent synthesizing the test results with other information and preparing the report is billable time. Thus, if a face-to-face productivity rule is applied to psychologists, not only are these billable hours not counted toward productivity but a unique skill of the psychology profession is also discouraged. Similarly, a productivity standard may expect the

psychologist to bring in a certain number of reimbursement dollars. However, certain job assignments may make this impossible. For example, if a psychologist is assigned to perform treatment services for primary obesity (when no other medical or psychological diagnosis is present), work with patient families without the patient present, attend staff meetings and rounds, or perform H&B services on the same day as a physician on the team, none of these services are currently reimbursable. Consequently, if psychologists are to have a financially sustainable role in medical settings, the productivity standards need to take into account the unique aspects of psychology practice and reimbursement methods. Without a level playing field, psychology productivity standards can leave the psychologist constrained from practicing his/her craft, and set up to fail.

## Working Toward Solutions<sup>2</sup>

In some cases, workable solutions for H&B billing for psychologists include either negotiating with a payer to “bundle” psychological and medical services together in to a single bill, or alternately to use “facility billing.” In facility billing, it is the facility (e.g., a hospital or clinic) that negotiates with the payer for H&B reimbursement as part of their overall contract with the payer. By using this method, the psychologist can sometimes be “grandfathered” onto the medical panel of a commercial insurance company. This solution depends upon the goodwill of the facilities billing department, though, and its willingness to advocate for the psychological services and see if an arrangement can be negotiated.

A second possible solution for the carve-out contractual dilemma was suggested by more than one mental health payer to the authors. The payers suggested using a *DSM-IV* [10] format to describe the medical condition. Using this approach, the medical diagnosis is listed on Axis III. If there is a diagnosis on Axis I or II, this can be listed and doing so will allow the services to be reimbursed. However, if there is not a psychiatric diagnosis, the mental health payer still requires a *DSM-IV* number in order to process the claim. To address this, some payers have suggested to the authors the use of the diagnosis 799.90 “Diagnosis deferred” on Axis I. As “Diagnosis deferred” is a valid *DSM-IV* code, the payer stated that this made the Axis III diagnosis acceptable to that insurance company’s billing policies and system. Thus, while the diagnoses were deferred on Axes I and II, the medical condition was diagnosed on Axis III, and that was the primary focus of treatment for the H&B services. Although this approach seems counterintuitive, in that it uses a *DSM-IV* format to define the medical diagnosis for H&B services, for some payers this was the solution that was recommended. If this was done, the H&B services could be

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<sup>2</sup> The reader should be aware that laws, regulations and acceptable business practices are in a constant state of flux, vary regionally, and vary among both payers and policies as well. While we have made every effort to supply correct information, it remains the responsibility of the professional to verify that a billing method is acceptable to both the payer and the institution.

reimbursed by the mental health carve-out payer, as it was now consistent with their contractual obligations. Readers would be advised to confirm the validity of this method with their payers prior to using it, and note that this method is *not* allowable under Medicare<sup>3</sup>.

The downside of billing the mental health payer for patients with medical conditions is twofold. First, as mentioned above using a psychiatric method for a medical patient seems counterintuitive. Second, in places such as integrated primary care centers, this makes reimbursement much more complex, as for any given patient, both the medical insurance and the mental health insurance would have to be billed. This problem remains, however, as long as carve-out contracts stipulate that the payer that reimburses behavioral medicine services is determined by the profession of the provider, not the diagnosis of the patient.

A third possible solution is that psychologists working in medical settings can often utilize traditional psychological diagnoses and billing codes. There is a high incidence of depression, anxiety, chemical dependency, and other mental health problems among medical patients. When present, these conditions can be reimbursed under the existing contractual rules. But the available data suggest that less than 50% of common medical patient populations (e.g., diabetes, pain, obesity, primary care) might be expected to present with an Axis I disorder [11–17], leaving the psychologist in the ethical quandary of searching for a *DSM* diagnosis for a patient without clear and primary psychiatric issues for the purpose of reimbursement [3]. Beyond this, there are also additional prospects for billing through the mental health payer as a type of psychological service.

At the time of this writing, *DSM-5* was recently published. The proposed revision includes redefined criteria for *Psychological Factors Affecting A Physical Condition*, and a new diagnostic concept, *Somatic Symptom Disorder*. This latter diagnosis subsumes a variety of conditions that have both medical and psychological components [18]. Together, these diagnoses may provide a means of funding behavioral medicine services through the mental health payer.

A fourth approach begins with the observation that for various historical reasons, neuropsychologists have often been allowed on medical panels, because they have been perceived as being “more medical than psychological.” So while neuropsychologists can be on the medical panel, other psychologists such as health psychologists are more likely to be excluded. This can lead to a number of strange situations. For example, psychology is the profession that specializes in the development of tests and questionnaires. However, because of the paneling problems reviewed, in many situations psychologists have more difficulties getting paid for testing by the

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<sup>3</sup> Note that this method, while acceptable to a number of payers at the time of this writing, utilizes the *DSM-IV* format, which is expected to be obsolete in the United States as of October, 2015. The *ICD-10*, which goes into effect on that date, does not use a multi-axial diagnosis, and at this time it does not have a code for “Diagnosis deferred.” Because of this, it remains to be seen how payers will implement H&B coding under the *ICD-10* system, and psychologists would be wise to be proactive in this regard. Coding “no diagnosis” psychologically may be acceptable.

medical payer than other professions. For example, in some cases a physician or a speech–language therapist may be more able to provide some psychological testing or assessment services than a psychologist, simply because these other professions have traditionally belonged to the medical panels, and under federal law, these non-mental health professionals are able to perform some psychological testing services.

Some psychologists have been successful in pointing out to medical payers that this situation defies logic. This is especially true when the medical payer *requires* presurgical psychological evaluations, and which the mental health payer states is not their responsibility to pay for. Psychologists in the field have successfully made the case to some payers that (1) H&B services are a contractually covered service under the medical plan, (2) some H&B services such as presurgical psychological evaluations are even required prior to certain surgeries, but (3) the payer has failed to include on their panel any providers able to offer these services. Some psychologists have argued that by failing to provide a means of obtaining a covered diagnostic service, and, on the basis of that, refusing to authorize surgery, the medical payer has failed to meet its contractual obligations to its patient subscribers. The remedy here, of course, was to allow psychologists to become members of the medical panel.

Fifth, the Centers for Medicare and Medicaid Services (CMS) has at times encouraged psychologists to utilize “incident-to” billing, using the medical professional’s credentials. This works in the following way: If a psychologist and a physician (or other medical provider) work together to provide physician/medical services, the services can be billed under the physician’s provider number, to get the full physician fee, under the Medicare provision for “incident-to billing.” In the case of psychology though, this makes the psychologist a second-class medical provider, whose services are only “incidental” to those of the other profession, and the other profession remains in full control of that treatment and must supervise and countersign all of the psychologist’s notes. Incident-to billing is complex, and certain rules must be followed when attempting to bill for services under this provision. The rules include the following [19]:

1. A physician personally performed an initial service
2. The “incident to” service must be judged to be an integral, although incidental, part of the physician’s professional service
3. The service is commonly rendered without an additional charge beyond the usual physician bill
4. The service is of a type commonly furnished in a physician’s office or clinic (and not requiring an institutional setting)
5. The service creates an employee expense to the physician
6. The service is under direct physician supervision, with a physician on premises to offer assistance as needed. Direct supervision does not require the physician’s presence in the same room.
7. The service is located within the physician’s office
8. The physician must continue to perform services at a frequency that reflect an active participation in the management of the course of treatment

9. The physician ordering a particular service need not be the physician who is supervising the service. Therefore, incident to services performed by auxiliary personnel and other aides are covered even though they are performed in another department of the clinic
10. Auxillary personnel who can perform these services include clinical psychologists, clinical social workers, physician assistants, nurse practitioners, clinical nurse specialists, certified nurse midwives, physical therapists and occupational therapists

Overall, while incident-to billing is possible for Medicare, there are so many conditions that in practice it is challenging to make work.

Despite everything, the H&B codes have been moderately successful. By about 2006, using Medicare numbers, the number of H&B services being billed each year came to approximate the usage of the commonly used code for psychological testing services. Following 2006, Medicare utilization of H&B services seemed to plateau [7]. However, during that same period, anecdotal evidence suggests that H&B utilization has increased within the private sector. Even so, at the time of this writing, there is no dominant financial paradigm for behavioral medicine in the field, and the changing financial horizon will likely require the individual practitioner to engage in financial, contractual, and reimbursement negotiations.

## **Negotiating with Insurance Companies**

As noted above, while single-payer systems like Medicare do not find H&B services to be problematic, private payers have responded to behavioral medicine services in various ways. If it becomes necessary to negotiate with payers to resolve reimbursement issues, the following suggestions are offered with regard to negotiating for H&B reimbursement. Many of these methods though are also useful for negotiating other reimbursement issues.

If you are employed by a clinic, hospital system, or academic setting, find out from the practice manager, medical director, or chair who is responsible for negotiating contracts with the insurance companies, and make your way through the layers until you are able to either directly be part of the negotiations or have a working relationship with those who do the negotiation. Having the support of your institution gives you a powerful ally in these negotiations. However, if you are in private practice, you can negotiate yourself as discussed below, or alternately work with your state psychological association to make these contacts.

For the individual practitioner, the best way to initiate negotiations with a payer is to contact the provider relations or provider management director of the payer. If you are a larger clinic, you probably have a provider relations contact in management at the payer that you can start with. You might speak to the person first, offer to send them some information for them to consider, and follow up with a call. The American Psychological Association Practice Organization has drafted a template for a letter that you can use to lobby for the reimbursement of H&B services, which



is included in Appendix 1. The letter you create should explain how H&B codes were created, what conditions and services these codes were meant to cover, the rules for using the codes, and it should highlight that these are covered by Medicare. It should also state that, typically, H&B codes are a commonly covered benefit. Also, note that they have no one that currently provides the services that they may well require. You might add a paragraph that reads something like this:

We are asking your assistance in establishing a new policy that specifies that when H&B services are provided by psychologist and other non-physician professionals, claims will be reimbursed under the medical benefits. In addition, we are asking for your assistance in re-processing claims for those services that were previously denied, because these were thought to be mental health services, or because a psychologist or non-physician billed these services.

Following the letter, it can be helpful to have a follow-up meeting/discussion with the insurers as needed to clarify any remaining barriers and have further discussions and/or follow-up meetings with ones that are not paying. If after these efforts you are still unsuccessful, contact the American Psychological Association Practice Organization, as they may be able to offer help. Further, in many states the State Insurance Commission can intervene on behalf of a patient to order the payer to reimburse the services in question. Alternately, reimbursement can be sought through the mental health payer.

When talking with the payers it is important to stress that the problem being treated is a physical health problem, not mental health, as such the H&B codes apply to the services being rendered and are reimbursable. Unfortunately, many payers still do not understand the concept of behavioral medicine services. Having an “elevator” speech or one page bullet document describing behavioral medicine services can be helpful. It can also be helpful to enlist the help of the patient’s physician, the patient, the patient’s employer, and the state insurance commission. Often, it is the patient’s employer who buys the insurance policy and sometimes can effectively pressure the payer into meeting their contractual obligations.

## **Providing Insurer’s Assistance**

Why should medical payers be interested in discussing reimbursement matters with psychologists? There is an increasing realization on the part of medical payers that it is in their best interest to explore behavioral health solutions. For the psychologist in discussion with payers, it is important to help the payer understand the potential financial benefits that stem from behavioral medicine services. For example, data exist showing that delayed recoverers from back pain are 57 times more expensive than average recoverers and that psychological interventions are economical and effective treatments for these patients [20].

A previous study reported that spinal surgery for pain is no more effective than interdisciplinary treatment that including psychological treatments or psychological treatments alone, and that psychological assessment can help to predict how

patients will respond to surgery. This study went on to compare the cost of a typical lumbar fusion to the cost of a standardized group cognitive behavioral therapy (CBT) approach to pain treatment, and determined that while these two treatments had similar outcomes, the surgical costs were 168 times greater than the CBT costs. As the cost of lumbar fusion during the initial hospital stay alone was US\$ 50,300 [21], health psychology treatments can be seen to be vastly less expensive. Further, psychological assessment can help to predict how patients will respond to surgery [8, 9]. Thus, psychological treatment is a very cost-effective option [22].

We are entering a time where the cost savings of psychological treatments for patients in medical settings is generating insurer attention. There is increased attention to chronic medical disease, for example, the data that patients with type 2 diabetes and depression cost more than 200% medically than patients with type 2 diabetes who are not depressed are becoming well known by insurers [23]. Overall, by helping insurers to become aware of model programs that are demonstrating clinical and cost benefit to targeted conditions, they will be better able to see the benefit in terms of both cost savings and improved patient care. Insurers are often not cognizant of the potential cost savings the psychological services can offer. There is anecdotal data that payers are concerned that reimbursing psychology services in medical settings will increase costs. Addressing psychosocial matters is sometimes seen as a kind of Pandora's box, which, once acknowledged, will increase medical costs. However, an examination of the literature strongly suggests that psychology interventions in medical settings are effective and economical [23, 24].

## **Concerns Related to Billing and Using Psychiatric Codes and Diagnoses for Medical Patients**

Historically, when psychologists could not bill for medical diagnoses, a psychologist could be tempted to report an alternative psychiatric diagnosis in order to receive payment. If no such condition is present though, this act violates the psychologist's legal and ethical responsibilities. Clearly, when a psychiatric diagnosis is the primary focus of treatment, a psychiatric service should be billed. For example, depression and anxiety are commonly seen in medical patients. In other cases though, if no psychiatric condition can be diagnosed, or if a behavioral health evaluation does not even explore psychiatric diagnoses, assigning a *DSM-IV* finding of "Diagnosis Deferred" is consistent with this.

## **The Move Toward Collaborative Health Care: A Double-Edged Sword**

There is increased recognition that behavioral, mental health, and substance abuse comorbidity is an important driver of health status, health care utilization, and cost [17]. At federal, state, and local levels an increasingly frequent response is to integrate mental health, substance abuse, and health behavior services into primary care practices. At first glance, this is a significant opportunity to implement the science of health psychology in a more robust fashion into medicine. However, there are obstacles to achieving that translation. First, to date there has been no consensus on the construct or operation of collaborative care. For example, the IMPACT work of Katon and Unutzer is the most researched program that is labeled collaborative care [25–28]. Its model is care management focused with psychiatric supervision and health psychology interventions are not critical components of the model.

Despite the increased interest in collaboration, there is no consistent agreed-upon financial model to support these services. Besides Medicare, the penetration of payment for use of the H&B codes while increasing is still modest in many areas. In the recently awarded CMS multistate demonstration projects, mental health was not a specified inclusion. There are hopeful illustrations of change. In Vermont, where the Blueprint for Health has been identified as the model for primary care reform, provision of mental health and substance abuse services is a core element of that model. In Rhode Island, the state's major private insurers have set a higher rate for H&B services provided by psychologists and trained social workers who provide those services in primary care.

### **Emerging Trends**

The area of financing psychology services in medical settings within current health reform efforts is a rapidly moving target. In the 2011 National Council for Quality Assurance standards, screening for depression and other mental health conditions is a scorable element. There is a requirement for an annual quality improvement project in the area. Recently, the American Academy of Family Physicians (AAFP) endorsed a Statement of Principles for the PCMH that suggests that mental health, substance abuse, and health behavior services must be integrated into the core of the PCMH or it will fail [3]. Within the discussions of accountable care organizations (ACOs), the inclusion of such services is an active question. As the future unfolds, we believe that inclusion of mental health, substance abuse, and health behavior services will be robust elements of the conversation.

What evidence is there that an integrated practice model can work? A noteworthy attempt at implementing a biopsychosocial treatment model is the Colorado Workers' Compensation System. This system mandated the use of treatment guidelines for injured workers that had special status as biopsychosocial laws [29]. A recent

financial study of the Colorado system used data gathered prospectively from 1992 to 2007 in 45 US states [22]. These data examined the medical treatment and disability costs of 520,314 injured workers in Colorado, and an estimated 28.6 million injured workers nationally. Although concerns are sometimes expressed that mandating psychological care for patients with pain or injury would “open Pandora’s box” and increase costs, the reverse effect was observed. Over the 15 years following the implementation of the biopsychosocial model, the rate of medical inflation in Colorado Workers’ Compensation was only one third that of the national average, which was saving an estimated US\$ 859 million in Colorado in 2007 alone. A subsequent follow-up study of the effects of economic recession on biopsychosocial treatment costs, the treatment costs of 32.4 million patients over a 17-year span, determined that an additional US\$ 760 million was saved by Colorado in 2009 [22]. Further, the results of this study suggested that during times of economic recession, financial incentives may increase incentives for misbehavior of patients and payers alike, making the biopsychosocial model even more valuable.

At this time, the Colorado studies are the only large financial studies of the cost benefits of the implementation of a biopsychosocial model that integrates medical and psychological care. While the results appear very promising for this approach, at this time little data are available regarding the economic impact of this type of integrated care on the medical economy.

## Summary

Psychologists have demonstrated their value in assessing and treating a range of mental health, substance use problems, and health behaviors in medical settings, and they continue to increase in value given the medical community’s focus on whole patient care. But the business of psychology is based on economics and contracts. We need to embrace Peek’s vision of 3 Worlds’ clinicians, simultaneously integrating the clinical, organizational, and financial elements of care [30]

We must be active in forging business relationships that allow us to do our work and to get paid. We work in a culture where psychology services have not been perceived as having specific identifiable value, and, in the long term, a specialty with no identifiable value has no economic value. In the long term, if we continue to see our identity as clinicians in our offices no matter what the setting, it will be the death of our profession. It is important to know the rules and follow them, but through the knowledge of those rules to change them demonstrate the value represented by the rest of this volume, make a living and get paid for beneficial psychological services.

## Appendix 1

### ***American Psychological Association (APA) Sample Language for Letters to Private Insurance Carriers Regarding Coverage of Health and Behavior Services***

It has been brought to our attention that your company is not currently reimbursing psychologists for services provided under the Current Procedural Terminology (CPT) health and behavior assessment and intervention codes. We would like to take this opportunity to enhance your understanding of the new codes and to discuss the value and effectiveness of health and behavior services.

### ***An Overview of the Health and Behavior Assessment and Intervention Codes***

The health and behavior codes were developed to provide psychologists and other health care providers with a way to accurately capture services that focus on the biopsychosocial factors affecting physical health problems. Examples of the physical health issues that psychologists might address under the new codes include patient adherence to medical treatment, symptom management, health-promoting behaviors, health-related risk-taking behaviors, and overall adjustment to physical illness. In almost all cases, a physician will already have diagnosed the patient's physical health problem before a psychologist sees the patient.

The assessment codes apply to services that identify biopsychosocial factors important to the treatment or management of physical health problems. The intervention codes reflect services used to modify biopsychosocial factors affecting a patient's physiological functioning, health, and well-being. The codes are published in the CPT manual issued by the American Medical Association (AMA) as follows:

- 96150 The initial assessment of the patient to determine the biological, psychological, and social factors affecting the patient's physical health and any treatment problems
- 96151 A re-assessment to evaluate the patient's condition and determine the need for further treatment
- 96152 Intervention services provided to an *individual* to modify the psychological, behavioral, cognitive, and social factors affecting the patient's physical health and well-being
- 96153 Intervention service provided to a *group*
- 96154 Intervention service provided to a *family with the patient present*
- 96155 The intervention service provided to a *family without the patient present*

As you are likely aware, developing new CPT codes is a stringent process subject to review by various AMA-coding committees. APA worked closely with the AMA

on the creation of the health and behavior codes because psychologists are among the leading health care providers whose training prepares them to furnish these types of services. In 2000, assisted by the National Association of Social Workers, APA conducted a survey to determine appropriate values for the codes and made recommendations to the AMA's Relative Value Update Committee (RUC) concerning values for the new codes. In 2001, the RUC recommended that the Centers for Medicare and Medicaid Services (CMS) adopt the values forwarded by the RUC.

CMS accepted the RUC's recommendation and included the codes and their relative values in the 2002 Physician Fee Schedule published in the November 1, 2001 *Federal Register* (66 FR 55245, 55463, 55499). At that time, CMS designated the codes as "active," meaning the codes would be reimbursable effective January 1, 2002 so long as Medicare covered them. Subsequently, CMS determined that Medicare would cover the health and behavior codes with the exception of code 96155 (family intervention without the patient present). CMS excluded code 96155 from coverage because Medicare pays only for services provided directly to Medicare beneficiaries.

### ***Psychologists' Role in Addressing Physical Health Problems Through the Use of Behavioral Assessments and Interventions***

According to the AMA's *CPT Changes 2002* manual, the new codes may be utilized by pediatricians, family physicians, internists, psychiatrists, psychologists, advanced practice nurses, clinical social workers, and other health care professionals within their scope of practice who have specialty or subspecialty training in health and behavior assessment/intervention procedures. However, physicians performing these services are directed to use the Evaluation and Management or Preventive Medicine services codes.

In order for a psychologist to provide both health and behavior assessment and intervention services to a Medicare beneficiary, he or she must be a "clinical psychologist" as defined in Medicare.<sup>4</sup> This means the psychologist has a doctoral degree in psychology and is licensed or certified by the State in which he or she practices to provide diagnostic, assessment, preventive, and therapeutic services directly to individuals.

As noted earlier, the new health and behavior codes are intended to be used with patients who have a physical health, not a mental health, problem. Although more typically recognized for their work involving mental health, psychologists also use their skills and abilities to treat patients suffering from physical health problems. When treating a patient for a mental health diagnosis, a psychologist would use the appropriate psychotherapy code, not one of the health and behavior codes.

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<sup>4</sup> The second category of psychologists, under Medicare, "independently practicing psychologists," may only perform diagnostic and testing services and therefore would be limited to providing services under the two health and behavior assessment codes.

We trust this letter explains the purpose for which the health and behavior codes were developed and clarifies that psychologists, along with certain other health care professionals, are authorized to provide services under the codes. We look forward to hearing that your company has decided to provide coverage of health and behavior services by psychologists.

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**Part IV**  
**Population Specific Consideration**

# Chapter 10

## Competency for Diverse Populations

Geneva Reynaga-Abiko and Tiffany Schiffner

### Introduction

The USA is an increasingly diverse nation. The USA currently comprises 50.7% women and 49.3% men with the following ethnic breakdown: 4.7% Asian American/Pacific Islanders, 12.8% African Americans, 15.4% Latina/os, 65.6% European Americans, and 1.0% Native Americans. Poor people make up 13.2% of the US population [1], with people of color, especially African Americans and some Latina/os, disproportionately likely to live in or near poverty [2]. The numbers of people who are lesbian, gay, or bisexual are estimated at about 3.5% [3] of the population, but the number of transgendered people is impossible to calculate. The diversity of the USA is likely to keep increasing due to immigration rates, an ever-widening gap between the rich and the poor, and various social movements leading to increased acceptance of interethnic marriage, identification as a sexual minority, and other shifts.

It is important to understand the rich diversity of the USA, but it is even more important to recognize the Eurocentric, heterocentric, and androcentric nature of psychology [4]. Multicultural psychology was specifically designed to combat this bias and all types of oppression [8, 26] (e.g., a type of injustice including bias, prejudice, discrimination, marginalization, etc.). We are still working hard to understand patients and their presenting concerns within cultural context. We define culture as “a pattern of learned beliefs, values and behavior that are shared within a group; it includes language, styles of communication, practices, customs, and views

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on roles and relationships” [5, p. 953]. Multicultural treatment is simply any encounter that occurs between people of different cultural backgrounds [6]. Because everyone is a conglomeration of their various cultural identities, every therapeutic encounter is multicultural [7]. (Readers are referred to Sue and colleagues [8] for a thorough overview of multicultural psychology.) Overall, cultural competence is a necessary set of skills for providers who wish to deliver high-quality and ethical care to all patients.

Several definitions of cultural competence have been offered in the literature. We view cultural competence as a set of problem-solving skills that include:

- a. The ability to recognize and understand the dynamics interplay between the heritage and adaptation dimensions of culture in shaping human behavior
- b. The ability to use the knowledge acquired about an individual’s heritage and adaptational challenges to maximize the effectiveness of assessment, diagnosis, and treatment
- c. Internalization (i.e., incorporation into one’s clinical problem-solving repertoire) of this process of recognition, acquisition, and use of cultural dynamics so that it can be routinely applied to diverse groups [9, p. 565]

Even after the advent of multicultural psychology, the norm is still considered European American, middle-class, heterosexual males [4] and everyone else is compared to this group. This comparison denies the fact that all groups are multicultural [7] and that culture affects symptom presentation, health behaviors and prevention, disorder conceptualization (i.e., how the person explains the disorder), attendance, and response to treatment. Psychology has yet to reach even a moderate level of multicultural competence as a field [10] as it is still assumed to be a specialty area rather than a core competency [11]. This chapter arose out of the continued necessity to discuss the myriad issues to consider when attempting to develop and implement cultural competence with a variety of culturally diverse patients. In order to achieve this standard of care, several factors must be addressed, including an overview of diversity in the USA, prevalence rates of mental disorders in each group, and its impact on treatment. We end the chapter with practical guidelines for working competently across cultures.

## **Diversity Areas to Consider**

This section discusses the most common cultural components that may affect one’s mental health. These include gender, sexual identity, race, ethnicity, immigration, socioeconomic status (SES), age, and spirituality. Although these are presented as discrete entities, it must be understood that everyone has all of these variables present in their lives, though some may be more salient than others [7]. Further, these sociocultural realities must be understood in combination, as it is never possible to divide people into distinct identities that can be dealt with separately [12].

## ***Gender***

Gender is a critical determinant of mental health. Because the USA is a patriarchal culture, men have more power and control over the socioeconomic factors in their lives, which affects their susceptibility and exposure to specific mental health risks [13]. In general, women are less likely to have access to higher education, continue to make less money than men for the same work, are more likely to be poor, especially if they have children, and are exposed to intimate partner violence at far greater rates than men [14]. Pressures created by women's multiple roles, gender discrimination, and associated factors of poverty, domestic violence, and sexual abuse combine to account for increased risk of poor mental health for women. Paradoxically, women live longer than men [15].

*Gender identity.* Gender identity refers to the social construction of gender and the fact that one develops a sense of being “male” or “female” based largely on culture, rather than their biological sex. Some people develop a gender identity that is different from their biological sex and are typically labeled “transgendered.” Intersex individuals, historically referred to as hermaphrodites, and individuals with certain chromosomal disorders are another example of people whose gender identities are not necessarily determined by their biological sex [16]. This forces us to critically evaluate the historically assumed gender binary, with many more options than simply “male” and “female,” especially considering that so-called gender variants can be found throughout history and in every society around the world [17].

When people identify with a gender that is different from what others expect, they are often oppressed, or are the brunt of discrimination, social rejection, and abuse. Transgendered, intersexed, and other individuals who do not conform to the archaic assumption of a gender binary are more likely to be rejected by their families of origin, bullied by their peers in adolescence, and endure physical, sexual, and emotional abuse from strangers as well as romantic partners [17]. These realities increase their risk of developing mental health conditions.

## ***Sexual Identity***

A person's sexual orientation is thought to develop very early in life [18] though it can change over the life span. Sexuality has traditionally been understood as an inflexible binary system (e.g., same-sex or opposite-sex attraction) but is now known to encompass a continuum including many possible combinations of sexual and emotional attraction [16]. In fact, one's sexual identity is much more than who they are attracted to and may become a political act.

Homosexuality, now considered a derogatory term, was conceptualized as a mental disorder until 1973, when it was finally removed from the *Diagnostic and Statistical Manual of Mental Disorders, Third Edition, Revised (DSM-III-R)* due to lack of empirical evidence [19]. Heteronormativity, or the idea that heterosexuality

is “natural” with all other sexual orientations aberrant, runs rampant in society [16] and prevents many people from fully accepting their sexual orientations. Therefore, the estimates of gay, lesbian, bisexual, and heterosexual orientations are inevitably inaccurate, as many people continue to hide under the guise of assumed heterosexuality. A note about transgendered individuals seems appropriate. They are often assumed to be “gay” or bisexual but this is a gross misunderstanding [17]. Sexual identity differs from gender identity, and transgendered individuals, just like everyone else, may be of any sexual orientation.

## ***Race***

Race has historically been defined as a biological reality that resulted in different skin colors and physical features. However, biology has failed to find evidence for a genetic basis to race and we now know that it only holds validity as a sociopolitical construct. In other words, the concept of race has taken on an important dimension in terms of how individuals identify who they are but ultimately has no meaning from a biological or genetic perspective [20], (pp. 9–21). A discussion of the politics and history of how race has been conceptualized in the USA is beyond the scope of this chapter, but it is worth mentioning that how people are labeled by the US government, such as through the Census, is neither static nor scientific [21]. Due to the fact that the term “race” has no scientific validity, understanding one’s ethnicity and ethnic identity is ultimately more valuable for capturing a deeper perspective of their worldview.

## ***Ethnicity***

Ethnicity may be conceptualized as the group(s) with whom a person shares a common origin and history [22]. Ethnicity is often mislabeled and confused with race in the USA. Thus, when terms like “Asian American” are used, this refers to a group of people originally from a country in Asia who now live in the USA. We prefer the term ethnicity over race when referring to people, as it is a more accurate reflection of a person’s background and the culture(s) that may inform their worldview. It is possible for someone to have more than one ethnicity.

*Ethnic identity.* Ethnic identity is a multidimensional construct that reflects one’s sense of self as a member of an ethnic group [23]. It is an integral part of an individual’s self-concept, influencing his or her perceptions, cognitions, affect, and behaviors [24]. It can change over time and across social interactions [25] and is not necessarily the same thing as one’s ethnicity. In other words, a person can technically be from an ethnic group without feeling strongly identified with that group. Therefore, we can never make assumptions about a person’s beliefs just by knowing their ethnic background. There are many different models of ethnic identity and the reader is encouraged to consult Sue and Sue [26] for a description of the various models.

## ***Immigration***

Immigration, or voluntarily moving from one's native country to another country, has many causes, from social to economic. Some immigrants move to the USA legally whereas others do not have the resources to do so. Some immigrants come to the USA with advanced degrees and great opportunities due to high status in their home country whereas others move to the USA because of lack of opportunities in their native land. Regardless of their background or reasons for immigrating, immigrants typically face discrimination in the USA they may not have experienced in their home country [27].

Early notions about the relationship between immigration and mental health were built on the premise that immigrants encountered difficulties and obstacles as they made their way into a new society. These hardships may have included problems finding quality jobs in safe work environments, encountering fewer opportunities to enhance incomes and build wealth, and engaging in a smaller set of social networks that provide instrumental and emotional support [28]. Due to the fact that all of these factors are related to health, early researchers considered immigrants to be at greater risk of mental health problems than their US-born counterparts. However, recent studies have found that at least some immigrant groups may experience better mental health than US-born individuals, as is the case with many Latina/o groups.

*Acculturation.* Acculturation is an individual's process of learning about and adoption of the dominant cultural values, beliefs, and behaviors and the degree to which the person maintains his or her native culture's values, beliefs, and behaviors [29]. Acculturation research most frequently uses the bidimensional acculturation model. It has four discrete categories: assimilation (i.e., reject native cultural values), integration (i.e., biculturalism—choose to maintain the heritage culture as well as engage in relationships with the dominant group), separation (i.e., choose to retain the heritage culture by avoiding interactions with members of the dominant group), and marginalization (i.e., no interest in maintaining either the heritage culture or the dominant culture) [30].

Every immigrant acculturates at different rates and in different ways, and the amount of time spent in a culture is not necessarily related to a person's sense of belonging in that culture [31]. Family members often have different acculturation levels and the younger members of the family typically acculturate faster [32]. Knowing a patient's acculturation status may provide critical information about what cultural values, beliefs, and behaviors the patient maintains [33], no matter how long they have lived in the USA.

*Language.* Language is an important variable in all counseling interactions. What may be most important in culturally responsive counseling is the therapist's ability to be sensitive to possible language differences between himself/herself and the patient, including verbal and nonverbal communication. Patients must be able to express themselves in a manner that is most comfortable and appropriate for them. At least 14% of the US population now speaks a language other than English in their home and Spanish is the most commonly spoken language other than English [1].

If a provider is not familiar with the primary language of the patient, incorporating trained interpreters into treatment is essential for competent care. It is crucial that the translator be someone other than a relative, be biculturally competent (i.e., competent in the culture of the mental health professional and competent in the culture of the patient), and understand mental health diagnoses and procedures [34]. Some states, such as California, are increasingly standardizing use of translators in medical settings, and translators are often available via telephone, but this remains a practice that is largely unregulated and, in our experience, unsatisfactory from the patient's perspective.

An additional approach to overcoming language barriers is through the use of "cultural mediators." Cultural mediators form part of the health care team, engaging in medical interpreting as well as interpretation of the cultural and social circumstances that may affect care. This enables providers to gain a more comprehensive understanding of the patient's needs, and to negotiate culturally appropriate plans of care [35]. Cultural mediators often can help bridge the chasm created by language differences.

### ***Socioeconomic Status***

SES illustrates one's position in society and includes household income, wealth, education, and family legacy, or lack thereof. In the USA, most people identify as "middle class" but this belies the increasing disparity in income distribution. Hence, the "American dream" of working hard and "making it" is increasingly being exposed as the meritocracy myth it has always been [36]. The phenomenon of widening gaps between the rich and poor reifies colonialist notions of European Americans in positions of privilege while oppressing people of all other ethnicities. While women and people of color have made gains in education and business, they are disproportionately more likely to be poor when compared to European American males [37]. There are increased risk factors for individuals of lower SES, including poor-quality health care, poor nutrition, increased stress, lower education, and other factors [38].

### ***Age***

The US population over age 65 continues to grow, currently comprising 12.8% of the population [1]. Women tend to live longer than men, and by age 85, there are twice as many females than males. Elderly women are more likely to live alone than elderly men, which decreases access to social support and may increase risk of mental disorders. People of color constitute the fastest growing segment of the elderly population [39]. Age discrimination continues to be a problem in the USA, and medical and mental health fields are no exception. The *DSM-IV-TR* [40] criteria for most mental disorders have a bias toward young adults, making it especially

important for mental health providers to be attentive to the unique needs and context of older adults. This is complicated by the fact that most psychologists were not trained to consider the unique needs of the elderly [41]. The ways in which people are treated as they age vary greatly across cultures, with some elderly people, such as European Americans, valuing their independence and ability to live alone, while others, primarily people of color, expecting to live with family members as a valued member of the family throughout their later years.

## ***Spirituality***

Approximately 96% of people in the USA hold some sort of belief in a spiritual being or presence [42], though there is great variation in how people identify spiritually. Belief in a divine power is labeled “spirituality” while subscribing to the practices of a faith-based community is understood as “religiosity” [43]. The two are not the same, and one may be spiritual without identifying as being religious. A spiritual identity can help people organize their world and make sense of events around them. Women tend to be more religious and spiritual than men, and people of color tend to be more religious than European Americans. People of color in the USA often use spirituality as a means of coping with the various oppressions they experience [44], and spiritual leaders may have greater success rates with treating symptoms than mental health professionals. Many members of the lesbian, gay, bisexual, and transgender (LGBT) population have been marginalized in religious communities, though there are an increasing number of LGBT-friendly faith-based organizations.

## **Prevalence of Mental Disorders by Culture**

Psychiatric disorders are the third most costly condition in the USA and depression is the second leading cause of life prematurely lost to death [45]. Suicide is the eighth leading cause of death in the USA and most people who complete suicide suffer from major depression at the time of death [46]. For example, Native American adolescents have the highest rates of suicide, and there are interesting ethnic and age differences with regard to suicide, making it relevant to all cultural groups. Mental disorders tend to be chronic and their effects range from loss of productivity to disability (temporary or permanent), homelessness, and, in some cases, suicide [45].

It is currently estimated that 26.2–29.5% of the US population has some type of mental disorder [47] and that, by age 55, 50% of the US population will have suffered from some type of psychiatric disturbance [45]. This is undoubtedly an underestimation because these data do not include somatization disorders, adjustment disorders, personality disorders [47], or culturally bound syndromes [26]. Available data suggest that mood disorders affect 9.5–11.3% of the US population, with 85%



of these cases considered moderate to serious, which means the disorder affects everyday life. Anxiety disorders affect 17.2–18.1% of the population, substance-related disorders 3.8–11.3%, impulsive control disorders 8.9%, and psychosis 0.5% [47]. Note that it is possible to have more than one diagnosis at the same time. Let us more closely examine how several of the cultural variables mentioned in the previous section relate to mental disorders.

## ***Gender***

There are important differences in incidence rates based on gender that are obscured when we only consider national averages. In the case of women, they are two to four times more likely to be diagnosed with unipolar depression than men. Bipolar disorder occurs at similar rates as men but women tend to have more depressive and fewer manic episodes [14], (pp. 254–255). Women are less likely to develop a substance disorder but twice as likely to suffer from an affective, anxiety, or somatoform disorder when compared to men [47]. Anxiety disorders have a longer course in women and women are more likely to develop post-traumatic stress disorder, even though there are no gender differences in exposure to traumatic events. Eating disorders are almost exclusively diagnosed in women [14], (pp. 256–257), though men increasingly suffer from these conditions as well.

## ***Gender and Sexual Identity***

Increased mental health disorders are seen among the LGBT population. It is likely that this is due to discrimination as well as internalized homophobia [48]. We know that LGBT youth are harassed more than their peers who identify as heterosexual and either male or female, leading to increased rates of depression, suicide, substance abuse, and relationship problems [19]. When we consider that members of the LGBT population are often rejected from their families of origin and religious organizations, groups that are often sources of refuge from an oppressive dominant culture for other marginalized groups, it becomes clear that LGBT individuals have decreased access to social support.

Heteronormativity and the gender binary remain common assumptions in medical and mental health settings, leaving LGBT individuals with few safe havens. This is especially true for transgendered individuals, whether they have undergone gender reassignment surgery or not, and a tenuous relationship with the medical establishment continues to exist for transgendered and intersexed individuals [16]. Domestic violence and sexual assault exist in LGBT communities but are often ignored by legal authorities and health providers, who continue to assume a heterosexual norm [14]. Therefore, the LGBT population has increased risk factors for mental disorders but fewer available LGBT-friendly resources for assistance.

## ***Race and Ethnicity***

When we combine European Americans, Latina/os, and African Americans, they make up 93.8% of the US population. European Americans represent the dominant culture in both numbers and institutionalized power. Latina/os and Asian Americans/Pacific Islanders are the fastest growing ethnic groups in the USA, though they remain largely oppressed by the dominant culture. In the body of psychology literature, European Americans have been the predominant ethnic group included in studies. Historically, research about mental disorders has ignored all other ethnicities [27], (p. 249). The information presented below is based on what limited data are available for all ethnic groups.

*African Americans.* Approximately 12.8% of the US population is African American [1]. In general, African Americans have rates of mental illness similar to the national norms but lower rates of depression and phobias. This is somewhat surprising, considering the institutionalized oppression African Americans continue to face and the fact that they are disproportionately likely to be unemployed and poor when compared to national averages [49]. Somatization is more common than the national average, and suicide rates among young Black males are as high as those found in the European American population, making it the third leading cause of death for African Americans 15–19 years of age [50].

*American Indian/Alaska Natives.* This heterogeneous ethnic group comprises 562 federally recognized tribes and more than 100 state-recognized tribes, representing 1.0% of the total US population [1]. More than 200 indigenous languages are spoken among American Indian/Alaska Natives, and roughly 20% of this group speak a language other than English at home [51]. In general, American Indians/Alaska Natives have higher rates of mental disorders than national averages, particularly regarding trauma and alcohol abuse. The rate of violent victimization of American Indians/Alaska Natives is more than twice the national average, which may be related to a rate of PTSD that is three times higher than the national average [52]. Similar to African Americans, young American Indian/Alaska Native males have much higher rates of suicide than any other age for this ethnic group [50].

*Asian American/Pacific Islanders.* Asian Americans and Pacific Islanders account for 4.7% of the US population [1]. This group is very diverse, with more than 43 different ethnic subgroups and 100 different languages represented among its ethnic subgroups. Roughly 35% of Asian Americans/Pacific Islanders live in households where there is limited English proficiency with an even greater number living in bilingual households [53]. While overall prevalence rates of diagnosable mental illnesses among Asian Americans/Pacific Islanders appear similar to the national averages, they show higher levels of depressive symptoms. Chinese Americans are more likely to exhibit somatic complaints of depression than are African Americans or European Americans. Filipino, Chinese, and Japanese Americans all have much lower suicide rates than European Americans. However, Native Hawaiian adolescents have a higher risk of suicide than other adolescents in Hawaii. Older Asian

Americans show a greater prevalence of dementia than the general population, and older Asian American women have the highest suicide rate of all women over age 65 in the USA [53].

*European Americans.* European Americans represent 65.6% of the US population [1] and are least likely to be poor or oppressed because of their ethnicity. Mood disorders affect about 11% of European Americans, anxiety disorders about 18%, substance-related disorders 11%, and impulsive control disorders about 9%. European American males are more likely to have a substance abuse disorder than females whereas European American females are twice as likely to be diagnosed with a mood or anxiety disorder than males [47]. This ethnic group has the highest rate of suicide in the USA overall [54]. The relatively high rates of psychological disturbance and suicide is paradoxical, given that European Americans are considered members of the dominant culture and therefore do not face the psychological consequences of institutionalized oppression.

*Latina/os.* Latina/os represent 15.4% of the US population and are the fastest growing ethnic group in the USA [1]. This group includes any person of Cuban, Mexican, Puerto Rican, and South or Central American descent. In the USA, most Latina/os are originally from Mexico (66%), followed by Central and South Americans (13%), Puerto Ricans (9.4%), and Cubans (3.9%) with the remaining 7.5% representing other Latin American countries [54]. Latina/os have the highest high school dropout rate in the USA, with only 52% of Latina/os graduating from high school [55]. Latina/os are disproportionately poor, though this depends on the specific Latina/o subgroup. Puerto Ricans and Mexican Americans have poverty rates that are more than double the national average of 13.5% while Cuban Americans' poverty rate is roughly similar to that of the USA overall [2].

The rate of mental disorders among Latina/os depends on their immigration and acculturation status. In general, Latina/os who were born in the USA demonstrate rates similar to national averages. In contrast, Mexican immigrants have lower rates of mental disorders than Mexican Americans born in the USA, and adult Puerto Ricans living on the island tend to have lower rates of depression than Puerto Ricans living on the mainland. Studies have found that Latina/o youth experience more anxiety-related and delinquency problem behaviors, depression, and drug use than European American youth [56]. Latina/os have a suicide rate that is half that of European Americans, but Latina/o adolescents who were born in the USA are more likely to attempt suicide than Latina/o immigrants who are adolescents [57].

## ***Immigration***

Data on mental disorders among immigrant populations are interesting, with most studies suggesting lower overall rates of mental disorders among the immigrants. However, for most immigrant groups, as they acculturate to US culture, mental disorders increase [27]. The reasons for this are not well understood but it seems

comprehensible that lower SES, discrimination, and the stress associated with acculturation may contribute to increased risk of mental disorders. It is difficult to fully understand this mental health trend because people immigrate for a variety of reasons. Groups from certain countries tend to be highly educated and of higher social classes (e.g., the Middle East, some African countries, South America, some Asian countries), and thus may experience stress at suddenly becoming an oppressed “ethnic minority” in the USA. Other groups are poorly educated and come to the USA with dreams of supporting their family in one of the richest nations in the world (e.g., Mexico, Central America, some Asian countries), only to find increased stressors associated with ethnic and class oppression, difficulty learning the English language, and poor chances of achieving citizenship in a complex political game of nation-based quotas and high anti-immigrant sentiment [27].

*Refugees.* Refugees, regardless of nation of origin, typically have very high rates of stress and trauma, given the forced nature of their move and the sociopolitical factors that led to the situation [27]. This displacement, in addition to the lack of choice in their current living situation and decreased locus of control, are additional risk factors for mental health struggles. Post-traumatic stress disorder, acute stress disorder, adjustment disorders, and long-standing personality changes are commonly found among refugees, even years after their initial move [58].

## ***Language***

Language does not have an impact on the prevalence of mental disorders per se but can impact one’s ability to express their concerns, thereby impacting diagnosis and treatment [59]. In fact, there are huge disparities in access to treatment for those who are not fluent in English, no matter their geographic location in the USA, as the majority of mental health professionals speak English. There remains an incredible shortage of bilingual and bicultural health and mental health providers, especially for languages other than Spanish, the second most commonly spoken language in the USA. Use of a translator may help mitigate these effects, but in health settings, only about 30% of patients who need translators ever receive one [60].

## ***Socioeconomic Status***

It has been found that with lower SES comes lower overall health, including mental health [38]. This seems to be related to at least two phenomena. First, it is possible that the person is poor because they have a chronic medical or mental health condition that prevents stable employment and is associated with high medical costs. However, it cannot be denied that there are systemic forces preventing many people from accessing a better quality of life [37]. For people in lower social classes, lack of good prenatal care, poor nutrition, poor-quality education (as public schools are

heavily impacted by the local tax base), decreased access to well-paying jobs, less likelihood of medical insurance with those jobs, poor quality of health care when it is received, and increased stress because of all these factors lead to increased risk of developing mental disorders.

## **How Culture Affects Symptom Presentation**

We have seen that cultural variables can impact prevalence rates of mental disorders and conditions. This assumes that the conditions were accurately diagnosed, which has been a topic of great debate for decades. Some consider mental disorders to manifest similarly worldwide, the etic approach, while others consider it only possible to understand symptoms in relation to local sociocultural norms, the emic approach. It must be made clear that US psychology has historically taken an etic approach, successfully imposing itself on most nations worldwide [61]. This is sometimes called the “Americanization” of psychology, though this refers to US psychology only, ignoring any other nation in North, Central, or South America.

It seems clear that both the etic and emic approaches hold merit. Some mental disorders occur equally in men and women around the world, such as bipolar disorder (0.4%) and schizophrenia (0.4%). These disorders are thought to have more of a biological component, though stress can exacerbate or prolong the symptoms. Other disorders vary greatly in men and women. For example, alcohol use disorders affect 2.8% of men but only 0.4% of women, though women’s alcohol use is increasing. All other disorders disproportionately affect women, which is thought to be due to social factors like gender discrimination, a higher workload than men, domestic violence, sexual and reproductive violence, and increased societal pressures [27].

Regardless of prevalence, there remain huge disparities in diagnoses. In the USA, women tend to be diagnosed with depression, anxiety, eating disorders, and other internalizing disorders while men tend to be diagnosed with substance abuse and impulse control disorders, even if they display symptoms similar to those displayed by women [14]. African Americans are disproportionately likely to be diagnosed with schizophrenia and paranoia, while groups who tend to speak other languages (i.e., Latina/os and Asian Americans) are often misdiagnosed with learning disorders and mental retardation [27]. Mental health problems are largely ignored in the elderly because of increased focus on medical problems [62].

## ***Culture-Bound Syndromes***

Most, if not all cultures, have their own conceptualizations of mental disorders [63]. These are called culture-bound syndromes in the USA, but this ignores the fact that all mental health conditions are bound by culture. In this way, the *DSM* should be

considered a tome of culture-bound syndromes as seen in the USA among European Americans. Instead, it is assumed to be relevant worldwide, with some additional syndromes to consider in certain cultures, a brief listing of which can be found in Appendix I of the *DSM-IV-TR* [40] (pp. 897–904).

African Americans experience culture-bound syndromes such as “isolated sleep paralysis,” an inability to move while falling asleep or waking up, and “falling out,” a sudden collapse sometimes preceded by dizziness [40]. Asian Americans/Pacific Islanders may experience culture-bound syndromes such as *koro* and *hwa-byung*. Primary symptoms of *koro* are the genitals shrinking into the body, possibly causing death. Some believe that the genitals are being stolen by supernatural methods [40]. *Hwa-byung*, or “suppressed anger syndrome,” is characterized by symptoms such as constriction in the chest, palpitations, flushing, headache, dysphoria, anxiety, and poor concentration [40].

Culture-bound syndromes seen in Latina/os include *susto* (fright), *nervios* (nerves), *mal de ojo* (evil eye), and *ataque de nervios*. Symptoms of an *ataque* may include screaming uncontrollably, crying, trembling, verbal or physical aggression, dissociative experiences, seizure-like or fainting episodes, and suicidal gestures [40]. Common culture-bound syndromes for some Native Americans include *pi-bloktog* and “ghost sickness.” *Pibloktog* includes symptoms of depressive silences, loss of consciousness, seizure-like episodes, and speaking in tongues. This is typically followed by the loss or perceived loss of a valued person or object. “Ghost sickness” is typically the result of a preoccupation with death or someone who is dead. Symptoms include bad dreams, confusion, feelings of suffocation, fainting, and hallucinations [40].

Culture-bound syndromes allow us to understand one’s symptom presentation in a way that is holistic and culturally relevant. If mental health professionals only apply a *DSM* framework to diagnosis, they will inevitably miss culture-bound syndromes [64], leading to misdiagnosis and possibly failed treatment efforts. This is especially true with individuals who are less acculturated to US dominant culture.

## How Culture Affects Treatment

We have seen how cultural factors relate to prevalence rates and symptom presentation, but they also affect treatment. Most psychiatric disorders go untreated, with only 32.9% of patients with a mental disorder receiving treatment. Nearly half (49.6%) of these patients are treated in primary care settings with 41.9% seen in a mental health service agency other than psychiatry [65]. Of those who do seek treatment, one third do not respond to psychotherapy and/or medical treatment [45].

The treatment of mental disorders varies with demographic factors. Women tend to seek treatment earlier than men and are more likely to be treated [14], (p. 260). The elderly are more likely to be treated in general medical care, even for mental health concerns. This is in direct contrast to those with higher education levels of any age, who are least likely to obtain mental health care in general medical settings, instead

opting for mental health specialty settings. Those people living in rural areas are the least likely to receive any kind of care, and this is true across sociocultural factors [65].

People of color are less likely to receive any kind of service for mental disorders, with African Americans 50% less likely to receive psychiatric treatment when compared to European Americans [65]. American Indian/Alaska Natives underutilize mental health services more than any other ethnic group, and Latina/os and Asian American/Pacific Islanders are also less likely to seek mental health treatment [26]. When people of color do seek treatment, they tend to seek help from primary care facilities, they tend to delay treatment until their condition is more severe, and they have higher dropout rates when compared to European Americans.

These phenomena may be due to the continued paucity of culturally competent care available in the USA [27], (p. 259). This means that, for several different reasons, most people with mental disorders do not reap benefits from clinical intervention [65]. The importance of cultural competence has been highlighted as a potential solution to eliminating the disparities within health care.

## Practical Guidelines

Based on the information provided in this chapter, we offer some guidelines for working with patients of a variety of sociocultural identities in a competent way. These include, but are not limited to, the following:

1. Continue the path toward multicultural competence by engaging in reading, training, supervision, and consultation with multicultural experts [66].
  - a. Consider the use of assessment tools to see how multiculturally competent you are. Examples include:
    - i. Multicultural Awareness/Knowledge/Skills Survey (MAKSS) [67]
    - ii. Multicultural Counseling Inventory (MC) [68]
    - iii. Cross-Cultural Counseling Inventory—Revised (CCCI-R) [69]
  - b. Engage in your own introspective cultural assessment through self-questioning, and interpersonal learning (e.g., community activities, diverse media and relationships) to consider the influence of culture and related areas of privilege on your identity [70].
2. Remember that patients must be understood as complex beings whose multiculturalism is present at all times [12]. In other words, do not privilege one sociocultural identity over another.
  - a. Consider the interaction of your cultural identities with that of each patient, even when you share some similarities with the patient.
3. Refrain from making assumptions about patients. Assess sociocultural variables that may be relevant with every patient, including those who do not visibly look different from you. This may be accomplished with a thorough clinical interview, assuming there is sufficient rapport established in the relationship, or through the use of formal measures, such as:

- a. The Multidimensional Acculturation Scale (MAS) [71], or the Multidimensional Acculturative Stress Inventory (MASI) [72], to measure acculturation.
  - b. The Visible Racial/Ethnic Identity Attitude Scale (VRIAS) [73], or the Multiculturalism Experience Inventory (MEI) [74], to assess ethnic identity.
4. Intentionally seek culturally related strengths and supports at the individual, interpersonal, and environmental levels for your patients [70].
  5. Adapt mainstream therapies and theoretical orientations to the cultural context of the patient [70].
    - a. Make culturally relevant diagnostic decisions, using the *DSM-IV-TR* and/or culture-bound syndromes as appropriate.
    - b. Administer culturally relevant treatment, using cultural mediators, community experts, and traditional healers as necessary [66].
    - c. Consider the cultural expectations and beliefs regarding medications [70].
  6. Ensure that your clinical practice is accessible to people from a variety of cultural groups. This includes everything from physical accessibility for people in wheelchairs to providing all materials in languages relevant to your patient [75].

## Conclusion

Culture affects all areas related to mental health and mental disorders, from symptom presentation to diagnosis and treatment. Multicultural research efforts and practice guidelines are slowly emerging, though psychology remains overwhelmingly ill equipped to respond competently to anyone who is not strongly identified with the dominant culture [76]. The goal of cultural competence is to conceptualize patients within a cultural framework, rather than taking a universalistic approach that pathologizes culturally diverse groups who differ from the mythical norm. The information and guidelines provided herein attempt to provide a foundation for providers interested in beginning their journey toward multicultural competence.

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# Chapter 11

## Working in Pediatrics

Robyn S. Mehlenbeck, Michelle M. Ernst and Leah Adams

### Introduction

Nowhere does the interface between clinical psychology and the medical experience pose as many interesting challenges and opportunities as in the field of pediatric psychology. Here, factors such as developmental level and the particularly strong influence of systems on children need to be considered in addition to other behavioral medicine variables. This chapter will review a variety of behavioral health issues in both acute and chronic medical experiences that children commonly encounter, and present evidence-based interventions designed to assist children and their families in managing these situations with an emphasis on both developmental and systems perspective.

### *Developmental Factors*

The period from infancy to early adulthood is a time of tremendous transformation and the impact of health issues will differ depending on the developmental stage, as will recommendations to facilitate effective coping. Psychosocial growth in early infancy occurs primarily through the parent–child relationship, and the quality of this attachment has been shown to predict factors such as emotional and

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behavioral regulation, social competency, and health outcomes [1, 2]. The development of behavioral self-regulation to meet changing environmental demands is a focus of early childhood experience [3] and may not yet be sophisticated enough to meet challenging medical situations without considerable support. For example, vaccinations are a common medical experience in this phase and parents are often concerned about alleviating anxiety and behavioral issues during a pediatric visit. In addition, during this phase, cognitive ability is rapidly changing to allow for more sophisticated understanding of experiences, including “illness” [4].

For a school-aged child, peer relationships become the catalyst for psychosocial development, and peer comparison informs children’s sense of self-efficacy and identity [2]. This may be challenging for children dealing with chronic illness which compromises their ability to do the full range of “normal” school-age activities. In addition, children in school become influenced by an increasing array of ecologic systems, all of which may compete with health behaviors for time and resources. For example, children with Type I Diabetes may not want to go to the nurse’s office to take insulin before lunch when it interferes with their social time.

Developmental stage may have a particularly strong impact on health outcomes during adolescence. This period is characterized by increasing value placed on peers and refining one’s own identity through taking on of various roles [2]. Normative “risk-taking” behaviors may have particularly negative health implications for adolescents dealing with chronic illness [5, 6]. For example, drinking alcohol can have more dire effects for adolescents on particular medical regimens (e.g., kidney sparing) as compared to their healthy peers, as can food restriction (e.g., children with cystic fibrosis). Adolescence is also marked by a strive toward greater autonomy, which is not always matched by competence in independent health self-management [7].

## ***Systems Involvement***

While all medical patients function within multiple systems of influence, the dependency of children renders them particularly affected by and vulnerable to the adults and peers with whom they interact. Child medical issues affect not only the child but also parents, siblings, extended family, schoolmates, and the health care team. The responses of each of these groups also affect the child. For example, the divorced parents of an obese child may have differing knowledge about obesity and divergent parenting practices, resulting in the child needing to function within two different levels of family support as well as different sets of foods available and eating-related expectations, goals, and consequences. Furthermore, the physical and psychosocial correlates of chronic illness may negatively interface with school attendance, and school teachers and administrators may have little experience managing a child’s specific illness [8]. A child with diabetes may need to eat a snack at certain times in a class that does not permit

snacking. Some children, however, would ignore the need for the snack in case the teacher would “get angry” or the child would be seen as “different.” How well the medical and psychosocial teams are able to interact with each of these groups will have a significant effect on the health of the child.

### ***Family Considerations***

There are several examples of evidence-based interventions at the family level [9]. Behavioral group treatment for children with Cystic Fibrosis (CF) and their families has been effective in increasing adherence to a high-energy, high-fat diet [10]. A multifamily group intervention has demonstrated efficacy in promoting adherence in children with Type I Diabetes [11] and behavioral family systems treatment has shown efficacy in decreasing conflict in families with children with diabetes and CF, respectively [12, 13]. Family systems interventions are also being studied to determine their ability to decrease posttraumatic stress symptoms in survivors of childhood cancer and their families [14]. Finally, there is strong evidence that families play a significant role in how children respond to procedural pain, and psychologists can help parents feel more effective in their role to help their child through a procedure [15].

### ***School Considerations***

Children and adolescents are in school for 8 h per day, often more if they are involved in after-school activities. Therefore, it is critical to take into account the interaction between medical issues and functioning at school. As mentioned above, managing medical issues can interfere with “normal” school functioning, but also highlights how the school health personnel can be enlisted to facilitate adherence and proper medical care during a large portion of the day for school-aged children [16]. Oftentimes, it is helpful to have a 504 plan in place at school for medical accommodations. A 504 plan ensures that a child who has a disability identified under the law receives accommodations to facilitate academic access and success. For example, a child with inflammatory bowel disease can have a 504 plan which includes the stipulation that they be allowed to go to the bathroom whenever needed, and the privilege of using an adult or more “private” restroom. It is important to work with school personnel, physicians, families, and the child to ensure the accommodations are as minimally intrusive in the school day as possible, and to communicate an understanding of the additional stresses medical care in schools put on everyone. Within a cooperative and creative environment, even children with extensive medical needs can continue to attend school [8, 16].

## ***Social Considerations***

Peers play a large role in childhood and adolescence, with positive peer interactions predicting many aspects of future functioning. However, children with chronic illness may experience school absences or altered school schedules, changes in appearance, restrictions on activities, physical complaints, and/or cognitive impairments [17], any of which may have a significant impact on peer relationships. A summary of the data suggests that most children with chronic illnesses do not struggle with peer issues, but those who do are more likely to be older (adolescents), have medically related restrictions on activities, have cognitive impairments, and/or appear physically different [18]. Given that peers can have both positive and negative effects on health behaviors, it is important for providers to assess the interface of peer relationships with both health and overall functioning [18].

One important developmental milestone within the social arena that occurs for children with chronic illness is the transition to adult care teams. Literature on this transition highlights that adherence and involvement in health care often decline after switching to adult providers, and a number of factors have been studied to better understand important psychosocial determinants of successful transfer of care [19]. Perhaps ironically, those patients with the most satisfaction and attachment with their pediatric health care team are most likely to experience these changes negatively, and a systematic approach is recommended to allow for greater comfort with new providers [19]. In addition, adolescents may yearn for taking a more “adult,” independent role in managing their illness without appreciating the implications of owning this role or the skill set needed [19]. In a joint effort to aid physicians in their care for adolescents, the American Academy of Pediatrics, American Academy of Family Physicians, and the American College of Physicians have published a clinical report focused on supporting the transition from adolescent medical care to adult medical care [20].

## **Acute Medical Involvement**

Nearly every child will face a medical problem during their childhood. Even healthy children deal with pediatrician visits, vaccinations, blood draws, or flu shots. While illnesses may vary in severity and duration, all children must learn to cope with medical involvement. Research indicates that children’s early medical experiences may influence the way that they perceive and cope with later medical events, highlighting the importance of *early* intervention in dealing with medical problems [21].

Most children who visit a medical setting will not be diagnosed with a chronic, debilitating illness. Instead, the majority will experience acute medical involvement during which they will have brief contact with a health professional. Common acute procedures include vaccinations and injections, blood draws, surgery,



and most emergency room visits. An expanding line of research has provided health professionals with guidance about how to best aid children in effectively coping with and adapting to acute medical stressors, particularly medically necessary procedures. Most studies focus on mitigating both procedural anticipatory anxiety (fear of expected pain prior to procedure) and management of pain or other aversive physical experiences (e.g., nausea, itching). Children experience pain due to a number of medical procedures, both routine (e.g., immunizations) and related to specific diseases (e.g., spinal tap) and injuries (e.g., dressing change). Beyond the physical pain that children may experience, the procedure itself may increase levels of fear and anxiety, which could interfere with the actual procedure. Studies show that early painful medical experiences are predictive of later pain, and this can follow into adulthood [22, 23].

## **Role of Parents and Health Providers**

Parents and health professionals can guide children during the medical procedure to minimize the pain that they experience. Because the anxiety experienced by parents or health care providers can negatively influence the child's success in coping with the pain experienced, it is worth noting that parents and health professionals should take note of *their own* reactions and behaviors during the procedure [23]. In fact, one study found that mothers' behavior accounted for more than half of the variability in children's distress during immunization [24]. Thus, it is important to provide the child's parents as well as other health care providers with tools to help the child through the experience. For example, although it seems counterintuitive, numerous studies have shown that attempts to reassure the child and apologize for the injection are associated with increases in children's distress during vaccination. Instead, reminders to use coping techniques and speaking to the child about non-medical-related subjects during the injection have been found to be effective in reducing overall injection-related distress [28] (See Table 11.1). Clinical psychologists should give parents strategies about how best to support their child during the procedure to ensure that parents do not inadvertently increase their children's levels of distress.

Physicians and nurses may have the means to help alleviate the pain associated with certain medical procedures by employing pharmacological interventions. For instance, anti-inflammatory medication can minimize pain, as can certain topical creams. However, many of these methods still require the use of needles and other anxiety-provoking objects for children who are undergoing medical treatment.

## ***Practical Considerations***

Techniques from cognitive-behavioral therapy have been shown to be successful in helping manage both the physical pain and emotional distress associated with

**Table 11.1** Sample non-pharmacological techniques for acute pain management*Anticipatory guidance*

Help the child to know what to expect. (No surprises!)

*Breathing techniques*

Blowing helps by relaxing the body and controlling breathing

Teach the child to “blow the pain away” by blowing a pinwheel, bubbles, or pretending to blow the birthday candles out

*Distraction*

Ideas for distracting activities: reading, texting, listening to music, playing video games, playing guessing games, playing board games, watching TV, talking to friends, and playing with favorite toys

*Guided imagery*

Helping the child to imagine themselves somewhere else, someplace that they find fun and/or relaxing. For younger children, fun is better! Have them describe to you all about the place and what they are doing using all of their senses

*Positive rewards*

Use a small reward for coping with a painful procedure. Kids love stickers, a small toy prize box, lollypops, etc. Never withhold a reward if the child cries, however, as crying is natural. The reward can then serve as a distraction

*Parents*

Guide parents on how to manage their own anxiety about their child’s pain. Also, research demonstrates that reassurance from parents is not helpful in reducing acute pain, but rather can exacerbate it. Parents are better helpers in distracting or talking to their child, playing a game with their child, or walking their child through the imagery technique

medical procedures [25, 26]. These techniques help prepare children before the medical encounter, help them cope during the procedure, and help them recover from the procedure/process and their experiences to enhance a sense of mastery [27]. Common cognitive-behavioral strategies are:

1. *Psychoeducation*: Clinical psychologists should educate children (2 years old and older) and their parents as to the purpose and process of the procedure, as well as what they might experience physically. It is critical that the information be honest and provided in a developmentally appropriate language. For example, Schechter and colleagues [28] recommend that providers should at minimum answer the following three questions for the child about upcoming injections:
  - a. What will happen? (Where will the injection site be? How long will it last?)
  - b. How will it feel? (How much pressure will be felt? How uncomfortable will it be?)
  - c. How can I cope? (What can I do to help myself through this?)

It is particularly important to engage older children in this discussion. For example, one useful strategy is to discuss with them their previous experiences with procedures in order to help them identify coping strategies that have worked in the past as well as address any particular concerns that will need to be addressed. Children can often assist in the development of coping techniques to use for a vaccination, drawing on their prior experiences in working through unpleasant situations.

2. *Modeling*: Younger children can understand what to expect when parents and health providers model the procedure before it occurs so that the child has another exposure in the setting. Modeling helps the child understand what to expect as well as watch an older role model complete the procedure successfully. For example, when children are diagnosed with Type I Diabetes, it is helpful for a parent to give himself/herself a saline shot and/or test their own blood glucose to model how the procedures are done, and the pain experience and coping.
3. *Distraction*: Distraction techniques, in which the child is helped to focus on something other than the injection, can also be beneficial *when the child has been properly prepared for the injection*. While some children will be able to use imagery (e.g., “imagine the amusement park”), others will need a concrete stimulus to focus on. Toys, puppets, and music are a sample of distracters that have been researched in the literature; although no stimulus has emerged as a clear “winner,” it should be noted that the type of distraction stimulus used should be developmentally appropriate for the child and some research suggests that more cognitively engaging distracters are more effective (e.g., playing a video game is better than watching video game) [29]. Some children respond very well to blowing bubbles during a procedure, which has both a distraction and relaxation effect.
4. *Relaxation*: Relaxation techniques, such as deep breathing, progressive muscle relaxation (PMR), and guided imagery, have been found to be effective in helping children manage pain during medical procedures [26]. The goal of these techniques is to have the child focus on something other than the negative experience of the procedure, the idea being that fear, anxiety, and pain are incompatible with a state of relaxation. Parents can be taught to aid children as they work on relaxation skills while undergoing the procedure. Parents and others should avoid simply telling a child to “relax” during a medical procedure, as this has been shown to intensify negative feelings [23]. Instead, the child should be coached to relax by doing something observable and active, such as clenching and releasing their fist.
  - *Deep Breathing*: Deep breathing, defined as slow, deep abdominal breathing, has also been shown to reduce children’s self-reported pain during injections [30]. While older children and adolescents may find it fairly easy to use breathing techniques, younger children may have more difficulty with this exercise. Parents and physicians can engage younger children in viewing deep breathing as a fun exercise. For instance, children may be told to imagine themselves “slowly blowing up a big balloon” in order to practice deep breathing [31]. A sample of teaching young children to practice deep breathing is in Table 11.2.
  - *Progressive Muscle Relaxation*: PMR is a useful tool to help teach relaxation because it is active and helps give children control over their bodies [32]. The goal of PMR is to help train muscle groups to relax, which has a direct effect on lessening pain, as well as being a distraction. A typical PMR script is found in Table 11.3.

**Table 11.2** Sample pediatric “snake breathing” script

---

Today we are going to learn a special way to breathe that will help you feel better. It is called “snake breathing.” It is really neat because it will help you calm down and keep your breathing calm

*First*, sit comfortably and put one hand on your stomach and the other hand on your chest.

*Second*, breathe in as deeply as possible *through your nose* and let your stomach fill with air.

Breathe in until your stomach goes out as far as it can. Make sure you can feel your stomach

going out! *Third*, put your teeth together and open up your lips a little as you breathe out

slowly *through your mouth*, making a snake sound as the breath leaves your mouth. It should sound like “sssssssss.” Again, let the air out slowly to see how long you can make your snake sounds

Repeat this three to five times, each time seeing if you can count a little higher in or out, and let me know which one you can count the highest on

---

- *Guided Imagery*: Some children respond well to guided imagery, where they are assisted in “going to a special place” and experiencing all the sensations associated with that place. Children are directed to pretend that they are “in a movie” and not “just watching it” in order to feel like they are truly in another place. This serves both as a relaxation and distraction strategy from the procedure at hand, and has been shown to be particularly effective in young children with good imaginations [33].
5. *Coping Statements*: Coping statements are meant to help children replace their catastrophic, negative thoughts with positive thoughts during the procedure. For example, a child who begins to think, “This will hurt too much for me!” may rely on a coping thought such as, “I’ve done this before, and it wasn’t that bad.” Older children may be able to come up with these thoughts on their own, while younger children may need help to create thoughts. Parents and health providers can also make creating coping statements enjoyable for children by having them write them down on cards to read during the procedure. Children should be encouraged to say the coping thoughts aloud in order to ensure that they are being articulated during the procedure.

## Chronic Medical Involvement

Many accepted definitions of “chronic illness” refer to a condition that lasts for a significant period of time, or is recurrent, interferes with a child’s normal activities, and requires extensive medical care [34]. Approximately, 16–18% of children are now classified as having special needs due to chronic conditions [35]. In contrast to more acute medical experiences, chronic illness has a significantly more lasting and broader impact on children, both in terms of physical and psychological and social functioning. Common pediatric chronic illnesses include Asthma, Type I Diabetes, Sickle Cell Anemia, Cancer, Epilepsy, CF, and others. There is a considerable research base attesting to the effectiveness of psychological interventions

**Table 11.3** Pediatric progressive muscle relaxation script*Instructions for progressive muscle relaxation*

Of note to provider, typically we ask the kids to hold the stretch or relax for 5 s before moving on to the next stretch/relaxation. Also, if pain is ever involved, do NOT do that particular part of the body (i.e., for recurrent abdominal pain, we often do not do the “elephant on the stomach”)

Close your eyes, get comfortable, then take a slow, deep breath in through your nose. You should feel the air fill up your stomach. Hold the breath for a second and then let it go out slowly, through your mouth. Now, take a few more deep breaths and let them slowly. Pay attention to how you feel—is your body heavy, is it light, is it tense, is it relaxed, do you feel calm, do you feel anxious? We are now going to help you relax more

We’ll start at your toes and work your way up your whole body. First, pretend to pick up pencils with your toes. Hold the pencils tightly! What feels tight? Where does it feel tight? Now, release the pencils and let your toes drop to the ground. Your toes may be wiggly or relaxed. Notice the difference between holding the pencils and then letting them go. Now, pick up those pencils again. Hold them, tighter, tighter, then relax. Let the pencils drop and wiggle your toes, getting rid of all the tension

Next, point your toes to the sky. Higher, higher...notice where your feet and legs feel tight or tense. Hold it...then relax. Let your feet fall down, enjoying the relaxation in your legs. Let’s do that again, pointing your toes to the sky, hold it...then relax. Feel your legs getting looser and more relaxed

Now, we’ll go to your stomach. Tighten your stomach muscles so tightly that if an elephant was stepping on you, you would stop his foot from squishing you! Hold it, but keep breathing, then relax. Let go of all your muscles, making your stomach nice and relaxed. Enjoy the relaxing feeling. Then, here comes that elephant again—tighten up your stomach and hold it...great job! Then, relax and enjoy

Next, I want you to pretend you have lemons in both hands and squeeze them very tightly to make lemonade. Hold it...notice where you feel tight or tense...your hands, your wrists, or your arms. Now relax, let your fingers fall down, wiggle them a little so that they feel like Jell-O. Notice how much more relaxed your hand feels. Let’s do that one more time. Squeeze the lemons, tighter, tighter, hold it.... Now release and enjoy how loose, relaxed, and warm your hands feel

Next, we are going to make muscles in our biceps like “muscle men” (arms up, bent at right angle at the elbow, and tense the biceps to “show off” the muscles). Make a super tight muscle and hold it, again, noticing where you feel tight or tense, hold it, hold it, and now relax and let your arms just fall to your sides... let the relaxation flow all the way down your arms as they drop toward the ground. You are feeling more and more relaxed, deeply relaxed, calm, loose, and relaxed. Let’s do this again. Make tight strong muscles...hold it.... Then relax, enjoying how loose and calm your body feels

Now, lift your shoulders all the way up to the sky. Keep the tension as you hunch your head down between your shoulders...good, hold it, hold it. Now, relax and feel the relaxation spreading through your neck, back, and shoulders. Let your shoulders fall back into the chair/bed. Enjoy how loose and relaxed your shoulders feel. One more time, lift your shoulders all the way to the sky. Hold it—feel where you have tightness in your neck, shoulders, and back. Then relax, again, letting your shoulders fall into the chair/bed, looser and looser, letting go more and more. Enjoy this relaxing feeling

Next, pretend you just ate a lemon. It is so sour that you tighten up your whole face, wrinkling your forehead, closing your eyes, and squeezing your lips—it was so so sour! Where is your face tight? Hold it, then release, letting your cheeks just relax, your eyes relax, and your forehead relax. Smooth out your face until your face feels like Jell-O. Enjoy. Now one more time, taste that sour lemon and squeeze your whole face tight. Hold it...then let go, further and further, more and more relaxed

Your whole body is now relaxed, may feel heavier and looser. You may feel warmer. Enjoy that feeling, your body is so relaxed. When you are ready, you can take a couple more slow deep breaths and open your eyes. You will feel very calm and relaxed

(particularly cognitive-behavioral strategies) for concerns related to pediatric chronic illness such as adaptive coping with illness-related limitations and symptom management (e.g., pain, nausea). Here, we will review two notable facets of pediatric chronic illness—initial diagnosis and adherence, as well as what is known about the relationship of chronic illness to mental health issues.

### ***Initial Diagnosis***

The decision to reveal a medical diagnosis to a child can be a difficult one for parents to make. Although most professional organizations, like the American Academy of Pediatrics, recommend that parents and health professionals disclose the illness to the child, there is less guidance about *how* this should be done [36]. Many parents cite concern about the child's distress following disclosure, the stigma associated with the disease, and uncertainty regarding whether or not a child will understand what the illness means. These concerns are understandable; however, there is considerable evidence suggesting that revealing the diagnosis can be helpful for a child [23]. In fact, failure to disclose medical illness can be detrimental to a child's health, as the child may find it difficult to understand why he or she should adhere to strict treatment regimens. Further, children may sense their parents' fear and draw their own extreme conclusions about the implications of the medical situation [23]. Research suggests that one of the best things that parents can do for their children is to maintain an open line of communication with their children about the diagnosis.

Although it is strongly advised to disclose the initial diagnosis to children, care must be taken to ensure that the level of disclosure matches the child's developmental level ([37]; see Table 11.4). Oversimplification of the illness may leave a child less equipped to face the impact of the disease, while an explanation that exceeds the child's cognitive level may leave the child confused and frightened. Health care professionals should be ready to help guide parents through the process of disclosing their child's illness.

### **Practical Considerations**

When thinking about diagnosis disclosure, parents and health care professionals should consider it to be an ongoing process, rather than a onetime conversation. Clinical psychologists should advise parents that honesty with their children regarding the children's fears of death, pain, and the opinions of others can help to minimize distress and behavioral problems [38]. To help parents prepare for this difficult series of conversations, physicians and other medical providers can participate in role plays with parents to help them practice telling the child about the illness, and they can also "quiz" parents about the illness to make sure that the child's parents are knowledgeable about the diagnosis. Just as disclosure is a process for parents,

**Table 11.4** Diagnosis disclosure based on the developmental level of the child. Adapted from Lesch et al [82] and New York State Department of Health AIDS Institute [83]

Stage	Illness explanation	Special considerations	Strategies for disclosure
Early childhood (2–6 years)	Illness explained based on <i>associations</i> (e.g., loose connections between objects, events, people that child perceives to be related to illness) Illness is “caught” Unable to explain link between cause and illness	Difficulty understanding internal functions Health, illness, and death are viewed relative to personal experience and ability to participate in peer activities	Use visual aids like drawings or puppets to illustrate concepts Use associations to concrete observations (e.g., “When you feel dizzy, checking your number can help tell us how to help.”) Avoid too many concepts, focus on concrete examples
Middle childhood (7–11 years)	Illness explained based on <i>sequence</i> Beginning of understanding that diseases can also be caused by internal mechanisms	Personal privacy increases in importance Awareness of differences in people increases Death is viewed as specific, concrete, and irreversible	Incorporate visual aids like media to explain concepts Use sequences (e.g., “Diabetes means too much sugar in the blood. Insulin is a hormone and works like a key to a door—it lets the sugar go from the blood into the cells to be used for energy. You give yourself insulin so that the sugar doesn’t keep adding up in your blood.”) Emphasize concepts of health, wellness, and body Include issues about privacy, stigma, and confidentiality using examples Ask what the child already knows about the illness
Preadolescence/ Adolescence (12+ years)	Body is viewed as a system Illness explained based on <i>interaction</i> of various elements Cause of illness can be described in terms of complex interactions between host, agent, environment, and/or genes	Peer group has a strong influence on behavior and decision making Self-consciousness increases Death is viewed in abstract terms, but child may feel “invincible”	Use visual aids like books or websites to demonstrate key concepts Can include slightly more complex language to describe concepts Include interactions between body systems, environment, and more as relevant (e.g., “Your immune system helps protect you from infections. Asthma is a condition in which your immune system is overactive in the airways of your lungs. Your inhaler can help reduce the overactivity.”) Ask what the child already knows about the illness

**Table 11.4** (continued)

Stage	Illness explanation	Special considerations	Strategies for disclosure
<i>Overcoming caregiver barriers to disclosing diagnosis to children</i>			
<i>Barrier to disclosing</i>			
Caregiver feels child is too young/ immature to understand diagnosis		Help caregiver understand how to describe functioning at developmental level (e.g., “This medicine helps you feel better when it gets tough to breathe.”)	Consider partial disclosure, with a plan to provide more information as the child develops
Caregiver fears child will not understand when to disclose versus not disclose (especially for highly stigmatized illnesses, like HIV)		Assess child’s ability to understand confidentiality and privacy	Help caregiver and child create a “contract” for who the child can and cannot tell
Caregiver fears that the child’s reaction will be too difficult to manage		Reassure caregiver that healthcare team will be supportive <i>before, during, and after</i> disclosure process	Have mental health referrals available Incorporate developmentally appropriate materials (e.g., puppets, books, websites) to aid in education Address false or negative ideas that the child and/or caregiver have about the illness Explain the value of expressing emotion, along with the potential negative effects of failure to express emotion
Caregiver guilt (especially for genetic or perinatally-transferred illnesses)		Allow caregiver to express guilt with provider Counsel to alleviate guilt, refer for additional mental health treatment if necessary	Include parent in a more affirming and helpful role with child to promote empowerment
Caregiver concerns about the types of questions that the child may ask		Help caregiver decide how to answer questions that may be asked Use role-play to help prepare caregiver to answer potentially embarrassing or painful questions	

practicing and following up with parents about their children’s understanding of their disease should be considered by medical providers to be a standard health check-in practice.

***Adherence***

Children who have been diagnosed with a chronic medical condition are often presented with a variety of medical treatments that can help them manage their disease. However, many of these treatments are complex, requiring children and their families to alter their daily schedules to maintain strict dietary regimens, exercise plans, and medication timetables. Adherence to these medical regimens can be difficult for children with medical illnesses, and research indicates that approximately half of children (50%) with a chronic condition do not adhere to treatment [39, 40].



**Table 11.5** Sample sticker chart for monitoring adherence and progress

Karen's new sticker plan							
	Mon	Tue	Wed	Thurs	Fri	Sat	Sun
Test blood sugar w/adult 4×/day							
Have adult give me my shots							
Stand still for each shot							

18 stickers=prize from mom or dad

Prizes may include: “alone time” with mom or playing cards, taking a walk, going for a treat, a sleepover with your best friend, or pick five items from the dollar store (no more than US\$ 5 total)

With any behavior plan, typically start w/75% of possible stickers that can be achieved and gradually increase amount of stickers needed to earn prize. If the child cannot earn 75%, then decrease the number of stickers needed (or number of goals) as success is critical to move forward

Fortunately, studies show that adherence to treatment regimens can be increased with relatively low-cost interventions [40, 41].

Most interventions that target treatment adherence can be divided into three categories: behavioral, educational, and organizational. While behavioral interventions focus on modifying the environment to promote a child’s adherence to their treatment, educational interventions rely on providing information to the child and his or her family about the specifics and rationale behind the physician’s prescription. Organizational interventions target the role of the institution in creating and disseminating treatment regimens (e.g., decreasing barriers to treatment, creating less burdensome treatment plans) [39].

Recent meta-analyses examining the effects of adherence interventions on medical treatment adherence have largely come to the same conclusions: (1) Multi-component interventions that include more than one type of intervention are most effective in increasing adherence to medical regimens and (2) the best combination of interventions to promote adherence includes behavioral interventions and education [39, 40]. It should be noted that although behavioral interventions are effective in increasing adherence on their own, education alone does not seem to significantly improve adherence [42]. However, the addition of education to behavioral interventions provides the greatest gains in adherence. In fact, in a meta-analysis of 71 studies of treatment adherence interventions with children with chronic illnesses (e.g., Asthma, Diabetes, CF, HIV/AIDS, Juvenile Rheumatoid Arthritis, etc.), children who received a combination of education and behavioral interventions had higher treatment adherence and were in better health, as measured by indicators like body mass index (BMI), pulmonary functioning, disease severity, and quality-of-life ratings [39].

### Practical Considerations

Given these findings, physicians and clinical psychologists should provide parents with behavioral tools to increase treatment adherence, along with education. Behavioral interventions include some form of monitoring (see Table 11.5 for sample form) to track adherence to specific treatment goal and some type of reward system designed developmentally for the child or adolescent. For some children, this may

**Table 11.6** Sample diabetes-related smart phone applications

	Cost (US\$)	Food database	Food tracker	Meds/ insulin	Glucose tracker	E-mail	Exercise
<i>Android</i>							
Diabetes Log	4.99		Y	Y	Y	Y	
Ontrack Diabetes	Free		Y	Y	Y	Y	Y
Agile Diabetes	0.99				Y	Y	
DiabetesManager	5.00		Y	Y	Y	Y	Y
Fat Secret	Free	Y	Y				Y
<i>Blackberry</i>							
Spark People—diet and calorie tracker	Free	Y	Y				Y
My Net Diary	Free	Y	Y				
Glucose and Health Tracker	5.99		Y	Y	Y		Y
An Office Yoga	2.99						
Glucose Tracker	2.99			Y	Y		
Glucose	3.99				Y	Y	
Glucose Tracker	13.99				Y	Y	
Livestrong		Y					
<i>iPhone</i>							
Diabetes Pilot	11.99	Y	Y	Y	Y	Y	Y
Glucose buddy	Free		Y	Y	Y		Y
Diabetes Buddy	4.99	Y	Y	Y	Y		
Track 3	5.99	Y	Y	Y	Y	Y	Y
dlife: Diabetes Companion	0.99	Y	Y	Y	Y	Y	Y
RapidCalc insulin dose tracker	5.99			Y	Y	Y	
ShopWell	Free						
Go Meals	Free	Y	Y				
Lose It	Free	Y	Y				
Diabetes Log	Free		Y	Y	Y	Y	
Spark People	Free		Y				
Livestrong		Y					
Calorie King	Free	Y	Y				

include creating a daily ritual with rewards for adherence; younger children often respond well to a sticker chart that highlights their success with adherence. Once a certain number of stickers are achieved, a special reward can be given. Rewards can include special time with a parent, which is a powerful reinforcer for a child, and does not have to have a specific (or any!) monetary value. Older children may be more strongly reinforced by receiving incentives like extra computer or social time. Older children also like to utilize technology to help track their progress, and often do better using a computer or other electronic devices. Apps are available to help monitor many health behaviors, including chronic illness treatments. For example, a teenager with Type I Diabetes may choose to use Glucose Buddy and Track 3 to track blood sugars and insulin on his/her smart phone (see Table 11.6). Further, health professionals should take the time to not only give the prescription for treatment but also explain why each component is being introduced, as this additional

information may motivate children and their families to adhere, especially if they understand the risks of non-adherence.

Environmental factors can also help maintain adherence. Setting up a house to facilitate easy entry and exit for someone in a wheelchair will promote leaving the home as a means of increasing the quality of life. Having a friend accompany the child to the nurse's office to test blood sugar will facilitate compliance with this task. Putting medications in a weekly pill counter will help with remembering what to take each day. Providers should brainstorm ways with children and parents to improve the environment in the home or other systems where the child goes during the day to optimize adherence.

Maintaining adherence to treatment is a process, and must be treated as such. Physicians, other health providers, and families should closely monitor adherence to ensure that the child is in the best possible health. It is worth noting that although the combination of behavioral and educational interventions has the most empirical support for promoting adherence to medical treatment, some children may also require additional treatment for psychosocial and emotional concerns that are not directly addressed by the intervention itself [39]. As such, adults involved in the child's life should remain aware of social and emotional challenges that may compromise adherence to the prescribed treatment.

### ***Mental Health Issues in Pediatric Chronic Illness***

As might be expected, given the experience of negative physical symptoms, treatment burden, and impact on valued childhood activities, children and adolescents with chronic illness tend to report worse quality of life than their healthy peers, and this differs depending on the type and severity of the illness [43]. However, many children with chronic illness do report high quality of life, with psychosocial variables such as hopefulness as a positive predictor of better experience [44]. In terms of psychopathology, such as anxiety and depression, research studies often have contradictory findings depending on the type of assessment, clinical criteria used, and age range. While the majority of children and adolescents coping with chronic illness do not seem to meet clinical levels of these disorders, recent reviews suggest that they do display somewhat higher levels of behavioral problems, particularly internalizing disorders [45], depression [46], and anxiety [47], suggesting that they are at a higher risk of development of these disorders. Factors such as illness uncertainty, parental perception of child vulnerability, and acceptance of condition may be relevant for the level of adjustment [48–50].

### **Practical Considerations**

It is important for health care providers to have a basic knowledge of common mental health issues for children, particularly anxiety, depression, and oppositional behavior. Brief screens are available [51], with the Pediatric Symptom Checklist

[52] being one of the most widely used tools which has been studied in both general pediatric settings and in specific illness populations [53]. Even in the absence of a standardized screening tool, generally asking children and parents about any significant changes in mood, cooperation, peer and family relationships, and school functioning can indicate the need for further discussion or referral to a mental health specialist. In many medical settings, a psychologist or behavioral health provider is available for consultation on the necessity of referral, or is already part of the medical team and sees each family. This can help normalize when mental health issues arise related to the chronic illness. While it is important to normalize the challenges of coping with chronic illness, health care providers should also convey the message that there are effective psychological and psychiatric treatments for general adjustment to illness as well as psychological disorders co-occurring with physical illness. Comfort in assessing basic risk assessment for self-harm is also a prerequisite for comprehensive management of pediatric chronic illness. Given that chronic illness can be a strain for the entire family and that parents need to take an active role in disease management, it is also important to look for signs of poor coping in caregivers. For example, parenting stress has been shown to be positively correlated with higher pediatric health care utilization [54].

## *Special Considerations for Specific Chronic Conditions*

### **Asthma**

Asthma is characterized as a chronic inflammatory disorder of the airways that involves intermittent and variable periods of airway obstruction [55]. In children, it is the leading cause of school absence and hospital stays. Families of children with Asthma face an array of management tasks, particularly when symptoms are persistent, that includes daily medication use, identification and avoidance of triggers, and management of exacerbations (i.e., making decisions on when to use “rescue” medications) [56]. While it has been well documented that good adherence to treatment recommendations lead to greater symptom control, decreased health utilization, and enhanced quality of life [57], this remains a very difficult pediatric illness to treat and maintain adherence. Some of the reasons include the episodic nature of Asthma “attacks” (which decrease the focus on maintenance medications as there is a perception that they are not “needed”), complex treatment regimens, and the disproportionate prevalence of Asthma in minority populations [58].

There are many roles for the pediatric psychologist in Asthma management including: (1) collaboration with pediatricians and specialists; (2) providing patient and family Asthma education, with particular attention to developmental and family issues; (3) identification and treatment of psychosocial barriers to adherence to treatment recommendations; and (4) implementation of psychosocial interventions to promote effective Asthma management by both the child and family [59]. Psychosocial interventions including self-management training, problem-solving

techniques, family-based interventions, and psychophysiological interventions (i.e., relaxation training and biofeedback) have all shown some efficacy in maximizing treatment adherence, improving family and physician communications and increasing Asthma education in a culturally sensitive manner [60].

## Diabetes

Diabetes, Type I Diabetes Mellitus (DM1) in particular, is a common and extremely difficult pediatric chronic illness, affecting approximately 1 in 523 children in the USA [61]. In children with DM1, the pancreas shuts down and stops making insulin. Insulin is required to regulate glucose metabolism, which is necessary for growth, activity, healing, and brain function. The management of DM1 is arduous and includes coordination of the amount and timing of insulin administration with results of blood glucose testing, the amount and type of dietary intake, and the frequency and intensity of physical activity [62].

Given the chronicity and the fact that children never get a “day off,” there are many issues that arise for the pediatric psychologist in working with children with DM1. Adherence is a major and potentially life-threatening issue, and the timing of blood sugar testing, counting carbohydrates, and calculating the correct insulin all bring notable challenges. Needle phobias are another challenge for many children, despite having to take up to four to five injections per day. Family conflict is often significant due to the high degree of family monitoring and involvement expected by endocrinologists. Sport participation, while definitely manageable and encouraged, provides additional challenges for children with DM1 due to impact on blood glucose. Finally, unlike other chronic illnesses, there is a particularly high comorbidity with psychological distress and depression, with up to 50% of children with DM1 experiencing at least one incidence of major depression across their childhood [63].

The evidence base is stronger for this illness than many others on increasing adherence [64] and decreasing family conflict [12]. Most interventions are conducted at the family level and a consistent finding appears to be that if the child/teen and their parents agree on the division of responsibility around diabetes care, there is less family conflict, increased adherence, and better medical outcomes [12, 65]. A recent study found higher reports of mothers’ and fathers’ monitoring uniquely related to better adherence, and higher reports of paternal monitoring were related to lower HbA1c, a longer-term measure/marker of blood glucose levels [66].

It has been suggested that psychologists should be involved in every pediatric endocrinology clinic [67], given the high risk of psychiatric comorbidity as well as the importance of family involvement. Psychologists are uniquely trained to help physicians and nurses engage families in a collaborative manner and increase agreement between children and parents regarding diabetes care and responsibilities. In addition, educating parents and providers regarding the ongoing role of parents in diabetes management for teenagers is essential, given that many parents tend to back out at this critical time and assuming teens are independent enough to manage their own care.

## Cystic Fibrosis

CF is a genetic disorder with current median-predicted survival rate of 37.4 years. Pulmonary complications result in the death of 95% of the patients (i.e., chronic lung infection and inflammation) [68]. The gastrointestinal system is also negatively impacted (e.g., poor nutrient absorption, CF-related diabetes), as is the reproductive system (e.g., infertility in 95% of males and 20% of females). Pain is common throughout the disease course [69]. Multiple daily treatments are prescribed, including airway clearance techniques for lung health maintenance and pancreatic enzyme replacements, high-caloric diet (110–200% of dietary referenced intake), and vitamin supplements for gastrointestinal issues. At times of pulmonary exacerbations, 2-week hospitalizations for intensive assertive community treatment (ACT) and antibiotics are typically required, with lung transplant considered the most aggressive treatment available [70].

There are many psychosocial aspects to CF, including coping with diagnosis/illness. CF is often diagnosed perinatally with a negative parent emotional reaction common, which can negatively impact child adjustment [71]. Children with CF list “being normal” as a primary concern, which can be difficult given how “visible” the disease is due to its negative effects on growth, the frequent coughing associated with pulmonary distress, the need to take enzymes with every meal, and school/activity absences or restrictions at times of worsening disease [72]. A complicating factor for peer support in CF is that health care providers recommend that children with CF not interact with each other in the same physical space due to infection control policies, thereby limiting another source of peer support which is available in other illness groups [73, 74]. Given the enormous treatment burden of CF, it is perhaps unsurprising that adherence rates to common treatments have shown to be around 50% for children and adolescents, with 30% of adolescents reporting no treatment at all [74, 75]. In early childhood, inadequate nutrient intake is a common problem, with much research exploring correlates of and behavioral interventions for problematic parent–child interactions around food intake [76–78, 79]. Later, assisting older children and adolescents in self-management skill development becomes the focus, with recent research exploring developmentally appropriate venues such as cell phone interventions [80]. Finally, end-of-life issues become salient as the disease worsens, resulting in the need for pediatric palliative care, including comprehensive symptom management, honest and skilled communication which optimizes addressing the spiritual and psychosocial needs of children and families, and follow-up support to bereaved families after patient death [81].

## Summary

In summary, working with children in medical settings can pose a more complex picture than working with adults. Developmental factors, multiple systems (family, peers, school, sports, etc.), as well as type of medical presentation (acute vs.

chronic) need to be considered. The good news is that there are effective interventions to help children, families, and practitioners with the multiple challenges medical issues bring up. From teaching children to cope with vaccinations or flu shots, to being able to swallow pills, to increasing adherence, pediatric psychology is helping advance the science and practice within medical settings for children, adolescents, and their families.

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## Chapter 12

# Psychological Problems at Late Life: Holistic Care with Treatment Modules

Lee Hyer and Ciera Scott

Below is a typical case for later-life patients. This particular man is best seen as one with multiple problems and needs. He has depression, anxiety, cognitive issues, somatic/sleep problems, as well as life adjustment concerns. He needs a coordinator who can assist him in his psychological, social, health, and practical problems/needs. This entails a holistic view of his situation and a considered approach to his plight. The answer then is not in a *Diagnostic and Statistical Manual (DSM)* diagnosis, not just in a medication for psychiatric care, and not in a private therapy session. It is in holistic care and case based on empirically supported therapies and social realities, as well as general health. This is not easily done.

Mr. B was referred by PCP for depression and complaints of memory disturbances. He is a 72-year-old African American man who lives with his wife. He has been married for 38 years and has two adult children. He has worked for the same ball-bearing company for 45 years and retired at age 65. In recent days, he is more retiring as he previously enjoyed socializing with neighbors and church group. He is also unsure of why he is here; “My wife told me I needed to come.” He presents with vagueness regarding details of early and mid-life; he acknowledges “tough” experiences but does not elaborate; and he relates his life story apathetically with a general paucity of content. He also denies feeling depressed, and shows no enthusiasm for what his wife has described as “prime interests.”

On the initial patient assessment, he was accompanied to the office visit by his wife. He demonstrates chronic pain from knee-related osteoarthritis and walks slowly with a cane, sits hunched over in chair. He complains frequently about pain. He is casually dressed as his clothing is not well arranged. He is, however, cooperative and communicative. His speech is clear but slow and

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of low volume, fluent without paraphasic errors. He is distractible with some unfocused effort. There is some evidence of psychomotor retardation.

He also has lost weight and has a decreased appetite. He has a history of smoking but quit 6 years ago; he has hypertension which is treated with hydrochlorothiazide; he has type 2 diabetes which is treated with glipizide; he has hypercholesterolemia which is treated with atorvastatin. His osteoarthritis is treated with nonsteroidal anti-inflammatory drugs (NSAIDs). He has had few surgeries (hernia repair) and has no allergies. He possesses substantial cardiovascular risk factors in the form of a history of smoking, hypertension, type 2 diabetes, hypercholesterolemia, as well as chronic pain.

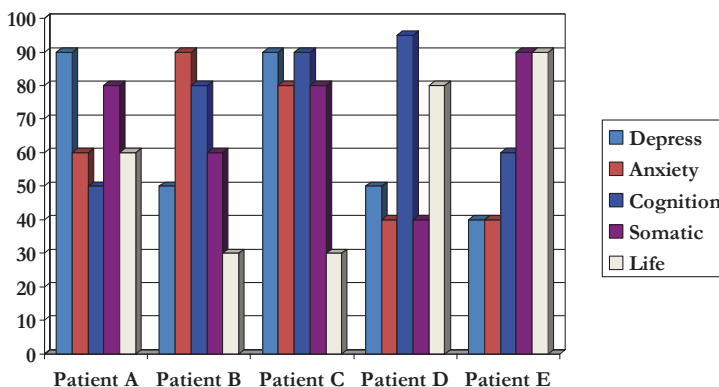
There is no history of depression. Now, the patient denies feeling depressed and has a loss of interest in seeing neighborhood friends and feels “He does” and does not enjoy former pleasures like softball. The patient complains of poor concentration and the wife reports that husband’s memory has become faulty and “disturbed.” He is also considerably more anxious than he has been in the past. He is not sleeping well as he ruminates. His wife reports changes in behavior as he is more irritable and raises voice frequently and is less talkative. He shows no apparent activities of daily living/instrumental activities of daily living (ADL/IADL) difficulties but complains that “everything just takes longer now.”

His symptoms at presentation suggest major depression, as well as anxiety. He scores 20 on the Patient Health Questionnaire (PHQ-9) with no positive endorsement of item 9; he scores 13 on the Generalized Anxiety Disorder 7-item (GAD-7). His Montreal Cognitive Assessment (MoCA) score is 21 suggesting mild cognitive disturbance and some memory recall and executive function impairment. He is also not sleeping (<5 h night) and is in pain (5/10). He is also increasingly anxious as he relates that he cannot tolerate his “poor ways” and is less efficient at everything. Psychiatric issues involve mild psychomotor retardation with some latency in speaking, hearing impaired, with delayed but adequate comprehension at increased volume, thought processes notably slow but otherwise unremarkable, and no delusions or hallucinations. General cognitive profile shows that he is oriented but not fully able to concentrate. He registers 3/3 items, recalls 2/3 after 5 min, and 3/3 with cueing, does name and repetition intact, has normal visuospatial functioning, and has poor insight. His judgment is intact.

### **Possible Diagnoses**

- Major depressive disorder (MDD)
- Dysthymia
- Generalized anxiety disorder (GAD)
- Endocrine-associated depression
- Pain-related depression
- Vascular depression
- Mild cognitive impairment
- Dementia

Patient C below best represents this patient. He has multiple psychological problems, including depression, anxiety, cognitive problems, and some somatic and sleep issues. The task of the health care provider is considerable: Case-base this patient. Assess on all dimensions. Develop a treatment plan (watch and wait method explained below). Establish a “watch and wait” procedure. Develop a plan. Bring in necessary personnel. Monitor the case. Be in for the long hall.



This chapter addresses the psychiatric and psychological components of older adults. What is the best way to address the modal psychosocial problems of late life, taking into account what science has to offer, what seems commonsensical, and what can be done? What are the reasonable concepts and learning required for care of older adults? Like Pascal, we must place our bets. With older adults, we witness a decline in being, a (likely) medically impacted person, a psychologically complex entity who is bothered by anxiety and depression, as well as somatic issues, and who has (probably) less cognitive power and in some cases considerably less. We are also living longer with several adjustment concerns. The translation of simple care at late life with multiple needs is upon us.

In the long run to benefit depressed or anxious elderly patients in the community, personalization of care must employ comprehensive common sense care algorithms targeting both modifiable predictors of poor outcomes and organizational barriers to care. Whether this care can be done on a grand societal level is perhaps unknown. We believe, however, that psychosocial care can evolve and move from intuitive to precision care. The latter has well-defined boundaries that a diagnosis assists and treatments match, but there is more. One does not need an advanced degree to know that if there is a bacterial infection, then an antibiotic is in order. But, we need skills to deal with closing the deal, follow-ups, side effects, messy socialization, personal reactions, iatrogenic nuances, and life. Older adults have side effects.

In the past 10 years, there remains a vacuum as results from trends have been enlightening but disappointing. The importance of medical care, use of selective serotonin reuptake inhibitors (SSRIs) and medication brethren, issues related to suicide, subsyndromal states, and validation of variants of cognitive-behavioral therapy (CBT) have been in play. But treatments work at best only 50% of the time and most often not permanently. People continue on as both system and self-change failures and patients often wax and wane as they get a little better before they come

to see you and at different times during the treatment. Long-term treatment is still largely an anomaly with little in the way of specific effects in therapies. Dismantling studies have not provided robust findings and it seems that general effects of care are greater than specific effects. We need better models.

Our position is simple: Treating “depressive symptoms” in isolation of the patients’ whole person, especially cognitive and physical limitations, risks slower or less-effective reduction in depressive symptoms. Targeting an organized patchwork of psychological problems, in this case depression, anxiety, cognitive impairment (CI), adjustment, and some disability, provides for a concerted effort to help the patient adapt and cope with their problems, promoting successful outcomes for the prime target, depression. Evidence for such multifaceted approaches to treatment is nascent, and so we must borrow from each problem and look at the efficacy for older adults, as well as what works for younger adults. While this is case based, with older adults it is more—it is a real everyday problem in treatment.

Applied science is not practical and we require a “reparticularization” of scientific knowledge to individual patients (Cassell 1991). This allows the practice of care for older adults not to go from science to practice but from science through patients and expertise, as well as clinical and real-life conditions, back to actual clinical practice. Experimental science is not a sufficient knowledge base for psychological practice.

## Model and Process of Care

Algorithms are perhaps brittle and often do not work well in the shadows; skilled decision makers are more sensitive to the context of problems at later life. We need informed and adaptive decision makers. The Sequenced Treatment Alternatives to Relieve Depression (STAR-D) study [20] showed us that only 33% of more patients with difficult to treat depression respond to four alterations in treatment with medications. We need a skilled therapeutic flexibility and response to this. Like schizophrenia, where the treatment of early responders is often found to be more cost effective than the treatment of early nonresponders, we need to know where and to whom we can best devote energies to. And for those who are not responsive, we need common sense care and reasonable treatment rubrics. In the cost-effectiveness vernacular, the early responder is considered a dominant choice over the early nonresponder, but beyond clinical acumen for matching patients with treatments, a clinician cannot choose which individuals will be early responders to a specific antipsychotic medication. We need clinical acumen for older adults so that these parameters can be available and known and the clinician can respond accordingly.

We do not need or require a crystal ball for what works with whom for older adults. Andreescu et al. [3] identified predictors of full response both at baseline and on change in depressive symptoms after treatment is under way. The authors used signal detection theory on pooled data from three acute treatment trials of either nortriptyline or paroxetine. They found that response by the fourth week of treatment was a critical factor in determining the probability of response by 12 weeks. Of course, a strong treatment response by the fourth week suggests that the treatment should continue. However, if only a moderate response has occurred

by that time, the clinician has to choose whether to continue the same treatment or do something different—switch to another treatment, for example, or augment the first treatment with another drug or a nonbiological intervention. Interestingly, in this study patients who had low levels of anxiety at baseline had a 61% chance of full response, whereas those with moderate or severe anxiety at baseline had a 39% chance of response. The probability of full response was even lower (33%) in patients who had experienced depressive episodes from early life. Using the probability of full response in treatment, then, decisions can spare patients from long exposure to treatments that have a low likelihood of success as well as from premature discontinuation of treatments that would likely be helpful.

Psychotherapy groups have been applying these ideas for many years (e.g., [46]). The score on the Outcome Questionnaire 45 (OQ-45) over three sessions affects outcomes. The American Association of Geriatric Psychiatry (AAGP) also has advocated for clinical prudence when there is no or a partial response early on in the treatment. So far, however, the empirical basis for personalizing treatment principally consists of post hoc analyses of unitary treatments (e.g., a course of an antidepressant or psychotherapy). While this knowledge is necessary, it is insufficient for two reasons. First, a one-disorder patient, like a depressed elder, faces a bewildering constellation of other health threats and social constraints and thus has many different contributors to poor treatment outcomes. Second, the skills available in various treatment settings and sectors can promote or inhibit treatment success.

We need an all encompassing-based model for change. We have argued for a “Watch and Wait” model [35]. This model posits that there are five areas of concern that are just sufficient for care. They include, cognition, depression, anxiety, health issues, and life problems. This last factor involves SES, caregiving, needs for living, and even long term care. Knowledge of these five domains, we believe, allows for the best grouping of variables for care. Importantly, they provide a profile where all influence care. We shall discuss these modules later in this chapter.

We need models of care then that encompass more than one diagnosis. Clinical and psychosocial predictors of response to single antidepressants or comprehensive interventions have been identified. These include anxiety, hopelessness, executive dysfunction, limitations in physical and emotional functions, chronicity of the current episode, and low income [11]. Such predictors can help in personalizing the first step of treatment for a given patient. Accordingly, a patient with one or more predictors of poor outcome may receive interventions targeting each modifiable predictor, as well as more vigilant follow-up. For example, a low-income depressed elderly patient whose symptoms did not respond to an adequate trial of an antidepressant and who is experiencing hopelessness may benefit from a trial of psychotherapy focusing on hopelessness as well as case management connecting him or her with social services.

## Backdrop

We are in the midst of a revolution in science, especially neuroscience, that is fast replacing usual care for all, but especially older adults. We of course do not yet know what causes aging and how we can prevent the harmful aspects of old age

[48]. We also have the limitations of our sciences; there is a 33% upper limit of any psychiatric therapy. Public health models suggest that we target “indicated or high-risk individuals” as most appropriate [35]. We also know that even small changes in core capacities of older adults can lead to large changes in complex behavior [71]. In psychiatry, it is reasonable to expect that only 38–46% get better (show a response) and that 1/2–2/3 will not remit [57]. We also know from the National Institutes of Health (NIH) conference on Alzheimer’s disease (AD) and cognitive decline in 2010 that very little is firm. Several “obvious” predictors are now wavering—adequate folic acid, low-fat diet, ETOH, vitamins, statins, cognitive rehabilitation, education, leisure, physical activity, metabolic syndrome, low social support, never married, homocysteine, obesity, and nonsteroidal anti-inflammatory drugs (NSAIDs). Maybe *Apolipoprotein E* (Apo-E), diabetes, smoking, and depression will prove eventful but even these “surefire” predictors possess noise. There are no firm biomarkers for AD and the diagnoses themselves are suspect [56].

In fact, we are in a taxonomy crisis where dementia, anxiety, and depression are concerned, especially at late life. The focus should be on identifying items that place a person on the continuum, not whether he or she is or is not in the group. The additive effect where many risk factors of genes and environment accumulate represents a better model of care. It is an aggregate effect. We have a poor recent history of efficacy in psychiatry and psychology.

**Over 50 years of research has suggested that the following are more true than not:**

1. The differential effectiveness of competing therapeutic approaches does not exist.
2. The superiority of psychopharmacological over psychological approaches is untrue.
3. The utility of psychiatric classification as determining the course of prescription medication is poor.
4. The short and effective treatments for older adults have weak effect sizes and large numbers needed to treat (NNT)

We do have reasonable facts, however. Prevention works [76] and about 25% remit with no treatment. With time, things can get better. Psychiatry clinics as they have been designed (set apart and medication driven) are becoming anachronistic where older adults are concerned. The “placebo effect” is strong in most treatments, certainly those relevant to psychiatry. In fact, a better statement for the efficacy of psychotherapy is that the real effect–placebo effect = a substantive effect. This is likely to be in single digits. Depression itself, except for the very impaired, is probably a placebo disease. The treatment response to depression is probably a placebo reaction. The NNT necessary for remission is quite high for most psychiatric disorders at late life. Most often, when change occurs, there is a response but no remission. “Omics” (genomics) too is not ready for prime time. There is now a firm belief that the careful look at the brain and body is necessary. Medically unexplained symptoms (MUPS)



are now the norm. Further, we know that the old-old (>85) are a distinct problem; treatment is generally less effective. Finally, as clinicians, we are constantly in the battle for the “best fit” for adaptation—the assimilation and accommodation dance whether through selective optimization and compensation (SOC) or other models. The exact match for this fit takes time and prudence.

What can health care providers do? We believe that prudence and data dictate that we should pay less attention to the nuanced differences in treatment (one antidepressant vs. another, one psychotherapy vs. another, medications vs. psychotherapy). While we should be aware of these, they help providers of older adults less than other age groups. Published reports suggest that attending to novel “significantly better,” or “evidenced based,” will result in better patient outcomes but doing so with older adults often diverts attention from the real-world issues and has only marginal evidence of benefit. Instead of presenting a comprehensive algorithm, then, for treating depression in older adults, or offering a canonical framework for describing or incorporating the complex interplay of medical, psychological, and social services into treatment planning, perhaps attention to the basics is more important [81].

The belief here is that the basics of care for older adults require some change. There is a need to march carefully over the case, proceeding from the real world, targeting issues, and entering mental health treatment. This requires assessment and monitoring as well as flexibility. There is no desire here to usurp the scientist–practitioner model as we need to do formal assessments and attend to the input of science. But, as noted before, we need more. Mast [52] argues for a “whole person” approach where “the person” of the diagnostic category becomes as important as the process of the diagnosis and treatment plan. We agree, but add that we need to apply

### **Basics of care for the older adult**

- Assuring social reality is in place (home, no alcohol, social care, etc.).
- Assure that the dosage is appropriate (not just medications). About 28% of older adults do not adhere to medication recommendations, and this is associated with poorer outcomes. Most patients do not seek a change in treatment if they are faltering.
- Consider non-pharmaceutical treatment first. It is true that these forms of treatment are not so much better than medications or the combo, *but* they have equal efficacy and are the least noxious. Efficacious treatment always involves some aspect of non-pharmaceutical treatment.
- Make sure a mental health professional is involved. The Healthcare Effectiveness Data and Information Set (HEDIS) study showed that they made a difference in only half the cases but this modality is always involved in the change in outcomes.
- Think about “watch and wait.” Monitor and wait for issues to confess themselves. The lack of clinically significant differences between treatment and placebo applies to mildly depressed patients.
- Frequent monitoring of patients’ symptoms and the frequent reconsideration of treatments may produce as much benefit for patients as a medication or psychotherapy and may fit better with the patient’s desires.

- Track outcomes. Use these as you would use laboratory values. Do not accept “Fine” as an outcome or marker of depression. If you are not measuring something, it has not occurred. Patients who just receive monitoring get better.
- Since remission rates are low, change treatments if patients do not remit for 6–8 weeks. Both longer time intervals and tinkering are the keys. Depression/anxiety/cognitive problems impact life downstream.

the better-known canons of our sciences to the person and formulate real plans that are titrated to tangible outcomes.

When dealing with older adults, we are often doing some application of translational research because few psychotherapy interventions have been designed expressly for elders. The translational component involves focusing on the time span of the problem, the nature and scope of hypothesis, dose adjustments, and patient population characteristics. Early on in therapy with older individuals, treatment is titrated. This includes a time frame that is short, hypotheses that are narrow in scope, small doses of the intervention, close monitoring of coping/potential, and choosing narrow treatment targets. In later phases of treatment, there is the requisite alteration in goals, which are simplified for reality’s sake. Psychotherapies are never just pure techniques to be used off the shelf. As this process has unfolded over the years, however, efforts to document the applicability of all-purpose psychotherapy research data appear to be relevant to older adults only if practiced in an aging-informed manner [32]. Both context and outcomes matter. With older adults, both are complex. For outcomes, the issue is never just symptom abatement. Rather, therapy should aim at symptom relief *and* improving overall quality of life (QoL).

**Some good news** The good news is that most psychotherapies developed for younger patients appear useful for older adults when applied in an age-informed and age-sensitive manner. [32]

## Best Predictors

We identify and briefly discuss the best predictors of our science for our modal psychosocial problems at late life, cognition, depression, anxiety, medical/somatic problems, and adjustment. We start with age.

### *Age*

Aging is complex and variable. The phenomenon of aging is itself a problem from most perspectives. We do not know well what cell senescence is, what causes the

allostatic load to not be processed well. We do not know the true savings in number of years lived for most of our treatment efforts. Just the idea of an 85-year-old who is optimally healthy coming for care is most probably problematic. Within 5 years, 80% will develop considerable medical problems. Variability itself is not an optimal sign at older ages. While this can be a nonevent for younger age groups and inherent within and between all biological systems, this is a problem at late life. Intraindividual variability (IIV) is associated with problems in cognition, especially working memory (WM), volumetric decline, demyelination, blood flow, vascular injury, and many neurological conditions.

Where age is concerned, we have had a culture change. In 1959, older people had the highest poverty rate (35%) followed by children (27%); by 2007, the proportion of older adults in poverty was 10%. In fact, in 2007, older people in the middle income group made up the largest share of older people by category (33%) with those in the high income group up to 31% (*Older Americans 2010: Key Indicators of Well-Being* [21]). Health ratings also were up. In 2008, 75% of people 65 or older rated their health as good, very good, or excellent; for 85 and older, these rates were still respectable at 66%. Life expectancy (the average number of years lived by a group of people born in the same year) along with a growing burden of chronic diseases also keeps rising ([83] Chap. 4 Case Based).

Percentages of lifestyle problems are also noteworthy. For starters, if you are a male in the USA and 65 years of age, you can expect to live an average 18.5 years; if you are 85, you can expect 6.8 more years. While life expectancy has increased by a year in the past decade, the time spent seriously sick is 1.5 years and time disabled has accrued by 2 years. For people 65 or above, diseases of the heart, followed by malignant neoplasms, and then stroke lead the way for death. Older men and women have hypertension and arthritis at rates over 50%. In 2008, 32% of people 65 or older are considered obese, 11% smoke, 25% spend time in leisure, and watching TV occupied the most leisure time (>50%): [81].

Related, we have a special problem with the old-old group, those >84. Interestingly, it is only at about age 80 that the vagaries of living become more apparent—the percentage of people with no disability rises, the percentage of people going into long-term care facilities increases, and the percentage of people married is lower. Older adults seek mental health at 3–6% levels (of all actual visits) as they see little connection between symptom and mental problems. Problematically, cognitive decline or depressive symptoms are actually more frequent in the old-old, but this is generally due to aging-specific variables. Not surprisingly, older adults seek mental health through somatic problems [39]. It is also true that the number of medications/person, number of medial visits, and number of falls, to name a few, are highest in this group.

Though professional, policy, and other recent developments portend an increase in service use, there has been scant empirical attention devoted to the current or recent utilization of mental health treatment by the elderly, and almost nothing is known about the correlates of mental health need and service use among older adults. Karlin and Fuller [38] examined patterns of serious mental illness, specific mental health syndromes, and service use among older (65+) and younger (18–64) adults throughout the USA, and the extent to which various factors predict mental

health need and the use and magnitude of mental health treatment. In addition, the study examined factors related to unmet need, as well as age group differences in perceived benefit from treatment. The findings reveal that older adults were three times less likely than their younger counterparts to receive any outpatient mental health treatment. Only 2.5% of older individuals utilized any outpatient mental health service in the past year, versus 7.0% of younger adults. These results indicate that the low rate of utilization by older adults may be partly a function of limited subjective mental health need. Importantly, though mental health problems appear to be significantly undertreated in older and younger age groups, Karlin and Fuller [38] also noted that those older adults who make it into services typically benefit considerably from treatment.

Common problems run the gamut from basic risk and safety issues to reasonable prevention. Major areas of focus would include polypharmacy, adverse drug events, medication compliance, fall prevention, continence care, and caregiver management of problem behaviors. These areas are problematic and can significantly impact the quality of everyday life.

**Special older adult concerns** *Common conditions go undiagnosed and untreated:* Too often, common and treatable conditions, such as CI, nutrition problems, sleep disorders, fall risk, overactive bladder and incontinence, mobility disorders, and depression, are undiagnosed.

*Health and care needs of the oldest old:* Included in this frail population are many minority and rural elders. The population of 85+ is the fastest-growing population and places the most demands on the health care system.

*Minority/disadvantaged:* African American and Hispanic elders especially are at greater risk of health problems and often receive less treatment for their conditions.

*Health literacy:* The Institute of Medicine has stated that “90 million people have difficulty understanding and acting upon health information.” The prevalence of limited health literacy is highest among older adults, minority populations, those who are poor, and medically underserved people. Training of health care professionals to improve their ability to communicate with their older patients is critical.

Older adults face many challenges as society’s view of their role transforms once they enter their sixth and seventh decades of life. The attitudes, values, and norms that have previously been constructed by society regarding aging are constantly evolving to accommodate the growing older adult population. However, a large segment of our culture adheres to negative stereotypes and prejudices associated with the process of aging. The practice of expressing prejudice and holding undesirable views towards a person due to their age—particularly older adults—is known as ageism. Ageism can be a significant problem as it can affect the perceived

functioning, cognition, and emotional health of an older adult. Coudin and Alexopolous [16] determined that older adults who were presented with an narrative-focused cognitive task after having read materials imbued with negative stereotyping towards older adults reported lower levels of subjective health and extraversion, higher feelings of loneliness, and more frequent help-seeking. These findings can be extrapolated indicating that older to the notion that older adults who internalize negative messages that they receive from society regarding aging may experience problems in maintaining a positive self-image and developing suitable coping skills to adjust to biopsychosocial changes they encounter as they age.

Aging is then replete with disease and impairment, often unrecognized or inadequately treated. But there are problems. Health confounds the results of age all the time. Health is based on self-reports and many studies simply overestimate the effect of age because they do not know about health. Ignorance of health in the study of morbidity does aging no favor. We have come to know that aging is a factor in people at risk across the life span, but it is really only a marker for other more important issues like cognition (brain at risk) in the identification process of persons at high risk for end-stage problems like AD. Once a mild cognitive impairment (MCI) or dementia diagnosis is given, all is probably lost in the long-term preventative sense. Age, at this point, reduces its value as a causal variable and cannot be viewed usefully as a basis for understanding cognitive changes.

### ***Brain Issues***

We have passed the decade of the brain (1990s) and are now firmly entrenched in the neuroscience era. At late life, this applies in spades. Older adults lose brain power and eventually lose functioning. Most often, they are correlated [69]. Denise Park [61] noted that the older brain presents with a symphony of degenerative expressions and develops scaffolding to address these, sometimes done well and sometimes not. All speed of processing and fluid tasks decompensate, while the person tries to adapt and assimilate/accommodate with skill training and coping. Increasingly too, we are seeing that cognitive training may make a difference. For cognitively healthy people, we know that mnemonic strategies work, that they improve but less than younger groups, that they can maintain skilled memory performance for 6 months, that they show little transfer, and that affect, attitude, and effort, as well as stress, matter. For cognitively less healthy individuals, we are now seeing that several studies are showing some promise [6, 49, 84, 88], that caregivers really can help with compensation strategies [35], and that multi-method packages with caregivers help (Hyer et al. in press).

It is now over two decades in which there was reasonably documentation that depression was a function of frontal-striatal problems [15]. Other studies through the years documented that more than 50% of patients with late-onset major depressive disorder (MDD) had such problems [23]. The influence of white and gray matter hyperintensities, as well as subcortical infarcts or hyperintensities, is

being associated with more severe symptoms, more hospital admissions for depression, longer hospitalizations for depression, resistance to medications, and executive function problems.

Late-life depression has been a special problem as far as brain issues are concerned. Knowledge of brain problems in the context of depression is informative in two ways. First, identifying persisting abnormalities during remission may indicate a high risk for relapse or persistent CI. Second, finding brain abnormalities predictive of poor outcomes of depression may initiate a search for their clinical correlates, which then can be used to personalize treatment. Wang et al. [86] used functional magnetic resonance imaging (fMRI) to compare activation and deactivation of brain regions in currently depressed elderly patients, elderly patients in remission from depression, and healthy elderly comparison subjects. The stimulus was an emotional oddball task, which activates or deactivates distributed brain networks and structures relevant to depression. The study documented activation changes that were limited to the depressive state as well as persistent changes occurring in both depressed patients and patients in remission from depression. Depressed patients showed attenuated activation of the right middle frontal gyrus and greater deactivation of the posterior part of the posterior cingulate relative to remitted patients and comparison subjects. The middle frontal gyrus exerts inhibitory control on emotional structures, and the posterior cingulate is connected to the hippocampus and the posterior cortex and participates in memory retrieval and self-consciousness [74].

Reduced activation of structures that participate in executive function (the supramarginal gyrus bilaterally, the left anterior cingulate, and the anterior part of the posterior cingulate) occurred both in depressed and remitted patients relative to comparison subjects. Executive dysfunction [1] and microstructural abnormalities in white matter-connecting structures that subservise executive functions [2] have been associated with poor or slow response of geriatric depression to antidepressant treatment. Taken together, then, these findings suggest that functional and structural abnormalities of networks relevant to executive dysfunction characterize a subgroup of depressed elderly patients who experience poor outcomes. This subgroup is quite large (>50%) and, even if these problems do not impact other older adults with depression at late life, these symptoms represent a prodrome for other problems downstream.

In the following text box, we outline how the brain is important in therapy with older adults. We start from the position that reregulation of neuronal networks parallels symptomatic changes in psychotherapy. Older brains confess their problems with symptoms, both cognitive and affective. Adjustment also suffers. Utmost, the psychologist is the manager of the therapy and, as such, he/she uses the brain as the explanatory mechanism for the dialogue. The mind and brain are indivisible; problems in life are reflected in or caused by brain input; and the use of the brain model can assist in the understanding of this. The therapist as neuroscientist can utilize and foster these issues.

### **Psychotherapist as neuroscientist**

- Mind and brain are indivisible.
- Reregulation of neuronal networks parallels symptomatic changes in psychotherapy.
- Narratives re-sculpture neuronal networks throughout life.
- Activation of the left hemisphere assists in top-down or placebo effect.
- Strategies of cognitive retraining assist in the treatment of depression and anxiety.
- Lower hippocampus-related anxiety and hypometabolism in temporal lobes create real brain-related memory problems and resistance to therapy.
- Placebo effect depends on the prefrontal lobes in a top-down cortical modulation of mood, emotion, and immune activity. Placebo effect is one of the core conditions of treatment—necessary and at times sufficient for change.
- Appreciate the centrality of stress: Early stress impairs! [17]

When it comes to the worst aspect of cognition at late life, dementia, the focus may be poorly targeted. The focus should be on a continuum of CI connected to health risk factors, lifestyle habits, and reasonable preventative targets. We need to see a “brain-at-risk” stance where we can learn that disease occurs long before symptoms are present. The vascular hypothesis and information from preventative cardiology make this point clear and convincing. It should be clear now that research on a variety of disciplines shows that cognition and mental health are intertwined across the life course.

We can add one more feature of age and brain: The idea of considering dementia without age is a nonstarter as the type of symptoms, the number of neuritic plaques, and the phenomenology of problems are different for differing older ages. There is then variability in the whole older group that is best reflected in the category of young-old and old-old. Cognition especially is the harbinger of problems of all sorts, both physical and mental, across the later years of life.

“The concept of dementia is obsolete.” [29, p. 2172]

### ***Anxiety***

The forgotten problem in the psychological care of older adults is the phenomenology of anxiety and what to do about it. Anxiety disorders are the most common psychiatric illnesses in the USA with approximately 30% of the population experiencing anxiety-related symptoms in their lifetime (Kessler et al. 2005). Current rates of anxiety extend to 10% with its symptoms actually doubling that number.

Most anxiety problems occur in early life (50–97%). In general, the fact that anxiety may attack in early or late life is unremarkable except for medical problems:

Late onset has more medical symptoms. In general too, early onset was most characterized by obsessive–compulsive disorder (OCD), panic disorder (PD), and specific phobias; late onset is most characteristic of post-traumatic stress disorder (PTSD), agoraphobia, adjustment with anxiety, and GAD.

While GAD levels (e.g., [58]), as well as depression and anxiety in general, are lower in older age than other ages (e.g., [28]), only 33% of older GAD patients reported using mental health resources (Blazer 2000). Older adults with GAD are more disabled, have worse QoL, demand a greater health care utilization than non-anxious groups [65]. Also, 90% of older adults with GAD report dissatisfaction with sleep and the majority report depression; however, problems with anxiety show first at primary care clinic (PCC)—both medication use and numbers are up. Younger ages also do better in terms of assessment and treatment where anxiety is concerned.

Anxiety is both brain based and unique at late life. As implied, the most common type of anxiety at late life is GAD. This type of worry is best connected to depression and often to medical problems. Worry and nervous tension (as opposed to specific anxiety syndromes, such as PD) are common presentations of depression in older people. Unfortunately, many physicians tend to focus on the symptoms of depression or anxiety alone, thus failing to consider the possibility of comorbidity. Often, patients who have both anxiety and depressive symptoms are more likely to be given a benzodiazepine rather than treatment for depression [60, 81]. Older adults with depression too often may worry about memory loss without showing objective evidence of memory impairment in simple tests of memory. These patients should be evaluated for symptoms of depression, with careful follow-up to watch for the development of dementia [17].

### **Anxiety facts**

GAD levels (e.g., [57]) and anxiety in general are lower at older age (e.g., [28]).

Research on subthreshold disorders with nonclinical older samples indicates that mental health is not better in older age.

Literature on the dimensional approach suggests that this is a better model of psychopathology.

Older individuals provide responses significantly different from those of younger adults, potentially requiring special attention in psychiatric care.

## ***Depression***

Depression has changed the face of confidence regarding the canons of established psychiatry. Yes, it exists and is prevalent, but its phenomenology is complex and varied. Older persons with significant depression may have fewer symptoms than the number required by the *DSM-IV* criteria for major depression. In one study [26], older adults who expressed feelings of hopelessness or worthlessness admitted to



thoughts of death or suicide and had at least two other symptoms of depression, were at increased risk for functional disability, CI, and psychological distress and death even if they did not display symptoms such as sadness or loss of interest or pleasure in activities that were formerly enjoyed (nondysphoric depression). Depressive symptoms are also associated with the development of functional impairment as measured by performance tests (avoiding reliance on self-report of function) in a similar study [62].

### **Depression issues at late life**

- “There is increasing evidence that symptoms of elderly depression may be etiologically distinct (e.g., more psychomotor retardation and anhedonia in vascular depression) and that focusing on subclusters of depressive symptoms, rather than relying on general depression assessment tools, may help enhance construct validity...” (p. 379)
- At the least, “It is apparent that the ‘oldest old’ (>75) present different from the ‘young old.’” (p. 379)
- At the least, “...the development of depression and cardiovascular dysfunction share molecular mechanisms, such as stress induced changes in inflammatory markers and neurotransmitter signaling, all related to common genetic elements.” ([50], p. 380)
- “The heterogeneity in symptom presentation among older adults diagnosed with MDD can potentially inform the development of the DSM-V.” [34, p. 387]

Older patients with depression may present with somatic complaints for which a medical etiology cannot be found or that are disproportionate to the extent of medical illness. Patients who express somatic symptoms as a manifestation of depression seem to be less willing to mention psychological symptoms to their physician [10]. Certainly, illnesses, such as pancreatic carcinoma or hypothyroidism, might cause symptoms that mimic depression. Therefore, addressing the patient’s psychological distress while appropriately evaluating the possible diagnoses is important. Clinical experience also suggests that physicians are less likely to move from recognition to treatment of the illness in older patients than in younger patients. Physicians, like patients and their families, are usually able to find a “reason” for depression in the older person. That said, treatment is often delayed or not pursued at all [12]. Physicians may believe that a medical illness is a contraindication to treatment with antidepressants, but older patients with physical illness seem just as likely to respond to selective serotonin-specific reuptake inhibitors (SSRIs) as older patients without physical illness [72]. Now, we know that psychotherapy can be as effective as antidepressants if not more so [35].

At late life too, several varieties of depression can exist. As intimated above, there are varieties of the phenomenology of depression. There are shades of grayness, as well. Major, minor, and mixed depression exist at late life. Annoyingly,

subsyndromal depression (often defined as >16 on Center for Epidemiological Studies-Depression (CES-D) but full MDD criteria are not met) is also a pervasive problem. All of these states are prevalent, all assert an influence on QoL, and all segue to MDD at some point, if not handled when the symptoms are first noted. These states are highly prevalent and have a propensity to convert to MDD, especially when there is a history of MDD [14]. Most patients do not solicit treatment.

Of interest too is that there are no clear biomarkers of depression. This is said despite the fact that there are MRI changes in late-life depression, that twin studies show that 16% of variance is attributed to CES-D, that 5HT2A and 5HT1A receptor-binding decreases with an increased incidence of homozygous “short” alleles in promoter region of 5-HT transporter, that corticotropin-releasing factor hypersecretes (in low-level doses, and that the HAM-D factors correlate with distinct brain regions). In addition, there is comorbid weight loss, cardiovascular disease, increased platelet activation, lower T cell response, poor blastogenic response to mitogens, high level of cytokine interleukin 6, as well as elevated homocysteine levels. Despite this, depression is generally not measured by biomarkers. That said, this state is best viewed as an epigenetic disease where nature and nurture dance for dominance.

Depression is often the driving force in the panoply of symptom domains discussed. In fact, anxiety seems to lead the pack in time to disorder, but depression is the core substance. Depression is comorbid with everything bad. On the one side of the coin, depression can be punishing. Styron [80] noted: “The gray drizzle of horrors induced by depression takes on the quality of physical pain.” But there is another side: Depression may be overrated. It is common as a sign and symptom. But its true prevalence may be considerably less than 12%, closer to 2%. If we mark depression as a true disorder that is debilitating, not episodic and marginal in intensity, it may be less serious a disorder and more a universal annoyance that peaks on occasion to cause some problems.

### ***Medical/Somatic Issues***

Older adults have historically utilized health services at higher rates than anyone and mental health services at substantially low rates. If they do seek help for mental problems, it is in primary care. We also know that medical care is directly related to mental health. It is estimated that more than 70% of medical problems, especially unexplained ones, are attributed to mental health issues. Modal problems for older adults regarding cognitive decline, depressive symptoms, anxiety issues, or unexplained somatic concerns are more than 50%. Patients with depression and significant comorbidities are especially costly to the health care system. Depressed patients with diabetes, for example, have more trouble adhering to their diet and checking blood glucose levels, and they exercise less, smoke more, and die at about twice the rate as those without depression. It is costly not to treat these people, to develop preventative programs for them, and have educative targets around diabetic problems.

The pathways leading to comorbidity of mental and medical disorders are complex and bidirectional [43]. Medical disorders may lead to mental disorders, mental conditions may place a person at risk for medical disorders, and mental and medical disorders may share common risk factors. Comorbidity between medical and mental conditions is the rule rather than the exception. In the 2001–2003 National Comorbidity Survey Replication (NCS-R), a nationally representative epidemiological survey, more than 68% of adults with a mental disorder (diagnosed with a structured clinical interview) reported having at least one general medical disorder and 29% of those with a medical disorder had a comorbid mental health condition [11, 25]. In addition to the high prevalence of these conditions, there is also evidence that having each type of disorder is a risk factor for developing the other. For example, among respondents to the 1999 National Health Interview Survey, another nationally representative epidemiological survey, the likelihood of having major depression diagnosed via a screening instrument increases with each additional reported comorbid chronic medical disorder.

Worse, medical conditions are most often grouped into “triads” (i.e., common co-occurrences of three diseases together). Psychiatric disorders were among seven of the top ten most frequent diagnostic comorbidity triads in the most expensive 5% of Medicaid beneficiaries with disabilities. The most common triad was comorbid psychiatric conditions, cardiovascular disease, and central nervous system disorders, which affected 9.5% of all beneficiaries and 24% of the most expensive group of beneficiaries. One of the most important drivers of the high costs is the high prevalence of mental disorders and chronic conditions in the USA (RWJ Report). The 2001–2003 National Comorbidity Survey Replication, an epidemiological survey, found that approximately 25% of American adults meet criteria for at least one diagnosable mental disorder in any given year [27], and more than half report one or more chronic general medical conditions [72].

When mental and medical conditions co-occur, the combination is associated with elevated symptom burden, functional impairment, decreased length and QoL, and increased costs [8, 73, 78]. The impact of having comorbid conditions is at least additive and at times may be synergistic, with the cumulative burden greater than the sum of the individual conditions. Comorbid mental and medical conditions are associated with substantial individual and societal costs [18, 88]. Melek and Norris [53] analyzed the expenditures for comorbid medical conditions and mental disorders using the 2005 Medstat MarketScan national claims database. They looked at the medical expenditures, mental health expenditures, and total expenditures of individuals with one of ten common chronic conditions with and without comorbid depression or anxiety. They found that the presence of comorbid depression or anxiety significantly increased medical and mental health care expenditures, with more than 80% of the increase occurring in medical expenditures.

We also note that other medical/somatic issues infect the QoL for older adults. Two that are prevalent are sleep and pain. Sleep problems become more common with age, affect QoL for individuals and their families, and can increase health care costs. Older people are often prescribed a range of drugs for their health problems (including with sleep), many of which have side effects. Total sleep duration

appears to show a modest improvement post treatment, which declines with time. Pain also is prevalent and asserts an influence over care programs. In fact, the more the person suffers from pain, the more each is resistant to treatment for any psychiatric disorder.

There is no easy summary here. Chances are that, if you have a mental problem and if you desire to seek help, you are probably depressed, anxious, have some cognitive issue, or are in pain and sleep deprived. Additionally, the thrust of care is towards more medications and a reduced adjustment. If you are treated, it occurs in PCCs and you are prescribed medication. Often, you are misdiagnosed as either a false positive or negative. If accurately diagnosed, you are not followed up well or the medications do not prove effective. Depression care invariably means antidepressant treatment (40%) or being tabbed as a false positive (45% false positives). You are also treated by primary care providers (PCPs; 50%; [7]). If you have anxiety, medical utilization increases with the number of anxiety diagnoses [44]. Also, if you say that your problem is somatic, your PCP misses psychiatric diagnosis (85%; [41]).

## *Adjustment*

The evidence is that adjustment suffers as these issues percolate at late life more than other ages. Adjustment problems are always salient but become a big issue if one of the following components is present. First, adjustment suffers just by getting older; at age 80, 60% of adults start having problems with instrumental activities of daily living (IADLs). This increases as spousal loss occurs and presence in long-term care facilities (LTC) expands. Second, adjustment is at issue when there are activities of daily living (ADL) or IADL functional problems. A 75-year-old male with one ADL problem has the rough life expectancy of an 85-year-old without one. QoL is also equated.

Third, cognition and function cohabit with ~40% of common variance [70]. Adjustment has an equal chance of predicting dementia and related problems as do neuropsychological or medical predictions. This is especially the case when IADLs are assessed. But, adjustment is often the forgotten component in care as the focus is on medical and psychiatric/psychological problems. Once one is in an LTC facility, adjustment becomes even more important.

Fourth, QoL is critical for reasonable living; QoL is adjustment. How the person lives, with whom, with what supports, money, options, and with the ability to act as they would like, become central to well-being. What is involved in happiness is complex but clearly involves the desire to be ambulatory, to have some resources, to be social, to feel some self-efficacy, and to live where the person desires. Some decades ago, Rowe and Kahn set the bar for successful aging very high. Only about 8% of older adults have this as a designation because most have medical maladies and limits on function. For our purposes, the presence of anxiety, depression, cognition problems, or medical concerns affects adjustment. Measuring and targeting common living/adjustment account for as much of the variance of change as any of the variables by themselves.

## ***Psychotherapy Works, Even at Late life***

In the main, psychotherapy does work. It is reasonably enduring as well but also not as effective as possible as many (most) patients do not fully remit. We start from the position that psychological problems at late life are best dealt with by the therapeutic response based on modular interventions, that the modal problems at late life, anxiety, depression, somatization (pain), and cognitive decline are joined at the hip, that emotional disorders have a similar underlying structure, that the components of core therapies, like CBT, problem-solving therapy (PST), and interpersonal therapy (IPT), incorporate the best modules for change. This then represents a unified approach to treating problems at late life. At base, this involves core psychotherapeutic responses of experiencing the emotion, changing the cognition, and behaviorally acting. In fact, psychotherapy in the twenty-first century is one in which there is a melding of theories and borrowing of techniques, making pure models of care (e.g., CBT) difficult to find.

The intervention of change for an older adult in turmoil is a beginning. The careful therapist will know that the chances of recurrence are high. The antidotes to this are awareness of its existence, a focus on relapse, an educational gathering of social resources, a team approach, and a loose monitoring over time. Good science can inform practice, and good practice is good policy. That said, there are many variables in the dance of therapy and the health care provider must act on clinical common sense before best practice when the two collide. There must then be an “epistemological politics” that can supplant one knowledge system for another.

“Advances in knowledge in the psychopathology of mood disorders seem to make it clear that the wrong target has been addressed. . . major depressive episodes will respond to most reasonable treatments in the short term or will remit on their own, but they will *almost always recur*. To be truly effective, treatments, whether psychological or pharmacological, must prevent recurrence of future depressive episodes.” Barlow, [5, p. 873]

When dealing with older adults, we are often doing some application of translational research because few psychotherapy interventions have been designed expressly for elders. The translational component involves focusing on the time span of the problem, the nature and scope of hypotheses, dose adjustments, and patient population characteristics. Early on in therapy with older individuals, treatment is titrated. This includes a time frame that is short, hypotheses that are narrow in scope, small doses of the intervention, close monitoring of coping/potential, and choosing narrow treatment targets. In later phases of treatment, there is the requisite alteration in goals, which are simplified for reality’s sake. Psychotherapies are never just pure techniques to be used off the shelf. As this process has unfolded over the years, however, efforts to document the applicability of all-purpose psychotherapy research data appear to be relevant to older adults if practiced in an aging-informed manner [32].

From this position, we can see that psychiatric treatment with medications is really a *psychological intervention*. We argue this for many reasons, including the fact that there are no specific effects of the antidepressants, that more caring and empathic physicians get better results, and that there is little relationship between dosage and plasma levels of antidepressant and outcome. In our experience, successful doctors get better results with a range of psychotropic medications, whatever is applied.

Both context and outcomes matter. With older adults, both are complex. For outcomes, the issue is never just symptom abatement. Rather, therapy should aim at symptom relief *and* improving overall QoL. Residual symptoms portend relapse or a lower QoL. But a careful and caring focus for the long term will assist. Reality constraints on outcome cannot be easily captured by research. These include the client's readiness to change, acceptability of the treatment and preferences of the client, caregiver acceptance, availability of desired or needed services, probability of third-party payer approval, tolerance of incongruous recommendations, prior treatment failures or successes, and side effects. Hence, with older adults, the big three components of therapy—research, clinical experience, and client characteristics—are added to by these generic background and living markers for adequate outcome coverage.

Although evaluation questions necessarily focus on the reasons why an elder is seeking treatment, such a narrow focus is not helpful for understanding process changes over time or other longer-term and broader concerns. In translating evidence-supported treatments to older adults and in targeting this to the most researched psychotherapy, CBT, we must concentrate on more general outcomes (not just diagnosis), as well as specific markers associated with the identified problem. For the treatment of depression, for example, CBT will involve the alteration of cognitions to reduce depressive symptomatology, as well as alterations within the context. As noted above, with older adults too, the therapy also demands a scientific attitude, a skillful and flexible delivery of services, quantitative monitoring of the client's progress, and an awareness of the personologic, interpersonal, and cultural characteristics of the client as well as QoL themes. The efficacy of change also resides in common factor details, the context of therapy.

Psychotherapy does not work as medicine; nonspecific factors are integral to both but prepotent for mental health care. This allows the patient to generate change, spontaneous recovery, self-generated change, placebo effects, resilience, post-traumatic growth, corrective effects of disclosure, and feedback. Always, there is a need to take into account the context of practice; evidence-based practice may not be practical. In addition, the therapist effects are at least equal to treatment effects. At late life too, the realities of practice that science cannot address well, such as socioeconomic status, medical comorbidities, and patient attitudes, are prevalent. In general, when clinical experience and science butt heads, the best advice is to opt for clinical experience. At late life but across the board, psychotherapy is both an art and a science.

### Rubrics of psychotherapy

- Psychotherapy is effective; effect size is  $\sim 0.8$ , indicating that the average treated person is better off than 80% of not in treatment [47].
- The apparent existence of specific psychological treatments for specific disorders is suspect [54].
- People are increasingly accepting mental health programs as a normal mode of treatment [31]. Also, most people will admit to emotional or life-style problems in the last year.
- The quality of the patient's participation is most determinant of outcome [59].
- Change as a result of psychotherapy derives from key ingredients or elements that transcend all approaches.
- Nonspecific components of the alliance, the placebo and the person of the therapist, are critical for change in mental health. Allegiance effects by the therapist are also substantial.
- The comparative effectiveness of drug studies versus psychosocial therapies is virtually equal. In fact, placebo closely approximates the effect size of both. The combined use of both types of therapies is more helpful only to some (e.g., treatment resistant or in acute phase only).
- Up to 10% deteriorate in psychotherapy and another 25% do not benefit at all [44].
- Monitoring or tracking patient outcome alone has an effect size of at least 0.4 [45].
- Between 6 and 9 weeks seems to be an initial marker for change; if there is no change by then, problems will likely continue.
- Clinicians practicing in multidisciplinary settings do better than sole practice models.
- Dropout rates in outpatient clinics total as high as 47%.
- How one copes with problems over time to prevent relapse is more critical than initial changes. Change then is not just managing symptoms.
- Particular treatments work because the patient is motivated, the therapist is likeable and competent, the alliance is firm, and feedback is applied.
- The psychiatric treatment with medications is really a *psychological intervention*.
- There are no specific effects of any of the psychiatric medications, especially the antidepressants.
- Most people with mental disorders remain untreated or poorly treated [85].
- Patients given "usual care" have a very high likelihood of remaining depressed.

## *Social Reality/Cost*

The issue for providers, health care administrators, and policy makers is to balance the essential tension between good care and cost. This is not easy as it requires a thoughtful program of preventative self-care and reasoned medical service utilization based on patient-centered input by the older adult and his/her caregiver/family. In the Institute of Medicine report, *Retooling for an Aging America* [36], a vision of health in America is laid out. First, the health care needs of the older population will be best served by a patient-centered, preference-sensitive approach. Patient centeredness includes taking into account the increasing sociodemographic and cultural diversity of older Americans. Second, services will need to be efficient so that wasteful and ineffective care is reduced. Third, interdisciplinary teams will provide comprehensive, seamless care across various delivery sites and be supported by easily accessible health information systems fitted to emerging care needs and delivery modalities. Last, older adults will be active partners in their own care until they no longer have the capacity for competent decision making. Ideally, there will be a partnership between provider and patient that includes: (1) clear information, (2) adoption of healthy lifestyles, (3) informed self-management of chronic conditions, and (4) increased participation in one's own care.

We do not do a good job of health care in this country. We spend twice the amount of other countries and end up in the middle of the pack on just about every outcome marker of health. Only 25% of people with a *DSM* diagnosis actually get treatment; only 10% of people with lifestyle problems (smoking, poor diets) ever seek professional help. Mental health is costly—really costly, more so than most medical problems. We have already established that unmet mental health needs lead to problems downstream. The pharmaceuticals have not changed this. We need a better model of care.

Socioeconomic status has long been viewed as a strong marker of QoL. Recent studies have illustrated the fact that socioeconomic status and our living environment begin to play an even more significant role in our QoL as we age, particularly with respect to the development of chronic diseases. Freedman et al. [22] utilized subject data from the 2002 Health and Retirement Study to postulate that a correlation exists between the characteristics of the neighborhood in which an older adult inhabits and his or her late-life morbidity. It was found that for women aged 55 and older, living in an economically disadvantaged neighborhood predicted the onset of critical heart problems. In addition, Freedman et al. demonstrated that older adults—both men and women—living in more highly segregated, higher-crime areas were at greater risks of developing cancer. Socioeconomic status determines more profoundly and predicts QoL and general health than perhaps any other researched factor. Lack of monetary resources, restricted access to quality health care, and environmental stressors add to the deterioration of older adults living in low-income environments. The practice of negative habits such as lack of physical activity, poor diet, and smoking also influences the onset of other chronic disorders such as hypertension and diabetes.



Gender and race should also be examined with regard to the aging process and the utilization of health care services to promote overall well-being. Income and wealth certainly influence health care resources available to older adults, especially considering the availability and costs of health maintenance (HMO) enrollment plans, Medicare, Medicaid, private insurance, and government assistance. According to Cameron et al. [13], women report more health needs and disability in terms of functional limitations and report fewer economic resources in terms of income. Davitt and Kaye [19] also investigated differences that exist with regard to quality of home health care offered to minority groups and other vulnerable populations due to current national health care policies. These are all factors considered when evaluating gender and racial disparities that may exist in older adults seeking preventative care, physician visits, hospital admissions, and home health care.

### *Caregiving*

It has been estimated that 65.7 million Americans served as caregivers in the past year. This is 28% of the population. Nearly one third of American households reported at least one person serving in an unpaid caregiving role. The typical caregiver is a female, taking care of one person on an unpaid basis. But more than one third (34%) report taking care of two or more people. Most are providing care for a relative (86%) and more than 1/3 are taking care of a patient. On average, caregivers have been on the job for 4.6 years and 31% have been doing this for 5 or more years. The typical person receiving the unpaid care is a female (62%) who is 61 years old and gets about 20.4 h per week of active care. Burden was rated as medium-high by 51% of respondents with 35% relying on paid caregiving and 66% on other unpaid caregiving. Stress of caregiving is notable [30, 33, 73].

Throughout the life span, levels of caregiver burden increase as the physical health and mental capacity of the care recipient deteriorate. Caregivers are often confronted with issues of frailty, cognitive deficits, and behavior problems at the hands of their ailing spouses. Lack of adequate coping skills and a positive support system can lead to caregivers experiencing depressive symptoms, problems with anxiety, and other emotional disorders. In addition, older adult caregivers who expend all of their time and energy into taking care of their loved ones often neglect their own personal health, resulting in a myriad of physical ailments.

The responsibility of caring for a spouse inherently holds an overall increase in burden. Pinquart and Sorenson [63] ascertained that spouse caregivers report high levels of physical burden, financial burden, and relationship strain between themselves and the care recipient. As a result, physicians, social workers, and mental health professionals who encounter older adults living in a caregiver dyad should extend resources that help improve the overall well-being of the spouse caregiver. Resources should include psychoeducational and support groups for couples living with a particular disorder (i.e., Parkinson's Disease, AD, stroke, etc.), skill-training programs focused on behavior management, depression, and anger management,

and psychotherapy of the CBT [24]. The physical and emotional well-being of the caregiver directly impacts those reciprocal aspects of the care recipient; therefore, health care professionals should promote increased self-awareness and self-care for the caregiver.

Not enough emphasis can be placed on how greatly impacted a spouse caregiver may be from exposure to the psychological, physical, and spiritual distress that their care recipient endures in their presence. According to Monin and Schulz [55], the nature of caregiving exposes caregivers to increased cognitive empathy, prolonged bereavement, and extended observations of physical pain in the care recipients. The emotional toll resulting from witnessing the decline of a spouse can also manifest itself as physiological distress such as fatigue and somatic symptoms. In addition, taking on the caregiver role causes some spouses to experience existential crises of their own regarding their legacy, personal values, and meaning in life.

### *The Domain Dance*

We have advocated for a holistic approach for the assessment and treatment of older adults. This is anything but linear and clean. The older adult is waiting to be parsed apart and better understood, but holistically. The most assessed targets involve cognition and depression. Cognitive compromise associated with late-life depression can present anywhere along a continuum from MCI to a frank dementia. A mood disturbance in an older adult can initially present as a subjective cognitive complaint. Likewise, the existence of depression can exacerbate previously existing cognitive difficulties. In community-dwelling residents, the combination of impaired cognition and depressive symptoms doubles in frequency at 5-year intervals beyond age 70; combined depression and cognitive dysfunction are present in 25% of individuals aged 85 years or older [4]. There is ample evidence that the presence of comorbid cognitive deficits is associated with reduced treatment responsiveness in late-life depression [37, 66, 75, 77, 79].

This applies to the other problem domains, anxiety, somatic/pain/sleep, and adjustment. Most psychosocial interventions for the acute treatment of geriatric major depression focus on “young-old” (average age of 65–70 years), cognitively intact, ambulatory older adults who can follow outpatient treatment [51]. Clearly, this is only a subsample of the population who are in need. Additionally, homebound, rural, and low-income older adults may not have the same access to effective interventions for depression as those living in situations more conducive to receiving traditional psychotherapeutic treatment [51]. Furthermore, interventions may not be available or appropriate for ethnically and culturally diverse populations.

We have also noted above that factors such as comorbid illness can also serve as a barrier for treatment. Evidence suggests, for example, that depressed older adults with comorbid physical illness and CI experience reduced intervention effectiveness which argues for a strong need for new evidence-based psychosocial interventions to help depressed older adults with CI and disability [64]. Studies

have not indicated significant treatment remission differences between early-onset and late-onset depression [42] although older adults who had an early-onset depression may be slower to remit [68]. This is because they have more “other” problems, principally cognition, anxiety, and pain/sleep.

What can providers do? We believe that the core treatment involves non-pharmaceutical interventions. This form of treatment is not so much better than medications or the combo, but they almost never cause harm and always lead to better results. As indicated, we believe that the “watch and wait” strategy is most important here. The judicious application of monitoring and waiting for success or failure to be expressed is suggested, where an observation period as a part of the treatment plan is considered good care.

The recent studies in primary care regarding depression (IMPACT) made one important contribution; the idea of a step care model with a watch-and-wait background. Mistakes are made in the care of mental health problems when decisions are made too quickly, empirical science is suspect, or commitment (of the patient) is not certain. Step care establishes a slow pattern of treatment in which the problem is assessed, monitored, and problem-solving interventions are slowly but deliberately introduced. Problems confess themselves. Recall that the social reality of the patient is of equal concern to the psychiatric problems and requires intervention. Frequently, the monitoring of patients’ symptoms and the reconsideration of treatments may produce as much benefit for patients as a medication or psychotherapy and may fit better with the patient’s desires.

Reality constraints for outcomes that cannot be easily captured by research include the client’s readiness to change, acceptability of the treatment and preferences of the client, caregiver acceptance, availability of desired or needed services, probability of third-party payer approval, tolerance of incongruous recommendations, prior treatment failures or successes, and side effects. Boyd et al. [9] in 2005 noted that best practice for an older adult who has high blood pressure, diabetes, arthritis, and depression involves more than 14 medications and as many non-pharmacological interventions resulting in excessive costs and many practical problems. Coordinated care is necessary for help and change.

## Conclusion

Psychological problems at late life are best dealt with by the watch and wait scaffold using modular interventions. The modal problems at late life, anxiety, depression, somatization (pain), and cognitive decline, as well as adjustment, are interactive. Dealing with these issues requires much of the health care provider. It is fortunate that emotional disorders have a similar underlying structure, and that the components of CBT, including PST and IPT, have modules that can be effective in care.

Something more than standard care is required. In a review of long-term care and the value of psychiatric medication, Reichman and Conn [67] noted that the

evidence in support of various models of psychogeriatric services in nursing homes liaison-style services that employed educational approaches, treatment guidelines, and ongoing involvement of mental health staff are more effective than the purely case-based consultation model. This latter model almost exclusively involved medication.

- “The narrow emphasis is not serving the nursing home population adequately. We continue to rely nearly exclusively on medication management in our clinical nursing home practices, even though our confidence in the efficacy and safety of the historically most treasured psychotropic agents has been seriously eroded.... We must acknowledge that the newer generation medication therapies have no been delivered substantial enough gains over their predecessors.”
- “What are the specific contributors to the display of mental illness in the nursing home? In this milieu, they are the physical environment, the processes of care, and the behavior of people (care providers and other residents).”
- “...it is time to shed our overreliance on biological determinants and the disease models of mental illness. It is time for a reappraisal.” [67, pp. 1050–1052].

We agree.

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# Chapter 13

## Practice in a Rural Setting

**Robert J. Ferguson, Amber Martinson, Jeff Matranga and Sandra Sigmon**

In 2009, Dr. Norman Anderson (CEO of APA) wrote a letter to Congress to support H.R. 3200, American's Affordable Health Choices Act of 2009:

At the same time, we urge you to consider adding provisions to the bill to recognize that mental health is integral to overall health and that behavioral factors play a critical role in the prevention and treatment of chronic health conditions. After all, modifiable behavioral factors, such as smoking, improper diet, lack of physical activity, and excessive alcohol consumption, are the leading causes of chronic health problems (such as heart disease, diabetes, and many forms of cancer). These behavior-linked conditions account for nearly 75 per cent of health care spending. Therefore, new and successful models of health care practice should include the integration of psychosocial and behavioral assessments and interventions, with medical care. Thus, psychology, as the science of behavior, has much to contribute to improving the health status of our nation and is integral to health care reform [1].

Although the above quote refers to health care in general, its significance for rural health care is paramount. The myriad roles clinical psychologists play in medical settings have steadily increased over the past 20 years. Despite substantial empirical contributions to the field of behavioral medicine, clinical psychologists working in primary care and other medical settings face multiple obstacles unique to rural populations. In this chapter, we highlight some of the distinct properties of working in integrated medical care settings in rural places. Topics covered include: (1) health characteristics of rural populations, (2) rural health disparities and health care access, (3) multiple relationships, (4) psychopharmacology consultation, and (5) the increasing use of telehealth and information technology (IT) in rural settings.

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## Definition of Rural

No single definition of “rural” is used across agencies or programs. However, the term “rural” is a definition made by exclusion—anything not urban is by default rural [2]. The US Census Bureau defines two types of urban areas: urbanized areas and urban clusters. An urbanized area is defined as a densely settled territory with at least 50,000 or more people, whereas urban clusters consist of at least 2,500 and less than 50,000 people. “Rural,” therefore, is classified as all population, housing, and territory not included within an urban area [3]. Although such definitions may be useful for classification purposes, they should be interpreted with caution. With more than 59 million Americans (21 %) currently living in rural communities [3], “rural America” actually consists of many small places scattered across the country and represents diverse geographic and cultural regions [4]. Psychologists working in primary care settings should be aware of this diversity to help create efficient collaborative or “integrated” care models in rural settings.

## Health Characteristics of Rural Populations

Challenges confronting health care providers and patients in rural areas differ from those in urban areas. Differences include: poverty, high rates of unemployment, cultural and social differences, less education, and lack of recognition by legislators that lead to disparities in health care not observed in urban areas [5, 6]. In addition, individuals in rural settings tend to have higher rates of chronic illness, experience more medical complications with chronic illness, and have less access to specialty care than their urban counterparts. While a little more than 20% of the US population resides in rural areas, less than 10% of physicians practice in rural regions [7]. Thus, in light of these qualities in rural populations (less health care access, more chronic illness, etc.), it is becoming increasingly urgent for psychologists who work in rural regions to become involved in medical settings to address these problems at “point of service.”

## Demographic Differences in Rural Versus Urban Populations

One of the most persistent stereotypes about rural America is that the majority of individuals are Caucasian. In general, this perception has validity given that the proportion of the rural population that is non-Hispanic white (82 %) is higher than in urban areas (66 %) [8, 9]. However, ethnic diversity is growing across many rural areas and is projected to increase [8, 9]. For example, Hispanics constitute 5.4 % of the rural population and represent the fastest growing ethnic group. From the 2000 to 2010 Census, there has been a 43 % increase in the Hispanic population with

estimates of 50 million currently [8, 10]. African Americans constitute the largest minority group (8.4%) in rural areas, although their growth rate has not been as rapid as that of Hispanics. Native Americans, Asian Americans, and Pacific Islanders constitute approximately 4% of the rural population and are also expected to steadily increase. Given the potential for an increase in patient diversity in rural areas, psychologists will likely face increased challenges posed by cultural and language differences [11].

In addition to racial and ethnic factors, individuals living in rural areas tend to be older (by roughly 25%) than those in urban areas. Across the USA, there has been a 21% increase in individuals aged 62 and older since the 2000 census [8]. Many rural communities have far fewer younger families [12]. Indeed, there is a long-standing history of young adults moving from rural to urban communities in search of career and economic opportunities. Conversely, there is a trend for older individuals to move into rural communities, drawn by recreation opportunities and quieter, less-congested places [12]. Older individuals bring new skill sets and have much to offer rural communities, but at the same time this may create new pressures on a small community health care infrastructure due to a greater likelihood of chronic illness and medical complication with age [12].

Rural communities also face economic hardships and educational shortcomings. Specifically, rural residents tend to be poorer and have an average per capita income of \$ 7,417 less than that found in urban areas [5]. This income gap is even greater for minorities living in rural areas. Further, individuals living in rural areas tend to rely more heavily on the federal Food Stamp Program, with 31% of the nation's food stamp beneficiaries living in rural areas [12]. Such economic disparities may, at least in part, be accounted for by the disparities in education that exist between rural versus urban areas. On average, individuals in rural communities complete fewer years of school than their urban counterparts although this appears to be changing with average education levels in rural communities steadily climbing. Overall, the face of rural America is constantly changing and psychologists should be familiar with demographic characteristics of its residents. Part of effective practice involves enhanced awareness of the population served. The racial, age, economic, cultural, and educational factors discussed can help improve understanding of their impact on rural population health status and how to design better health services to meet community needs.

## **Illness Differences in Rural Versus Urban Populations**

Individuals who live in rural America encounter a variety of distinct stresses and illnesses as varied as rural America itself [13]. State legislators across the nation agree that mental health problems are a serious, widespread concern in rural communities [14]. Although mental illness is common in both rural and urban areas (i.e., 25% of the American population in any given year is affected by a psychological disorder), individuals in rural communities experience significantly higher rates of suicide

[15] and depression [16]. In particular, the suicide rate for older adult males and Native American youth in rural areas is substantially higher than in urban areas [17]. Furthermore, adults living in rural areas who suffer from depression tend to make more suicide attempts compared to their urban counterparts [18]. Higher rates of suicide attempts may be influenced by lack of risk detection in rural health care settings. For instance, despite the fact that depression is common in rural communities, physicians practicing in rural areas detect 50% less depression in patients compared to urban physicians [19]. The implication of this lower detection rate suggests the need for increased training for health care providers in rural primary care settings [4]. This is a specific area where psychologists can improve rural health care through working in integrated practice.

In addition to experiencing greater rates of suicide and depression, individuals in rural communities can experience increased life stresses such as cyclical farm crises, natural disasters, social isolation, high poverty rates, limited childcare resources, high unemployment, and fewer educational opportunities [13]. There is also social stress associated with reduced anonymity through living in a small community. Rural residents who experience mental illness and other personal matters (e.g., sexual trauma) may be reluctant to seek services for fear of being identified by community members. Given the links between stress and increased rates of psychopathology and acute and chronic disease, implications of these sources of social stress are far reaching and deserving of further public policy and research attention.

## Health Disparities

According to NIH [20], health disparities are defined as “avoidable differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States.” Individuals in rural areas are less likely to have employer health care and/or prescription coverage, more likely to abuse alcohol and methylphenidate, and are more likely to die from accidents. In addition, individuals in rural areas often work in high-hazard occupations, have to commute long distances to work, and travel longer distances to get health care. These demographics may also lead to higher rates of traumatic stress, depression, and substance abuse associated with injury.

Despite a high rate of mental health comorbidity (about 60%), there is generally less access to mental health services for rural individuals [13]. Other health disparities for rural individuals include higher rates of chronic illness (as seen above), less oral health services, higher obesity rates, and fewer options for physical activities. Women in rural areas are more likely to give birth to children with fetal alcohol syndrome when compared to urban women. Moreover, rural women also have higher rates of chronic illnesses and greater morbidity than urban women [21]. Higher rates of cancer, cardiovascular disease, diabetes, car accident deaths, hypertension, and smoking are also found in rural populations [22].

## Health care Access

Collaborative health care in which physicians and psychologists work to provide comprehensive care is sorely lacking in rural areas [6]. It is quite likely that integrated psychological and medical health care providers could address much with prevention in rural areas, especially in chronic illness, and help reduce complications and morbidity. However, other barriers to health access may be social and attitudinal. For example, in close communities, individuals may not seek health care for lack of privacy and concern of psychiatric stigma (e.g., domestic abuse, substance abuse, depression, or anxiety disorders). Findings on gender-specific attitudinal barriers to health care access demonstrate that some males may be less likely to report depression, whereas women may be less likely to report substance abuse [21]. Economic hardship in rural areas is also a barrier to health care access, particularly for children with special needs (e.g., dental care, therapy, medications, preventative care) [23]. These children are less likely to be seen by a pediatrician, lack access to appropriate specialists, and their families may not have sufficient funds or insurance coverage for needed treatment.

## Multiple Relationships in Rural Medical Settings

As seen above, addressing attitudinal barriers such as psychiatric or mental health stigma is an important consideration when designing and implementing psychological services in rural medical services. However, for any psychologist who has worked and lived in rural communities, it is not always easy or possible to assure complete privacy of the professional relationship between psychologist and patient, even in specialty practice. In the high-patient-volume world of integrated psychological and medical care, avoiding multiple relationships is not always possible.

Multiple relationships have the potential to harm a patient or the therapeutic relationship. However, a blanket prohibition against them is not realistic and may not always be advisable in rural areas [24–26]. The Ethics Code for the American Psychological Association (APA) [27] states that:

A psychologist refrains from entering into a multiple relationship if the multiple relationship could reasonably be expected to impair the psychologist's objectivity, competence, or effectiveness in performing his or her functions as a psychologist, or otherwise risks exploitation or harm to the person with whom the professional relationship exists. Multiple relationships that would not reasonably be expected to cause impairment or risk exploitation or harm are not unethical.

Ethicists such as Schank point out that avoidance of multiple relationships in small communities can have some negative implications and the psychologist may need to carefully weigh out decisions [24]. For example, because the rural psychologist may have a greater understanding of the social and cultural context in which the patient is immersed, implementation of a behavioral treatment plan may be tailored to the patient's social context. An illustration of this would be the provision

of anxiety or adult ADHD treatment planning for an individual who works in a particularly busy and hectic clinic. The health care setting may be in the same building where the psychologist works, and thus the probability of potential contact outside the professional relationship may be high. However, because the psychologist works in a similar setting, he or she can craft a behavioral plan with the patient that is tailored to the patient's work environment of multiple demands and interruptions during the day. To address the confidentiality concern, the patient and clinician may opt for self-guided in vivo exposure over a clinician-guided approach, for example.

An increased likelihood of contact with patients outside the health care office may be a cause for compartmentalizing roles rather than relationships. This is particularly so when psychologists work in medical settings and may see a high volume of patients in shorter visits. The pivotal question according to Schank and Skovolt [26] is whether the likely benefit of the multiple potential relationships outweighs likely harm to the patient. Barnett, Behnke, Rosenthal, and Koocher [28] recommend consideration of the following in such circumstances:

- a. Will doing this (the treatment plan) be helpful to my patient?
- b. Will this action likely harm anyone?
- c. To whom do I owe an obligation or allegiance in this situation? (patient, physician practice, both)
- d. Will this action likely promote dependence on me by my patient?
- e. Are my actions consistent with how other psychologists treat their patients?
- f. Have I allowed my judgment to become impaired as a result of inadequate attention to my own care or needs?

Recommendations for minimizing the risk of harm or unethical conduct in rural medical settings can include [24]:

1. Obtain informed consent that would include discussion of overlapping relationships and how they will be handled. In a busy primary care setting with 15-min visits, obtaining written consent is not necessarily practical; one option for the primary care psychologist is to have support staff obtain a written copy for the health care office and review it in brief verbal discussion in the initial office visit.
2. Thoroughly document any overlapping relationship along with the rationale, any consultation with other professionals, and any discussion with the patient (such as seeing a patient who also works in the local town office).
3. Set clear boundaries and expectations with oneself and with patients. As the probability of out-of-office contact increases, it is increasingly important to discuss roles, expectations, and limits with the patient. This can be done succinctly. For example: "If there is an encounter in the community, out of respect to your privacy and confidentiality, I won't acknowledge you unless you initiate contact, in which case I'll respond."
4. Confidentiality may require unique considerations in comparison to work in urban settings. For example, the psychologist working in rural settings may need to be extra careful about the source of patient information—whether it was derived in a confidential office setting versus a community contact. It is not uncommon for staff members to know patients personally, see patients walk out

of the exam room, and later say to the psychologist, “Did you know...?” If this happens, it is advisable to simply and politely inform the staff not to discuss details but thank them for the concern.

5. Ongoing consultation is highly recommended. Telephone and other forms of consultation such as peer supervision may be particularly helpful in a rural area to address unexpected multiple relationships and other ethics concerns that can arise.

## **Psychopharmacology Consultation**

The mental health needs of patients in medical settings combined with increased shortages of doctoral-level psychopharmacologists create an opportunity for psychologists in rural medical services to make significant contributions to psychotropic medication management [29]. There is a significant shortage of psychiatrists nationwide [30]. Rao, quoted in Muse and McGrath, reports that there was a 36.5% decrease in psychiatry residents from 1992 to 2000 [31]. Moreover, there is a shortage of physicians in rural areas [7]. Thus, there is an ever-widening gap between doctoral psychopharmacologists with advanced training in behavioral health care, and the supply of such professionals. The lack of access to doctoral-level psychopharmacology is even more pronounced in rural areas at the time of this publication.

Psychologists with appropriate training (a postdoctoral master’s degree) in psychopharmacology have been prescribing in the military for more than 15 years, and prescribing psychologists are now employed in rural regions with the Indian Health Service of the US Department of Health and Human Services. While at the present time there are few states where psychologists are licensed to prescribe psychotropic medications (New Mexico and Louisiana, both states with large rural regions), psychologists with psychopharmacology training make medication recommendations in many, if not most, states. The licensing boards in 14 states have issued specific statements noting that if the psychologist has adequate training, it is not outside his or her scope of practice to provide such consultation [30].

## **Telehealth and Consumer Health Informatics**

In its report on rural health care, the Institute of Medicine (IOM) [32] identified several key distinctions between rural and urban populations when it comes to health services. Each of these was touched on earlier in this chapter, but the IOM report sheds light on where opportunities exist to use IT to improve rural health services. These include: (1) a chasm in health care quality, (2) reduced numbers of health care providers in primary and specialty care, and (3) rural populations have a greater mix of health problems where patients tend to be older, suffer more chronic illnesses, and have more health risk behaviors such as sedentary lifestyles and smoking [32].

IT and the use of telehealth services hold great promise in addressing these rural health disparities through improving access to health services and education. By logical extension, psychologists who work in rural integrated medical settings are in a good position to not only promote use of these technologies but also help guide IT and telehealth policy and implementation. After all, use of IT is ultimately a behavior.

Three areas of IT in rural health care are of particular interest: (1) direct clinical services and telehealth (health and mental health service), (2) telehealth law and regulation of clinical services, and (3) use of consumer health informatics (CHI) to improve patient health (e.g., electronic patient and provider education, shared medical decision making). Information to help clinicians in rural integrated medical settings to start using more IT services will also be presented below.

## Direct Clinical Services and Telehealth

According to the US Health Services and Resources Administration (HRSA), “telehealth” is defined as:

The use of electronic information and telecommunications technologies to support long-distance clinical health care, patient and professional health-related education, public health and health administration. Technologies include videoconferencing, the internet, store-and-forward imaging, streaming media, and terrestrial and wireless communications [33].

The rapid advancement of IT has far outpaced our understanding of the efficacy or usefulness of various new ITs applied to a variety of rural health problems. By the time this chapter comes to press, there will no doubt have been numerous changes to the technology landscape. Development of new applications for mobile communication devices is exponential along with development of new devices themselves. However, there is an accumulation of telehealth research evidence over the past two decades that support three broad conclusions. First, in general, telehealth services for direct patient care are accepted by many in rural settings [34]. Second, they are by and large effective for numerous health problems [35–37], and, third, they are more effective than the alternative of no care in large geographic regions [34]. Reviews and meta-analyses do point to some conclusions about different telehealth modalities used for different rural health problems. These are summarized here.

*Telephone.* Behavioral interventions by telephone with either landline or mobile device can be widely used to address health and mental health problems and are highly suited for rural health care [38, 39]. They may also be used to supplement face-to-face services with infrequent office visits [35–38]. Telephone-based treatments for anxiety disorders tend to be more effective than those for depression [35] and telephone-based cognitive behavioral therapy (CBT) can also produce better physical function outcomes among those with disabilities due to chronic illness [36]. This is particularly so if the chronic illness or condition is not immediately life-threatening [37]. Given the simplicity of the telephone and widespread access, telephone-based treatments hold great promise in rural health care delivery.



*Videoconference.* Beyond telephone-based treatment, videoconference technology that involves real-time audio and video interaction has been shown to have wide acceptance and satisfaction among rural patients [34]. Videoconference technology usually links multiple health centers where patients can receive treatment or education in a structured health care setting close to home (e.g., local hospital, patient-centered medical home, etc.). Applications such as Skype allow patients to receive treatment or education at home if they have the appropriate streaming capacity. However, there remain concerns about appropriate encryption to protect privacy in addition to questions of patient safety when rural patients are seen in unsupervised settings such as home (e.g., increased risk of adverse events such as suicide, acute delirium, or acute medical crisis). Both clinicians and researchers alike are proposing safety protocols to deal with adverse events with videoconference or other IT media [40].

*Internet.* The Internet can add many intervention modality options which include audio, videoconferencing, or “older” online methods such as instant messaging (live “chat” with the clinician or peer counselor) or educational materials in text, audio, or video clips. When these educational supplements are added to video conferencing or other telehealth formats (telephone), this appears to enhance satisfaction and adherence to treatment completion [41]. In addition, there is evidence that a computer-based support system (which may be online or can interface with the electronic medical record; EMR) can help nonexpert clinicians in primary care to provide effective CBT for anxiety disorders [42]. Internet, telephone (landline or wireless), and videoconference technologies can all be used in isolation or a variety of combinations. All methods will continue to evolve and clinicians who work in rural medical settings should be aware of their development, efficacy, and safety and be prepared to offer these services if it will benefit the health of the community served. To stay current on these matters, the following online resources are recommended: the APA Practice Organization ([www.apapracticecentral](http://www.apapracticecentral)), the American Telemedicine Association ([www.americantelemed.org](http://www.americantelemed.org)), and HRSA ([www.hrsa.gov](http://www.hrsa.gov)). HRSA has a Rural Health IT Toolbox available to help clinicians in rural areas implement telehealth and IT clinical services.

## **Telehealth Law and Regulation**

At the time of this publication, laws and rules regulating telehealth and IT services are being developed but will change with advancing technology, evidence of efficacy of services, and varying needs of states and regions. In late 2010, only 22 states had telehealth laws and only three states, California, Kentucky, and Vermont, had telehealth laws pertaining to psychologists [43]. Further, it was not clear if language of the laws in these three states allows for telehealth psychological practice within medical settings, or if it presumes that psychological practice takes place only in traditional independent or mental health practice. This raises concern. For example, psychologists using telehealth services in California must provide verbal

and written consent prior to the service. This consent must include the following elements: potential risks, benefits and consequences of using telehealth services, summary of all confidentiality protections, a statement that clinical information used in telehealth services cannot be shared for research (this requires separate consent), and the right to withdraw or withhold consent at any time. While the California law is good for consumer protections, it may also be burdensome for integrated care practices that can involve people from numerous disciplines such as physicians, nurses, pharmacists, medical assistants, social workers, dieticians, and psychologists—all of whom may use telehealth services with distant patients. This may require the use of multiple written forms for each discipline within an integrated practice and lead to confusion and errors. Moreover, patients and families may be confused or burdened by signing multiple telehealth consent forms if they see more than one practitioner in the practice via telehealth—such as the physician, psychologist, and dietician in a diabetes management program. Therefore, it is important that evolving telehealth regulation for psychologists take into account psychological practice in medical settings where the clinician is part of an interdisciplinary team and documentation requirements are sensitive to this health care context.

Adding to legal complexity is practicing across state lines where the practitioner is in one state and the patient is receiving services in another. Some states may require practice only in the state of jurisdiction. The Vermont law, as of 2010, stipulates that psychologists must be licensed in Vermont in order to provide telehealth services to patients in the state [43]. Such services are subject to Vermont Psychology Board regulation. This matter is well worth watching over time as IT is not limited to an interstate matter but one that is global. For example, the state of Maine shares most of its land border with Canada, not the USA. Therefore, rural interstate IT-based practice will no doubt also be subject to international health regulatory agreements.

Another consideration in telehealth and IT regulation is which services are reimbursable for which health care providers. In 2011, psychologists are included on the roster of providers who can receive reimbursement for telehealth services by the Centers for Medicare and Medicaid Services (CMS). Covered services include both health and behavior services and psychotherapy via telehealth delivery [44]. However, there are a number of limitations which will likely change with time and broader use of telehealth. These include: (1) technology to be used is limited to real-time interaction with *audio-video* devices, and not “store-forward” methods such as e-mail, or test data (in contrast with radiology, which may use stored images for review at a later time, but CMS does not consider this an example of telehealth at present); (2) reimbursement is limited to patient recipients in designated regions such as rural health professional shortage areas or a county located outside of a metropolitan statistical area; (3) patients receiving services must be in a provider’s office, hospital, rural health clinic, skilled nursing facility, or federally qualified health clinic [45]; and (4) claims submitted, at least for 2011, must use a GT modifier along with the appropriate billing code [46]. As seen, CMS reimbursement requirements at the time of this publication do not reflect current data that

demonstrate some positive outcomes with use of other media such as telephone or Internet. Thus, rules and laws that regulate the use of telehealth services will likely change with the advancement of IT technologies.

In summary, it is important for psychologists who work in medical settings to get involved in the regulatory development process in their home states. Often, legislators will contact state psychological associations to help craft regulation. Many state associations may not have active psychologist members who work in medical settings and thus well-meaning telehealth regulation that is developed may reflect independent or traditional mental health practice—not that which is integrated in medical settings. It is therefore of great importance that rural psychologists who work in medical settings be involved with their state associations to point out important qualities of integrated psychological practice in order that telehealth services regulation is crafted with these considerations in mind.

## Consumer Health Informatics

For purposes of this volume, we have distinguished CHI from telehealth on the basis that we regard telehealth as implying direct provider to patient care, consultation or provider–provider/administrator communication. By contrast, CHI may refer more to consumption and use of health information by patients, families, or communities to manage their health. CHI is also a means of translating that information into effective clinical practice. Therefore, health care providers are also consumers of CHI. An estimated 10 million people search the Internet daily for health information [47]. CHI may include tailored recommendations or information, can be used with or without a health care provider, and may address a number of health behavior matters including implementation of evidence-based practice, medical decision making, “disease management, lifestyle management, tracking observations of daily living, health promotion, self-care and care-giving.”[47]

There are direct implications of CHI for psychological practice in rural integrated medical settings. Gibbons et al. [48] in a systematic review concluded that CHI can enhance benefits and positive outcomes of existing treatments in contrast to treatment alone. These effects appeared strongest in the use of CHI in mental health outcomes. Thus, CHI applications can supplement rural health care where there are shortages of providers. CHI applications also appear most effective if they involve individual tailoring, personalization, and behavioral feedback [48]. Psychologists can play an important role in designing individualized feedback for CHI applications. An example may be in medical shared decision making where CHI can be used to supplement patient-centered decisions about prostate cancer in primary care [49]. Psychologists are in a good position to know the limits, risks, and benefits of CHI to enhance rural service. In designing rural integrated health care practice, psychologists can use the Gibbons paper to help guide practice design and use CHI effectively for targeted problems.

## Summary

In this chapter, we outlined some of the important distinctions between rural and urban population health, important matters psychologists should be aware of when working in rural integrated medical settings, and what topics to be sensitive to when considering using IT to supplement rural health care. Specific take-home points are:

- Epidemiologic and demographic characteristics of rural populations—most tend to be older, have more chronic health problems, more likely to have problematic health habits, and tend to have higher proportions of Caucasian individuals. However, minority populations in rural America are growing fast.
- Most individuals in rural settings will have less access to specialty health care and thus receive the bulk of service through primary care settings.
- Psychologists working in integrated medical settings should be sensitive to balancing ethical concerns of privacy against continuity of care with other providers (or against having no behavioral care at all) when working with individuals or groups of patients.
- Rural psychologists in medical settings may become the de facto “expert consultant” on many topics within the practice and thus multiple relationships may be unavoidable.
- As expert consultant, appropriate training (the postdoctoral master’s degree) in psychopharmacology may be highly useful in busy primary care or other medical practice setting since there is a shortage of rural prescribers of psychotropic medications.
- IT holds great promise to address rural health disparities. It can improve both health care access and quality with both telehealth and CHI. Psychologists well informed of these services can help develop them in the rural health care settings in which they work.

In closing, some final practical steps are recommended for rural psychologists contemplating getting involved in integrated medical practice. These are:

1. Rural psychologists who are considering part- or full-time work in medical settings should receive as much information and training as possible in integrated psychological practice. Review of this handbook is a good start.
2. Know the demographic and public health characteristics of the population with which you work. Know which chronic diseases or conditions are most problematic and strain scarce health care resources and offer targeted services for these. Such targeted services can include helping the medical practice establish shared medical appointments [50], offer patient “workshops” for chronic illness or symptom management (small groups of 4–5 patients, family in three visits), community educational discussions, and of course individual treatment service or smooth referral to specialty care for individual patients. An example in our region is offering combined evidence-based cognitive-behavioral-medical rehabilitation for chronic pain [51]. Maine leads the nation in admission to substance abuse treatment centers for opioid addictions that evolved over the past two decades due to a confluence of factors, but one contributing source was

lack of provider and patient education in chronic non-cancer pain management. Offering the above services targeting such problems as chronic pain can add to health care quality and individual health outcomes and can address population health needs.

3. Consider receiving training in psychopharmacology to offer consultation services to the practice.
4. Be aware of telehealth laws and regulation in your state and what services may be offered. Use the resources cited in this chapter to stay abreast of both the regulatory changes and emerging evidence-based treatments used with telehealth.
5. Consider offering guidance in the infrastructure development and use of CHI, with services such as shared medical decision making, patient and family education services, and provider education (continuing medical education) and consultation. Psychologists' knowledge of behavior can help optimize the usefulness of CHI in medical settings as suggested by Gibbons [48].

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**Part V**  
**Medical Specialties and Settings**



# Chapter 14

## Clinical Psychologists in Primary Care Settings

Anne C. Dobbmeyer and Benjamin F. Miller

### Introduction

Clinical psychologists desiring to work in a medical setting targeting an extremely diverse set of patients, medical conditions, and psychological problems need look no further than primary care [1]. Primary care providers (PCPs) offer frontline assessment and treatment for most medical concerns, serving patients throughout the life span with interventions that include prevention, tertiary care, and chronic disease management. Even psychiatric conditions, often assumed to belong in the realm of specialty behavioral health clinics, comprise a major domain of primary care service delivery. For example, the majority of psychotropic medications are prescribed by primary care physicians and not by psychiatrists [2]; nearly half of individuals who receive treatment for behavioral health conditions receive their care solely from their primary care provider (rather than specialty mental health), if they receive treatment at all [3]. The National Comorbidity Study found that between 1990 and 1992, only 25% of individuals with a serious psychiatric disorder received any professional assistance, and this increased slightly from 2001 to 2003 to 40% [3]. Additionally, it has been estimated that up to 70% of primary care visits consist of a preventable illness often involving a health behavior [4]. Although PCPs function as the primary behavioral health service provider for the majority of patients across the USA, barriers in time, training, and skill may impact the quality and amount of behavioral health care they provide.

Behavioral health providers practicing within primary care thus have the opportunity to deliver a much-needed service addressing needs of both primary care patients and the primary care service delivery system more broadly. The primary care environment

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affords the behavioral health provider the possibility of engaging in a stimulating practice using a skill set that is well matched to that of a clinical psychologist. Effective behavioral health integration in primary care requires skill in addressing a wide range of behavioral health concerns as well as health problems that are initiated, exacerbated, or maintained by a diverse set of psychosocial factors. Moreover, the ability to provide preventive services in a population health model and interact effectively as part of an interdisciplinary medical team is crucial for success [5–8].

## Primary Care and Patient-Centered Medical Home

Before moving further, it is important to define relevant primary care terminology. Even the basic term “primary care” may connote several different meanings. According to the American Academy of Family Physicians (AAFP), primary care is defined as “care provided by physicians specifically trained for and skilled in comprehensive first contact and continuing care for persons with any undiagnosed sign, symptom, or health concern (the ‘undifferentiated’ patient) not limited by problem origin (biological, behavioral, or social), organ system, or diagnosis. Primary care includes health promotion, disease prevention, health maintenance, counseling, patient education, diagnosis and treatment of acute and chronic illnesses in a variety of health care settings (e.g., office, inpatient, critical care, long-term care, home care, day care, etc.). Primary care is performed and managed by a personal physician often collaborating with other health professionals, and utilizing consultation or referral as appropriate. Primary care provides patient advocacy in the health care system to accomplish cost-effective care by coordination of health care services. Primary care promotes effective communication with patients and encourages the role of the patient as a partner in health care [9].”

Designation as a “primary care” clinic therefore is not determined by medical specialty or discipline, but rather by type of care provided. Family medicine and internal medicine physicians, nurse practitioners (NP), and physician’s assistants (PA) most frequently come to mind when thinking of primary medical care. However, pediatric clinics as well as obstetrics and gynecology (OB/GYN) clinics may also function as primary care clinics. Specific issues in working within pediatric and OB/GYN settings are covered in separate chapters; our focus will be most relevant for psychologists working in primary care clinics staffed with family medicine and/or internal medicine providers. Complicating matters further is the growing discussion and emphasis on primary care as a “medical home” or “patient-centered medical home (PCMH).” Interestingly, the concept of the medical home is not a new one, but has been around since the 1970s when pediatrics began discussing a central source for children’s medical records [10]. Over the years, other professional medical associations have offered their take on the concept of the medical home, and there appears to have been a shift to address chronic disease. This shift is likely in response to the significant public health implications, but also because of the rising frequency in which patients present to primary care with several chronic conditions

[11, 12]. The concept of a medical home allows for a continuous relationship with a medical provider addressing specified medical problems over an unspecified period of time, which has the benefit of enhancing the relationship between provider and patients that extends beyond the presenting complaint [13].

Although a full review of medical home terms is beyond the scope of this chapter, the following key points are important to know. In 2008, a number of primary care stakeholders and organizations (American College of Physicians, AAFP, American Academy of Pediatrics, and the American Osteopathic Association) developed a consensus statement on PCMH. In conjunction with this, the National Committee for Quality Assurance (NCQA) developed standards and guidelines for recognition and certification as a PCMH. Several of the NCQA core PCMH principles have direct bearing on primary care behavioral health services. One such principle specifies that a PCMH involves a “whole person orientation,” [14] where personal physicians address all aspects of patients’ health care, either through managing the care themselves or arranging appropriate care from other professionals. Furthermore, a PCMH will provide care that is coordinated or integrated to assure patients receive necessary, appropriate care. The increased emphasis on addressing behavioral health within PCMH is clearly reflected in the 2011 NCQA standards for PCMH. Numerous elements within the six standards involve activities related to mental health, substance abuse, or health-related behaviors. They include, for example, requirements for identifying and addressing behaviors affecting health; improving patient/family self-management and self-efficacy; screening for developmental problems; screening for depression; and implementing evidence-based guidelines for managing a condition related to unhealthy behaviors, substance abuse, or mental health conditions [15]. It is clear, therefore, that integration of a clinical psychologist into a primary care practice has great potential for contributing to the PCMH concept through enhancing care of the “whole person” (emotional, cognitive, behavioral aspects of functioning, in addition to physical symptoms) in an integrated manner within the primary care clinic. Some have called specifically for the inclusion of behavioral health into the medical home [16].

## **Behavioral Science, Family Medicine, and Internal Medicine**

Having behavioral health specialists on staff in primary care clinics is not a new development. Psychologists, as well as other behavioral health professionals (e.g., social workers, masters’ level counselors), have functioned within primary care settings for many years. Of the medical specialties, family medicine residency programs in particular have a long tradition of incorporating behavioral science faculty to increase family medicine residents’ ability to address psychological and behavioral concerns [17]. Examining family medicine and internal medicine training curricula can be a helpful tool in elucidating relevant distinctions between these two specialties. The Accreditation Council for Graduate Medical Education (ACGME)

is responsible for the accreditation of medical residency training programs, including family medicine and internal medicine. The primary training difference of relevance to behavioral health providers in primary care settings is that family medicine training includes human behavior and behavioral health as a core component to the medical knowledge curriculum. Family medicine is also the only medical discipline that has a requirement for a behavioral science faculty to be a core part of the training program [18]. This behavioral science faculty may be a clinical psychologist, but could also be another behavioral health professional such as a licensed clinical social worker. Clinical psychologists' skills and training are well suited for the behavioral science position in that they would likely be able to address ACGME program requirements, which stipulate that family medicine residents should "acquire knowledge and skills in this area (human behavior and mental health) through a program in which behavioral science and psychiatry are integrated with all disciplines throughout the residents' total educational experience [19]." However, the functions of the behavioral health specialists in family medicine residencies vary widely, ranging from delivering largely traditional behavioral health patient care, to training family medicine residents in fundamental behavioral health assessment and treatment skills, to serving as an internal consultant for primary care team members (e.g., team building, improving communication of medical team, etc.). Behavioral health assessment and treatment skills are so important for primary care that the Society for Teachers of Family Medicine (STFM) board has recently approved a set of core behavioral science principles to be incorporated into family medicine residency training. STFM's core principles can be found online at <http://www.stfm.org/group/behavioral.cfm>. An excerpt of the STFM behavioral science core principles states: "The role of behavioral science faculty is to consult and teach physicians and other health care providers; treat patients and families on emotional, family, and psychosocial issues; contribute to the knowledge base through research, publications and presentations; and continually upgrade one's knowledge and skills in behavioral science."

These STFM core principles for behavioral science in family medicine residency shape the work of behavioral health specialists directly involved in family medicine residency training programs. As broad principles, however, they lend themselves to multiple forms or models of integrated or collaborative care. Furthermore, many behavioral health professionals providing integrated primary care services are not involved in family medicine residency programs (e.g., may be integrated into internal medicine clinics) and may provide integrated care in a different manner than described by STFM. Thus, there are numerous ways in which behavioral health and primary care have been integrated. We will discuss various approaches to collaboration in primary care settings, including newer, emerging models, in more detail in this chapter.

It is relevant to note that for the medical specialty, whether family medicine or internal medicine, context remains the mediator in which the behavioral health providers integrate primary care services. For example, clinical psychologists who integrate into primary care clinics staffed primarily by family medicine physicians can expect that these providers have some degree of exposure and experience

regularly working alongside a behavioral specialist, which their internal medicine counterparts may not have had. Strategies for building trust and successful collaborative, consultative relationships may need to be modified accordingly.

Another key difference typically seen between an internal medicine and family medicine practice involves the age range of the patient population, with family medicine clinics typically seeing patients across the age spectrum from infancy through older adulthood, and internal medicine clinics serving primarily adult to older adult populations. Thus, to be maximally helpful, a clinical psychologist providing integrated services in a family medicine clinic will need to effectively address behavioral health needs of children and adolescents, as well as adults. Helpful resources exist for providing integrated services in clinics serving children and adolescents [20, 21]. Primary care is where the majority of patients receive their health care, yet a precipitous decline in medical students entering into primary care (e.g., family medicine, internal medicine) has been documented since 1997 [22]. Likewise, some authors have indicated that there may be a workforce crisis when it comes to both primary care physicians and trained behavioral health providers working together in integrated or collaborative care models [23]. There exists substantial opportunity, therefore, for clinical psychologists interested in working within primary care settings.

## **Models of Integrating Behavioral Health Services in Primary Care**

When attempting to describe the types of behavioral health care in primary care, various models and definitions exist which often confuse more than they clarify [24]. Several authors have called for a more formal and standardized nomenclature in order to move the field of behavioral health in primary care forward [25, 26]. In an attempt to remain consistent and also clarify uses of different terms frequently seen in the literature, this section defines common collaborative and integrated care terminology; additional information can be found in Miller et al. [26].

Collaborative care constitutes a broad spectrum of approaches to communication and interactions between primary care and behavioral health providers. The term describes ongoing relationships between behavioral health and primary care clinicians over time [27]. Collaborative care is not a fixed model, but a larger construct consisting of various components which, when combined, create models of collaborative care [28, 29]. It may best be seen as an overarching, umbrella term under which more specific models of collaborative care may be found. These specific models of collaborative care include coordinated care, colocated care, care management, and integrated care. The primary care behavioral health (PCBH) model is a specific subtype of an integrated care model. Finally, the terms “patient-centered care” and “medical home” (discussed earlier) represent broad approaches to interaction and care, rather than specific models of collaboration.

In coordinated care, behavioral health providers and PCPs largely practice separately within their respective systems. Contact between the two systems occurs primarily through the referral process. Information regarding mutual patients may be exchanged as needed, and collaboration is limited outside of the initial referral [30]. Typically, the referral initiates with the PCP and ends with the behavioral health provider. This is the type of interaction many psychologists are used to having with PCPs. For example, a behavioral health clinician may have an outpatient office several miles away, but still operate in what is classified as a coordinated care model. This model is often confused with the term colocated, which is a descriptive term applied when behavioral health services are provided in the same location as the primary care clinic. In coordinated care, the level of collaboration between medical and behavioral health providers is typically lower than in other forms of collaborative care, such as care management and integrated care models (defined later).

Colocated services by definition require behavioral health providers and primary care providers to share office space. Colocated services may fall along a spectrum of collaboration, however, depending on the degree to which assessment and treatment approaches are integrated. For example, a colocated service could operate in a manner consistent with a coordinated, care management, or integrated care model.

Care management models have been researched more extensively than other models of collaborative care. Care management models of collaborative care occur when a targeted program is developed to address a specific high-impact disease or problem area (e.g., depression, congestive heart failure). Care managers, often behavioral health nurses, may provide assessment, intervention, care facilitation, and follow-up [31]. Care managers may take on multiple roles including educating patients on their specific illness, assisting patients with medical decisions, monitoring patients through treatment, including follow-up and facilitating referrals [32, 33]. One of the more researched and executed models of care management is the Improving Mood Promoting Access to Collaborative Treatment for Late Life Depression (IMPACT) model. Information on the IMPACT model can be found throughout the scientific literature [33] and on the Internet—<http://impact-uw.org/>. Although many care management models are provided as colocated services (on-site), care management services can also operate from off-site locations, relying on electronic medical records and telephone and internet contact with patients. Of note, the literature on care management models contains some interchangeable use of the terms “care management” and “collaborative care,” rather than reserving the use of “collaborative care” for a broader, overarching term encompassing multiple forms of behavioral health in primary care, as used here.

Integrated care models involve tightly interwoven behavioral health and primary services, on-site teamwork, and a unified care plan. Integrated care typically has been described as seamless care, whereby patients do not differentiate between the treatment of their “mental” health and “physical” health [30]. It is colocated, where behavioral health providers are embedded in and function as members of the primary care team, with high levels of collaboration with each team member to optimize preventive, acute, and chronic care services. All providers work together on a shared treatment plan and documentation occurs in one integrated medical record.

One approach to implementing integrated care that has been written about extensively and implemented in a number of large health care systems (e.g., Veterans' Administration, Department of Defense) is the PCBH model [34, 35]. In the PCBH model of integrated care, the behavioral health professional functions as a behavioral health consultant (BHC) as part of the primary care medical team. The BHC assists the PCPs in assessing behavioral health problems, developing behavioral health treatment plans, and implementing brief interventions focused largely on patient education, development of self-management skills, and home-based practice. BHCs typically see patients from one to four focused (15–30 min) appointments [34–36] but may see a patient many times over his or her years of care, especially for chronic health conditions (e.g., diabetes, chronic pain, obesity). Given the substantial practice modifications necessary for successful implementation of an integrated care model, implementation of the PCBH model will be discussed in more depth later in this chapter.

### ***Horizontal and Vertical Integration***

The different approaches to assessment and intervention in the models described above reflect the population health goals of integrated primary care, which aim to improve the behavioral health of the population across a broad spectrum of problems, as well as provide specific intervention pathways targeting high-frequency or high-impact problems. Strosahl [37] described these two approaches to integration as “horizontal” and “vertical” integration. Horizontal integration aims to affect as much of the population being served as possible. By integrating horizontally, a psychologist would not limit his/her interaction with patients to a specific disease or type of intervention, but would aim to assist the patient and the PCP with the full range of physical, emotional, cognitive, environment/social, and behavioral domains that are affecting symptoms, functioning, and quality of life. Vertical integration is not the opposite of horizontal integration, but rather a complimentary approach to integrating behavioral health into primary care [37]. The vertical integration approach is a targeted approach to specialized populations, similar in some ways to what might be seen in a care management model. An example may be prescreening all patients with diabetes and intervening with a cognitive-behavioral intervention on those patients who screen positive for depressive symptomatology. Others (e.g., Blount [30]) have an organized treatment approach and population target in a similar manner.

### **Collaborative Care Outcomes**

The evidence to support collaborative care has largely focused on outcomes of one specific type of collaborative care: care management models targeting depression. The research base has yet to robustly investigate or support the possible range of benefits of collaborative care more broadly defined to include models of integrated

care such as PCBH. A recent systematic review examining collaborative care comes from the Agency for Healthcare Research and Quality (AHRQ) [38]; Discussion of the AHRQ review has occurred elsewhere, but there remain key elements of the findings which are important for clinical psychologists interested in working in primary care. First, the systematic review concludes that integration of behavioral health into primary care achieves positive clinical outcomes. Second, of the 33 studies included, 26 were focused on models of depression care; therefore, authors were unable to conclude whether the effect of the outcomes were based on the level of integration or the amount of attention paid to the disease being examined [38]. Overall, the authors stated that while there needs to be more research to determine what models or model components are associated with improved outcomes, continuing to integrate behavioral health into primary care remains a worthy pursuit.

Recently, there have been national efforts to expand the empirical evidence base on the effectiveness of collaborative care. Using a practice-based research network framework (PBRN), a network was created specifically for examining collaborative care practices. The Collaborative Care Research Network (CCRN) was developed to implement a national, practice-based research agenda to evaluate the effectiveness of collaboration between psychology, substance abuse, and other behavioral health providers and primary medical care. As a subnetwork of the AAFP's National Research Network PBRN, the CCRN is a first of its kind examining the clinical, operational, and financial components of collaborative care. More information on the CCRN can be found at [www.aafp.org/nrn/ccrn](http://www.aafp.org/nrn/ccrn).

Finally, as an output of one of the CCRN's first grants, a national research agenda was set for behavioral health in primary care [25]. This research agenda contained not only specific areas for the field to begin studying but also a call for the field to have consistent language and metrics to evaluate all the disparate integration efforts occurring throughout the country.

## **Implementing Collaborative Care: Focus on an Integrated Care Model**

Detailed description and guidance for all forms of collaborative care discussed earlier is beyond the scope of this chapter. However, we believe it is important to detail the PCBH model of integrated care, due to the high degree of practice modification typically required for successful implementation compared with models involving less collaboration (e.g., coordinated care) or collaborative care restricted to one or two problem areas (as is commonly seen in care management models).

Although specialty behavioral health providers are most likely to enter into primary care and offer behavioral health services, many have had limited training and education in the area of primary care psychology or applying clinical psychology skills in a different context such as primary care [23]. While many clinical psychologists have diverse training in treating health conditions, using these skills in a different context and service delivery culture may pose a problem for some.



The culture in traditional behavioral health or specialty behavioral health settings allows for psychologists to perform full intake assessments and comprehensive treatment plans taking into consideration each aspect of the biopsychosocial model. As a clinical psychologist operating in primary care, there are several different cultural variables which should be attended to prior to initiation of services. These cultural variables, which include focused assessment, time efficiency, decisiveness with limited data, cognitive-behavioral expertise, skills for enhancing motivation to change, and many others, have been well documented [39].

Although the skills of a clinical psychologist practicing in a specialty behavioral health model function as a foundation for providing collaborative care in a PCBH model, the goals and methods of successful PCBH service delivery necessitate changes in both assessment and intervention approaches. The population health approach used in the PCBH model typically uses one to four (but can be more) focused (15–30 min) appointments in order to effectively help the primary care team and the patient address a range of health concerns (physical and mental). As such, the standard, outpatient psychological assessment and full course of traditional psychotherapy is a poor match with what is offered and what is needed or appropriate in this model of care. The following sections will detail the shift a clinical psychologist must make in evidence-based screening, assessment, and intervention to be effective in the PCBH model of care.

### ***Screening and Assessment***

Screening and assessment within a PCBH model differ in two fundamental ways from typical specialty behavioral health settings. First, population-level screening and identification of patients in need of behavioral health intervention is emphasized to a greater degree than is typically found in specialty behavioral health settings. This may occur through administering screening questions to all clinic patients, or could involve systematic identification of high-risk patients through metrics kept in electronic medical record (EMR) systems (e.g., hemoglobin A1c levels, cholesterol, body mass index, current or lapsed prescription of antidepressant medication, etc.). In a PCBH model, the BHC works closely with the medical team to determine which problem areas to target in the population (typically high-prevalence or high-morbidity/mortality problems) and how the team and BHC together can best accomplish the screening. This will vary substantially by problem area, record-keeping system, and clinic. When functioning in this capacity, the BHC is providing vertically integrated services, which has many parallels to the care management model described earlier.

Second, any screening or assessment methods used (whether population-based screening protocols or more comprehensive biopsychosocial functional assessment measures) need to be focused and efficient. They must be quick and easy for the patient (or medical team member) to complete, easy to score and interpret, and straightforward for patients and PCPs without extensive training in psychometrics to understand. It is important to note, however, that brief assessment measures

should not be used in isolation to arrive at a psychiatric diagnosis. Rather, these instruments can guide clinical questioning, which remains essential for making accurate diagnosis. The BHC may assist the medical team in understanding the appropriate use of brief measures in the tasks of screening and diagnosis.

The following illustrates the differences in screening and assessment in the PCBH model using depression as an example. If the medical team determines a goal of improving recognition and treatment of depression in the enrolled population, universal screening may be adopted. Use of the Patient Health Questionnaire-2 (PHQ-2) [40] could be administered to every new primary care patient, and/or administered yearly to each patient. Due to its brevity, ease of use (may be administered by clinic support staff or nurses), psychometric qualities, and cost, the PHQ-2 is well suited for broad primary care depression screening. For those who screen positive on the PHQ-2 (or others suspected of having a depressive disorder), diagnostic clarity can be enhanced through administration of the Patient Health Questionnaire-9 (PHQ-9) [41]. The PHQ-9 consists of nine items assessing depressive symptoms (the first two items are identical to the PHQ-2) as well as an item assessing functional impairment. It may aid diagnosis, as well as provide an estimate of symptom severity, and typically takes less than 3 min of physician time [42]. Other measures consistent with a PCBH model of care include the Duke Health Profile (DUKE), [43] the Hospital Anxiety and Depression Scale (HAD Scale), [44] and the Primary Care Evaluation of Mental Disorders (PRIME-MD) [45]. The DUKE is a 17-item self-report questionnaire assessing mental and physical health functioning (including depression). This instrument requires more time for administration and scoring; hence, it is not as useful for screening all primary care patients, but rather those who have been identified by their medical providers as possibly having behavioral health needs. Permission for use must be obtained from the author; however, use for noncommercial purposes is typically granted free of charge. The HAD scale consists of 14 self-report questionnaire items, with seven each assessing depression and anxiety. Originally validated with general hospital outpatients, it has been found to have adequate psychometric properties when used with primary care patients, psychiatric patients, and the general population [46].

Thus, the selection of specific formal screening and assessment measures differs in a PCBH model, with emphasis on instruments requiring minimal administration and interpretation time. The approach to assessment through clinical interview also differs. Rather than an in-depth, lengthy interview aimed at differential diagnosis, detailed psychosocial history, and comprehensive formulation and treatment plan, assessment by a BHC has a more narrow focus. The assessment typically takes about 15 min and revolves around the referral question; obtaining an accurate *Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV)* differential diagnosis is often not the primary goal. Rapid problem identification and brief assessment of primary symptoms is followed by functional assessment to understand the context and consequences of the problem. From there, the BHC provides a summary and conceptualization of the problem and moves into collaboratively developing a behavior change plan. Hunter, Goodie, Oordt, and Dobbmeyer [39] provide detailed guidance on conducting an initial assessment within a PCBH model.

BHCs need to be aware of resources for assessment and diagnosis that their primary care colleagues may be using, for instance the *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Primary Care (DSM-IVPC)* [47]. The *DSM-IVPC* provides a set of algorithms to aid PCPs in diagnosing the behavioral health disorders that most commonly present in primary care clinics. There is minimal emphasis on multiaxial diagnosis, step-by-step decision trees are provided in workbook fashion, and psychiatric jargon is reduced. Familiarity with the *DSM-IVPC* may provide the BHC with a common language when discussing assessment and diagnosis with PCPs.

## ***Intervention***

In addition to approaching assessment differently, the BHC also needs to adapt intervention strategies to be appropriate for the PCBH model. Treatments that work when delivered in specialty behavioral health clinics in 50-minute weekly appointments over the course of several months do not fit well in a PCBH service delivery model. Although substantial evidence exists regarding empirically supported treatments (ESTs) for behavioral health disorders using specialty behavioral health interventions, much less research has investigated outcomes of brief, focused PCBH visits in primary care. Thus, the BHC must develop a repertoire of skills to adapt treatments that work in specialty settings to ones that are appropriate for the primary care environment. Towards this end, it can be helpful for BHCs to have both a broad, conceptual framework for approaching the task of adapting ESTs for primary care work and specific guidance for particular problem areas. Fortunately, there exist helpful resources in the literature in both arenas. Robinson [48] discusses general principles involved in adapting ESTs to the primary care setting, while several recent publications describe recommended specific intervention approaches for conditions frequently encountered by BHCs in primary care [6, 34, 39, 49].

Robinson [48] describes nine primary care program goals that can guide the adaptation of specialty ESTs to a successful PCBH approach. She describes how the goals involving primary care service philosophy and population served necessitate approaches that allow much larger numbers of individuals to receive behavioral health services (e.g., 20–30% vs. 3–5% of population), along a continuum of symptom severity (e.g., prevention to tertiary care, using a stepped care approach). With the more diverse primary care population, interventions should be modified for a population characterized by greater numbers of males, lower educational and literacy levels, poorer health, and higher comorbidities than might be found in traditional specialty behavioral health intervention protocols. A patient-centered approach leads to interventions that align more closely with primary care patients' expectations for interventions that are brief (e.g., four to six, 30-minute appointments), action oriented, and include advice. Patient education and self-management approaches replace lengthy specialty psychotherapy approaches. Assessment, intervention, relapse prevention, and risk management are shared and reinforced by the entire medical team.

As mentioned previously, a small but growing number of publications have further addressed the challenge of how to adapt ESTs to more closely align with these primary care program goals [6, 34, 39, 50]. These authors provide practical guidance on how to address a variety of common problems found in primary care in a brief, consultative PCBH model. Topics range from common behavioral health problems, such as depression, anxiety, panic disorder, attention deficit hyperactivity disorder (ADHD), bereavement, and insomnia, to problems more explicitly related to physical health or health behavior change (e.g., obesity, diabetes, cardiovascular disease, asthma, chronic pain, medical non-adherence). Most of the described interventions utilize principles and approaches found in or adapted from behavior therapy, cognitive therapy, motivational interviewing, and “third-wave” behavior therapies (e.g., mindfulness-based approaches; acceptance and commitment therapy, ACT). Overall, the clinical consensus is that these approaches tend to work best in addressing behavioral health needs in a manner consistent with PCBH goals. High emphasis is given to incorporating patient education handouts, home-based practice assignments, linkages with community resources, increased use of telephone contacts, and availability of educational, skill-building classes.

## **Challenges to Integration**

There exist numerous challenges to integration, many of which have been described extensively elsewhere [38, 51–54]. Here, we will focus on several challenges to primary care integration: working within clinics with a training mission, developing a viable financial model for collaborative care, and basing services on limited outcome evidence for various models.

### ***Training Environment***

Whether a family medicine or internal medicine clinic, both settings may house a medical residency program. The benefits of integrating behavioral health services into a clinic with a residency program are numerous, perhaps most importantly, having the opportunity to shape the practice of new physicians in a manner consistent with the goals of collaborative care. Training environments contain unique challenges for the integrated behavioral health provider, however. By their nature, residency programs result in high turnover of medical providers, with residents rotating in and out of the clinic on a regular basis. Furthermore, in some programs residents may only be in the primary care clinic for part of the week. This provides a challenge for a PCBH model of care, in which the BHC needs to develop close working relationships with the PCPs. BHCs integrated into clinics with residency training programs need to devote extra time to building and maintaining relationships with the residents, as well as maintaining strong relationships with the supervising physicians, who remain as points of consistency in the staffing.

## ***Funding***

How do clinical health psychologists get paid for providing integrated primary care services? There are various avenues for reimbursement of services; Robinson and Reiter [34] provide an overview of several approaches. These include obtaining seed grants for program initiation and sustainment, funding the position without direct billing (i.e., not conceptualizing the BHC as a revenue producer but as a team member who enhances PCP efficiency and system/team functioning), or billing third-party payers for services. Billing may be done using the Current Procedural Terminology (CPT) psychotherapy codes, or the newer health and behavior codes, which may more accurately reflect the nature of integrated primary care services [55]. Medicare reimburses for health and behavior codes while Medicaid reimbursement often varies state to state; some private health insurance companies have begun to reimburse for these services as well. It is clear that no one funding method works in all settings; clinical psychologists will need to work closely with clinic administrators and billing specialists to determine viable financial models.

## ***Evidence***

Ideally, clinical psychologists working in collaborative care models could turn to the empirical literature for guidance on program development, assessment, intervention, and consultation strategies. As should be clear from the above review of the outcome literature, this is not yet possible for many areas of collaborative care. There does exist clear evidence that care management models, particularly when targeting depression, lead to improved outcomes [38]. Few studies have examined outcomes of the horizontal integration approach, such as that found in the PCBH model of integrated care. A growing body of literature offers guidance, based largely on expert opinion, for providing such services; additional empirical study is needed [25].

## **Developing Competence in Collaborative Care**

The benefits of integrated primary care services do not come without a unique set of challenges. Successful integration requires much more than modified clinical skills in assessment and intervention. Understanding the primary care culture, developing skills in practice management and consultation, navigating the world of primary care coding and billing, and gaining knowledge about common psychotropic medications represent just a few of the competencies required for effective primary care integration.

There exist a number of resources to assist interested clinical psychologists in developing competency in providing collaborative care, particularly in an integrated

care model. Graduate programs, [56, 57] predoctoral internships, [58, 59] and postdoctoral fellowships [60] have all started offering some level of training in primary care; however, these efforts still appear to fall short for meeting the demand that will be in primary care for behavioral health providers [23, 50]. Therefore, programs have emerged that offer training for clinical psychologists who may have not had any formal training in primary care. One such program offered through the University of Massachusetts Medical School is entitled Primary Care Certificate Program in Behavioral Health, and offers a six-session workshop on applying psychological skills in primary care [23]. Others have called for a new degree to be granted that specializes in behavioral health as the training of graduate programs has not evolved along with the needs of the health care system [61]. Additionally, published resources provide guidance for overcoming common difficulties in the implementation and sustainment of integrated services, and for addressing a wide spectrum of common primary care problems in an integrated care model [6, 34]. See Chap. 3 for additional information about training psychologists for the demands of the future.

## Conclusion

Interest in collaborative primary care services continues to grow, as evidenced by increasing attention in the professional literature described above. Clinical psychologists desiring to provide collaborative behavioral health services in primary care bring knowledge and skills in addressing not just traditional behavioral health problems but also the wide array of medical conditions that present in primary care clinics. Preparing to approach this emerging area of practice requires understanding of the existing models of collaborative care, ranging from integrated care models such as the PCBH model approach, to care management models, to coordinated care approaches. The existing literature contains guidance on implementation of these models, as well as a small but growing body of data on outcomes of collaborate care. Further outcomes research, broadening beyond care for depression, is warranted. Advocates for collaborative care also will need to continue to explore options for financial viability to ensure sustainability and growth of this integrated approach to health care. Training programs for gaining competence in integrated primary care services exist and continue to expand, providing opportunities for interested clinical health psychologists and students to hone their skills in providing care for the mind and body within a collaborative care medical home.

Integrating clinical psychology into primary care can be a real and obtainable solution for health care. As it stands, the current health care system is incapable of meeting the comprehensive health care needs of the American public [62]. Fragmentation within the system artificially separates the mind and the body. Integrating psychology into primary care and the medical home more accurately addresses the construct of health, since separating the two leads to inferior care [63].

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# Chapter 15

## Women's Health: Obstetrics and Gynecology

Pamela A. Geller, Alexandra R. Nelson, Sara L. Kornfield and Dina Goldstein Silverman

### Introduction/Background

Recent shifts toward the integration of mental health care in primary care settings have made clinical psychologists practicing in women's health care settings an indispensable asset to both patients and medical providers. Women of all ages have higher rates of primary and specialty care visits than men, and many women of reproductive age receive primary and preventive health care within obstetrics and gynecology (ob/gyn) settings where medical providers are often the first professionals to triage and address complex mental health problems [1]. Low-income or immigrant women, who face extensive financial and social barriers to adequate health care, may have limited access to mental health care services outside of a community primary care or women's health care clinic [2], and they may be more likely

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to forego mental health treatment unless it is available within an integrated care setting. Extensive research has documented higher rates of depression and anxiety symptoms and other psychiatric disorders, e.g. [3, 4], among lower socioeconomic status (SES) women, which further underscores the importance of engaging these women within the context of women's integrative health care.

Women's health care settings provide not only assessment and treatment of gynecological conditions or prenatal care but also offer routine screenings, provision of contraception, immunizations, and referrals to specialists. For their primary and preventive care needs, women may visit women's primary care settings, ob/gyn settings, and specialty settings such as maternal-fetal medicine or reproductive endocrinology practices, HIV/AIDS clinics, or breast and gynecological cancer clinics.

Cost effectiveness and convenience are some of the benefits of integrated care in ob/gyn and women-centered practices. Collaborative care generates faster and longer-lasting recovery from troubling symptoms and more symptom-free days than incremental outpatient care [5, 6] and integrated mental health care increases access and rates of treatment [7–9]. Most patients prefer receiving their mental health care in an integrated care setting [10, 11], which may be especially expedient for women who juggle multiple roles, including demanding jobs and “second shift” work as caregivers for dependent children, grandchildren, or aging parents [12]. Identification and treatment of psychological distress in women's medical settings may reduce obstacles of insurance parity and increase access to time-limited, empirically based treatment and psychotropic medication [13–15]. Further, women are at greater risk of intimate partner violence and victimization [16], and provision of psychological services within women's medical settings enables victimized women to gain access to valuable resources in a safe and confidential setting. A biopsychosocial approach can maximize the benefits of integrative care for women, addressing the multiple factors contributing to comorbid psychiatric and medical conditions.

## **Increasing Integration of Clinical Psychologists in Ob/Gyn Settings**

Integrating mental health and health psychology services into women's primary medical care settings is increasingly apparent in the public and private sector. Integrated care models are used extensively in Federal organizations such as the US Air Force, Army, and Veterans Administration (VA) [17]. With its recent promotion of integrated care [18] and increasing rates of female veterans utilizing services [19], the VA may provide insight into adaptable treatment approaches in women's health care settings. Emphasizing short-term evidence-based care to maximize treatment adherence and symptom reduction, community-based outpatient clinics (CBOCs) provide medical and psychological services more proximate to veterans' homes than tertiary care sites [20]. The convenience of this treatment model may be especially beneficial for women residing in rural areas and those providing care for children and elderly or ailing family members who may not prioritize their own

healthcare needs. In a primary care behavioral health (PCBH) model of service [21], psychologists are embedded within primary care and women's clinics and are available for on-the-spot consultation with patients who screen positive for mental health problems or are otherwise identified as likely to benefit from mental health services [18, 22, 23]. In such settings, psychologists can provide brief interventions utilizing behavioral approaches to enhance coping skills and improve functioning through evidence-supported strategies such as skills training, psychoeducation, and motivational enhancement [17]. Psychologists in settings such as these also can provide psychoeducation to primary care physicians, ob/gyns, and other health providers about communication, screening, and intervention techniques to address wide-ranging mental health concerns.

## **Function of the Clinical Psychologist in Women's Health Care Settings**

The function of a clinical psychologist in women's health care settings may include brief cognitive screens and more in-depth psychological assessments, consultation to interdisciplinary team members, including triage and crisis management, medication referrals, and referrals to specialty inpatient or outpatient mental health treatment settings. Other responsibilities can include short-term, empirically validated treatment of individuals, couples, and families, as well as psychoeducational groups for a wide range of concerns including symptom management, treatment adherence, lifestyle change, and caregiver support. Group facilitation for coping with infertility, perinatal loss and the psychosocial challenges of pregnancy, postpartum depression (PPD), and childcare, for example, are additional services in the provenance of clinical psychologists. Further, clinical psychologists can provide training and consultation to support student and resident education. Thus, a clinical psychologist in an ob/gyn setting can successfully navigate multiple roles as a provider, a liaison, and an educator, to enhance team-based, comprehensive care.

## **Importance of Collaborative and Contextual Assessment and Treatment**

Ideally, psychologists working within an ob/gyn setting collaborate with medical providers throughout assessment and treatment to ensure continuity of care and encourage the integration of information from an interdisciplinary perspective. Contextual assessment is an essential aspect of a comprehensive conceptualization of the presenting problem and medical diagnosis. This entails an understanding of a woman's life phase, as well as "discerning how the woman is affected by her relationships and by her interaction with cultural, spiritual, political, economic, biological, psychological, and familial factors" and history of stressful life events (e.g.,

caregiving responsibilities, work stress, trauma) [24], reflecting comprehensive conceptualization of the individual that facilitates targeted and appropriate treatment approaches.

## **Contextual Factors Relevant to Care of Women in Ob/Gyn Settings**

Women face unique psychosocial and mental health challenges, including stress from multiple roles and caregiving responsibilities, relational context, and possible exposure to violence. Given their potential impact on women's health, these factors are briefly discussed.

*Stress* Women routinely report higher stress levels than men in research investigations [25–27] and recent surveys [28]. Investigations into the effects of stress on women's health have led to contradictory findings [29–31]. To understand the full implication of stress for women's physical and mental health, sources of stress in women's lives warrant consideration.

While traditionally women have shouldered the majority of domestic work and caregiving responsibilities for children and elderly parents and relatives, employed women now constitute 46.8% of the US labor force [32], including more than half of women with young children and children under the age of 18 [33]. Managing multiple responsibilities has been associated with deleterious mental health effects as a result of women's overextension and conflicting demands [34], experiences that have been implicated in family conflict [29] and poorer mental health [30, 31]; however, for women without young children, employment has been shown to be a protective factor for positive mental health [31]. The nature and quality of multiple roles, such as the presence of a strong social support network and perception of control over one's job, have been shown to positively impact women's health, especially that of minority women [35–37].

The burden of caregiving for aging family members is another significant source of stress for women. According to data from the National Longitudinal Survey, a large number of caregivers in the USA today are female, primarily middle aged, and likely members of the "sandwich generation" who are caring for elderly parents and/or other relatives while simultaneously raising children [38]. Further, many caregivers report having a full-time job, compounding multiple demands. The deleterious physical and emotional impact of caregiver burden has been addressed extensively in literature [39–41] and ranges from depression, sleep disturbances, disordered eating and hypertension to financial problems, higher risk of developing chronic disease, and increased morbidity and mortality [40, 42, 43]. The effects of caregiver burden are particularly damaging for lower-income, minority, or immigrant women [40, 42] due to limited access to social services such as day-care centers and home care attendants.

Psychologists are uniquely equipped to facilitate an increased locus of control, a stronger sense of self-worth, and enhanced time and stress management skills in order to reduce women's stress levels and improve their mental health.

*Relational Context and Mutuality* Mutuality, a variable particularly important to women's mental and relational health, warrants recognition and attention from psychologists in integrative ob/gyn settings. Jordan [44] and Miller and Stiver [45] defined mutuality as an inner sense of connection to others and the ability to create, sustain, and grow in relationships with others, seen as the focal nucleus of human social and cognitive development. A mutual relationship is, therefore, an interdependent dynamic whereby each party listens, feels heard, and contributes from an equal and shared standpoint, resulting in psychological growth [44, 45]. Genero and colleagues [46] cite a variety of studies that attest to mutual exchanges among women facilitating emotional resiliency, coping strategies, self-disclosure, social support, and a continued mutual psychological growth [47].

Psychologists in ob/gyn and primary care settings can incorporate and address mutuality and relational quality in women's interpersonal relationships to promote improved mental and physical health. Couples' counseling and individual psychotherapy are among the modalities that clinical psychologists in women's health care settings can use to help women improve their relationships with their partners and other loved ones. Support groups facilitated by psychologists can also help to promote mutuality and reduce isolation among patients suffering from distressing gynecological conditions or obstetrical complications, such as infertility, pregnancy loss, or sexual dysfunction. Further, to increase mutuality in the relationships between female patients and their medical providers, clinical psychologists can teach providers strategies to enhance therapeutic communication, including motivational interviewing techniques, and can develop programs aimed at increasing multicultural competency among providers. Psychologists can also facilitate psychoeducational groups to help women learn necessary advocacy skills to obtain high-quality medical care.

*Exposure to Violence* Women are nearly twice as likely as men to suffer from post-traumatic stress disorder (PTSD), with lifetime prevalence rates ranging between 10 and 13% and the course more chronic in women than men [48–52]. Intimate partners are the predominant perpetrators of violence against women [53, 54]. Every year between 2 and 4 million women in the USA experience violence perpetrated by intimate partners [55, 56], and low-income women, particularly those who are unemployed and have low levels of social support, are likelier to experience symptoms of PTSD [54]. Women who screen positive for PTSD tend to report more psychiatric problems, including comorbid anxiety disorders and depression, as well as a lifetime history of exposure to domestic violence [50], which, in turn, contributes to suicide and drug and alcohol abuse [54]. For a woman who has experienced violence, a therapeutic relationship with a psychologist in an ob/gyn treatment setting can facilitate access not only to evidence-supported treatment for depression, anxiety, and PTSD but also to life-saving functional resources, such as shelters and referrals for legal and financial counseling. Education of medical providers on

recognizing symptoms of and assessing for intimate partner violence and on intervening with women and their partners and families is another important service that psychologists can provide.

## **Crosscutting Themes**

As evidenced above, a number of contextual variables influence the experiences of women in medical treatment settings. While women may present in ob/gyn settings with a wide-ranging spectrum of concerns (e.g., prenatal and postpartum care, menopause, genitourinary cancers, sexual dysfunction, and sleep and appetite disruption), depression, anxiety, and PTSD can emerge comorbid with the presenting concerns and are best addressed by clinical psychologists. Evidence-supported strategies to promote treatment adherence, compliance with treatment demands and lifestyle modifications, and effective communication with medical providers are common themes in potential functions of clinical psychologists within the ob/gyn setting. Finally, clinical psychologists can play a pivotal role in empowering female patients as they traverse the complex medical and emotional management of potentially stressful ob/gyn concerns.

## **“Review of Evidence” of Select Conditions that Present in ob/gyn Settings**

While a number of conditions may be relevant to women’s health overall, we have selected for our brief review those more commonly seen or more commonly treated by clinical psychologists in ob/gyn settings. As noted, associated with many of these reproductive health concerns are psychological/psychiatric sequelae such as depression and anxiety, relationship challenges, shame and body image, the experience of stress, and specific challenges relevant to women’s roles and phase of life (e.g., caregiver issues). We refer to psychosocial issues when major findings relevant to these factors exist in the current research literature. For each area, when evidence in the research literature exists for the benefit of psychological intervention, this information will be presented. We begin with a discussion of mental health issues surrounding pregnancy and childbirth, followed by discussion of other select reproductive health concerns seen in ob/gyn including sexual health and functioning, pelvic pain, urinary incontinence (UI), and perimenopause/menopause. Although infertility is typically treated within the medical specialty of reproductive endocrinology, issues relevant to the psychological experiences and psychological management of infertility may commonly present within the ob/gyn setting and may be comorbid with other medical concerns germane to ob/gyn (e.g., pregnancy loss). Therefore, we have chosen to include this important topic in this chapter.

## ***Mental Health Issues Surrounding Pregnancy and Childbirth***

Around the time of childbearing, in addition to excitement and joy, some women may experience a range of concerns, fears, and psychiatric symptoms. Such symptoms can occur during pregnancy as well as during the postnatal period regardless of the outcome of the pregnancy. When pregnancy ends in miscarriage or stillbirth, symptoms of grief, in addition to psychiatric symptoms, also may result. This section highlights common responses to these reproductive events and discusses the opportunity clinical psychologists working within ob/gyn settings may have in the prevention, assessment, and treatment of adverse reactions, as well as in assisting women in their preparation for childbirth and adjustment to various life changes during and following pregnancy.

**Antenatal Depression** With the potential for significant hormonal, psychosocial, and quality-of-life alterations, the time of pregnancy and childbearing is associated with the emergence or worsening of depressive and anxiety symptoms for many women [57–61]. During pregnancy, corresponding to rates in similarly aged non-childbearing women, 8.5–11% of women meet the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) criteria for major or minor depression [62–64]; however, the possible adverse consequences to maternal health, fetal development, and birth outcomes make antenatal depression distinct. Moreover, nearly half of women who experience antenatal depressive symptoms will develop depressive symptoms in the postnatal period [60]. While the prevalence of severe major depression appears lower during pregnancy than after [65], pregnant women with personal and family histories of mood disorders may be at increased risk [66–68]. For women who discontinue antidepressant medication due to pregnancy, risk may be further escalated [69].

**Postnatal Depression and Psychosis** The three most commonly described postnatal responses include postpartum dysphoria, PPD, and psychosis, with onset most evident within 30 days following childbirth [70–72]. Postpartum dysphoria, or “baby blues,” which is mild and transient, often manifests as tearfulness and depressed mood that peak at about the 5th day post partum. Largely attributed to normative hormonal fluctuations, it is estimated that 26–85% of all mothers experience postpartum blues regardless of sociocultural context or environmental factors [73, 74]; the wide range can be attributed to varied assessment techniques employed across studies [70, 75, 76].

PPD resembles other forms of major depressive disorder in its persistence, severity, and symptom constellation, although there may be a greater frequency of anxiety, somatic complaints, and sleep disturbances [77]. Occurring in 10–16% of women in the first 6 months after they have given birth, onset usually is within 2 weeks of childbirth [70, 72]. Rates of PPD appear relatively consistent across countries as indicated by community-based surveys—many of which used the Edinburgh Postnatal Depression Scale (EPDS) [78]; estimates vary when other assessment tools are employed and depending on how the time frame of the postnatal



period is defined [79]. Economically disadvantaged women experience higher incidence of PPD [63].

In addition to significant physiological changes following delivery, major adjustment is required because of changing social and personal circumstances, particularly following the birth of the first child. Life events (e.g., marital discord), limited social support of an appropriate nature, and personality factors also may play a role [72, 80]. Unrealistic expectations, such as the belief that maternal–infant bonding will occur easily and is immediately positive and fulfilling, also may contribute to PPD [74, 79]. While psychosocial stressors and hormonal shifts have been implicated in the development of PPD, personal psychiatric history is a significant and well-documented risk factor: A prior episode of PPD or depression during a previous pregnancy increases a women's risk by approximately 50–62%, and 20–30% of women with a history of major depression prior to conception develop PPD [68, 72].

The rarest, but undoubtedly most severe, of the three postpartum conditions is postpartum psychosis, which occurs in 1–2 of every 1,000 deliveries and across all societies [74, 77, 81]. Symptoms resemble those of schizophrenia, with the content of hallucinations and delusions often thematically associated with pregnancy, childbirth, or the infant. Suicidal and infanticidal ideation can be present, but homicidal-ity is rare. Symptoms such as confusion and attentional deficits similar to an organic brain syndrome also may be present [82]. Primary risk factors include a personal or family history of psychiatric illness, such as bipolar disorder. As research has not confirmed an association between this condition and purely biological or social factors, a diathesis–stress interaction appears the best explanation for postpartum psychosis at this time. Women who experience postpartum psychosis are at elevated risk of later episodes, and over half of women with postpartum psychosis also meet criteria for PPD [81].

**Perinatal Anxiety** Although less researched than depressive disorders, there is a growing evidence of an increased risk of general anxiety symptoms (particularly for first-time mothers), as well as the emergence or relapse of specific anxiety disorders such as panic disorder and obsessive-compulsive disorder (OCD) throughout the perinatal period [59, 70, 83–85]. In addition, given the pain, lack of predictability, and risk (albeit small) of significant morbidity and even death for the mother and her child, many pregnant women experience anticipatory anxiety about childbirth. Those who experienced a previous delivery that was particularly painful, traumatic, and/or involved medical complications (e.g., preterm delivery, emergency cesarean section, stillbirth, neonatal death) may express their fears of childbirth in the form of PTSD or OCD symptoms [83, 86].

Maternal anxiety has been associated with various pregnancy complications and outcomes, such as low birth weight, premature delivery, asphyxia, preeclampsia, emergency cesarean section during labor, PPD, and problems with infant–maternal attachment [87]. Another issue of growing concern is that some women respond to their birth-related anxiety by requesting a cesarean delivery without a valid medical reason in order to avoid the experience and fears associated with vaginal delivery. Because of the substantial risks associated with cesarean deliveries as well as the

costs (e.g., financial, recovery time) and the ethical issues raised, elective cesarean deliveries remain controversial [88].

With OCD, intrusive thoughts often center on the mother causing harm to her fetus or infant. Unlike postpartum psychosis, women recognize the thoughts as unreasonable and unwanted and avoid acting on them, albeit while experiencing fear or anxiety and sometimes avoiding or refusing to care for the newborn [59]. Notably, independent of OCD or postpartum psychosis, over 40% of women with PPD and between 34 and 65% of new parents in healthy community samples report experiencing obsessive thoughts about harming their offspring [83, 89, 90].

**Consequences for Offspring** Perinatal psychiatric disorders and limited maternal attachment in the postpartum period have consequences not only for the woman but also for the developing child in terms of cognitive deficits and emotional and behavioral disturbances [91–93], as well as eating or sleeping difficulties [94, 95]. Women experiencing postnatal mood and/or anxiety symptoms, as compared to women without mental health complications, are less likely to initiate and more likely to stop breastfeeding early in infancy [96, 97], more likely to delay or avoid vaccination of their children [98], and more likely to skip outpatient pediatrician visits and require acute outpatient or emergency room care [99].

**Intervention** Clinical psychologists working within ob/gyn settings have the advantage of evaluating pregnant women for risk factors as well as current depressive and anxiety symptoms during one or more of their prenatal visits, as well as during the 6-week postpartum visit. During pregnancy, assistance with physical health-related issues such as management of gestational diabetes and smoking cessation can be provided. Clinical psychologists can work with women to promote adherence to prescribed modified lifestyle regimes while also managing the emotional and physical challenges associated with pregnancy and pending parenthood. They can also meet with women and their partners to address their specific concerns and manage their fears related to labor and delivery. Preparation for childbirth might include such empowering approaches as developing realistic plans for labor and delivery and teaching couples to incorporate relaxation and guided imagery techniques. There is empirical support that psychological intervention, including cognitive-behavioral treatment and patient education, can result in alleviation of anxiety, withdrawal of requests for cesarean deliveries, and shorter durations of labor [86, 100].

Educating women and families that some anxiety in the perinatal period may be normative, while moderate or severe symptoms of depression or anxiety that interfere with functioning are serious concerns, is important. For women with notable risk factors, such as a personal history of a psychiatric disorder and/or cessation of psychotropic pharmacotherapy due to pregnancy, assessments can be completed more frequently and prophylactic treatment options can be considered [101]. For women experiencing current symptoms of anxiety and depression, early identification is critical and treatment options effective during nonreproductive times can help reduce potential pregnancy-related complications [61, 70, 77, 102–105]. In addition to cognitive-behavioral approaches, interpersonal psychotherapy (IPT)

targeting relational issues is particularly effective with this population [106]. Facilitation of support groups to assist women with adjustment to motherhood and specific parenting challenges (e.g., caring for premature or special needs infants or higher-order multiples) can help relieve stress.

In terms of postpartum psychosis, onset typically occurs within the first 72 h to 2 weeks following delivery; however, since risk remains high for several months, women with a psychiatric history should be monitored closely [81]. While the prognosis for postpartum psychosis is much more positive than for other psychotic disorders, the experience frequently requires inpatient psychiatric treatment, which can be devastating for women and their families. Comprehensive treatment models for women experiencing significant perinatal psychological issues, which provide efficacious treatment and facilitate their connection with their newborns and social networks, such as the newly opened Perinatal Psychiatry Inpatient Unit at University of North Carolina's Center for Women's Mood Disorders, hold tremendous promise to reduce the burden of adverse mental health responses during this important life phase.

**Perinatal Loss** Regardless of whether a pregnancy is desired or planned, the experience of a reproductive loss is stressful and can have significant mental health consequences. Miscarriage, which involves the spontaneous death of a fetus prior to 20 completed weeks of gestation, occurs in approximately 15% of clinically recognized pregnancies, with risk varying significantly by age (e.g., 9% for women aged 20–24 years, but 75% for women over age 45 years). [107] Stillbirth, defined as late fetal death after 20 weeks of gestation, occurs in approximately 1% of singleton pregnancies, with higher risk in multiple pregnancies. Overall, black women have a 2.2-fold increased risk of stillbirth relative to white women, with factors contributing to risk varying by race and gestational age [108].

Reproductive loss constitutes an unanticipated, traumatic experience that can result in considerable physical pain and discomfort for many women, and is life threatening in some cases [109, 110]. Physiologically, the pregnancy and life of the unborn child(ren) have ended, and psychologically, sadness, grief, guilt, anger, and self-reproach as well as fears about one's ability to carry a subsequent pregnancy to term can ensue [111, 112]. Concern about physical symptoms (e.g., continued bleeding or discharge), and possible underlying genetic factors or undetected medical illness that may have contributed to the loss, can evoke anxiety.

Investigations that have used comparison groups to examine psychological distress in the aftermath of a miscarriage versus a live birth have documented that miscarriage is a risk factor for depressive reactions ranging from depressive symptoms [113–115] to minor and major depressive disorders [116, 117]. A history of major depression is a risk factor for a recurrent episode. Studies specifically examining anxiety symptoms following a miscarriage found mixed results, although those using comparison groups suggest that anxiety levels may be elevated to an even greater degree than depressive symptoms immediately after loss, and that the elevation may be sustained for at least 4 months [115, 118, 119]. Miscarriage appears to increase risk of a recurrent episode of OCD, but not for panic disorder or specific

phobia [120]. Risk of PTSD also appears elevated following loss [121]. As many as half of women experiencing perinatal loss become pregnant again within a year, with such subsequent pregnancies involving heightened maternal anxiety relative to first pregnancies [113, 115, 122, 123].

Societal recognition of perinatal loss as valid to be mourned and an event that may result in significant psychological symptoms lags behind current research. Further contribution to social isolation and distress can occur when such losses are minimized or not acknowledged by important others, including family members and friends, who may be uncomfortable talking about death. Particularly with early loss, even medical providers may not fully legitimize the loss experience and may not be prepared to provide the needed support, information, or referrals; they may be pressured for time and not evaluate or appreciate a woman's individual psychological responses [124].

**Intervention** Clinical psychologists can assist women after loss by facilitating communication with health care providers, which has been shown to lead to less dissatisfaction after loss [124]. For example, validation of the loss as "real" and having their grief acknowledged as legitimate, discussion with a medical provider regarding expected physiological changes, the cause of perinatal loss (if known), and implications for future reproductive plans, as well as specific evaluation of psychological symptoms and functioning and the provision of appropriate intervention, may help offset more enduring psychological consequences of the loss and help reduce anxiety in subsequent pregnancies.

Because the grieving process may be compounded by limited social support and the challenge of managing feelings associated with the loss of a child unknown to others, attention to psychosocial factors such as women's relationships is important. Women may need to address feelings of anger toward others who are pregnant and discuss options regarding what and how to communicate about the loss experience with extended family members, friends, and coworkers. Assistance with maintaining intimate connection with their partners and children, as well as attachment to future children, also may be needed [125, 126]. In terms of promoting healing, women may be responsive to ideas around meaning-making and ritual to grieve and remember. Moreover, helping women anticipate and plan for psychological responses in the year(s) following the loss, particularly on the actual due date, or the annual anniversary of the loss, can be beneficial.

Interventions utilized to address distress, loss, and grief in other populations also can be efficacious for women experiencing perinatal loss. This may take the form of individual or couples therapy of a cognitive-behavioral nature, mindfulness-based approaches, and IPT, for example. Support groups also can be implemented although a woman's individual circumstances should always be considered when advising and treating women following loss. Internet resources may help provide needed information for women as well as providers and may be a source of potential support [127, 128]. Geller, Psaros, and Kerns [129] identified eight quality websites and summarized their attributes on a stand-alone table that can be distributed to women. There is a need for studies investigating ethnic-racial and cultural

differences in coping following perinatal loss, as well as the role of factors such as religion and spirituality [130].

### ***Other Health Concerns Relevant to Ob/Gyn Settings***

**Sexual Health and Functioning** Women with concerns related to sexual health and functioning are likely to present to their ob/gyn for evaluation and treatment. Comprehensive and holistic approaches to treatment may include emotional, mental, and physical components that are best addressed by clinical psychologists. Female sexual functioning is comprised of a complex and dynamic interplay of physical, emotional, and psychosocial variables. When any of these levels are significantly disrupted by illness or injury, sexual dysfunction can result [131]. While medical disease or injury may be the cause or precipitating factor for some sexual dysfunction, medical treatment may be insufficient to treat the problem [132]. Basson and colleagues [132] call for psychological and interpersonal problems, which may involve past sexual abuse or genital trauma, to be addressed prior to treating any associated sexual dysfunction.

While epidemiological data on female sexual dysfunction are limited, it has been estimated that up to 43 % of women complain of at least one sexual problem and up to 33 % of survey and clinical samples fall within a specific problem category [133]. Therefore, clinical psychologists in an ob/gyn setting may encounter a fair number of patients in need of support or treatment for these disorders. Female sexual dysfunction can lead to a major loss in quality of life and have a significant impact on interpersonal relationships. For many women, sexual dysfunction is physically disconcerting, emotionally distressing, and socially disruptive [132].

Optimally, women experience sexual desire, arousal, and pleasure from sexual activity. However, disruptions may occur along this trajectory, which typically are broken down into four major categories of sexual dysfunction: desire, arousal, orgasm, and sexual pain. Each of these categories will be addressed in the following section and treatments will be detailed below.

Disorders of desire have been classified into two diagnostic types in the DSM: (1) hypoactive sexual desire (HSD) disorder, which describes absence of sexual fantasies/thoughts and desire or receptivity to sexual activity and (2) sexual aversion disorder, which refers to phobic aversion to and avoidance of sexual contact. Both of these disorders are persistent and must cause personal distress in order to be diagnosed [134]. Studies largely show that perimenopausal women have higher rates of low desire for sexual activity, which has been reported by almost a third of premenopausal women [135]. Basson [136], however, points out that women's motivations for sexual activity are complex. Although many women may report having low or absent spontaneous desire, this is not always indicative of a disorder [137]. Qualitative research shows that many women do not differentiate between desire and arousal [138], making disorders of desire even more complicated to diagnose.

The definition of sexual aversion disorder was recently expanded to incorporate current thinking about the overlap of subjective and physiological aspects of female

sexual arousal. It is defined as “the persistent or recurrent inability to attain or maintain sufficient sexual excitement, which causes personal distress.” [139]. Sufficient sexual excitement is differentiated into two categories: a personal or emotional feeling of arousal versus adequate genital or other physical response. Until recently, the lack of subjective excitement was not considered when diagnosing a disorder of sexual arousal, so prevalence rates were only based on those reporting little or no lubrication or genital swelling. An important finding for the understanding of women's sexual health and functioning is that the defining correlation between subjective arousal and genital congestion (erection) so strongly found in men is actually not found in women [140–143]. Instead, women's sexual arousal is more strongly associated with thoughts and emotions triggered by the state of sexual excitement [144]. In studies using photoplethysmography to measure volumetric changes in vaginal engorgement, women diagnosed with disorders of arousal were able to experience adequate genital response to sexual stimulation despite not experiencing subjective arousal [144, 145]. Whereas previously this may have been labeled as a sexual disorder, these findings may help medical or mental health professionals to be aware of other situational, psychological, or interpersonal factors that may interfere with a woman's sexual arousal. Some situational reasons for low desire may include concerns about safety, privacy, risks of unwanted pregnancy, or sexually transmitted diseases (STDs), or simply that the encounter is awkward or rushed [136]. Interpersonally, a poor or conflictual relationship with a sexual partner can contribute to low arousal; Bancroft, Loftus, and Long [135] found that the stronger the emotional intimacy with the partner, the less distress about sexual functioning occurred. Lastly, a woman's arousal is directly tied to her psychological functioning. Hartmann and colleagues [146] found that low self-image, mood instability, and anxiety and worry (without meeting clinical definitions for a mood disorder) were highly correlated with complaints about sexual desire and arousal. Other psychological issues which may complicate sexual arousal include memories of past negative sexual experiences such as sexual assault or abuse, expectations of negative outcomes (e.g., pain, partner's sexual dysfunction), or worry about sexual performance (achieving sufficient lubrication or orgasm) [138].

Disorders of orgasm are also difficult to study and may be complicated by varying definitions. The widely accepted definition of female orgasmic disorder reflects DSM-5 criteria and involves marked delay, infrequency, or absence of orgasm or markedly reduced intensity of orgasmic sensation that causes distress or interpersonal difficulty. [147]. While the DSM differentiates between women who have generalized versus situational anorgasmia, the clinical consensus is that women who can achieve orgasm during masturbation or with partnered manual stimulation but not during intercourse alone would not meet criteria for diagnosis of the disorder [148]. Studies of women with female orgasmic disorder note that a high percentage are diagnosed with a comorbid disorder of sexual arousal, indicating that the criteria that anorgasmia must follow a phase of normal sexual excitement is often ignored [148], which may artificially inflate the reported rates of women with disorders of orgasm. Lastly, it is important to consider that women can have a satisfying and pleasurable sexual experience without orgasm and that for many women

orgasm is not the goal of sexual activity [136]. Clinical psychologists can empower women to recognize that the female sexual response cycle is different from that of men and that satisfying sexual experiences without orgasm do not necessarily connote a failure or disorder.

*Disorders of Sexual Pain Include Dyspareunia and Vaginismus* Dyspareunia is pain in the genital region that severely disrupts sexual function. It is one of the most common types of sexual dysfunction encountered in both gynecological and general medical practice [149], with roughly 61 % of all women who are or have been sexually active suffering at some point from dyspareunia [150]. While physical factors contribute to dyspareunia, psychological factors also play a large part in the etiology of the disorder [151]. Bancroft [152] suggested that insufficient vasocongestion resulting in too little lubrication may play an important role in the pathophysiology of dyspareunia. However, it is important to note that a DSM diagnosis is made when the patient complains of recurrent or persistent genital pain before, during, or after sexual intercourse that is not caused exclusively by lack of lubrication or by vaginismus [139].

Vaginismus is a condition in which a woman's pubococcygeus muscles reflexively contract making any kind of vaginal penetration, including sexual intercourse, either painful or impossible [153]. This reflex is not consciously controlled by the woman and often results in distress over the inability to engage in partnered sexual penetration or extremely painful intercourse [154]. Primary vaginismus occurs when a woman has never been able to have penetrative sex or experience any kind of vaginal penetration (e.g., insertion of tampon, undergo a Pap smear) without pain. Reasons that primary vaginismus may occur include: a history of sexual abuse, rape, or attempted sexual abuse; domestic violence or conflict in the early home environment; having been taught that sex is immoral, vulgar, or demoralizing; fear of pain associated with penetration; and being sexualized at an early age [155]. It is noteworthy that these causes are generally psychosocial in nature, pointing to the intersection of psychology and medicine to manage this disorder. Secondary vaginismus occurs when a woman who has previously been able to achieve penetration develops the spontaneous tensing of the pubococcygeus muscle. This may be due to physical causes such as a yeast infection or trauma during childbirth, or it may be due to psychological causes. Women suffering from vaginismus may be unable to tolerate penetration or have intercourse but may be quite capable of becoming sexually aroused, lubricating, and even experiencing multiple orgasms with manual or oral stimulation [153].

**Interventions** Clinical psychologists can play an integral role in the treatment of female sexual dysfunction. Striepe and Coons [24] emphasize the importance of attending to contextual factors that contribute to the genesis and maintenance of problems in female sexual functioning, including medical, cultural, and social-relational factors that if ignored might contribute to self-blame and internalization of difficulties with sexual functioning. Of note, such contextual factors can lead to changes in sexual functioning that are adaptive responses but that can be highly distressing [156]. Given the relevance of these factors in gender-specific

conceptualization and treatment of sexual dysfunction, clinical psychologists may be well positioned to perform comprehensive and broad-based assessments to augment medical care. Supporting this, Basson, Althof, and colleagues [132] noted that medical management alone may be insufficient to address sexual dysfunction, even when sexual dysfunction is precipitated by a medical problem. Numerous psychological and behavioral approaches, specific to each facet of sexual dysfunction, have been recommended. Some note that psychological and interpersonal problems, as well as past sexual abuse or genital trauma, should be addressed prior to treating related symptoms of sexual dysfunction [132], although these factors may warrant ongoing sensitivity and attention. Treatments for disorders of sexual functioning are highly varied; some are specific to certain disorders, while others are aimed at more generalized sexual dysfunction and distress, which can complicate translation of research into practice. Given the important psychosocial aspects of women's sexual dysfunction, there remains a need for further development and evaluation of interventions to address these wide-ranging concerns.

Interdisciplinary and multimodal care related to women's sexual functioning has been recommended to promote empowerment and sexual knowledge [24]. Strieppe and Coons [24] underscore the importance of exploring the full contextual setting of a woman's sexual concerns to alleviate and avoid self-blame. This might include consideration of life-span sexual relationship history, biomedical aspects of sexual dysfunction, issues of gender identity and sexual orientation, and an understanding of female sexual functioning. Additional recommendations for collaborative, multidisciplinary assessment and management of female sexual dysfunctions include comprehensive medical and psychosocial history, including history of abuse, depression, substance abuse, and other relevant factors, as well as careful evaluation of the specific sexual complaint (e.g., pain, low arousal). Symptoms, past and present context, onset, sexual response, role of partner, and presence of distress should also be evaluated [132]. Finally, patient-centered approaches to both evaluation and treatment are recommended [156]. Attention to these critical aspects of evaluation and conceptualization can facilitate development of targeted informed, empathic, and empowering treatment of women's individual concerns.

With these factors in mind, psychologists may perform specific interventions or styles of intervention, utilizing various evidence-based and evidence-supported treatment approaches to treat broad or targeted problems with sexual functioning. Some psychologists may provide "sex therapy," a specialized form of intervention that may be conducted in individual, couples, or group formats and can draw upon a variety of intervention techniques [157]. Sex therapists are encouraged to be pro-sexual, pro-relationship, and encouraging of a functional and comfortable sexual style [158]. While seminal works in this field emerged in the 1960s and 1970s [159–161], recent advances have included integrated medical and psychological therapy, mindfulness-based interventions to enhance arousal and desire, and Internet-based delivery of sexual therapies [157]. Contemporary sex therapy also reconceptualizes female genital pain disorders to focus on pain management rather than functional impairments [158]. Using a broad range of techniques, sex therapy approaches may be used to address a range of sexual concerns or complaints.



Some interventions have been developed and tested for efficacy to address specific sexual disorders and dysfunctions. Numerous behavioral approaches, as well as psychoeducation and cognitive and emotionally focused components, can help to attenuate symptoms of sexual dysfunction and improve emotional coping. Some of these interventions are described below. However, of note, studies describing these interventions describe average outcomes of treatment components and outcomes, often among groups, that do not capture the complexities of individualized, contextually informed approaches. It is also important to consider outcome measurement, which may not capture the scope of women's goals in addressing their sexual distress. For example, the common measure of vaginal penetration in successful treatment of vaginismus does not address a broader goal of women's sexual pleasure [132]. Despite these limitations, however, these studies may inform the treatment of women's sexual dysfunction within the ob/gyn setting.

Multimodal psychological and behavioral treatments have been developed to aid in the management of vaginismus and pain-related disorders, with promising outcomes for desired sexual functioning (e.g., engagement in penetrative sex) and pain reduction. For example, a sex therapy approach for women with primary vaginismus, comprised of several behavioral components both for women and their partners such as exercises for vaginal dilation, systematic desensitization, relaxation of the pubococcygeal muscle, and application of analgesics and muscle relaxants, appeared to facilitate initial and regular intercourse and orgasm among the majority of those treated, and enabled more than 60% of women to achieve pregnancy [162]. Another cognitive-behavioral therapy (CBT) intervention incorporating sexual education, relaxation, gradual exposure, cognitive therapy, and sensate focus with written and audio media for use in daily practice facilitated vaginal penetration when delivered in both group and minimal-contact bibliotherapeutic formats, although effect sizes were small [163]. Psychological interventions may provide useful alternatives to surgical procedures in the treatment of certain disorders. One example used a group-based, multimodal CBT intervention, resulting in reduced pain and improved psychological functioning among women with dyspareunia due to vulvar vestibulitis. These outcomes were comparable to surface electromyographic (sEMG) biofeedback or vestibulectomy (removal of innervated vaginal tissue) [164].

Low sexual desire and sexual distress may also be treated with multimodal interventions. Tools to aid in assessment of low desire include the Female Sexual Function Index (FSFI) [165] and the four-item Hypoactive Sexual Desire Disorder Screener (HSDD) [166]. While medical interventions for low desire may include a testosterone patch for (perimenopausal) women with low desire [167], CBT provided by clinical psychologists may be effective. For instance, one psychoeducational intervention, co-led by a gynecologist and mental health provider, employed mindfulness, self-observation, cognitive restructuring, and couples' communication to target sexual arousal and desire, relationship dissatisfaction, body image, depression, and maladaptive beliefs about sexuality, improving both sexual desire and distress [168]. Additionally, a group-based, couples CBT sex therapy program targeted women's HSD, incorporating education, couples' sexual intimacy exercises, sensate

focus, communication and mutual reinforcement training, cognitive restructuring, and sexual fantasy training, helping to improve both marital and sexual quality of life [169].

Clinical health psychologists may also treat sexual dysfunction through increasingly utilized mindfulness-based approaches [157, 170]. One study conducted within a clinical population of women with a history of childhood sexual abuse (CSA) presenting with sexual concerns and distress found that a brief, mindfulness-based intervention (MBT) produced similar decreases in sexual distress compared to a traditional, brief CBT intervention, but found a greater concordance of subjective and physiological genital sexual arousal among the MBT group, suggesting greater engagement with present-moment sexual arousal [171].

Clinical psychologists might also provide very brief or virtual interventions to address sexual dysfunction. For instance, Smith, Beadle, and Schuster [172] implemented a group medical visit addressing women's sexuality, female sexual response, and issues related to female sexual dysfunction in a single, 2-h, group session including didactics, CBT exercises, and a review of sexual accessories and self-help resources. Significant improvements were seen in multiple facets of sexual functioning from baseline to follow-up assessment, and many women elected to follow-up with additional medical or psychological intervention, suggesting that this single session could impact ongoing engagement in these health care behaviors [172].

Internet-based intervention may be of value as an adjunct to treatment provided by clinical psychologists or to address the needs of women who may not seek face-to-face support. One such program for women with sexual dysfunction and their partners, which included structured modules and e-mail contact with a therapist, was associated with improvements in multiple facets of sexual function, including declines in the frequency of sexual problems and improvements in relational communication and sexual and emotional intimacy [173].

The prevalence of complaints of sexual dysfunction among women and the significant psychosocial contexts relevant to female sexual dysfunction highlight the need for more treatment research. Such research should address the substantial variability in the type of sexual dysfunction, contextual factors, and related complaints, as well as variability in comorbid medical conditions that may underlie or relate to sexual dysfunction, and which may complicate translation of research to practice.

## **Pain**

Clinical psychologists can play an important role in the treatment of women with chronic pelvic pain (CPP), with the American College of Obstetrics and Gynecology (ACOG) stating that psychological evaluation and intervention should be included in routine care for this population [174]. A high prevalence of negative psychological and socio-environmental correlates of CPP underscores the importance of biopsychosocial conceptualization within this population [175]. Psychosocial

assessment should identify target problems, inform treatment planning, and establish baselines for measuring treatment outcome [176]. Client-centered consulting approaches are recommended to maximize therapeutic benefits of medical and psychosocial assessment and intervention [177].

CPP refers to noncyclical, localized pain that is constant or recurrent in the lower abdomen for at least 6 months. Pelvic pain is relatively poorly understood, and although symptoms may be similar among women, variability exists in definitions and descriptions of pelvic pain, depending on duration, location, and type of pain [178, 179]. CPP is distinguished from other pelvic pain conditions such as dysmenorrhea (occurring during the menstrual phase) or dyspareunia (occurring during intercourse) [180] which have differing suspected etiologies [174]. Nearly 15% of women in the USA experience CPP, and more than half do not know its cause [180, 181]. Physical evaluations are often inconclusive, although possible etiologies and risk factors include pelvic adhesions, endometriosis, irritable bowel syndrome, dilated pelvic veins causing reduced blood flow, and altered spinal cord and brain sensory processing that enhances pain perception, as well as pelvic inflammatory disease and history of miscarriage [179, 182]. CPP is also associated with younger age and less education, as well as psychosocial factors like history of sexual or physical abuse, anxiety, depression, hysteria, and somatization [178, 183]. Importantly, absence of evidence of organic pathology may lead to conclusions that pain is psychogenic and consequent feelings of stigmatization, disempowerment, and invalidation, which may lead women to disengage from health care [184]. Additionally, women with medically unexplained CPP may experience challenges when working with their medical providers, such as perceived skepticism, poor comprehension, rejection and dismissal, and blame, and may feel pressure to convince providers of their somatic pain [185]. These health care-related challenges underscore the important role of clinical psychologists to assess and treat women with CPP in an empathic, non-judgmental, and empowering manner.

CPP can be very severe and debilitating, correlating with greater number of missed work days and disrupting performance of work- or home-related tasks, reducing activity, and requiring patients to lie down or stay in bed, use a wheelchair, and seek emergency care [181, 183, 186]. Common themes reported by this population include negative mood, decrease in activities, fear, feeling misunderstood, frustration with the medical system, helplessness, negative impact on self-image, impact on sexual functioning, and jealousy of healthy people [187].

The most common psychological complaints among women with CPP are affective disturbances [188], with a large majority of women (82%) reporting that CPP interferes with their mood at least moderately [181]. Current or recent depression and greater levels of depressive and anxious symptomatology are more likely in women with CPP compared to healthy comparison groups [183, 187, 189–191]. Sexual or physical abuse history increases risk of depression, anxiety, substance abuse, and somatization [189, 192]. Given these risks, clinical psychologists should assess for abuse history, including rape or molestation and associated psychological consequences, as well as problems with mood and psychosocial functioning [176, 186]. Further, trauma-related events could lead to psychogenic CPP and should be

assessed in relation to the onset of pain, aided by diaries to track patterns and triggers [186]. Additionally, instruments such as the West Haven-Yale Multidimensional Pain Inventory can be used to assess for pain severity, mood, control, interference, response from spouse, and functional and health status [188].

Women with CPP experience more sexual problems than healthy controls, including pain, avoidance, nonsensuality, and vaginismus, and are more often diagnosed with adult sexual dysfunction [181, 189, 191]. This relationship is mediated by anxiety and depression [191]. History of sexual abuse, reported in over 60% of CPP patients [183, 189], increases the risk of sexual problems including satisfaction, closeness, and pain, and therefore warrants evaluation [176, 191, 193]. For the clinical psychologist, such assessment might include inquiry regarding the presence, frequency, and impact of such experiences, with attention to intra- and interpersonal or relational contexts and consequences.

**Intervention** Unclear pathophysiology among many women with CPP has been implicated in inadequate treatments that are restricted to relief of symptoms [179]. Pelvic pain with known etiology may be treated surgically through interventions including hysterectomy, oophorectomy with hysterectomy and hormone replacement therapy, and adhesiolysis. It might also be treated pharmacologically, including narcotic analgesics as well as antidepressants to reduce pain symptoms or through multidisciplinary treatments including psychosocial components such as those described below [182]. Alternative medicines, such as herbal and nutritional therapies, magnetic field therapy and acupuncture might also be used [174]. ACOG guidelines have concluded that psychotherapy adjunctive to medical treatments improves outcome and should be considered [174]. Importantly, these interventions are marked by limitations, including time intensiveness and limited acceptability of psychological counseling and invasiveness, reproductive implications, and side effects of surgical and hormonal interventions [179].

Treatment goals for CPP patients include treating pain and psychosocial correlates, reducing suffering, minimizing disability and controlling symptoms to improve functioning and quality of life, and preventing recurrence [188]. Interdisciplinary pain management teams including clinical psychologists are often recommended [177, 186]. While treatment for CPP may include a wide range of therapeutic interventions, we focus this section on the types of treatment most relevant to the clinical psychologist providing services within the ob/gyn setting, such as those incorporating behavioral and psychosocial approaches to intervention.

Few studies have investigated psychosocial treatments specifically in women with CPP. Recommendations for comprehensive pain management programs for CPP often follow general chronic pain management models. Heterogeneous clinical presentations and etiologies of CPP warrant heterogeneous, multidisciplinary treatments [194]. Techniques should include psychoeducation, skills training (e.g., relaxation techniques, distraction techniques, cognitive restructuring), behavioral rehearsal of learned skills, goal setting, behavioral activity programs, and stress management techniques [176, 186, 188, 195, 196]. Additionally, operant behavioral therapies may be useful to increase reinforcers for "well behavior" and reduce

reinforcers for pain and pain-related behaviors [195]. Coping techniques, exercise, biofeedback, and counseling for depression or other problems are also utilized [196].

Some studies have evaluated such programs with promising results. For instance, an early, small-sample pilot study of a comprehensive pain management approach using acupuncture with weekly psychotherapy sessions and daily pain diaries resulted in at least a 50% reduction in pain among most patients, with nearly all reporting substantial decreases in affective distress [195]. Another trial tested a multidisciplinary treatment approach directed by a psychologist, nutritionist, physiotherapist, and gynecologist, deviating from standard medically oriented approaches by addressing pain with equal attention to possible organic, psychological, dietary, and environmental causes, with most patients receiving psychosocial treatments, resulting in significantly greater improvements in pain, functioning, and associated symptoms [194]. Therapeutic benefits can also result from less comprehensive approaches, such as those demonstrated in a 3-day written emotional expression intervention [187]. There may also be therapeutic benefits of history taking, examination, and explanation of pain-related issues, and evidence has shown that women may report reduced pain and anxiety following a simple diagnostic laparoscopy [177].

Individual psychotherapy may be recommended for patients suffering from a clinical psychiatric problem, such as depression, anxiety, eating disorder, or PTSD. Although it should be noted that psychosocial correlates such as emotional distress and sexual abuse may not be causal [185], these experiences nevertheless warrant clinical attention, evaluation, and potentially treatment. Trauma-focused treatment may be appropriate if indicated and cases of domestic violence should be referred for direct intervention with a clinical psychologist or other mental health professional [188]. Treating clinical psychologists working with women with trauma histories should have experience with abuse-related issues [174]. Specific, targeted approaches, including substance abuse treatment for those with substance abuse, sexual therapy for those with sexual dysfunction, or couples therapy for those with CPP-related relationship strain, may also be appropriate.

Because CPP patients are seeking medical care for an apparent medical issue, they may not be prepared to discuss psychosocial stressors that might be associated with their pain; thus, they may respond more positively to active, didactic psychotherapies than to nondirective therapeutic approaches [197]. Many women with CPP do not seek or receive treatment for their condition, suggesting that those who do may represent a unique subset of the affected population [180]. Additionally, it is important that providers treating women with CPP take care to normalize the patient's experience, to acknowledge both physical and psychological causes and consequences of pain, and to avoid invalidating their experiences of pain [186, 197].

**Urinary Incontinence** Women with UI most commonly seek treatment within the ob/gyn setting [198]. However, the vast majority of individuals with UI (93%) do not readily seek medical treatment [198, 199], perhaps due to shame, fear of surgery, and hopelessness regarding treatment efficacy, as well as depression and associated anhedonia and decreased self-efficacy [198, 200]. Psychologists may

help to identify those at the greatest risk of negative outcomes in order to provide intervention or referrals. Tools can aid in assessing case complexity, including the American Urologic Association Symptoms Score and the INTERMED, an interview evaluating psychosocial status and health care needs [201, 202]. Patients with low complexity have lower urological symptoms, treatment interruption, and psychological distress compared to high-complexity patients, who may have poorer clinical outcomes following medical treatment [201].

UI refers to involuntary urinary leakage, which may be frequent and regular or may be a discrete event [199]. Women may experience stress incontinence, or urinary leakage during activities like coughing, sneezing or walking, urge incontinence due to strong and sudden urges to urinate, and mixed incontinence, involving both stress and urge incontinence [203]. Though more common among older adults, UI affects women of all ages, peaking during menopause for women under 65. Median prevalence rates range from roughly 12% among women aged 15–24 to about 33% among women aged 45–54 [199]. Across adult women, stress incontinence is most common (accounting for half of cases), followed by mixed incontinence (32%) and urge incontinence (14%) [199]. Risk factors for UI include chronic cough, depression, functional or motor impairment, general health status, lower urinary tract symptoms, stroke history, obesity, and parity (at least three deliveries) [199, 203].

Quality of life is adversely affected by UI, with an estimated two thirds of women with UI reporting quality-of-life decrements [198, 204]. Urge incontinence, daily UI episodes, and moderate-to-large amounts of urine lost are all associated with lower quality of life [205]. UI symptoms can impact social, physical, and emotional activities, as well as work performance and travel [198, 206]. UI is associated with sexual problems, with a quarter of women with UI reporting impairments in their sexual life, which might include urinary leak interfering with intercourse, as well as problems with sexual desire and orgasmic phase disorder as well as sexual anxiety [198, 204, 207].

UI is also associated with depression [205, 208]. A longitudinal, epidemiologic study found that depression may cause UI, but that UI may not cause depression [200]. The known comorbidity of these conditions warrants attention, particularly from clinical psychologists practicing in the ob/gyn setting. Younger age (18–44 years old) and urge and mixed incontinence are linked to depression among UI patients [205, 208]. Women with UI who have depression have more physician visits and rate their UI as more severe compared to those without depression [205]. Given elevated rates of major depression and panic disorder among women with UI, particularly those with urge incontinence, routine screening for these psychiatric conditions is recommended [205].

**Intervention** Very few psychological interventions for UI patients have been tested, suggesting a need for more research in this area. In general, the majority of interventions for UI employ behavioral strategies to control UI symptoms, which in turn impact psychosocial targets. Individualized, patient-centered treatment, including those related to medical management as well as relationships, self-image, appearance, motivation, and treatment expectations, to address specific goals is

recommended both for treating physicians and for clinical psychologists working with this population [205].

Given the role of physiotherapeutic, behavioral techniques in treating UI symptoms, psychologists may play important roles in assisting both patients and medical providers with behavioral planning, management, and adherence. Such strategies may be used independently or incorporated into multimodal packages that include: behavioral and lifestyle changes (e.g., changing fluid intake habits, weight loss, bladder training with timed voiding); physiotherapy (e.g., pelvic floor exercises, use of auxiliary devices to increase pelvic floor strength, biofeedback, electrical stimulation of the pelvic floor, use of vaginal pessaries); surgical treatments (e.g., retropubic colpo-suspension and other surgical methods); and pharmacological treatment (e.g., estrogen therapy, tricyclic antidepressants, and other pharmacological agents) [209].

By treating urinary symptoms, behavioral interventions can influence psychosocial outcomes. For instance, behavioral therapies (e.g., pelvic floor muscle exercises, bladder retraining) have been found to decrease the proportion of patients reporting moderate-to-extreme levels of worry about urine loss during intercourse among women with stress incontinence [210]. Participation in a management program providing a variety of behavioral and/or pharmacological interventions resulted in decreases in mental distress, practical inconveniences, and social restrictions caused by UI [211]. Stress reduction strategies may also hold promise. A study by Baker, Costa, and Nygaard [212] piloted a very small-scale intervention for UI that utilized Mindfulness-Based Stress Reduction (MBSR), with participants reporting significant decreases in the number of incontinence episodes per day, as well as improved symptom and health-related quality of life, providing preliminary evidence of the possible benefits of mindfulness-based approaches to treat both physical and emotional consequences of UI.

Cognitive approaches and other multimodal features have also been explored in conjunction with behavioral techniques. Among a predominantly female sample of adults and older adults ranging in age from 42 to 91 years with problematic urinary leakage or frequency, an intervention consisting of 6 weeks of daily administration of an audiotape with relaxation, music, and cognitive strategies, along with written information, produced more comfort and fewer urinary symptoms than written information alone [213]. Another small-scale intervention for adult women with a history of unsuccessful UI treatment included a comprehensive assessment, psychoeducation, behavioral treatment approaches, bladder diaries, cognitive techniques, relapse prevention, and supportive contact. Participants reported improvements in incontinence-related quality of life and rated the program as “very useful,” while improvements in bladder functioning emerged after the intervention ended [214].

## **Perimenopause and Menopause**

Perimenopause, the transitional period leading up to the final cessation of ovulation, and menopause itself may be associated with negative symptoms for women, including uncomfortable physical symptoms and the role transition that accompanies

the loss of fertility. For some women, menopause may be accompanied by grief at the loss of reproductive capability, dissatisfaction with the idea of aging, and poor adjustment to physical changes. In early perimenopause, women are more likely to feel confused, uncertain or negative about the physical and social changes taking place [215]. Dillaway [216], however, suggests that while biomedical literature discusses the menopausal change in negative terms, likely due to the focus on physical symptoms, feminist literature finds that women may experience menopause as a positive or neutral experience. Many women may find freedom or relief in relinquishing their reproductive capacity, giving up the stresses of pregnancy prevention and menstruation; however, women such as these are unlikely to visit a psychologist, as they may not perceive the menopausal change as a negative experience. Clinical psychologists in the ob/gyn setting can be useful in aiding women who are experiencing adjustment to the end of fertility negatively by providing psychoeducation about what the symptoms mean and normalizing an individual's experience of her menopausal symptoms. Mansfield, Theisen, and Boyer [217] reported that women want accurate information about what to expect during the transition to menopause, including information about what is normal, the course of the transition, what distressing or uncomfortable experiences they might expect, potential health problems, and what to do about distressing experiences and problems if they occur. These authors found that uncertainty about what to expect and what is normal are common stressors and information provided by a clinical psychologist in the ob/gyn setting can provide a sense of mastery with regard to understanding and coping with changes.

During menopause, a woman's body gradually begins to produce less of the hormones estrogen and progesterone. Onset usually occurs between ages 45 and 55 years. Current diagnostic criteria specify that a woman has reached menopause when she has not had a period for 12 consecutive months. Physical symptoms of menopause include but are not limited to experiencing changes in the timing and/or flow of menstruation; hot flashes or becoming warm in the face, neck, and chest; night sweats and sleeping problems that can cause fatigue or stress; vaginal changes wherein the vaginal tissue becomes dry or thin resulting in painful intercourse; and osteoporosis [218].

While a thorough review of the literature [219] posits that menopause does not cause depression, other findings regarding onset of depressive symptoms during the perimenopausal period suggest otherwise. For example, Matthews and colleagues [220] found that menopausal women are at no higher risk of mental health problems than premenopausal women in a study of 541 initially premenopausal women conducted over 3 years. In contrast, Cohen and colleagues [221] in a more recent study found that perimenopausal women with no history of depression were at higher risk of developing depressive symptoms than women who remained premenopausal. Hunter [222] found that being under stress before menopause, having hypochondriacal concerns (i.e., bodily preoccupation and disease phobia), and a sedentary lifestyle were more highly associated with onset of depressive symptoms during perimenopause. Similarly, she posits that stressful life events and SES may have more impact on mood than menopause itself. When menopause occurs for these



women, they may experience the cumulative effects of these issues (i.e., bereavement from loss of a spouse, etc.) [222]. McKinlay and colleagues [223] found that perimenopausal women who were depressed were more likely to have been widowed or divorced, or to have worries about a family member. Other common complaints associated with depression during menopause are that reduced fertility may leave a woman questioning her role as mother and nurturer. A lack of interest in sex due to vaginal dryness and discomfort may cause relationship problems. While new onset of depressive symptoms may or may not be more prevalent during menopause and beyond, the National Comorbidity Survey found an increased risk of recurrence of major depression in women aged 45–54 years [224]. Similarly, while menopause has not been found to increase anxiety symptoms, women with preexisting anxiety disorders or symptoms were found to experience more uncomfortable physical symptoms of menopause, specifically hot flashes [225].

Other psychosocial symptoms that can appear at this time include sleep difficulties and insomnia that may not have been present prior to menopause. Perimenopausal and postmenopausal women commonly complain of disturbed sleep, including trouble falling asleep and frequent nocturnal awakenings [226]. Sleep disturbance appears to be accounted for by the stage of menopausal transition more so than other potentially explanatory factors such as age, vasomotor symptoms, sociodemographics, and psychological and physical health, among women with either natural or surgical menopause [226].

There are several assessment measures available specific to perimenopausal women that may be helpful for clinical psychologists evaluating women during this life stage. It is important to remember that similar to pregnancy, menopause is accompanied by physical symptoms that can skew results on more traditional mood assessments (i.e., Beck Depression Inventory, BDI; Beck Anxiety Inventory, BAI), so comprehensive clinical interviews should consider that changes in weight, sleep, or appetite may be indicative of menopause-related hormonal fluctuations, not solely the onset of depressive or anxiety symptoms. Assessment tools such as the Women's Health Questionnaire (WHQ) [227], Menopause Rating Scale (MRS) [228], and Menopause-Specific Quality of Life (MENQOL) [229] may be useful tools.

Medical interventions recommended for menopausal symptoms involve hormone replacement therapy (HRT), which uses artificial estrogens, progesterone or progestins, and sometimes testosterone to relieve the discomfort associated with naturally decreasing levels of these hormones in a perimenopausal woman's body. HRT is used for short-term symptom relief and usually does not exceed 5 years of use; however, young women who undergo surgical or other early menopause may remain on HRT until the natural age when menopause would be expected to occur [230]. HRT has been associated with significantly higher rates of breast cancer, heart attacks, and strokes [231, 232], raising public concerns. Therefore, psychosocial interventions to deal with the uncomfortable symptoms of menopause are now being explored so that women can avoid the potential harmful effects of HRT when possible.

**Intervention** Hot flashes and psychological distress are common targets for psychosocial interventions for menopause. Cognitive-behavioral interventions can serve as effective alternatives to HRT and may be preferred by patients. A systematic review of experimental studies evaluated psychoeducational or skills-based therapies, including CBT and relaxation approaches to treat hot flashes and vasomotor symptoms of menopause. Among 14 studies, all demonstrated significant reductions in vasomotor symptoms among intervention groups [233]. Psychoeducational interventions can help women to prepare for and manage menopause. For example, a workshop-based intervention addressing knowledge, beliefs, expectations, physiological changes, health implications, HRT and other therapies, psychological and physical preparation for menopause, behavioral goal setting, and communication was provided to premenopausal women and improved participants' knowledge and beliefs and decreased intention to use HRT compared to a control group, in both short- and long-term follow-up. Of note, control participants also reported some benefits, perhaps reflecting therapeutic benefit of completing menopause-related assessments [234, 235]. Furthermore, a lengthier psychoeducation-based intervention addressing biological, physiological, psychological, emotional, and social facets of midlife, including lectures, group activities, role playing, feedback, and support, was associated with significant improvement in attitudes toward menopause and in perceived severity of physiological, psychological, and emotional symptoms, compared to a no-treatment control group [236].

Relaxation interventions also can be effective for menopause-related symptoms. For example, women with frequent hot flashes who practiced diaphragmatic breathing and breath awareness reported significant decreases in hot flash intensity, anxiety, and depression compared to placebo and wait-list controls [237]. Additionally, a very small-scale study of six postmenopausal participants evaluated the efficacy of applied relaxation with home-based practice, and all patients reported decreased hot flashes and menopausal and psychological symptoms [238]. Mindfulness-based interventions also can be utilized to assist with quality of life and coping with hot flashes. Carmody, Crawford, Salmiorago-Blotcher, Leung, Churchill, and Olendzki [239] evaluated MBSR in late menopausal/early postmenopausal women with frequent hot flashes, teaching mindfulness techniques with between-session practice, and found that MBSR participants improved in degree of bother from hot flashes, quality of life, sleep, anxiety, and perceived stress, compared to wait-list controls, with outcomes maintained at follow-up.

Multicomponent treatment packages have also been developed. Such programs have ranged in duration and typically incorporate components including relaxation techniques, cognitive restructuring, coping with sexual and body image challenges, education in paced respiration, problem solving, nutrition and exercise, Kegel exercises, and sexual reeducation [240–243]. These treatment programs have resulted in numerous improvements in multiple menopausal symptoms (e.g., hot flashes, mood), vasomotor symptom frequency, sleep problems, depression, anxiety, relational satisfaction, sexuality, subjective ability to influence life phase, acceptance of body change, and controllability of mood.

Psychosocial interventions may be combined with medical interventions. For example, Anarte et al. [244] paired hormone therapy (HT) with a psychological intervention comprising group sessions including education on menopause, counseling for problem-solving and coping skills, and symptom treatment with cognitive-behavioral approaches. Compared to HT alone, the combined intervention resulted in more improvements in multiple physical and psychological symptoms including anxiety, depression, and emotional alteration [244]. Results support the potential additive benefits of combined interventions for menopause.

## Infertility

Clinical psychologists are increasingly interested in treating women with infertility and may provide valuable services within medical settings where infertility may present, including ob/gyn settings. Literature addressing the unique and significant psychosocial context of infertility, such as cultural emphasis on childbearing and relational dynamics that can develop in response to one partner's infertility, has expanded over the past decade [245], providing insight and guidance for clinical psychologists treating this population.

Twelve percent of couples experience fertility problems, with 7.4% meeting criteria for infertility, or the inability to become pregnant within 1 year of regular, unprotected intercourse [246]. Infertility has many potential etiologies, including polycystic ovarian syndrome, endometriosis, low sperm count or motility, and lifestyle factors such as obesity and smoking, and risk of infertility increases with age [246, 247]. Treatments that can assist in conception include ovulation induction, surgeries, intrauterine insemination, in vitro fertilization (IVF), and third-party reproductive options like donated gametes and gestational carriers.

A wide range of psychosocial sequelae are associated with infertility (for a review see [248]). Infertility-related challenges include adjustment to initial diagnosis, decision making regarding treatment or other family-building resolutions, intimate and social relationship strain, and social stigma. Fertility treatments can be costly, invasive, and demanding, and may produce unpleasant side effects including physical discomfort, mood disturbance, and fatigue, and many women require multiple treatment attempts to achieve pregnancy. Emotional distress and difficulty coping are leading reasons for discontinuing fertility treatment [249–251].

Women with infertility often experience significant stress related to social, romantic, and sexual relationships, as well as concerns regarding parenthood and childlessness [252, 253]. Such stress is associated with marital and interpersonal conflict, sexual dissatisfaction, depression, anxiety, reduced quality of life, reduced self-esteem, and lower confidence to cope with treatment [253–257]. Women perceiving stigma or difficulties communicating about emotional experiences of infertility are at particular risk [258, 259]. As such, assessment of social support, marital satisfaction, stress, and coping strategies is recommended via clinical interviews or objective measurement both prior to treatment and annually thereafter [260].

Infertility has been associated with depression, anxiety, and other psychiatric symptoms [261–265]. Women with prior treatment failures may be at increased risk of distress [266, 267]. Grief may result from treatment- or pregnancy-related events including failed cycles and loss of hope to become a parent, and normal grief should be differentiated from complicated bereavement and/or depression [248]. Women and couples with infertility may underreport psychological distress or marital problems due to fear of being denied medical treatment [267]. As such, clinical psychologists can provide critical assistance in assessment of patients at risk. Some fertility patients may experience adverse psychiatric reactions to fertility treatment, perhaps due in part to interactions with hormonal treatments, such as depression, anxiety, irritability and mood lability, and less commonly, psychotic experiences; greater risk is present in women with prior histories of psychiatric disorders, indicating a need to monitor psychiatric symptoms before and during treatment [248]. Specific instruments have been developed to assess stress and distress related to infertility, including the Fertility Problem Inventory (FPI) [253] and the Fertility Quality of Life tool (FertiQOL) [268].

**Intervention** Women with infertility underutilize psychosocial services, even those who recognize elevated stress levels [269]. However, many psychosocial interventions for women with infertility have been tested, with demonstrated efficacy using a variety of approaches [269]. These interventions may effectively relieve distress for women seeking to become pregnant without presenting fetal risks associated with some psychotropic medications [248]. Clinical psychologists in ob/gyn settings may increase accessibility of such services, facilitating their utilization among women with infertility.

Kainz [270] identified four broad considerations for women with infertility: cognitive attributions, sexual problems, marital relations, and psychological consequences. Interventions often utilize group-based approaches incorporating social support, cognitive-behavioral coping skills, and stress management. A review of interventions found that many produced favorable outcomes on affective variables (most commonly anxiety and depression), with fewer consistently positive outcomes for relationship functioning. Efficacious treatments tended to be 6–12 weeks in duration [269] and protect against expected worsening of functional and relational problems over time if untreated [271].

Though not designed to meet the needs of women with clinical distress levels, group psychoeducational and skills-based interventions have produced more positive outcomes than individual, emotion-focused counseling [269]. For example, Domar and colleagues [272] have tested a comprehensive mind/body program incorporating stress-related psychoeducation, group relaxation, cognitive restructuring, self-empathy and compassion, exercise and yoga, and mindfulness, along with peer counseling and a “buddy system,” which resulted in numerous symptom improvements including decreased depression and anxiety [272, 273]. An abbreviated adaptation of this program also demonstrated several psychological and psychosocial improvements and outperformed a non-CBT support group on several outcomes. Another cognitively focused program for couples or individuals undergoing

IVF resulted in improved stress management, social support and anxiety [274], and a group-based, couples intervention addressing coping, stress management, communication, relationships, and treatment-related decision making was found to be effective in increasing communication and increasing marital benefit [275]. Another group approach found that both emotion-focused and problem-focused coping skills led to decreased distress, noting that attenuation of initial gains in the problem-focused group suggested relative efficacy of emotion-focused coping training for this population [276].

Support groups that do not incorporate structured cognitive-behavioral approaches are also beneficial. Domar and colleagues [271] provided support group sessions allowing women to “check in” about infertility-related issues and found that participants reported significant improvements in stress-management skills and styles, marital distress, anxiety, and mood at follow-up, underscoring the salience of social support at the foundation of group interventions.

Individual or couples counseling may be warranted or preferable for some women. Boivin and colleagues [277] recommend counseling for patients with high levels of distress, patients requiring third-party reproduction (e.g., gestational carriers), and patients seeking fertility services for reasons other than medical infertility (e.g., lesbian and single women). For women suffering from minimal–moderate depression, a cognitive-behavioral intervention including relaxation, infertility education, and cognitive restructuring resulted in greater improvements in depression, anxiety, social function, and psychosomatic symptoms than treatment with fluoxetine [278, 279]. For couples with idiopathic infertility, a CBT program focusing on attitudes toward task-oriented sex, sexual satisfaction, thoughts of helplessness, and marital communication skills was associated with improved marital distress and adherence to timed intercourse. Sperm quality also improved, and roughly a third of couples achieved pregnancy within 12 months [280].

Brief, self-directed, and/or psychoeducational interventions have also been investigated among women with infertility. For example, one study providing information or information plus counseling sessions to couples during IVF treatment appointments found that counseling did not significantly improve IVF outcome; however, both groups reported reduced anxiety [281]. Additionally, a brief coping intervention using twice-daily self-administration of positive reappraisal statements while awaiting IVF results provided a low-intensity, easily implemented method of increasing positive feelings, outperforming positive self-affirmative statements [282]. Written emotional expression during fertility treatment also holds promise, with reduced stress reported among participants completing three daily, 20-minute emotional writing tasks completed during fertility treatment, while stress increased at follow-up among control participants completing neutral writing tasks [283]. The Internet provides another venue for self-directed interventions. For example, a psychoeducational program addressing coping skills and communication with partners and providers produced slight improvements in infertility-related stress, treatment-related self-efficacy, and perceived informativeness [284]. Internet-based interventions are an emerging area of research interest [285, 286], but thus far, results have been fairly modest.

Clinical psychologists should aim to collaborate with medical providers to facilitate recognition and proactive treatment of psychiatric needs of their patients with infertility [248]. Psychologists may provide a wide range of direct counseling and patient-centered, nonprofessional services to infertility patients, including outreach, individual or couples counseling, psychoeducation and provision of written materials, promotion and coordination of support services, and education of medical professionals regarding the unique needs and concerns of their patients [277, 287].

## Resources Relevant to the Care of Women

There exist several resources that may be useful to clinical psychologists working in women's primary care or ob/gyn practices. The American Psychological Association (APA) has issued guidelines for psychological practice for a variety of specific groups and settings, including practicing with girls and women [288], with lesbian, gay, and bisexual clients [289], with older adults [290], and within health care delivery systems [291]. However, there are no guidelines or competencies for clinical psychologists practicing in women's health care settings, and current guidelines on health care delivery systems do not address women's health in detail. Other disciplines have adopted competencies with a more circumscribed focus, such as the Nurse Practitioner Primary Care Competencies in Specialty Areas: Adult, Family, Gerontological, Pediatric, and Women's Health [292]. The focused nature of these competencies may be used as a model that can be applied to the development of guidelines for psychological practice in these particular areas. Treatment guidelines are available online from the American Psychiatric Association (<http://www.psych.org>). As Educational Affiliate members, clinical psychologists may access the ACOG's Guidelines for Women's Health Care (<http://www.acog.org>).

## Conclusions and Future Directions

In a health care setting, clinical psychologists are uniquely poised to address a number of psychological issues associated with women's health across the life span. As consultants, or as part of treatment teams, psychologists are able to empower women to navigate the health care system and provide valuable services, including evaluation and assessment, psychosocial counseling for a variety of issues, and interventions to promote medical adherence and behavioral management of various conditions, as well as facilitation of appropriate referrals when necessary. That biological, interpersonal, intrapersonal, contextual, and outcome-related factors are highly relevant to successful treatment and management of women's health [24] underscores the significant potential contributions clinical psychologists can make to health and well-being of women. As such, clinical psychologists have the potential to improve medical outcomes, patient satisfaction with medical care, and quality of life for women and families.

Despite the prevalence of psychological distress and concerns among women in ob/gyn settings, psychological and behavioral treatments have been understudied to date, reflecting a need for greater research attention. In many cases, interventions utilized to treat psychological distress in other populations can be efficacious when treating mental health sequelae specific to women's health issues. For some of the ob/gyn conditions discussed above, specific treatments have been developed and tested, with promising results; however, varied methodology, small sample sizes, use of nonrandomized designs, and variable assessment tools and target outcomes limit the available research. In some cases, multimodal treatment packages have not been dismantled so active and essential treatment components are not always known. Continued research is needed to extend this work. Also essential is the translation of such empirical research to practice, as well as the evaluation of treatment programs and approaches already in place.

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# Chapter 16

## The Hospital-Based Consultation and Liaison Service

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### Introduction, History, and Background

Psychosocial factors have a broad and substantial impact on patient presentation in the inpatient medical setting. Research clearly demonstrates that psychosocial factors play a crucial role in the etiology, pathophysiology, treatment, and clinical outcomes of numerous chronic and comorbid diseases [1–5] as well as postsurgical outcomes and recovery [6]. Given that psychiatric and behavioral symptoms can have a significant influence on chronic and acute illness, it is not surprising that inpatient medical settings have reported significant psychiatric issues in approximately

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35% of all inpatients [7–9]. These psychiatric comorbidities can have negative consequences on medical outcomes [10, 11] as well as fiscal outcomes (e.g., increased length of stay and repeated readmission) [7, 12, 13]. Beyond clinical psychiatric diagnosis, the multiple stressors of the hospitalization can negatively impact the quality of life for even high-functioning patients [14–17]. Unfortunately, these psychosocial factors are often poorly recognized and managed within the hospital setting [18]. For example, less than 5% of admissions across the hospital appear to receive a mental health consult [19, 20], far less than the one third of patients estimated to have psychiatric comorbidity.

A hospital-based psychology consultation-liaison (CL) service plays a vital role in identifying and mitigating the negative impact psychosocial factors may have on a patient's medical condition, health behaviors, and/or emotional adjustment. The CL psychologist is called upon to provide psychological intervention services to patients admitted to the hospital with psychological and behavioral issues related to acute and chronic medical illnesses or patients with premorbid psychiatric disorders who are acutely and/or chronically ill. The interface between psychology and physiology has been acknowledged since precivilization [21], although the formalization of medical education at the turn of the nineteenth century separated psychology from medical training. Psychology was largely excluded from medicine until the mid-1950s, at which time major leaders in the medical and mental health fields highlighted the need to reintroduce psychologists into their faculties [22]. This corresponded with the formalization of the fields “behavioral medicine” and “psychosomatic medicine,” both of which emphasized the biopsychosocial model of disease. Historically, psychosomatic medicine evolved within the biomedical model, was based on the psychoanalytic model, and was focused on the etiology and pathogenesis of disease, and care was delivered by psychiatrists. The emergence of psychiatric CL services during the middle- to late-twentieth century corresponded with the psychosomatic movement [23]. Behavioral medicine, however, tended to be more focused on treatment and prevention of physical disease by way of behavioral change [24, 25].

Today, the role that CL psychologists take in the hospital setting depends on the CL model. Drotar [26] lists four major consultation models for interfacing with the medical system. The least-focused consultation occurs within the *indirect consultation*. For example, “curb-side” consults occur when medical team members informally seek advice from the psychologist. The least-collaborative consultation occurs within the *independent* model. The psychologist, who is outside of the care provider team, assesses and diagnoses (and sometimes, provides treatment) in isolation. This is a “consultation” without “liaison” model. In the *collaborative* model, the psychological and health care team members work together. Each contributes their own expertise toward assessing and intervening within a biopsychosocial model. Finally, the most integrative consultation takes place within *systems approach*. This takes a broad, system-level analysis to assess and plan biopsychosocial interventions along multiple factors influencing the patient's experience in the health care system [26]. It is likely that real world consultation is a combination of many of these models occurring conjointly.

CL service provision varies on multiple dimensions. One dimension is team *make-up*. Consulting psychologists often work on multidisciplinary teams that may include a psychiatrist, social worker, and/or nurse, in addition to a variety of trainees. Available team members can dictate a range of services provided (e.g., medication management would only occur if a service includes a psychiatrist). A second dimension is the *scope* of the issues and populations that the CL team targets. For example, a CL team can be a “general” service working with any issue, or can be more focused, such as a “substance abuse” CL team. Similarly, a CL team can be available to all units in the hospital, or be limited to working with discrete units based on relationship and funding models (e.g., the oncology CL service). A third dimension on which CL teams differ is in their *function*. Some CL teams focus on assessment and recommendations only whereas others also provide intervention during inpatient admission. A fourth dimension is *conceptualization*. Some services are guided by a more traditionally psychodiagnostic model involving formal testing, broad assessment across typical psychosocial arenas, and *Diagnostic and Statistical Manual of Mental Disorders (DSM)* [27] diagnoses, whereas other services may be more likely to focus assessment on specific referral questions, with a movement away from a more psychopathological perspective unless psychiatric diagnosis is inherent to the referral question [28]. For example, in a referral for procedural anxiety, a CL psychologist may do a comprehensive evaluation resulting in a *DSM* diagnosis, or may instead focus assessment on the environmental contexts and specific psychosocial factors relevant only to the procedural anxiety.

The “liaison” piece of CL speaks to the integration of the psychologist in the health care team, and the degree of liaison that a CL team provides is based on the model of consultation. Specific liaison activities can occur across multiple venues. For example, CL psychologists may offer formal didactics (e.g., Grand Rounds, medical residency curriculum, or nursing education series) with topics including adherence, challenging families/patients, psychosocial factors, pain management, practicing within the biopsychosocial model, developing parent–child attachment within the context of chronic illness, procedural anxiety, differential diagnosis, and recognizing psychopathology within the medical setting. Liaison work can also occur during provision of routine medical care, such as attending medical team morning rounds. During rounds, the psychologist can observe and provide insight and recommendations into family–patient–physician interactions and can model optimal communication. The psychologist also can highlight psychosocial issues and ask relevant questions. In addition, the psychologist can help in identifying families needing intervention, or providing specific behavioral/communication strategies for health care providers to facilitate a specific patient’s care [29]. There is evidence to support the effectiveness of staff training in behavioral medicine topics on knowledge, attitude change, and clinical practice [30].

CL in general and liaison work in particular are centered on collegial relationships. Relationship building is key to the collaborative approach to treatment and to increasing the utilization and appreciation of consultation services. One important set of relationships is between the CL psychologist and attending physicians. Attending physicians often change on a team within a 1- or 2-week schedule. As a

result, developing relationships and lines of communication needs to occur quickly and sometimes repeatedly across the course of a consultation. Drotar [26] also discusses several physician-related influences on collaborative outcomes including the physicians/sub-specialists beliefs about the need and effectiveness of collaboration with psychologists, their skills in identifying appropriate referral questions, the situational constraints (e.g., time pressure, reimbursement), and previous utilization and satisfaction with behavioral health services in the past.

Collaborative relationships extend beyond those with physicians because in most medical settings numerous health care providers are involved in care provision (see Table 16.1), especially for the most psychosocially and medically complex patients. The importance of viewing the service as a team emphasizes the need for a coordination of the different disciplines as opposed to multiple professionals competing for overlapping territory and role functions. One way to avoid professional territorialism is to understand the unique contribution each team member offers to patient care, as well as to understand where potential “overlap” may appear. When the contributions to be made by individual providers are not well delineated, competitiveness, political hostility, poor communication, and confusion can occur and negatively impact patient care [31].

While psychosocial “support” is offered by numerous health care providers (pastoral care, social work, nursing, etc.), the role of the psychologist is distinctive given specialized training in the (a) role of biopsychosocial factors in the etiology, maintenance, exacerbation, and progression of disease, (b) assessment and interpretation of empirically validated psychological measures, and (c) implementation of empirically developed interventions for the diverse forms and degrees of psychopathology among the medically ill. Nurses play a key role in both assessment and implementation of intervention recommendations as they are at the bedside providing around-the-clock care. Occupational and physical therapists may observe maladaptive coping behaviors and may help to increase behavioral activation (BA) to improve mood and physical recovery. Holistic health or child life (in pediatric settings) may augment relaxation strategies critical for pain management or procedural anxiety. Social work can provide emotional and instrumental support and assist with stressors such as limited resources and lack of entitlements. Pastoral care can be helpful in providing families support with more existential issues (e.g., such as acceptance) and in identifying important sources of social support. Utilizing all health care providers often results in the most consistent and effective interventions. Taking a multidisciplinary approach to treatment planning helps to provide effective consistent care with targeted goal setting and reinforcement. For example, developing a behavioral plan to facilitate participation in physical therapy should be conducted in conjunction with the physical therapist (to ensure that positive reinforcement is given effectively during therapy) and nursing (to make sure the patient is ready for therapy and provide verbal reinforcement for successful completion of goals).

**Table 16.1** Inpatient health care team members with whom CL psychologists may collaborate

Title	Role
Attending physician	Physician (with medical degree) who oversees the medical care of the patient while they are in the hospital
Medical student	Student in medical school without medical degree who is closely supervised by more advanced members of medical team
Resident	Physician who has completed medical school and received medical degree and is now in residency (i.e., graduate training) receiving more advanced training under the supervision of an attending physician
Intern	Resident in the first year of residency
Fellow	Physician who has completed their residency training and is taking additional training in one area of medicine
Nurse	Health care professional who typically is assigned to a small number of patients and manages the medical needs and orders for that patient
Advanced practice nurse	Nurse who has completed additional training and may have admitting prescribing privileges. Also called nurse practitioners or clinical nurse specialists
Patient care assistant	Assists the nurses in meeting the patient's needs
Patient attendant	Provides constant observation in the patient room, as needed, to ensure patient safety
Respiratory therapist	Provides breathing treatments for patients
Occupational therapist	Works with patients to develop, recover, or maintain daily living and work skills
Physical therapist	Works with patients to promote the ability to move, reduce pain, restore function, and prevent disability
Recreational therapist	Works with patients to promote emotional and physical well-being of the patient as well as help with reintegration into the community
Speech therapists	Works with patients to address speech, language, and other oral-motor deficits
Psychiatrist	Physician with specialized training in psychiatric disorders and psychopharmacology
Social worker	Licensed professional who helps to locate community programs to provide resources (e.g., education, financial, counseling, home health care) for patients and their families and may provide supportive counseling
Child life specialist	In pediatric settings, provides emotional support around hospitalization, developmentally appropriate involvement in activities and education, as well as support around medical procedures
Chaplain	A member of the clergy available to patients and families for pastoral care and spiritual support

## Review of the CL Evidence

*Prevalence of CL Services.* Details on the prevalence of psychology consultation-liaison services, or even the prevalence of psychologists on psychiatric consultation-liaison services, are limited. Callaghan et al. [32] reviewed 48 papers on adult

“liaison mental health services” published between 1975 and 2001 and reported that psychologists were part of a multidisciplinary liaison team in 32% of the studies reviewed. Shaw et al. [33] surveyed inpatient pediatric consultation liaisons, and over 60% of the responding services had a psychologist as part of the CL team. In those teams with both psychiatry and psychology involvement, the vast majority (80%) were directed by a psychiatrist. Only 4% of services were a stand-alone “psychology” CL service. Duplicate psychiatry and psychology CL services were identified by 11% of the respondents. Because of the lack of evidence pertaining solely to psychology consultation-liaison services, the following review of research is based largely on psychiatry consultation-liaison services (which may or may not include psychologists).

*Practice Patterns of CL Services.* Descriptive research on practice patterns in adult consultation liaison indicates common consultation requests for services, including behavior problems (including nonadherence), mood disorders, substance abuse issues, and suicidality assessment [34, 35]. Recent studies (primarily using *DSM-III-R*, *DSM-IV*, and International Statistical Classification of Diseases (ICD-10) diagnostic systems) find that common diagnoses include mood disorders, adjustment disorders, substance use disorders (SUDs), anxiety disorders, delirium and somatoform/psychogenic disorders with “no diagnosis” given to between 1 and 17% of patients seen [19, 34–36]. Commonly provided interventions include psychotherapy and psychiatric medication management [34]. One study comparing practice patterns within one CL service in 1990 versus 2000 highlighted the significant reduction in the recommendation of psychotherapy in 2000 (4.4%) versus 1990 (22.7%), with the authors noting that a psychologist was on the team in 1990, but not in 2000 [34].

For pediatric consultation-liaison services, high-frequency referral questions include general coping/adjustment, depression, suicide assessment, anxiety, psychiatric medication evaluation, differential diagnosis/management of somatoform disorder, trauma, and nonadherence [33, 37, 38]. Parent adjustment issues have also been referred [38]. There are less data on psychiatric diagnoses assigned and specific interventions used within pediatric CL, but Carter [38] reported that, using *DSM-IV* criteria for a sample of 104 pediatric patients referred, over half of the patients were given an adjustment disorder diagnosis, with the remaining patients receiving a wide range of diagnoses. In this same sample, interventions provided by the pediatric CL service included supportive therapy, coping-strategies intervention, and facilitating outpatient resources [38].

*Clinical Outcomes.* Conducting clinical outcome research on the efficacy of CL services for improving psychosocial, health outcomes, or fiscal outcomes is very difficult. Challenges include difficulty in obtaining an appropriate “control” group of patients (e.g., unethical to not do consultations when requested for sake of science), need to combine illness types because of small number of patients for any one illness, lack of control over multiple confounding variables (e.g., worsening disease status, medication changes, timing of consult, involvement of other psychosocial provider), and even lack of control over intervention (e.g., other health



providers may not follow through on recommendations) [39, 40]. However, there are numerous case series and single-subject designs demonstrating the effectiveness of psychological interventions (primarily cognitive-behavioral therapy; CBT) conducted with hospitalized pediatric and adults patients across a range of outcomes including procedural refusal/distress [41, 42], food refusal [43, 44], psychogenic symptoms [45], and pain [46].

There is also a smaller literature using between-group designs to support the use of psychological interventions commonly implemented in CL services in the hospital setting. For example, in one case-control-controlled study, CBT applied to medically unexplained symptoms decreased bodily complaints and negative mood, improved awareness of psychosocial components of symptoms, and increased motivation for outpatient therapy in intervention patients relative to standard hospital treatment [47]. Another study used random assignment to one of the two inpatient pain rehabilitation units in the same hospital to compare CBT supplementation in the pain program with standard pain program, and demonstrated improvements in depression and pain relative to the control unit [48].

A recent intervention reported by Broadbent et al. exemplifies the utility and effectiveness of brief CBT interventions on cognitive, emotional, and functional outcomes for both patients [49] and their spouses [50]. In this study, 116 inpatients hospitalized for acute myocardial infarction without serious comorbid psychiatric problems were randomly assigned to a treatment as usual control group (psychoeducation and invitation to cardiac rehabilitation classes) or to a brief CBT group. The CBT intervention consisted of three separate half-hour sessions conducted by a psychologist which focused on psychoeducation, exploration of myocardial infarction-related cognitions and how these thoughts related to behavior, developing a personal action recovery plan for returning to work, exploring benefits and costs of behavioral change, discussing behavior change methods and goal setting, and discharge planning including addressing anxiety about discharge and development of healthy home routines. For those patients with spouses, an additional session occurred prior to the final session which included both patients and spouses and explored spousal myocardial infarction-related cognitions and reviewed the patient's personal action recovery plan as well as the spouse's role in recovery. In comparison to the control group, patients who received the intervention were more likely to return to work more quickly, were more likely to return to full-time status, understood their illness better, felt better prepared to leave the hospital, were less anxious after returning to work, and made fewer phone calls to their medical providers during the 3-month follow-up period [49]. Furthermore, compared with the spouses of patients in the control group, spouses who had participated in the intervention reported less distress about their spouse, fewer concerns related to myocardial infarction, better understanding of the illness, and lower anxiety about the patient doing physical activity. The patients' rating of spousal anxiety was also lower in the intervention group compared to that of the control group [50]. Thus, this brief three-session inpatient CBT intervention, which could be easily implemented within a CL service, resulted in positive emotional, functional, and medical system utilization outcomes.

*Consumer Satisfaction.* Given the push of many institutions towards quality improvement in order to stay competitive in today's costly managed care system, the measurement of patient/consumer satisfaction is becoming increasingly popular. While consumer (either referring health care provider or patient) satisfaction has been neglected in CL research, the information available suggests that consultation-liaison services are satisfactorily received [38, 51].

*Fiscal Outcomes.* CL services have attempted to document their contribution to cost control in the hospital setting by investigating the impact of CL services on fiscal outcomes. Given the relationship that has been found between psychiatric issues and prolonged hospitalization [13, 52], the impact of CL on length of stay has been the most studied cost-offset variable, with some studies suggesting that early consultation may be related with shorter hospitalizations [53]. However, other studies do not demonstrate any association between consultation and cost-offset, albeit most of the research involves psychiatrically based CL services which may be more costly [54]. As discussed previously, methodological issues, including ethical concerns, lack of rigorous control groups, and lack of ability to control at which point during hospitalization CL is initiated, render general conclusions about whether CL services reduce hospital expenditures challenging [55, 56].

## The Consultation Process

*Referral Process.* Multiple factors appear to be related to the decision by health care providers to refer patients for a CL consultation. The nature of the patient presentation appears to impact referrals, with those patients who are more disruptive or displaying increased psychiatric dysfunction being referred earlier in admissions [53, 57]. There is some evidence to suggest a longer length of stay and a higher mortality rate for those patients referred later during admissions versus those receiving earlier consultation [53, 58]. Certainly, intervening earlier in high-risk patients or situations is likely to prevent the development of entrenched maladaptive behaviors or interactions patterns. The physician's decision to refer for consultation has been shown to be related to physician concerns, such as fear that patients may not like the referral, be stigmatized by the referral, or become more distressed if their psychosocial issues are explored [59, 60]. Therefore, increased education, positive reports by families, and more liaison work are essential to facilitate appropriate referrals. There is increasing awareness of the need to develop brief screening measures for adult [61, 62] and pediatric patients [38, 63] to improve the identification of patients in need of behavioral medicine services or who may be at risk for extended admissions and poor discharge status.

Once the need for referral has been identified, the referral is communicated to the CL service by way of written orders, direct phone calls, and, increasingly, by encrypted medical technologies such as electronic medical records, e-mail, or text messages. Direct communication with the referring provider is critical because

collaborative agreement on consult goals has been associated with positive ratings by referring health care providers on goal attainment, and on health care provider/patient/family satisfaction with services [38]. It is also important to clarify the urgency of the referral matter. Seeing a patient within 24 h of referral is a common quality indication [64]. However, some referral issues are more time sensitive or urgent such as suicidal ideation, refusal to comply with critical medical care, or substantial behavioral disruption putting the patient, family or health care providers at risk. For CL teams comprised only of psychologists, discussion with the provider may result in the consensus that another service may be most appropriate, such as a consult for social services or psychiatry. For multidisciplinary CL teams, this discussion should clarify which member of the CL team (e.g., psychologist, social worker, or psychiatrist) should conduct the consultation.

*Background Assessment/Assessment of System.* Reviewing the medical chart provides the medical context for understanding the patient presentation. The medical chart documents all the available information on the multidisciplinary care received by the patient and includes the patient's medical history, demographic and social data, laboratory tests, vital signs, review of medication history, adherence to medical plan in past, adherence to outpatient appointments, frequent hospitalizations, earlier consultation reports and consultations from other providers, imaging, pathology reports, and enrollment in approved clinical trials. It is especially important to review psychoactive medications (e.g., benzodiazepines, opioids, antidepressants, antiseizures, and cholinergic medications) in order to place current psychological presentation in context. For example, it is critical to be mindful of recently given medications (including PRN or "as needed" medications) when assessing a patient's cognitive status since sedating medications may interfere with your assessment. Beyond looking at the medications that have been prescribed, it is essential to see which medications have actually been given. For instance, it is not uncommon for medical teams to stop some psychotropic medication prior to surgery then neglect to reorder the medication during recovery. Furthermore, it is important to keep psychosocial history in mind when reviewing medication list. For example, a certain dose of analgesia may be effective for most patients but ineffective for an opioid-addicted patient. Given the wealth of information encompassed in the medical chart, it is important for the CL psychologist to develop an efficient scanning routine to minimize the time spent reading through charts and maximize the retrieval and consolidation of the relevant clinical information. Computerized records are increasingly becoming the norm, greatly facilitating this process.

Next, obtaining the perspectives of other care providers both within the system and (when possible) outside of the system can help guide both assessment and intervention and resolve questions from the medical chart review. Discussing the referral question with the bedside nurse can provide invaluable information about the specific context of concerns as well as provide a broader perspective on patient functioning and family dynamics. Similarly, speaking with other key health care providers intimately involved in matters related to the referral question (e.g., speaking with the physical therapist when a patient is having panic attacks during

physical therapy) provides essential information while also establishing and maintaining a collegial relationship which is vital for multidisciplinary interventions.

*Patient/Family Assessment.* Due to the acuity of medically hospitalized patients and the realities of the modern hospital environment, a high degree of flexibility and problem solving is required when conducting the evaluation with the patient. The patient's privacy may be compromised by the presence of medical and nursing staff, visitors and roommates, and multiple distractions may exist such as beeping computerized monitors. In addition, patients' ability or willingness to engage may be compromised by illness- or treatment-related factors such as feeling physically ill or being in pain, being sedated by medication, sleep deprivation, or agitation or confusion. Many consultation needs are identified by the medical team rather than the patient, who may not understand the rationale for the consult or even be aware that a consult was placed. Some patients interpret the presence of a mental health provider as a sign that their medical situation is not being appropriately validated or that someone thinks they are "crazy." Patients' own biases against mental health care provision based on their own previous experiences, stories they have heard, or media images may also impact engagement. Therefore, the CL psychologist must be prepared to deal with the patient's resistance, fear, anxiety, and lack of knowledge on how they might benefit from the consultation.

Acknowledging the ambivalence that the patient may experience in meeting with a psychologist and soliciting their feelings related to the consultation can be important first steps in conveying genuine concern about the patient, the importance of focusing on helping the patient for their own sake (i.e., not just because the physician is "upset" with them) and identifying patient-generated goals for the consultation. Other strategies to maximize rapport include minimizing interruptions by checking in with nurses so that critical care can be completed before beginning, posting "please do not disturb signs" and letting the patient guide whether or not friends or family members should be present. The patient may be accustomed to care providers standing at the foot of the bed looking down at them; just the simple act of pulling a chair up next to the bed in a position which maximizes the ability of the patient to maintain eye contact may establish a different dynamic than what is had with other care providers.

Issues of confidentiality should be discussed, particularly what type of information will likely be shared with the medical team and the degree of specificity of that information. While most patients have signed the hospital's consent to treat document which includes the consent to seek consultation/intervention from other hospital services, informed consent for assessment and treatment should also be obtained per American Psychological Association (APA) guidelines (except in the case of assessment to determine mental capacity) [65]. Even if the hospital has requested the consult for a patient who is declining services, it is still reasonable to attempt to meet with the patient in order to inform them about the process so that their consent is truly "informed." Oftentimes, patients will agree to meet with the psychologist once in-person contact has been made.

*Patient Interview Data* The actual content of the information collected may differ as a function of the referral question, the orientation of the CL service, and the amount of time available to conduct the evaluation (e.g., 1 h vs. 30 min prior to critical procedure that patient is refusing). For example, some CL services conduct complete psychiatric evaluations on all patients, resulting in a 5-axis mental health diagnosis in all cases [66]. In these cases, a comprehensive broad psychosocial assessment would include:

1. *Mental status exam*, including appearance, cognitive status, mood, affect, psychosis/safety risk assessment, thought processes/content, speech, appearance, insight, judgment, and impulse control.
2. *Psychiatric history*, including careful review of history of any psychiatric symptoms/episodes, inpatient hospitalizations, outpatient therapy, known diagnoses received and suicide attempts (including method and intention). Also, assess family psychiatric history.
3. *Substance abuse history*, including drugs used and/or choice, age at first use, current usage patterns, drug-related psychosocial and physiological consequences, means of supporting habit (including HIV-risk behaviors), longest period of abstinence in uncontrolled situations, and past rehab/detoxification admissions. Also, assess family substance abuse history.
4. *Social history*, including living/housing situation, marital status, presence of children, employment, and insurance status. Also includes quantity and quality of social support as well as factors that affect the patient's status such as cultural/ethnic identity, sexual orientation, religion and immigration status (legal/illegal), domestic violence, military status, and education level/literacy.
5. *Referral concern specifics from patient perspective*, including the history of the specific referral concern, the patient's attributions and concerns, often utilizing direct quotes that capture the patient's language related to the concern.

In other situations, the evaluation may be much more focused on the immediate referral concern, especially if relevant to immediate medical care. For example, in these situations, the assessment might include:

1. *Mental status exam*, focusing on appearance, affect, mood, and noting only areas of concern
2. *Referral concern specifics* as noted above
3. *Current symptomatology related to referral concern*, including behavioral, cognitive/emotional, interpersonal, and physiological
4. *Biopsychosocial areas most directly related to referral concern*, such as relevant family/peers/academic/work issues, premorbid emotional functioning, medical- or disease-specific factors impacting presentation, presence of other stressors, and previous/current coping strategies

Development and use of routine intake/follow-up forms can assist with data collection and written reports (see Appendix A for examples).

*Standardized Assessment.* The use of standardized assessments can be an important component of gathering valid data quickly. There are common standardized

instruments to assess cognitive status in adults, including the Montreal Cognitive Assessment (MoCA) [67], the Mini Mental Status Exam (MMSE) [68], and the Confusion Assessment Method [69]. Additional measures to evaluate emotional status include the Derogatis Brief Symptom Inventory [70] and the Beck Depression Inventory (BDI) [71]. Similar measures have been developed to be used in pediatric populations [38].

*Behavioral Observation.* Beyond what is documented in the mental status exam, behavioral observation directly related to referral concern is also important. Observing the antecedents and consequences for behavior can illuminate both etiology of behavior and guide intervention. For example, observing an actual dressing change with a patient referred for anticipatory anxiety can be instrumental in targeting interventions for both patients and health care providers. In addition, it is often useful to observe any variability in behavior that may occur in the presence of different family members or medical staff.

*Written Documentation.* All written consultation reports should include basic information such as name of patient, service-requesting consult, reason for and date of consult, mental status examination, critical information obtained during assessment, impressions/recommendations, psychologist's future plan of care, and contact information. While some services will document all information that was obtained, other services will record only the pertinent "need-to-know" information particularly salient to the referral question, the conceptualization, and the plan of care. The medical chart typically has fewer protections than does a mental health chart [72], so documentation should be written with the expectation that the patient/family will read the note, health care providers will communicate findings to the patient/family without fully understanding the context/ramifications of the information, and the information could be stigmatizing or otherwise unhelpful in uneducated hands. Accordingly, considerable thought should go into which information is presented and how it is communicated. When more sensitive information needs to be included, consultation notes can be considered "mental health progress notes" and separated from the medical progress notes. However, this is often counterproductive to multidisciplinary collaborative care [72]; thus, many psychologists in the hospital will choose to place their consultation reports among the general medical progress notes to maximize usefulness to health care providers and amend their documentation accordingly. Psychologists in the medical setting need to be cognizant of the issues related to the management of health care information, in particular the Health Insurance Portability and Accountability Act (HIPAA) legislation [72].

The most helpful and important section of the written consultation report is the impressions/recommendations section. Here is where the conceptualization of the patient is captured, and, when done well, it provides a comprehensive clinical snapshot of the patient including the biopsychosocial context for patient presentation as well as team recommendations so that other providers can provide more empathic and effective care. The impressions section should include highlighting patients' psychosocial strengths to fortify as well as areas of concern or deficits. Caution should be used when generating hypotheses (or stating definite etiologies)

for patient presentation which stray too far from data collected directly from assessment. In some cases, the CL psychologist may not be fully confident about a conceptualization due to the brief nature of the evaluation or the medical compromise of the patient. In these cases, it is better to offer one or two possible hypotheses about patient presentation rather than extrapolate too far from what is known.

When deemed appropriate or necessary, assessments should include a diagnostic impression of the patient including Axis I–V based on the current *DSM* [27]. Of course, many patients seen for a consultation do not meet criteria for a significant psychiatric disorder, and are instead typically functioning individuals who are now in a highly stressful situation that is exceeding their coping resources or requiring yet-to-be-developed new coping skills. In this case, psychologists who need to generate a diagnosis in order to facilitate billing for reimbursement from mental health funds typically will use the *DSM 309* “Adjustment Disorder” diagnoses or the *DSM 316* “Psychological Factor Affecting Medical Condition” diagnosis [27]. However, there is increasing awareness in the behavioral medicine and medical field that assigning a psychiatric diagnosis and tapping mental health funds when addressing psychosocial concerns directly related to a medical issue may not be appropriate [37, 73]. See Appendixes B and C for sample case reports.

This movement toward conceptualizing health-related problematic emotions or behaviors as a function of the medical diagnosis rather than psychopathological corresponds with the development of alternative billing options accessing medical funds and bypassing need for psychiatric diagnoses. For example, health and behavior (HB) Current Procedural Terminology (CPT) codes, which became active in 2002, are used for evaluation and management of behavioral issues directly related to medical issues, and are billed under the appropriate medical diagnosis [37, 74]. Reimbursement issues persist for these codes in that some commercial insurances and Medicaid do not cover them. However, in some instances HB CPT codes reimburse at higher rates than do mental health CPT codes, and educating insurance companies on the rationale for services and use of HB codes can improve reimbursement rates within institutions [37]. Growing use of HB codes among psychologists working in the hospital setting will likely improve utility of these codes. Given that most CL services do not cover their costs by professional fees and therefore require other sources of funding to function (thereby making them more vulnerable to funding cuts), maximizing reimbursement is important [39, 40].

It is often important to go beyond the written report and convey impressions and recommendations directly to the physician. This is especially true when there is a need for patient advocacy, such as a patient is not feeling that the team is being collaborative, or when the psychologist believes that the patient would benefit from an alternate treatment direction (e.g., delaying a procedure until the patient has been taught skills to manage anxiety). Discussions with health care providers which place the patient within a broader biopsychosocial context can facilitate perspective taking and patient-centered care. Verbal interactions allow health care providers to ask clarifying questions, or to problem solve on how to put recommendations into action. It is frequently these conversations which are the foundation for collegial relationships.

*Coordination of Care.* During the CL evaluation of patients with complex medical issues, the psychologist may learn that the patient does not understand their medical status, the services involved in their care, or the treatment plan. Alternatively, the CL psychologist, in speaking to the multiple disciplines involved with the patient as part of the system assessment, may also become aware of inconsistencies in the treatment plan or information provided. A care conference with a family-centered care approach helps all involved in the treatment utilize the same methods and communicate with the same language to reach a working consensus. The CL psychologist can maximize the effectiveness of this intervention by working with the patient to clarify patient concerns, then provide this information in advance to health care providers. The CL psychologist who requests the care conference may also be expected to lead it, and running the meeting effectively and keeping it to the agreed-upon time limit are essential for health care providers' ongoing willingness to partake in these activities. A written record of the information provided and treatment plan discussed is extremely helpful for both the patient and health care providers.

The CL psychologist also plays a crucial role in addressing post-discharge treatment needs. Occasionally, the consultant may have to consider the appropriateness of an inpatient psychiatric treatment. This decision requires familiarity with the voluntary and involuntary legal statutes of the state and local mental health acts, an evaluation of the suitability of available psychiatric units, and a determination that the psychiatric unit can provide the necessary medical/surgical care required by the patient. In general, transfer to an inpatient psychiatric unit is not appropriate until the patient's acute care medical issues have been resolved. Other times, the CL psychologist will arrange for outpatient follow-up services, either with the same psychologist to enhance continuity of care or with other providers in the patient's community. When follow-up care is transferred to another provider or agency, it is helpful to have the patient sign a release of information so that information can be shared with the new mental health provider, especially if they may not be familiar with relevant medical issues. Discharge plans should be initiated as early as possible and in conjunction with social services, particularly for patients who lack health insurance.

## **Evidence-Based Intervention Approaches**

In addition to assessment to enhance comprehensive conceptualization of patients and to make team recommendations, consulting psychologists should always consider what intervention can be done to improve patients' hospital and post-discharge experiences. Psychologists doing consultation-liaison can capitalize on the hospitalization as a "teachable moment" when the adverse event resulting in the hospitalization may render a patient particularly open to changing health-related behaviors [75]. In addition, patients are often in very stressful situations and are being asked to cope with new information, activities, and experiences in the hospital, for which



they may not have the skills to adapt. Hospital-based psychosocial interventions can have important, immediate, and transformational impacts on individuals. Typically, interventions are pragmatic, short term, use a biopsychosocial approach, and are based on a comprehensive assessment of the biological/medical aspects of the patient. There are a wide range of empirically based interventions targeting emotional and behavioral adaptation to consider. Although most interventions are studied and applied in outpatient populations, they can be generalized to the inpatient setting.

*Cognitive-Behavioral Therapy.* The cognitive-behavioral model posits that the content of a person's thoughts impacts both emotion and behavior. Typical interventions for CBT include thought, emotion, and behavior monitoring to provide clarity on their interaction, challenging unhelpful thoughts with "evidence" documented through behavior tracking, and the use of goal setting, successive approximation, and contingent reinforcement to directly change behavior [76]. Numerous clinical studies testing CBT support its utility for a wide range of mental health issues [77]. CBT has also been shown to be efficacious in promoting adjustment and/or health behaviors in numerous adult medical populations such as chronic pain patients [77] and individuals with cancer [78], atopic dermatitis [79], chronic fatigue syndrome [80], and coronary heart disease [81]. Furthermore, it has been shown to be successful with pediatric health concerns such as obesity, abdominal pain, headache, encopresis, procedural pain/anxiety, feeding problems, and adherence [76, 82]. As noted previously, CBT has been effectively utilized in inpatient medical settings.

*Behavioral Activation.* BA is based on the theory that depression is an avoidance behavior in response to an environment characterized by low levels of positive reinforcement and/or high levels of aversive responses [83]. The goal of BA is to reengage patients with specific activation strategies in order to break negative avoidant behaviors and increase opportunities for positive experiences [83]. Interventions focus on engaging in scheduled, preferably pleasant and positively reinforcing, activities while monitoring behaviors and mood in order to examine their relationship. BA has been shown to be efficacious for a wide range of clinical issues with children and adults [84]. It has also improved mental health status in medical populations, such as patients with cancer [85], and is being tested as a means to promote healthy behaviors such as improved nutrition [86]. BA has not been tested specifically in the hospital environment, but may be particularly relevant in terms of implications for both mental and physical health [87]. Physical injury, illnesses, need for rest, and/or isolation due to infection risk may reduce opportunity for patients to engage themselves in diverting or pleasant activities. For example, due to fear of pain, postsurgical patients may avoid physical activity such as sitting up in bed to visit with family or to take a walk to the gift shop, with negative implications for both their physical recovery and their mood. The consultation psychologist can collaborate with patients and health care providers to create a list of activities pleasurable to the patient and appropriate based on medical status (e.g., daily living skills, asking friend to come visit, doing a puzzle). Articulating clear expectations, guidelines, and steps toward reasonable goals can increase positively reinforcing

activities. A schedule is one way to provide predictability, highlight activity as the goal, and measure success.

*Acceptance and Commitment Therapy (ACT).* ACT is a cognitive-behavioral intervention that promotes cognition acceptance rather than change. The goal of ACT is the enhancement of psychological flexibility in order to take value-driven meaningful and adaptive action. Psychological flexibility is enhanced through helping individuals distinguish between their thoughts and themselves as the observer, enhance attention to the present moment, and reduce experiential avoidance of negative emotions or cognitions in order to have a broader, more adaptive behavioral repertoire [88]. There is growing research that supports ACT as an efficacious treatment for a range of mental health issues [88], although some have questioned the methodological rigor of ACT studies [89]. ACT has been applied to health-related concerns, with efficacy reported for diabetes self-management [90], chronic pain [91], epilepsy [92], and smoking cessation [93]. Application of ACT to an inpatient hospital setting has not yet been documented, but the focus on engaging in meaningful activities even while having unpleasant experiences may be particularly relevant for hospitalized medical patients who are asked to participate in health-promoting behaviors that may be aversive or who are facing chronic, sometimes life-limiting, illness for which “avoidance” is impossible. In addition, ACT has been utilized in a relatively brief intervention (BI) format (e.g., 4-h intervention for chronic pain [94]), which may be conducive to the hospital setting.

*Motivational Interviewing (MI).* MI is a counseling approach to healthy behaviors by targeting the exploration and resolution of client’s ambivalence to make behavior change [95]. MI is sometimes used as a precursor to other interventions, such as CBT. While originally developed for the substance abuse population [96], MI has been used effectively across a broad range of health issues including hyperlipidemia [97], cystic fibrosis [98], acute stroke [99], diabetes [100], asthma [101], and HIV [102]. MI has been less studied in the inpatient hospital setting although there are promising results for its use in the emergency department to decrease both drinking-related risky behavior [103] and tobacco use [104]. As an intervention that has been utilized in brief encounters, MI dovetails well with the consultation model. Negative associations with the hospital experience may highlight patients’ own arguments for positive behavioral change, making MI during the inpatient consultation particularly effective.

*Relaxation-Based Interventions.* Two psychological interventions that particularly target the mind–body interface are self-hypnosis and biofeedback, both of which are frequently used in medical populations. During self-hypnosis, the therapist helps the patient enter a “hypnotic” stance which involves physical relaxation, absorbed and sustained attention on targets, lack of judgment or censoring, and altered sense of time, location, and self [105]. Then, suggestions are made for the purpose of strengthening coping responses both during and after the hypnotic experience [105]. Hypnosis has been found to be effective in enhancing coping and/or functioning in numerous medical and physical disorders, such as pediatric and adult chronic pain

[105, 106], conversion disorder [107], asthma [108], postsurgery recovery [109], burn treatment [110], and chemotherapy adverse effects [111]. The ability of hypnosis to bring immediate relief during periods of acute distress renders it a highly valuable intervention for psychologists working with medical inpatients.

Biofeedback is a biobehavioral intervention which uses real-time monitoring of physiologic responses to enhance voluntary control of targets such as the relaxation response or specific muscle control [112]. Biofeedback has been shown to be effective for a variety of medical conditions including migraine and tension headache, temporomandibular disorders, chronic pain, and urinary incontinence [112]. Typical biofeedback protocols include multiple sessions, although there is some evidence to suggest that even a one-session biofeedback intervention can be effective [113]. Biofeedback can be easily used in the inpatient medical setting due to user-friendly software requiring only a laptop computer and finger sensors (e.g., Heartmath LLC, <http://www.heartmath.com/>; Wild Divine, <http://www.wilddivine.com/>), or simple finger thermistor, and it may be particularly helpful in reducing anxiety and enhancing patients' self-efficacy and sense of control in a situation which may be minimizing these experiences. Before using biofeedback in the hospital setting, it is important to review the procedure with health care providers to insure its safety given medical status thermistor, and contraindications for use may include physical injury-preventing typical nervous system responses, use of sedating medication, and significant malnourishment.

## **In Practice**

### ***Specific Clinical Issues***

*Depression.* Depression is one of the most common reasons for referral to the inpatient CL psychologist, with prevalence ranging from about 14 to 50% in patients referred for psychiatric consultation [36]. Depression is characterized by negative cognitions (e.g., catastrophic thinking, hopelessness, guilt, perceived lack of control) and mood states (e.g., sadness, irritability, anhedonia) as well as impaired behavioral (e.g., withdrawal, avoidance, reduced self-care) and physiological (e.g., impaired sleep, lethargy, and decreased appetite) responses [27]. Clinical and sub-clinical depressive symptoms tend to be high in medical populations and even higher in inpatient medical settings [114]. The symptoms and prognosis of chronic diseases are negatively impacted by depression (i.e., heart disease, stroke, diabetes mellitus, HIV/AIDS, and cancer) [115]. Depression can also interfere with important behavioral health factors (i.e., decision making or adherence) and effective communication. There are a number of factors related to the inpatient experience that may contribute to increased presentation of depressive symptoms, including perceived or actual loss of control, physical illness or confinement interfering with access to pleasurable activities, and negative affect corresponding with aversive

procedures and prognosis. Assessing and ameliorating depressive symptomatology are important for maximizing effectiveness of inpatient stays.

Evidence-based assessment strategies specific to depression have been developed for use in health care settings [116]. Several caveats should be kept in mind when assessing depression in inpatient medical settings. Many medications may have sedative effects, and sleep interruption can also result in behaviors that mimic depression (i.e., sleep difficulty and lethargy). In children, steroids may increase behavioral acting out and irritability. In addition, patients may have very different presentations to medical teams during early morning rounds/assessments than they may have throughout the day with bedside care providers and/or family and friends. CBTs have been shown to improve depressive symptoms across a range of ages [77, 83, 88], but intervention strategies may need to be modified to accommodate the inpatient settings. For example, sedation may interfere with a patient's ability to monitor thoughts and identify pleasant activities to enhance BA. Typically, it is useful to focus on the depressive symptoms that are most proximally interfering with medical treatment and/or recovery. Monitoring mood ratings and functional status will determine intervention success, such as a 25% improvement in mood ratings or participation in 75% of required activities or social interactions.

*Anxiety.* Anxiety is understood as a normal adaptive cognitive and autonomic response to a perceived threat which can, in the extreme, create significant impairment and distress. Both clinical and subclinical anxieties are highly prevalent in medical settings [117] and can exacerbate symptoms of medical illnesses [115]. Anxiety is also often associated with chronic physical disorders (i.e., hypertension, arthritis, asthma, ulcers) [118]. Considerable stress is reported in association with both pediatric [14, 16] and adult [15, 17] medical illness and treatment. There are multiple sources for anxiety in hospital patients, including new diagnosis (or uncertainty of diagnosis), aversive procedures, pain, acute stress reactions to medical trauma, and heightened arousal/fear in response to the general hospital experience. It is critical to understand the etiology and manifestation of anxiety in order to properly target intervention, and a careful interview as well as behavioral observation is important. Sometimes, it is challenging to distinguish anxiety from physiological responses such as pain or respiratory distress, therefore ongoing collaborative assessment is critical. It is also possible that the patient's experience of anxiety symptoms may be directly due to the physiological effects of a medical condition [27] or effects of medication.

CBT treatment for anxiety has been widely studied and its efficacy has been well established [77, 119]. Much of this research has been conducted with adults, but manualized treatments have been adapted for children [120]. CBT (which is focused on exposure to the anxiety-provoking stimuli and often includes relaxation and/or self-hypnosis) has been used with hospitalized medical patients for anxiety related to procedures and traumatic medical events [14, 49, 121]. Given the medical setting, some essential components of CBT may be contraindicated, and creative implementation or focusing on other CBT aspects is necessary. For instance, a consult may be requested for a ventilator-dependent patient with a tracheostomy

who is having panic attacks during care, resulting in acute respiratory distress. In this case, inducing a panic attack for purposes of exposure is not reasonable, and more graded exposure to the stressor will be necessary, perhaps with adjunctive anxiolytic medication during care until sufficient skills are developed. Oftentimes, educating patients on upcoming procedures or providing more medical information can be very helpful in reducing anxiety, although the amount of information and how it is presented needs to be matched to patient preferences for information and developmental level [122]. More recently, brief and/or “stepped” versions of CBT (including computer-based applications) have been used successfully in primary care settings, which may translate well to the hospital stay [123]. Treatment success can be monitored through use of distress ratings (both within session for exposure activities and global daily ratings) and recording positive behavior engagement, with criteria set as engagement in feared activity with low distress.

*Mental Status Change/Delirium.* Delirium is an acute disturbance of consciousness not accounted for by a preexisting or evolving dementia, depression, or a psychotic process. Behavioral symptoms of delirium include disorientation, disorganized thinking, decreased alertness, agitation, hallucinations, delusions, and/or emotional lability, which can all fluctuate frequently interspersed with lucid periods [27]. Delirium is the most common psychiatric syndrome found in the general hospital setting, occurring in 10–24% of the general hospital population, 10–60% of post-surgical patients, 60–80% of intensive care patients, and up to 90% of terminally ill cancer patients [124]. Risk of delirium increases with age [27, 124] and older patients may present with a “quiet delirium” during which atypical behaviors may include withdrawal or classic symptoms, but to a lesser degree [125]. Individuals experiencing delirium have increased mortality and morbidity and have longer hospitalizations [124]. The etiology of delirium is best characterized as multifactorial, and common causes of delirium include exacerbation of preexisting disease, drug toxicity or interactions, and infections with accompanying sepsis. Sleep deprivation, which is notoriously compromised in the hospital setting, is also associated with delirium [126].

Delirium must be distinguished from dementia which is a progressive decline in memory and at least one other cognitive area in an alert person and is rare in patients under the age of 50. Diagnosis of delirium is based on clinical observation; no diagnostic tests are available although screening tools may be of assistance (e.g., the MMSE and the Confusion Assessment Method) [127, 128]. Treatment of delirium involves targeting and treating any physiologic source of delirium. Treatment of symptoms of delirium can include both pharmacologic and nonpharmacologic interventions, although using medication may actually exacerbate delirium. Strategies that the CL psychologist can recommend include removal of immobilizing devices (e.g., IV lines, physical restraints) as soon as possible, promoting day–night cycle, decreasing social isolation, providing adequate cognitive and physical stimulation (e.g., physical therapy), providing orientation mechanisms (e.g., hearing aids, eye glasses, clock/calendar), and improving nutrition/hydrations [124].

*Substance Use Disorders.* Nine percent of the US population meets criteria for an alcohol or drug use disorder [129] and about 1 out of every 14 hospital stays involves a substance-related diagnosis [130]. Research shows that untreated alcohol and drug users bear a disproportionate burden of medical and mental health problems [131], highly utilize emergency and acute care hospital services [132], and are more likely to be readmitted with untreated acute and chronic health conditions [133, 134]. Only 25% of substance users in need of formal treatment ever seek it and because alcohol and drug dependence still carry significant stigma, patients often do not communicate the extent of use to their providers [135, 136]. The relative lack of education in both medical and psychology graduate programs regarding substance abuse leads to poor identification, treatment, and appropriate referral of patients with SUDs [137]. Hospitalized patients with undetected SUDs face risks that include life-threatening substance withdrawal; development of agitation, anxiety, and delirium; inadequate analgesia and sedation; problematic ventilator management and weaning; and serious levels of psychological and physical distress [138], resulting in increases in both complexity and costs of treatment [139]. In an effort to improve the care of patients and training of future clinicians in the acute care hospital setting, some hospitals across the country have developed Substance Abuse Consultation Services to assist with the management of their hospitalized patients with suspected SUDs [75]. The Substance Abuse Consultation Service, sometimes separate from the CL service and sometimes combined, serves to advocate for substance-using patients with medical conditions, such as ensuring that these patients receive appropriate pain management. Murphy et al. [75] have described the development and implementation of a substance abuse consultation service as a complement to the CL service.

Withdrawal is a medical experience particularly salient in patients with SUDs. While some patients present to the hospital in withdrawal, other patients will develop withdrawal during a hospitalization due to lack of access to substances. Withdrawal symptoms vary according to class of substance used, but generally are the opposite of the effects of the substance [27]. Delirium tremens (DTs) is the most severe manifestation of alcohol withdrawal that can occur within 72 h to 10 days following the last drink, and symptoms include agitation, global confusion, disorientation, hallucinations, fever, and autonomic hyperactivity (tachycardia and hypertension). Risk factors for developing DTs include coexisting acute illness, long duration of alcohol intake, large volume of alcohol intake, severe withdrawal symptoms prior DTs, prior history of seizures, prior history of detoxification, and intense alcohol craving. DTs is a medical emergency that requires prompt recognition and treatment as it can be fatal (current mortality rate is from 5 to 15%) as a result of respiratory failure and cardiac arrhythmias. Patients may need to be transferred to intensive care units to prevent these complications. While withdrawal from alcohol or drugs is more notable, nicotine withdrawal can increase anxiety or heighten cravings for cigarettes in as little as 1 h from the last cigarette, with symptoms worsening within 1–3 days after abstinence [140]. In instances when long-term smoking cessation is not realistic, a nicotine patch is sometimes used to combat these symptoms.

An SUD-related hospitalization is a potential entry point into appropriate, substance abuse treatment services and primary care. Hospitalization provides a unique opportunity to address the negative impact of high-risk behaviors on the patient's health. MI [95] and BIs [141] are the most common counseling approaches used to promote inpatients to engage in self-directed change and/or to seek additional psychosocial treatment for these disorders. Brief empathic interventions consisting of even a single session can decrease substance consumption and improve health outcomes [141]. For injection drug users not ready for treatment or at risk of relapse, harm reduction may be an effective strategy for reducing risk by educating them on where to access new needles and syringes, safe disposal and storage of needles/syringes, safe techniques for injection, and how to prevent overdose. Hospitalization also provides an opportunity to obtain a sexual risk assessment, screen for sexually transmitted infections, and provide risk-reduction counseling regarding HIV.

*Somatoform Disorders.* Somatoform disorders are characterized by presence of physical symptoms that are not adequately explained by a medical condition [27]. They are some of the most common psychiatric conditions found in medical inpatients [8], with somatoform pain disorder, hypochondriasis (misinterpretation of physical symptoms or functions leading to preoccupation with a belief that one has a serious disease) and conversion disorder (medically unexplained voluntary motor or sensory symptoms) particularly prevalent [142]. Patients with somatoform disorders incur higher outpatient and inpatient medical utilization and health care costs [143]. Current theories of somatoform disorders highlight the role of attentional processes such as heightened monitoring of bodily processes/experiences and of cognitive factors, such as catastrophic misinterpretation of bodily sensations [144]. Cognitive-behavioral interventions have been effectively used to treat somatoform disorders [145], including one-session CBT [144]. For some somatoform disorders, such as conversion disorder, an inpatient multidisciplinary rehabilitative approach involving psychology and physical/occupational therapy is most helpful [146, 147].

*Coping with New Diagnosis/Chronic Illness.* Hospitalization often coincides with the distressing experience of receiving a new diagnosis of a medical problem or experiencing a worsening of medical status in a chronic illness. Individuals and families are faced with coping with challenges such as loss of control, changing self-image, increased dependency, stigma, and possibility of living with long-term illness and disability [148]. The period immediately following the new diagnosis of a medical condition poses the greatest risk of psychosocial distress among patients and family members [149, 150], and while most patients subsequently adjust well to their illness, some remain at higher risk for psychological problems [148, 149]. A number of factors have been shown to be related to the better adjustment to chronic illness. For example, establishing health-promoting family routines and rituals can have positive effects on both mental health and medical status [151]. In addition, matching coping strategy to specific stressor, such as problem-solving coping in areas over which a person has control and accommodative coping in areas where a person does not have control, may also improve psychosocial outcome [152]. Acceptance of the medical diagnosis has been shown to improve both psychological

adjustment and engagement in treatment [90, 153] whereas avoidance-oriented strategies may initially seem beneficial but are less adaptive in the long term [153]. In fact, post-traumatic growth (“adversarial growth”), in which individuals report positive changes as a result of their medical illness, has also been reported and linked with factors such as acceptance, problem-focused coping, and perception of control [154]. Thus, the CL psychologist in the inpatient setting has multiple targets of intervention, including facilitating acceptance, helping patients match coping style to stressor, facilitating development of family routines, and highlighting areas of control. Interventions designed specifically to prevent maladjustment and enhance adaptation to medical illnesses have been shown to reduce patient distress and can be adjusted to the inpatient setting [148]. Depending on patient presentation, treatment approaches for anxiety (e.g., relaxation techniques), depression (e.g., CBT), and psychoeducation can be utilized. Clinicians can help by normalizing responses and reinforcing adaptive coping skills. Children’s coping can be enhanced by developing behavioral plans to provide predictability and control (i.e., schedules), with positive reinforcement for health-promoting behaviors.

*Pain.* Pain is one of the most frequent and severe symptoms experienced within the medical setting, with estimates of pain prevalence ranging from around 40 to 60% of inpatients [155–158]. Estimates of inadequately treated pain range from 20 to 30% for both pediatric [159] and adult patients [160]. Unmanaged pain contributes to increased personal suffering and extended hospitalizations and costs [161]. The term “pseudoaddiction” is used to describe apparent drug-seeking behavior in patients with severe pain that is not adequately treated and is distinguished from true addiction by its resolution with adequate pain control [162]. Pain patients are likely more often referred to the CL service when medical management has been unsuccessful, when the clinical team believes psychosocial factors have a major role in pain behaviors (e.g., somatoform pain disorder [27]), or when there is a breakdown in patient–provider communication around pain management [163]. Rather than conceptualizing pain from either a medical *or* a psychosocial perspective, multidisciplinary approaches have been consistently shown to be most effective [164].

Current theories of pain emphasize the role of psychosocial factors in the pain experience such as pain-related beliefs, emotional distress (particularly anxiety, depression and anger), stress, behavioral avoidance/inactivity, environmental responses to pain behavior, and attentional processes [165]. Catastrophizing about the pain experience has been shown to be a significant predictor of chronic pain persistence, as has other maladaptive cognitions such as the belief that pain is uncontrollable or that a complete absence of pain is necessary for functioning adequately. Anxiety about the risk of increased pain when active, low self-efficacy, over-solicitous family members, and cumulative trauma experiences also seem to contribute to worse pain presentation [166, 167]. In addition, women tend to be more at risk of chronic pain than men [168]. Awareness of these factors related to longer-term pain duration is helpful for the CL psychologist in identifying high-risk patients. Chronic pain is associated with psychological comorbidity and, when long-standing, increased



suicide risk, so a thorough assessment of affect and depressive cognitions is also important.

There are a number of well-validated measures to assess pain in both children [169] and adults [155]. Psychological treatments, primarily based within the CBT model, have been shown to be efficacious for both pediatric [170] and adult [171] pain management, including procedural pain [172]. CBT has been used in inpatient pain rehabilitation programs [173], and this approach can generalize well to the hospital setting, especially when part of a multidisciplinary treatment plan. For example, referrals to physical therapy can avert or improve activity-avoidant behaviors in patients, prevent more global deconditioning, and provide data to combat catastrophic thinking. Using self-hypnosis and biofeedback can help with physiological tension reduction and cognitive distraction [174, 175]. With patients who have been undertreated for pain and are presenting with pseudoaddiction, establishing trust between the patient and the health care team as well as providing appropriate and timely analgesics to control the patient's level of pain is important. Patient fears of unremitting pain, as well as feelings of unacknowledged suffering and helplessness, need to be addressed. Systemic interventions can include providing health care providers and family members guidelines on maximizing patient coping, teaching health care providers communication strategies which validate patients' pain while still promoting psychosocial interventions [176], and using stimulus control such as increasing room brightness [177]. While a reduction in pain ratings is a natural desired outcome (e.g., to below a "5" on a 10-point scale, or a reduction of 25%), increases in functionality are also indicative of treatment success.

*Nausea/Emesis.* Anticipatory nausea and vomiting, understood as a classically conditioned behavioral response to repeated episodes of physiological nausea and emesis, are frequently seen in oncology patients undergoing chemotherapy [178], and may also be related to gastrointestinal disorders such as cyclic vomiting [179]. Patients with higher levels of sympathetic reactivity are thought to condition easier [180] and pretreatment cognitions and expectations of nausea may be predictive of chemotherapy side effects [181]. Untreated anticipatory nausea can affect adherence to treatment protocols and possibly worsen the course of illness [178]. Cognitive-behavioral techniques, particularly relaxation, hypnosis, attentional distraction, and desensitization, are efficacious in treating anticipatory emesis [178], and can easily be employed in the inpatient setting. Distraction may be particularly helpful for pediatric patients [182]. Ratings of nausea or recording emesis occurrences can indicate whether treatment is having the desired effect.

*Loss Issues: End of Life, Disfigurement.* One of the most difficult outcomes of medical illness is the loss of life. In addition to aversive physical symptoms, individuals in the terminal stage of an illness face considerable emotional distress. Heightened rates of depression and other psychiatric disorders have been reported [183], and should be treated due to their effects on quality of life, communication, and decision making [184]. Family members of the patient also experience considerable psychosocial challenges [183]. Multiple treatment approaches have been used to facilitate coping during this stage, with little evidence supporting one approach over

others. In general, psychosocial support facilitating open discussion of fears and concerns, meaning-making out of experiences, clarification of values and reasonable goal attainment, and helping patients maintain a sense of themselves despite physical changes may facilitate quality of life [183]. Facilitating communication is one of the key functions of the CL psychologist. Providing strategies for discussing medical status with family members is often appreciated. For example, in the case of a dying child, it is recommended that the child “take the lead” with regard to how much and what type of information is shared [185]. The CL psychologist can also take a critical role in clarifying patients’ wishes for treatment, particularly if the family members’ wishes conflict with those of the patient [186]. Finally, providing the family with resources for grief and bereavement counseling following the patient’s death is another important role of CL psychologists. This is particularly important given the limitations involved with inpatient work that typically preclude follow-up services from being provided once the patient is no longer hospitalized. CL psychologists should work in conjunction with other support services available (e.g., palliative care, social work, child life, and pastoral care). Additionally, liaison support for members of the health care team, particularly those involved in patient care over long periods of time, should be offered when possible.

Coping with loss of physical capacity or change in body appearance is another potential CL referral. Disfiguring traumatic events (e.g., burns), congenital malformations (e.g., cleft lip/palate), or disease processes (e.g., amputation) are often associated with emotional difficulties such as depression, general anxiety, shame, body image anxiety, and interpersonal difficulties such as social anxiety [187–189]. Emotional distress related to disfigurement can extend the hospitalization stay, attesting to the importance of inpatient assessment and intervention [190]. Neither severity nor visibility of disfigurement has consistently predicted psychological outcomes; rather cognitive and behavioral factors, particularly those relevant to social anxiety, appear to be more correlated [189]. Cognitive-behavioral strategies, whether targeting general coping or more specific social anxiety, have been shown to be effective with these patients [189]. Components of CBT can begin during the hospitalization, such as using exposure and cognitive techniques (e.g., coaching patients to go to the gift shop while monitoring cognitions and mood) to facilitate anxiety related to being seen by other people.

*Suicidal Ideation.* Medical patients in general, and hospitalized medical patients in particular, are at an increased risk for suicidal ideation and attempts [191, 192]. Inpatient suicide is infrequent, with the most common method being hanging [193]. Post-discharge is when the majority of suicide attempts occur, often within the first month [194]. Risk factors present in medical patients which predict post-discharge suicidal behavior include substance use, depression, delirium/dementia accompanied by agitation and impulsivity, high level of external stressors, significant emotional distress by new diagnosis or management demands of a chronic illness, and poor prognosis [191, 193]. More typical risk factors, such as known psychiatric illness or past suicidal behavior, are not as common in suicidal general hospital patients [193]. Suicidal risk is assessed routinely during full diagnostic evaluations;

consultants who take a more referral-focused approach to assessment and intervention need to be mindful that common reasons for referral are also risk factors for suicidal behavior, and maintain a low threshold for asking about suicidal ideation. When suicidal ideation is present and the patient is deemed at risk of self-harm, continuous observation protocols should be implemented as well as daily involvement of a mental health provider [193]. Immediate treatment goals are crisis management, post-discharge safety plan development (typically including vigilant observation by loved ones), and facilitation of timely outpatient psychological or psychiatric intervention upon discharge. Whereas safety contracts do not appear to be a consistent deterrent to self-harm behaviors, and inpatient treatment has not been found efficacious in clinical trials, outpatient psychosocial treatments, particularly CBT, have demonstrated positive effects in reducing the risk of future self-harm [193, 195].

*Treatment-Interfering Behaviors.* CL psychologists are frequently consulted at the point that a patient's behavior is negatively impacting medical progress. This can take the presentation of patient refusal to take medication or participate in procedures/therapies, combative behavior compromising patient and provider safety as well as preventing medical care, patients who threaten to leave against medical advice (AMA), or patients/families whose interaction style is a deterrent to collaborative and effective medical care. In each case, a careful patient- and system-focused assessment is essential for honing in on appropriate team recommendations and effective intervention targets. For example, a child refusing to take his medication in the hospital may have a premorbid oppositional defiant disorder, lack pill-swallowing skills, not know the importance of the medication, be afraid of the effect the medication may have on him, be overwhelmed by the hospital experience and is seeking "control," be angry at his family for allowing the hospitalization to occur so is refusing to do a behavior that they clearly wish him to do, be disoriented by other medication, or be emotionally distressed by pain or lack of sleep (or a combination of these). Misunderstanding the etiological or maintaining factors of the behavior can result in deterioration of psychological and medical status. For example, health care providers may interpret anxious behaviors as oppositional, and take a confrontational rather than a supportive approach to managing the patient. The function of the CL psychologist is to provide immediate evidence-based intervention appropriate to the more relevant etiologic factor, with constant monitoring of behavioral compliance toward a goal often established by medical necessity.

More aggressive acts may be related to a primary condition (e.g., head trauma), medications (e.g., corticosteroids), substance withdrawal, under-managed pain, or secondary to comorbid psychiatric conditions. When urgent crisis management does not correct the behavior, the CL psychologist may recommend constant observation or restraints to ensure patient safety in the medical/surgical setting. Out of respect for medical necessity and individual autonomy, these recommendations are extremely serious and require documentation of medical need, follow-up monitoring, and reporting of consequences. Constant observation and restraints should be implemented for the shortest possible time with the least restrictive, though effective, means available, and are *never* used only for the convenience of medical staff.

Assessment and treatment of underlying issues that contribute to the patient's need for these interventions should be promptly and thoroughly assessed and mitigated. In all cases, safety of patient, other patients, and visitors and health care providers is of paramount importance, and all appropriate safety measures, including use of hospital security, should be considered.

Patients leaving the hospital AMA occurs in approximately 2% of all hospitalizations and increases patients' morbidity and mortality risk [196]. Factors increasing the likelihood of an AMA discharge include Medicaid/lack of insurance, lower socioeconomic status (SES), male gender, younger age, and substance abuse. The CL psychologist is frequently called urgently as the patient is preparing to leave the hospital. In these cases, the ability to quickly build rapport and provide immediate emotional support and crisis management is essential. Other interventions include clarifying underlying motivation for AMA, facilitating patient–physician communication, problem solving within the system to address reasonable patient concerns, and dealing with substance use issues if indicated [196].

Noncompliant patients (and families) are often perceived as “difficult” by health care providers, as are patients who present with psychiatric premorbidity, medically unexplained symptom, and poor communication skills. While medical teams may not label the patient as such at the time of referral (although some do!), the CL psychologist who senses frustration or anger on the part of the team may wish to probe further into the affective quality of the patient–provider relationship. It is important for the consulting psychologist to identify the source of the patient's frustration, let angry patients vent, legitimize feelings while not validating dysfunctional cognitions or condoning inappropriate behavior, and place firm limits as quickly as possible on verbally or physically abusive patients. At times, the CL psychologist may identify team behaviors that are exacerbating problematic relationships, such as avoiding contact with the family due to past aversive experiences [197]. Research also suggests there are physician characteristics such as high work stress or presence of depression or anxiety which may increase the likelihood of a patient being perceived as “difficult.” [198] Working with the medical team to understand their role in the difficult interaction and follow-through on team-focused recommendations is important, and benefits from established collegial relationships. Advocating for the patient by helping the team understand the biopsychosocial context for patient's presentation can improve patient–team communication and collaboration.

### ***Other CL Activities***

*Presurgery Psychosocial Evaluation.* Just as psychosocial factors play a role in health generally, there is a considerable research base supporting the predictive value of psychosocial factors postsurgical outcomes. With the limited supply of organ availability, pretransplant psychosocial evaluation has become an important component of identifying which patients are more or less likely to be successful posttransplant [199]. Thus, the CL psychologist in the inpatient medical setting

may be asked to contribute to a multidisciplinary evaluation related to transplant decision making. While a broad psychosocial assessment approach can be utilized, several important areas need to be targeted such as understanding of medical status and implications of transplantation, resource availability to manage significant impact on quality of life, and past health behavior patterns (e.g., adherence) which will be predictive of postsurgical health behaviors [199, 200]. Rapport building may be particularly challenging during these assessments because patients and their families are (or should be) aware that the information they provide will be shared with the medical team and may impact decision to transplant. Therefore, it is critical that the evaluation is presented as a means to identify any potential barriers that may need to be addressed in order to maximize successful transplant outcome, with appropriate interventions provided.

*Capacity for Decision-Making Evaluation.* Patients' informed consent to treatment is a legal necessity prior to any intervention. Inpatient CL psychologists are often requested to evaluate patient ability to give informed consent when patient presentation calls their mental capacity for this decision making into question. The key components of giving informed consent are the ability to understand the relevant medical information (with the assumption that the appropriate information has been presented), to demonstrate appreciation of the consequences of the options offered, to engage in rational evaluation of the options, and to clearly communicate a choice (see Table 16.2) [201]. Issues of capacity for medical decision making are more salient in medical and psychiatric conditions affecting cognitive processes (e.g., traumatic brain injury, stroke, dementia, or schizophrenia), but presence of these conditions alone does not automatically indicate lack of capacity [201]. Assessment of mental capacity to give consent should occur within the context of a careful interview, and several standardized instruments have been developed particularly for the purpose of accessing functional ability relevant to competence [202]. In the inpatient setting, it is critical to be mindful of temporary factors that may impact the ability to give informed consent such as immediate distress related to the hospitalization and medications that affect mental status. When a patient is found to not fulfill the criteria for capacity, the first step should be to attempt to ameliorate the barriers to competency. When this is impossible due to patient factors or impractical due to medical urgency, identification of substitute decision makers can proceed—this can be the physician in situations of medical emergency, whereas identification of legal representatives occurs in other cases [201].

### ***Other CL Issues***

*Cultural Issues.* Appreciation of the role of culture in patient presentation is important for the CL psychologist, whether the task is to diagnose mental disorders, facilitate coping with medical illness, or enhance engagement in medical treatment or family–team communication. Culture also impacts the manifestation of

**Table 16.2** Legally relevant criteria for decision-making capacity and approaches to assessment of the patient

Criterion	Patient's task	Physician's assessment approach	Questions for clinical assessment <sup>a</sup>	Comments
Communicate a choice	Clearly indicate preferred treatment option	Ask patient to indicate a treatment choice	Have you decided whether to follow your doctor's [or my] recommendation for treatment? Can you tell me what that decision is? [If no decision] What is making it hard for you to decide?	Frequent reversals of choice because of psychiatric or neurologic conditions may indicate lack of capacity
Understand the relevant information	Grasp the fundamental meaning of information communicated by physician	Encourage patient to paraphrase disclosed information regarding medical condition and treatment	Please tell me in your own words what your doctor [or I] told you about:	Information to be understood includes nature of patient's condition, nature and purpose of proposed treatment, possible benefits and risks of that treatment, and alternative approaches (including no treatment) and their benefits and risks
Appreciate the situation and its consequences	Acknowledge medical condition and likely consequences of treatment options	Ask patient to describe views of medical condition, proposed treatment, and likely outcomes	The problem with your health now The recommended treatment The possible benefits and risks (or discomforts) of the treatment Any alternative treatments and their risks and benefits The risks and benefits of no treatment What do you believe is wrong with your health now? Do you believe that you need some kind of treatment? What is treatment likely to do for you? What makes you believe it will have that effect?	Courts have recognized that patients who do not acknowledge their illnesses (often referred to as "lack of insight") cannot make valid decisions about treatment

Table 16.2 (continued)

Criterion	Patient's task	Physician's assessment approach	Questions for clinical assessment <sup>a</sup>	Comments
Reason about treatment options	Engage in a rational process of manipulating the relevant information	Ask patient to compare treatment options and consequences and to offer reasons for selection of option	<p>What do you believe will happen if you are not treated?</p> <p>Why do you think your doctor has [or I have] recommended this treatment?</p> <p>How did you decide to accept or reject the recommended treatment?</p> <p>What makes [chosen option] better than [alternative option]?</p>	<p>Delusions or pathologic levels of distortion or denial are the most common causes of impairment</p> <p>This criterion focuses on the process by which a decision is reached, not the outcome of the patient's choice, since patients have the right to make "unrea-sonable" choices</p>

<sup>a</sup> Questions are adapted from Grisso and Appelbaum [31]. Patients' responses to these questions need not be verbal. From *N Engl J Med*, P.S. Appelbaum, Clinical practice: assessment of patients' competence to consent to treatment, 357, 1834-40. Copyright © 2007 Massachusetts Medical Society. Reprinted with permission from Massachusetts Medical Society

psychopathology. For instance, a stress/anxiety response common in one culture may not neatly correspond with *DSM* diagnoses [203]. In addition, there are cultural variances within medical conditions and systems. For example, culture-related differences are observed in pain expression on behalf of the patient and pain estimation on behalf of the care provider [204]. Patients' understanding of their illness, motivation for treatment, and adjustment to their medical status and engagement may all be highly influenced by cultural norms related to hierarchy or autonomy, with cultural influences particularly salient during high-stress medical events such as determining do not resuscitate (DNR) status [205]. Different cultures have various understanding of the mind–body interface, which will likely impact psychoeducation related to biopsychosocial models of illness [206]. The CL psychologist is typically in the position of needing to assess and conceptualize a patient's presentation in a relatively short period, appreciating relevant biopsychosocial factors and their interaction with the hospital culture. The act of meeting with a mental health professional may have different connotations depending on the patient's cultural background, and willingness for emotional disclosure as well as normative responses for mental status examinations is also culturally variant [206]. The CL psychologist must have a working understanding of cultural issues common to the patients they are likely to see in order to place the patient's presentation in the most appropriate context to facilitate optimal psychological and health outcomes. The CL psychologist should also be familiar with legal and pragmatic issues related to the use of foreign-language interpreters [207].

*Developmental Considerations.* Incorporating a developmental perspective when conducting CL work is critical for effective conceptualization and intervention. For example, children of the same age can vary dramatically in their cognitive and emotional maturity, particularly during a hospitalization when they may present with temporary emotional and behavioral regression due to stress. Educating the medical team on children's cognitive capacity and premorbid functioning is important for optimizing the child's experience with health care providers. Providing children coping skills and coaching parents on appropriate types of support and levels of expectations are common CL activities. Adolescents, for whom independence and maintenance of peer social interactions are of primary concern, present with their own unique issues for inpatient hospitalizations [208]. Adolescence is a time when one is striving to be independent, so the lack of control and privacy that accompanies hospitalizations can be a notable challenge for teenagers, and may impact collaborative efforts. Research has shown that not only do adolescents want their care providers to be honest with them but they also want to be part of their medical care and have their concerns heard by providers [209]. CL targets often include facilitation of this communication and helping parents have realistic expectations for independence and responsibility for their adolescent. Hospitalized adults may experience considerable concern about financial status, or impact of illness on their family. Hospitalizations of elderly patients may be complicated by diminishing cognitive capacity as well as need for permanent discharge planning. Differential assessment for depression in the elderly may be particularly complex due to overlap



with symptoms of dementia such as disorientation, memory loss, and distractibility [210, 211]. Consulting psychologists also need to advocate for patients whose developmental status makes them particularly vulnerable, such as detection and reporting of child or elder abuse [212].

*Role of Family/Caregiver.* Family factors impact the emotional and physical outcomes of patients; thus, it is important for the CL psychologist to evaluate critical family variables when possible in order to provide the most comprehensive intervention and/or recommendations. In a commissioned report by the Committee on Health and Behavior, Weihs, Fisher, and Baird [213] report on the committee's findings related to families and health behavior and identify several protective and risk factors related to psychological and medical outcomes (see Table 16.3) [213]. Much more needs to be learned about these relationships, which are nuanced. For example, moderate family cohesiveness may be more predictive than high family cohesiveness, and being part of a highly coordinated family appears to put a patient at risk, perhaps due to less focus on own self-care and needs [213]. Family-focused interventions appear to lead to positive health behavior and family functioning outcomes [213]. For the CL psychologist consulted during rather brief hospitalizations, tackling long-standing family issues may appear daunting and unrealistic. However, the hospitalization of a loved one can bring into focus for families the importance of all family members within the system, and may set the stage for openness to look further in outpatient mental health settings into unhealthy family dynamics affecting psychological and health outcomes for all family members. At times, the psychological functioning of a family member may actually be the target of the referral, particularly if it is negatively impacting the patient's hospitalization. For example, parental stress, anxiety, and feelings of guilt and helplessness that often accompany having a hospitalized child can affect the parents' ability to provide discipline and structure to the ill child, thereby increasing the child's tendency to act out.

## Summary/Future Directions

To summarize, the hospital-based CL psychologist acts as a patient advocate by carefully assessing pertinent biopsychosocial factors critical to the referral concern, performing a patient-centered, strength-based, and system-minded analysis of the patient presentation, which is then communicated to the medical team to increase their understanding of the patient experience. The CL psychologist intervenes in real time to improve important treatment targets across multiple levels of the system, including the patient, family, and health care team, thereby promoting optimal psychosocial and medical outcomes as well as facilitating patient-provider relationships. The clinical psychology assessment and clinical outcomes research literature provides the CL psychologist with the necessary skills and tools to be confident in their use of evidence-based practice within their own area of specialty. And, because hospitalization may be one of the first venues a patient has for mental health

**Table 16.3** Summary of malleable family processes linked to disease management among targeted chronic diseases

Consistent linkages	Suggestive linkages requiring more study
<i>Protective factors:</i>	
1. Family closeness, mutuality, connectedness	1. Ease and comfort with direct communication about personal issues
2. Caregiver coping skills	2. Emotional expressiveness with little avoidance of emotional issues and little use of guilt
3. Mutually supportive family relationships	3. Moderate to high levels of emotional involvement
4. Clear family organization	4. Secure attachments
5. Direct communication about the illness and its management	5. Tolerance of repetition, ritual, and routing
<i>Risk factors:</i>	
1. Intrafamilial conflict, criticism, blame	6. Family time for recreation
2. Psychological trauma related to diagnosis and treatment of disease	7. Problem-solving capacity
3. External stress	8. Congruence of beliefs within the family about health and disease
4. Lack of extra-familial support system	9. Integration of rituals and routines in family life
5. Disease interrupts family member's developmental tasks	10. Families able to invest in disease management collaboratively and jointly own the disease
6. Perfectionism and rigidity	11. Family adjustment to diagnosis predicts family adjustment to disease management
	12. Patient-health provider alliance

(Copyright © 2002 by the American Psychological Association. Reproduced with permission. The official citation that should be used in referencing this material is Weihs K, Fisher L, Baird M. Families, health, and behavior: a section of the Commissioned Report by the Committee on Health and Behavior: Research, Practice, and Policy, Division of Neuroscience and Behavioral Health and Division of Health Promotion and Disease Prevention, Institute of Medicine, National Academy of Sciences. Families, Systems and Health: The Journal of Collaborative Family Health Care. 2002;20(1):7–46. The use of APA information does not imply endorsement by APA)

services, CL assessments, interventions, and recommendations can initiate long-needed mental health interventions within the inpatient “medical home.”

Clearly, hospital-based consultation liaison is an integral part of comprehensive patient care in the inpatient setting. However, more research is needed to further demonstrate and enhance its value and viability. While evaluation of clinical outcomes is methodologically challenging, determination of quality indicators (e.g., timeliness of referral) is one way to evaluate CL service effectiveness, as is more comprehensive assessment of patient, family, and health care providers’ satisfaction with services provided [20, 214, 215]. Because of the challenges of using traditional quantitative scientific methodology to determine if interventions conducted in the naturalistic setting are effective, utilization of other methods of determining clinical effectiveness, such as quality improvement methodology, can facilitate collection of outcome data in real time, thereby providing ongoing feedback to guide intervention strategies [216, 217]. With more systematic collection of these types

of process, satisfaction, and clinical outcomes, CL clinicians can make meaningful contributions to the small extant published literature base. Qualitative research methods can also be used to flesh out important CL-related issues. Finally, CL psychologists can broaden their impact on patient experiences by working at the institutional level to bring behavioral health principles to routine hospital care [216]. Bringing tested behavioral medicine interventions into the daily work processes of health care providers can truly change biopsychosocial care provision.

## **Appendix A: Sample CL Initial Intake and Follow-Up Session Forms**

### ***Behavioral Medicine Inpatient Consultation-Liaison Service***

Initial consultation

Requested by:

Reason for referral:

Date of consult:

Persons interviewed:

Admission information:

Pertinent medical history:

Consent to this consultant:

Mental status exam

Appearance:

Affect:

Mood:

Behavior:

Orientation:

Level of consciousness/attention:

Suicidal/homicidal ideation:

Patient insight:

Family insight:

Patient approach to evaluation:

Family approach to evaluation:

Current referral concern

History:

Patient subjective:

Family subjective:

Symptomatology

Behavioral:

Cognitive/emotional:

Interpersonal:

Physiological:

**Relevant medication**

Relevant psychosocial factors (include only most relevant to referral question)

Family relations/functioning:

Interaction between physical/psychosocial factors:

Academic/work functioning:

Social/interpersonal functioning:

Patient's premorbid functioning:

General coping, strengths:

Patient's psychiatric/substance use history:

Patient's traumatic events:

Family's psychiatric history:

Family traumatic events:

Most salient ongoing psychosocial stressors:

Coping strategies:

Pleasurable activities:

**Intervention**

Impressions/recommendations

Plan

Collaborative contacts

Disposition

Consultant signature and contact information

***Behavioral Medicine Inpatient Consultation-Liaison Service***

Follow-up session

Current referral concern update

Mental status exam

Intervention

Impressions/recommendations

Plan

Collaborative contacts

Disposition

Consultant signature and contact information

**Appendix B: Case Example of Adult Consultation*****Reason for Consultation***

Disruptive, crying, verbally abusive to staff, demanding to sign DNR DNI orders.

Rule out suicidality

Mr. S is a 48-year-old admitted to the hospital from a nursing home for work-up of an inflammation in his arm. He has a history of chronic pain (has intrathecal mor-

phine pump) after being run over by a garbage truck (injured legs collar bone feet, walks with a cane), also has a previous medical history of hypertension, hepatitis B, trigeminal neuralgia secondary to neuroma (right jaw).

**Medications:** Morphine, Oxycodone, Zolpidem, Paroxetine, Cephalexin

**Psychiatric History:** Major depressive disorder, anxiety, Output treatment 1993–1999 Inpatient 2000.

**Social:** Grew up in suburbs, did not complete high school. Gay identified—partner died of HIV in 1999. Previous employment in Medieval Times Amusement Park (he was a knight), ski and scuba diving instructor. Homeless, now living in a nursing home for the past 3 years. Unemployed on SSI. Mother died of Alzheimer’s, sister died of HIV. One married sister in New Jersey. History of recreational substance use.

On interview patient denied suicidal, homicidal, or paranoid ideation. Denied auditory or visual hallucinations. Endorsed difficulty eating and sleeping secondary to chronic pain. Misses being active but is future oriented writing song lyrics which he hopes to sell. States he is ambivalent about living or dying because he has lived a full life and as chronic and intractable as his pain is he would not actively chose to end his life. States he understands DNR/ DNI because his lover was a physician. Reports that DNR means that if he had a stroke he would not be poked and prodded. States would never accidentally overdose on pain medications as he is very careful with them. Says he enjoys living but is prepared to die when the time comes. Also said I’m not ready to die because I’m not done with my bucket list—need to sell my songs. Understands the alternative to DNR and does not want any life-saving measures. Also understands that DNR/DNI puts him at risk of dying earlier than he may otherwise.

Discussed with patient his behavior on the unit. Patient admitted to “acting up” because he wanted attention and felt that he was being ignored. Gave patient feedback on how medical staff found him to be rude and disruptive and explored with patient more effective ways to get his needs met. Patient was able to gain some insight to fact that not everyone thought his “jokes” were funny and we role played better communication skills to providers. Gave feedback to providers that patient has been socially isolated and developmentally behaves as an adolescent.

MSE: Alert, oriented X 4, poor eye contact, currently calm cooperative, mood euthymic, affect appropriate, speech fluent, thought process linear goal directed, thought content not bizarre, cognition grossly intact, average intelligence, insight, judgment, impulse control fair to good.

Axis I MDD, anxiety disorder

II deferred (traits evident)

III. chronic pain, neuromas, hepatitis B, trigeminal neuralgia

IV nursing home resident, no family contact, poor social support, unemployed

V=40

Impression: 48-year-old male requesting DNR/DNI in context of intractable pain. Patient is not suicidal and understands the risks and benefits and alternatives to DNR/DNI.

## **Appendix C: Case example of pediatric consultation**

### ***Behavioral Medicine Initial Consult***

Requested by: Generalist Inpatient Service (originally initiated by ICU)

Reason for referral: R's post-traumatic stress symptoms

Family members interviewed: R's mother Ms. S; R observed

Consent to this consultant: Yes

### ***Background/History***

Admission information: R is a 4-year-old African American boy who was admitted 10 days ago after accidentally being caught beneath a moving lawn mower. He sustained several injuries to his body, most notably to his left leg which required a below-the-knee amputation after several days of admission. Due to medical improvement, he has been transferred out of ICU to a step-down unit with on-going needs for pain management/sedation, rehabilitation and frequent OR trips for debridement and dressing changes. When debridement is complete, he will be transferred to the inpatient physical rehabilitation unit.

Pertinent medical history: None

### ***Mental Status Exam***

R was lying in bed watching TV. He appeared his stated age. When I came in he whimpered a bit but did not protest. He refused verbal engagement, and paid no attention to me while I met with his mom in the room. He appeared anxious, visually tracking me closely when I approached. When the consulting rehabilitation physician came in to examine him, R mildly protested but allowed the examination without behavioral opposition.

### ***Current Referral Concern***

History: As per the medical team, R is displaying considerable anxiety ever since awakening from constant sedation postamputation. According to his mother, R does not have any history of anxiety.

Family subjective: Ms. S reported that R is not acting "like her child," and worries that he will always be emotionally traumatized.

### ***Symptomatology***

Behavioral symptoms: Will scream or cry when examined or moved. Will say "no" or "don't" while sleeping. Resists having blankets taken off his body, resists looking at bandaged leg. Startles easily (e.g., when lines are beeping). Not eating very much, having trouble sleeping. Cries out in his sleep and appears to have night terrors.

Cognitive/Emotional symptoms: Very distressed, facial/body tension, appears constantly anxious.

Interpersonal symptoms: Not easily engaged with others, very little spontaneous conversation.

Physiological symptoms: Phantom pain, sleeping difficulties, high levels of physiological stress.

### ***Relevant Psychosocial Factors***

Family relations/functioning: Ms. S is in the military. R typically stays with Ms. S unless she has to go “in the field” for training, during which periods he stays with his father (parents divorced). At the time of the accident, he had been living with his father.

Emotional/Behavioral functioning: R is described by Ms. S as a very happy, active child with no notable behavioral/emotional concerns.

Child’s psych/Traumatic events: None noted other than current event. It is possible that R finds frequent separations from his mother to be emotionally challenging but that was not discussed.

Family’s psych/Traumatic events: None noted.

Current stressors: Adjusting to trauma of accident, amputation, pain and hospitalization

Coping strategies: None currently identified.

Family approach to evaluation: Somewhat cautious but willing.

### ***Intervention***

In addition to assessment, following interventions were conducted today:

1. Introduced my role and provided emotional support to Ms. S.
2. Provided psychoeducation to Ms. S. on the post-traumatic stress response from a developmental perspective, relating to R’s presentation.
3. Validated Ms. S’s concerns about R’ stress response while also discussing signs of improvement (R more willing this afternoon to let a physician examine him, compliant with attempting to raise his left leg).
4. With Rehab physician, described to Ms. S structure and purpose of inpatient rehabilitation. Provided education regarding R’ ability to return to full level of functioning while also acknowledging how difficult it is to have faith in this process.
5. Discussed importance of establishing a schedule and predictability for R in order to help him regain a sense of order and safety.
6. Modeled praising of R for brave behaviors during physician exam, which Ms. S began to do as well.

### ***Impression***

Given the multiple traumatizing events R has experienced during the past few days, it is understandable that R is demonstrating high levels of anxiety with re-experiencing of traumatic event (during sleep), avoidance of accident-related cues, and hyperarousal (all characteristic of post-traumatic stress responses). Ms. S is appropriately concerned about R's stress responses.

### ***Recommendations***

R's coping will be enhanced by providing a consistent, predictable environment with limited care providers in order to increase his sense of order and mastery, decrease his need for hypervigilance, and maximize his ability to develop supportive inpatient relationships. While it will be important to provide R the opportunity to "re-experience" his trauma in a controlled, supportive setting, this will need to be carefully done in developmentally appropriate ways with providers with whom R has a trusting, supportive relationship; thus, it is likely that this focus of treatment will wait until he has transferred to the Rehab unit. Until R and I have developed more rapport, initial focus of treatment will be on providing recommendations to family and treatment team.

### ***Plan***

This provider will:

1. collaborate with health care providers to develop predictable schedule for R
2. discuss with nursing staff importance of having consistent nursing team for R
3. discuss with Ms. S importance of allowing R opportunities for emotional expression
4. teach Ms. S ways to implement relaxation strategies with R.
5. discuss Ms. S's concerns with inpatient rehabilitation team in anticipation of R's transfer to that unit.

### ***Collaborative Contacts***

Have spoken with Dr. X of referring service today at 1,500 to review impressions, interventions, recommendations and plan.

### ***Disposition***

Ongoing



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# Chapter 17

## Endocrinology

**Felicia Hill-Briggs, Stephanie L. Fitzpatrick, Kristina P. Schumann and Sherita Hill Golden**

Clinical psychologists working within medical settings often encounter patients with endocrine-related disorders. This chapter will focus on the most prevalent endocrine-related disorders in which psychologists play a role in clinical care: type 1 and type 2 diabetes mellitus (T2DM) and obesity. Clinical psychologists provide care for patients with diabetes mellitus and with obesity in both inpatient and outpatient medical settings and through general medical consultation and liaison services or through specialty care clinical practices for these disorders. Key epidemiological and pathophysiological aspects of these disorders are described and evidence-based assessment and behavioral interventions are discussed.

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## Diabetes Mellitus

Diabetes is a chronic, metabolic disorder characterized by high levels of blood glucose resulting from insulin deficiency, insulin resistance, or both [1]. In normal metabolism, glucose, the component of food providing the main source of fuel for the body, enters the bloodstream. This stimulates the pancreas to automatically produce and secrete the correct amount of insulin to move the glucose from the bloodstream into the cells. In order for glucose uptake to occur, insulin must bind to receptors on the body's cells, allowing the cells to take in glucose for growth and energy [2]. In persons with diabetes, this process is disrupted. The pancreas may produce little or no insulin and/or the insulin may be unable to bind to the cells' receptors. In this case, glucose is unable to enter the cells, so it remains in the blood in high concentrations and subsequently overflows in the urine, ultimately leaving the body. If untreated, hyperglycemia can lead to long-term microvascular complications (i.e., retinopathy, nephropathy, and peripheral and autonomic neuropathy) and macrovascular complications (i.e., coronary heart disease, cerebrovascular disease, and peripheral arterial disease).

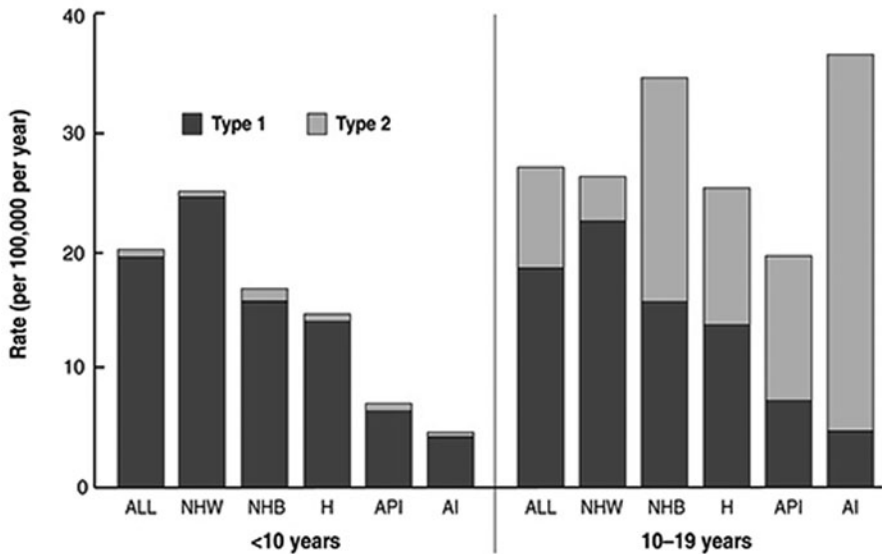
### *Type 1 Diabetes*

Type 1 diabetes, which accounts for 5–10% of all diabetes, is considered an autoimmune disease [1]. Although it is more commonly diagnosed during childhood, there are exceptions in terms of late onset and slow progression of the disease [1]. Type 1 diabetes is characterized by  $\beta$  cell destruction, such that patients are entirely insulin deficient and require insulin administration to sustain life [1]. While the majority of cases are caused by autoimmune destruction of  $\beta$  cells, some forms of type 1 diabetes do not have a clear etiology and are characterized as idiopathic [3].

The SEARCH for Diabetes in Youth Study also provides the best estimates of the prevalence of type 1 and type 2 diabetes among children and adolescents [4]. During 2002–2005, each year, 15,600 children and adolescents were newly diagnosed with type 1 diabetes [4]. The highest prevalence of type 1 diabetes is among non-Hispanic White children and adolescents (24.8 per 100,000 for children < 10 years of age; 22.6 per 100,000 for those 10–19 years old). Figure 17.1 shows prevalence rates of type 1 diabetes in youth under the age of 20 years.

### *Type 2 Diabetes*

Type 2 diabetes is the most common type of diabetes, accounting for 90–95% of all cases of diabetes in the USA. Symptoms (e.g., fatigue or nausea, frequent urination, unusual thirst, weight loss, blurred vision, frequent infections, and slow healing of wounds or sores) may come on very slowly and some individuals may not notice



**Fig. 17.1** Prevalence of new cases of type 1 and type 2 diabetes among youth younger than 20 years, by race/ethnicity, 2002–2005. (Reprinted from: Centers for Disease Control and Prevention. National Diabetes Fact Sheet: national estimates and general information on diabetes and prediabetes in the United States, 2011. Atlanta, GA: US Department of Health and Human Services, Centers for Disease Control and Prevention, 2011. NIH Publication No. 11-3892. February 2011)

any symptoms until the disease is more advanced. Type 2 diabetes is most often diagnosed in adults; however, the incidence of type 2 diabetes in children is quickly growing [4, 5].

Type 2 diabetes is characterized by deficient  $\beta$ -cell function (insulin-producing cells in the pancreas). Although  $\beta$  cells are not completely destroyed in type 2 diabetes, typically the  $\beta$  cells are unable to secrete sufficient amounts of insulin or the individual's body cells may be resistant to the insulin that is secreted. Over time, the  $\beta$  cells may become less and less capable of secreting insulin leading to hyperglycemia. Diagnosis of type 2 diabetes may not occur for a number of years after the pathophysiological processes have started because clinical symptoms may not be present for some time [1].

Development of type 2 diabetes is associated with a number of risk factors, including: age  $\geq 45$ , overweight/obesity (body mass index (BMI)  $\geq 25$ ), family history of diabetes, routine physical inactivity, race/ethnicity (e.g., African American, Hispanic American, Native American, Asian American, Pacific Islander), identified impaired fasting glucose (IFG) or impaired glucose tolerance (IGT), previous history of gestational diabetes, hypertension ( $\geq 140/90$  mm/Hg), high-density lipoprotein (HDL) cholesterol  $\leq 35$  mg/dl and/or triglycerides  $\geq 250$  mg/dl, polycystic ovary syndrome (PCOS), and history of vascular disease [1, 4]. Obesity leads to increased insulin resistance and subsequent hyperglycemia. In fact, approximately 80% of people with type 2 diabetes are overweight or obese [4].

**Table 17.1** Prevalence of diabetes mellitus and prediabetes among adults (aged  $\geq 20$  years) in the USA

Population	Prevalence, diagnosed diabetes	Prevalence, prediabetes
Total <sup>a</sup>	18,300,000 (8.0%)	81,500,000 (36.8%)
Male <sup>a</sup>	83,000,000 (7.9%)	48,100,000 (44.9%)
Female <sup>a</sup>	10,000,000 (8.2%)	33,400,000 (28.8%)
Non-Hispanic white male <sup>a</sup>	6.8%	45.4%
Non-Hispanic white female <sup>a</sup>	6.5%	27.9%
Non-Hispanic black male <sup>a</sup>	14.3%	31.6%
Non-Hispanic black female <sup>a</sup>	14.7%	27.1%
Mexican–American male <sup>a</sup>	11.0%	44.9%
Mexican–American female <sup>a</sup>	12.7%	34.9%
Cuban Americans <sup>b</sup>	7.6%	Unavailable
Central and South Americans <sup>b</sup>	7.6%	Unavailable
Asian Americans <sup>b</sup>	8.4%	Unavailable
Puerto Ricans <sup>b</sup>	13.8%	Unavailable
American Indians and Alaska Natives <sup>b</sup>	14.2%	Unavailable

<sup>a</sup> Data from Roger VL, Go AS, Lloyd-Jones DM, Adams RJ, Berry JD et al. Heart Disease and Stroke Statistics—2011 Update: A report from the American Heart Association. *Circulation* 2010

<sup>b</sup> Data from Centers for Disease Control and Prevention. National diabetes fact sheet: National estimates and general information on diabetes and prediabetes in the United States, 2011. Atlanta, GA US Department of Health and Human Services, Centers for Disease Control and Prevention

Type 2 diabetes is a significant and growing public health problem in the USA, affecting approximately 8.3% (25.8 million) of the US population [4]. Table 17.1 presents prevalence rates of diabetes and prediabetes among US adults. Additionally, approximately 7 million Americans are undiagnosed and 79 million Americans have IFG, placing them at risk for developing type 2 diabetes, heart disease, and stroke [4]. These statistics are elevated in racial and ethnic minority groups. Specifically, it is estimated that among persons aged 18 and older, 8.2% of White Americans, 12.9% of Black or African Americans, 16.3% of American Indians or Alaska Natives, 9.1% of Asian Americans, 23.7% of Native Hawaiians or Pacific Islanders, and 14.3% of Mexicans or Mexican Americans have diabetes (self-report of diagnosis by a physician) [6]. Based on data from the SEARCH for Diabetes in Youth Study, during 2002–2005, there were 3,600 children and adolescents newly diagnosed with type 2 diabetes annually [4]. The prevalence of type 2 diabetes was higher in children between the ages of 10 and 19 compared to children less than 10 years of age from 2002 to 2005 (Fig. 17.1). Non-Hispanic White children had the lowest prevalence of type 2 diabetes with African-American and Navajo girls having the highest prevalence.

## *Diagnosis of Diabetes*

Typically, individuals with type 1 diabetes often present to clinical settings with acute symptoms of diabetes including significantly elevated blood glucose [1].

Diagnosis of type 2 diabetes at times may be delayed because the patient is asymptomatic or is unable to recognize and/or report his/her symptoms. Screening for diabetes in asymptomatic patients includes either hemoglobin A1C ( $\text{HbA}_{1\text{C}}$ ), fasting plasma glucose (FPG), or a 2-hour oral glucose tolerance test (OGTT).  $\text{HbA}_{1\text{C}}$  (referred to as A1C going forward) is a measure of glycemic control over the past 2–3 months [2]. An A1C of  $\geq 6.5\%$  indicates diabetes [1]. Additionally, an FPG of  $\geq 126$  mg/dl is indicative of diabetes if the test result is confirmed by repeat testing [1]. A random (nonfasting) plasma glucose concentration of  $\geq 200$  mg/dl is indicative of diabetes and warrants further testing via A1C or FPG [1]. The final, less commonly used method for diagnosing type 2 diabetes is the OGTT. As with the FPG, this test is done in a fasting state. A blood sample is collected from the patient, then he/she consumes a glucose solution with 75 g of anhydrous glucose dissolved in water. After waiting 2 h, the patient's blood is sampled again to determine how well his/her body processed the glucose [2]. A plasma glucose concentration of  $\geq 200$  mg/dl after the 2-hour waiting period would be indicative of diabetes if the test result is confirmed by repeat testing [1]. For each of these testing methods, repeat testing is not required for diagnosis if there are unequivocal clinical signs of hyperglycemia. If two different methods of diagnosis are used and results are discordant (e.g., A1C and FPG), the test with results above the diagnostic cutoff should be repeated for confirmation of diagnosis [1].

### ***Screening for Prevention***

Persons at high risk for type 1 diabetes (i.e., previous occurrence of hyperglycemia or family history of type 1 diabetes) are recommended to undergo screening, which consists of measurement of islet autoantibodies [1]. Research has shown that early intervention for patients with IGT or IFG can reduce the incidence of type 2 diabetes [7]. For this reason, the American Diabetes Association (ADA) recommends that health care providers begin screening in adults of any age who are overweight and have one or more risk factors for type 2 diabetes. If tests are normal, they should be repeated every 3 years. In normal-weight adults without risk factors for type 2 diabetes, screening should begin at age 45 and continue every 3 years [1]. Screening should be conducted with children who are overweight (BMI > 85th percentile for age and sex) and have two additional risk factors (e.g., family history of T2DM, race/ethnicity, signs of insulin resistance, and/or maternal history of diabetes or gestational diabetes during pregnancy).

### ***Diabetes Clinical Care***

The ADA recommends that people with diabetes receive medical care using a physician-coordinated, integrated care team with the patient and his or her family in the center and actively involved in decision making [1]. The medical care

team consists of a variety of professions from physician to psychologist. Initial medical visits should consist of a comprehensive diabetes evaluation performed by the physician and follow-up visits (typically every 3 months) should include a review of symptoms (particularly episodes of hypoglycemia or hyperglycemia) and testing of A1C [1]. The primary treatment goals of diabetes are blood glucose control (A1C < 7.0%), blood pressure control (less than 130/80 mmHg), and cholesterol control (low-density lipoprotein (LDL) < 100 mg/dL; HDL > 40 mg/dL for men and > 50 mg/dL for women; triglycerides < 150 mg/dL). Specifically, for type 1 diabetes, the ADA recommends the following: (1) multiple-dose insulin injections; (2) matching insulin dose to carbohydrate intake, premeal blood glucose, and anticipated physical activity; and (3) use of rapid or long-acting insulin depending on frequency of hypoglycemia episodes [1]. These recommendations are based on results from the Diabetes Control and Complications Trial (DCCT), which included 1,441 persons with type 1 diabetes [8]. In this trial, it was observed that intensive glucose control (i.e., near-normal HbA<sub>1C</sub> of 5.5–7.0%) with pharmacologic treatment, as compared with conventional glucose control, resulted in a 54% reduction in progression of retinopathy and a 47% reduction in development of proliferative or severe nonproliferative retinopathy, which persisted for decades [8, 9] but no effect at trial conclusion on macrovascular outcomes. However, a 9-year follow-up post DCCT observed a macrovascular benefit as well in participants initially randomized to tight control: 42% reduction in cardiovascular disease (CVD) outcomes, 57% reduction in risk of nonfatal myocardial infarction, stroke, or CVD mortality, with persistence of this protective effect over decades [10, 11].

Similarly, the UK Prospective Diabetes Study (UKPDS) was conducted with 3,867 persons with type 2 diabetes. Tight blood glucose control resulted in a 25% reduction in microvascular endpoints, and a 16% reduction in cardiovascular complications (combined fatal or nonfatal myocardial infarction and sudden death), although not statistically different from the control arm at trial conclusion [12]. A 10-year follow-up of the UKPDS participants found that those in the tight glycemic control groups, relative to the conventional control group, had long-term reduction in myocardial infarction, ranging 15–33%, and in all-cause mortality, ranging 12–27% [13]. Thus, intensive glycemic control is also ideal for those with type 2 diabetes; however, medical treatment varies greatly depending on a number of individual factors (i.e., degree of insulin production, insulin resistance, ability to maintain adequate glycemic control, etc.) and ranges from dietary changes through medical nutrition therapy to oral medications to exogenous insulin. The ADA recommends an oral medication regimen, often metformin, for persons who are newly diagnosed with type 2 diabetes [1]. Psychologists working with this population may also see patients with prediabetes who are prescribed a low dose of metformin. For patients with type 2 diabetes who are significantly symptomatic including hyperglycemia or elevated A1C, the ADA recommends insulin therapy [1].

Medical nutrition therapy is strongly recommended for those who have prediabetes or diabetes and should consist of individualized counseling with a registered



dietician [1]. Individual or group diabetes education sessions (e.g., glucose self-monitoring, insulin injection, diabetes self-management) with a diabetes educator are often recommended by the medical care team for newly diagnosed people. A psychologist may be an integral person within the clinical practice or involved in patient care by referral. Psychologists are typically involved in the care of persons with diabetes in outpatient or inpatient settings to help address a number of relevant challenges in diabetes management including: adjustment to diagnosis, onset of new complications, stress management, assessment and treatment of comorbid depression and anxiety, and facilitating treatment adherence (e.g., diet, exercise, medication, self-management of blood glucose).

## ***Review of the Evidence***

### **Diabetes Practice Guidelines Pertaining to Behavioral Goals**

The ADA has established evidenced-based clinical and behavioral/lifestyle targets for optimal diabetes control (Table 17.2) [1]. Educational and behavioral interventions have been established to help patients achieve these targets as well as enhance glucose monitoring and medication adherence. The purpose of educational interventions is to help increase patients' knowledge about diabetes and the behaviors needed to manage the disease. Behavioral interventions aim to help patients put the knowledge to action—establishing goals and using behavioral strategies to make health behavior changes and to improve diabetes control.

### **Interventions**

#### **Diabetes Self-Management Education**

Diabetes self-management education (DSME) is an important component of disease management [14]. The ADA recommends that all patients receive DSME at the time of diagnosis and as needed thereafter to help patients initiate and maintain key self-management behaviors [1]. DSME focuses on seven specific behaviors known as the AADE (American Association of Diabetes Educators) 7: healthy eating, physical activity, self-monitoring of glucose, taking medications as prescribed, problem solving, healthy coping, and reducing risks [15, 16]. DSME is intended to influence immediate (learning), intermediate (behavior change), post-intermediate (clinical improvement), and long-term (health status improvement) outcomes [15]. A meta-analysis by Norris and colleagues [17] demonstrated consistent reduction in A1C immediately following DSME intervention ( $-0.76\%$ ), 1–3 months following intervention ( $-0.26\%$ ), and  $\geq 4$  months following intervention ( $-0.26\%$ ). The authors further elaborated to state that optimal impact of DSME is achieved with increased contact between providers and patients and

**Table 17.2** Clinical and behavioral goals for management of diabetes and cardiovascular disease [1]

Targets	Practice recommendation
<i>Clinical</i>	
HbA <sub>1c</sub>	<7.0%
Blood pressure	Systolic < 130 mmHg; diastolic < 80 mmHg
Lipids	LDL < 100 mg/dl HDL > 40 mg/dl (men); > 50 mg/dl (women) Triglycerides < 150 mg/dl
<i>Behavioral/lifestyle<sup>a</sup></i>	
Smoking cessation	Advise all patients not to smoke Include smoking cessation counseling and other forms of treatment as a routine component of diabetes care
Weight loss	Recommended for all overweight (BMI 25.0–29.9 kg/m <sup>2</sup> ) and obese (BMI ≥ 30.0 kg/m <sup>2</sup> ) patients with diabetes Either low-carbohydrate, low-fat calorie-restricted, or Mediterranean diets may be effective in the short term (up to 2 years) Physical activity and behavior modification are important components of weight loss programs and are most helpful in maintenance of weight loss
Physical activity	Perform at least 150 min/week of moderate-intensity (walking) aerobic physical activity In the absence of contraindications, perform resistance training three times per week Retinopathy, peripheral, and autonomic neuropathy may necessitate modification
Nutrition	Monitor carbohydrate intake (using carbohydrate counting, choices, or experience-based estimation) to achieve glycemic control The use of the glycemic index and glycemic load may provide a modest additional benefit for glycemic control Saturated fat intake should be <7% of total calories Routine supplementation with antioxidants, such as vitamins E and C and carotene is not advised because of lack of evidence of efficacy and concerns related to long-term safety
Alcohol	One drink/day or less for women and two drinks/day or less for men

<sup>a</sup> Behavioral/lifestyle recommendations are Level of Evidence A (clear evidence from well-conducted, generalizable, randomized controlled trials that are adequately powered) or B (supportive evidence from well-conducted cohort studies) with the exception of the alcohol recommendation, which is Level E (expert consensus or clinical experience)

longer-term interventions with more consistent follow-up [17]. DSME was delivered in a group format in the majority (65%) of clinical trials included in this review. DSME providers included: physicians with teams (25%), interdisciplinary teams including nurses and dietitians (20%), nurses alone (13%), dietitians alone (13%), self-administration via computer-assisted instruction (7%), and lay health care workers (3%) (provider information was not reported in 20% of the included trials). The vast majority (88%) of DSME programs were conducted in clinical settings [17].

## Behavioral Interventions

### *Meta-analyses of Effectiveness of Behavioral Interventions in Diabetes*

Previous meta-analyses of behavioral management interventions for diabetes have demonstrated moderate positive effects on physical, knowledge, compliance, and metabolic control outcomes and small positive effects on self-care and psychological outcomes [18, 19]. Gary and colleagues [20] conducted a meta-analysis of randomized educational and behavioral interventions in adults with type 2 diabetes and found that educational/behavioral interventions successfully reduced A1C by 0.43%, fasting blood glucose by 24 mg/dL, and weight by 3 lbs. Included interventions varied widely in terms of conceptual framework (e.g., Social Action Theory, Patient Empowerment), frequency of contact (range 1–19 months; median=5 months), mode of intervention (e.g., 52% group, 65% individual, 26% telephone outreach), and interventionist training (e.g., 39% nurses, 26% dietitians, 17% physicians, 9% psychologists). The majority of interventions focused on diet (70%) and exercise (57%) with fewer interventions focused on medication adherence (35%) or blood glucose monitoring (26%) and no studies reporting a specific focus on psychosocial aspects of diabetes self-management (e.g., coping, comorbid mental health disorders, etc.) [20]. As can be seen by this review, there is little consistency in educational and behavioral interventions in type 2 diabetes across clinics and clinicians. Ismail and colleagues [21] conducted a meta-analysis of randomized control trials (RCTs) utilizing a psychological intervention in adults with type 2 diabetes to explore the effect of psychological therapies (primarily cognitive behavioral therapy (CBT) or supportive counseling) on diabetes control. Their review indicated significant improvement in A1C (−0.32%) and psychological distress (e.g., depression, binge eating, stress, etc.) in patients participating in psychological interventions as compared with control groups [21]. Alam and colleagues [22] conducted an updated meta-analysis of RCTs utilizing a psychological intervention in adults with type 2 diabetes to explore the effect of psychological interventions (primarily CBT or supportive counseling) on glycemic control and psychological status. This review demonstrated significant improvement in A1C (−0.54%) with an improvement of 0.51% in interventions delivered by generalist practitioners and 0.57% in interventions delivered by psychological specialists.

### *Lifestyle Modification for Diabetes Prevention*

Research has demonstrated the efficacy of lifestyle and pharmacological intervention in the prevention or delay of onset of type 2 diabetes in adults with IFG, IGT, or both [1]. The Diabetes Prevention Program (DPP) was an RCT in which overweight and obese adults who were at increased risk for type 2 diabetes were given metformin (an oral diabetes medication) twice daily or an intensive lifestyle intervention, with the goal of 7% weight reduction and 150 min/week of physical activity. The intensive lifestyle intervention was delivered in an individual format for the first 6 months consisting of a 16-session curriculum addressing diet, exercise, and be-

havior modification [23]. Monthly individual and group sessions occurred after the initial 6 months to reinforce behavioral changes. At baseline, 53% of participants met criteria for metabolic syndrome (three or more of the following characteristics: large waist circumference, elevated blood pressure, low levels of HDL cholesterol, high triglycerides, and elevated FPG). Following intervention, the incidence of metabolic syndrome was reduced by 41% in the intensive lifestyle intervention group and 17% in the metformin group, as compared to placebo [24]. Furthermore, the lifestyle intervention group reduced the incidence of diabetes by 58% and the metformin group by 31% compared to placebo in 3 years [23]. Ten years post randomization, the incidence of diabetes was reduced by 34% in the intensive lifestyle group and 18% in the metformin group, as compared with placebo [25].

### *Cognitive Behavioral Therapy*

The meta-analyses discussed above [21, 22] have discussed the evidence that CBT has demonstrated efficacy in improving glycemic control in patients with diabetes. In this context, specific CBT techniques (e.g., relaxation training, changing maladaptive thought processes, and behavioral goal setting) are particularly useful in helping patients to reduce stress and make behavioral changes. As an example, Surwit and colleagues [26] conducted a trial of stress management training as an adjunct to diabetes education. Patients ( $n = 108$ ) with type 2 diabetes underwent five sessions of diabetes education with stress management training or five sessions of diabetes education alone (control). The stress management training included cognitive and behavioral approaches to reduce stress (deep breathing, progressive muscle relaxation, guided imagery, recognition of life stressors, and thought stopping) and psychoeducation on the health consequences of stress. At the 12-month follow-up, patients in the stress management group had reduced their A1C by 0.5% compared with the diabetes education group. Further, 32% of patients in the stress management training group reduced their A1C by  $\geq 1\%$  while only 12% of the education-alone group achieved this reduction. The trials reported in the meta-analyses by Ismail and colleagues [21] and Alam and colleagues [22] generally included 6–12 sessions of CBT, conducted in either group or individual format, primarily by psychologists (some interventions were conducted by nurses, dietitians, and/or exercise physiologists). In many cases, other disciplines (e.g., dietitians and nurses) were included in some sessions or portions of sessions to provide education on specific topic areas such as medication use, managing hypoglycemia, and nutrition.

### *Problem-Solving Therapy*

Problem solving, defined by the AADE as “a learned behavior that includes generating a set of potential strategies for problem resolution, selecting the most appropriate strategy, applying the strategy, and evaluating the effectiveness of the strategy,” has been designated as one of seven key diabetes self-management behaviors [15]. Problem-solving therapy (PST), initially described by D’Zurilla and Goldfried [27] and refined by D’Zurilla and Nezu [28] facilitates patients through learning the

problem-solving process, which consists of: (1) identifying and clearly defining the problem; (2) brainstorming or generating a list of potential solutions; (3) making a decision; and (4) implementing the decision and verifying if it was effective. See Schumann and colleagues [29] for a thorough discussion of traditional PST and the application to diabetes self-management. Based on findings from two recent systematic reviews, overall studies that incorporated problem solving for diabetes self-management into the intervention demonstrated significant reduction in A1C as well as improved adherence to health behavior recommendations including dietary intake and psychosocial outcomes such as depression and patient-provider communication [30, 31].

Hill-Briggs and colleagues [32] translated traditional PST into a problem-focused diabetes self-management training program: Project DECIDE (Decision-making Education for Choices in Diabetes Everyday). In a pilot study, the DECIDE intervention was tested in both a condensed version (consisting of one session of diabetes and CVD education followed by one PST session) and a comprehensive version (consisting of one session of diabetes and CVD education followed by eight problem-solving modules) in a sample of low-income African-American adults with type 2 diabetes. At 3 months post intervention (from 6 months to 1 year following baseline), results indicated that the intensive DECIDE problem-solving approach was effective in lowering A1C by 0.71 % and improving diabetes knowledge, problem solving, and self-management behaviors [32].

### *Motivational Interviewing*

Motivational interviewing (MI) has roots in Carl Roger's client-centered approach to therapy and strives to enhance patients' motivation for behavior change through collaborative exploration of ambivalence [33]. More than a clinical intervention, MI is a clinical approach that emphasizes collaboration between the clinician and the patient, evocation of the patients' thoughts and values, and autonomy of the patient. Clinicians are taught to express empathy, enhance self-efficacy, roll with resistance, and develop discrepancies to help the patient see the difference between his/her current behavior and his/her goals. Additionally, clinicians are encouraged to use OARS counseling skills: *Open-ended questions, Affirmations, Reflections, and Summaries* to elicit patient change talk and commitment to change [34]. Initially, MI was used primarily in substance abuse treatment [35], but over time, it has expanded into other domains, including health behavior change. MI is particularly useful in health settings because it can be applied in brief, goal-oriented medical interventions. Hettema and colleagues [36] published a review of more than 400 MI articles and approximately 70 MI outcome studies. Their findings demonstrate that MI is particularly effective in promoting treatment engagement and adherence when it precedes or is added to other standardized treatment. West and colleagues [37] conducted an RCT with 217 obese women with type 2 diabetes and demonstrated that women in the MI condition lost significantly more weight than women in the control condition at 6 months (−4.7 kg vs. −3.1 kg). In addition to enhanced weight loss, women in the MI condition also demonstrated greater adherence to

the treatment program (i.e., session attendance, number of weekly self-monitoring diaries, average dietary rating, and changes in caloric expenditure in moderate-to-vigorous exercise). The findings persisted to the 12-month and 18-month follow-up time points. Psychologists can play a critical role in conducting or training other health professionals in MI to individualize treatment planning and supplement existing patient services in medical settings.

### *Treatment for Comorbid Depression and Diabetes*

Patients with diabetes are two to three times more likely to develop depression than patients without diabetes. Approximately 20% of patients with diabetes have a depressive disorder, and nearly 40% experience symptoms of depression [38]. Evidence indicates that there is a bidirectional relationship between diabetes and depression [39]. This relationship is complex, involving neuroendocrine, metabolic, and behavioral mechanisms. From a psychosocial and behavioral perspective, the burden associated with self-management of diabetes and coping with diabetes-related complications may result in development of depression. In addition, there are a number of factors related to depression (e.g., physical inactivity, poor diet, poor medication adherence, activation of neuroendocrine and inflammatory responses), which can induce insulin resistance and onset of type 2 diabetes [40].

Systematic reviews have discussed the evidence that CBT has demonstrated efficacy in treating depression in patients with diabetes [41]. In CBT, patients and clinicians work together to identify goals for behavior change while identifying maladaptive thoughts, behaviors, and emotional responses. CBT helps patients to cope with stress, which is highly beneficial for reducing depressive symptoms. As an example, Lustman and colleagues [42] conducted a trial of CBT in patients with diabetes and major depressive disorder. Patients ( $n=51$ ) with type 2 diabetes underwent 10 weeks of CBT and diabetes education or diabetes education alone (control). At the 6-month follow-up visit, remission of depression (i.e., Beck Depression Inventory (BDI) score  $\leq 9$ ) was noted in 70% of patients in the CBT group, compared with 33% of patients in the control group. Additionally, the CBT group noted improvement in A1C ( $-0.7\%$ ) while A1C worsened in the control group ( $+0.9\%$ ).

While Lustman et al. found improvements in diabetes outcomes resulting from CBT in depressed diabetic patients, the literature generally has found that when CBT is focused on treating depression in patients who have comorbid depression and diabetes, treatment improves depression but does not improve diabetes self-management behaviors or clinical outcomes [41]. A collaborative team model, TEAMcare, presented by Katon and colleagues [43], demonstrated efficacy in improving mood disorders as well as diabetes and cardiovascular outcomes, concurrently, in complex patients. The TEAMCare approach utilizes a nurse case management model, with supervision by a team of experts that includes the physician and a psychologist and/or psychiatrist [44]. TEAMcare combined support for self-management with pharmacotherapy to treat depression, hyperglycemia, hypertension, and hyperlipidemia. Nurses attended a 2-day training to learn depression management, behavioral strategies, and glycemic, blood pressure, and lipid control. Nurses helped patients

to solve problems and set goals for self-management using a variety of motivational enhancement techniques. Patients also received self-care materials to assist with depression management (i.e., a book and video) and disease management (e.g., blood pressure or blood glucose meters). At the 12-month follow-up, patients who received this collaborative intervention demonstrated reductions in: A1C, LDL, SBP, and depression compared with the control group [43].

### *Behavioral Interventions for Children and Adolescents with Type 1 Diabetes*

There are evidence-based behavioral interventions that have demonstrated effectiveness in children and adolescents with diabetes and their families including behavioral family systems therapy (BFST), PST, and coping skills training.

*Behavioral Family Systems Therapy* BFST is a multicomponent intervention for children and adolescents with type 1 diabetes, and their families, that consists of four main components: problem solving, communication skills training, cognitive restructuring, and functional–structural family therapy [45]. Previous research has examined the effect of applying BFST to improve diabetes-related family communication and problem solving as well as adolescent management of type 1 diabetes [46–49]. BFST for diabetes (BFST-D) was delivered as a 12-session intervention for single families led by a psychologist [48, 49]. BFST-D significantly improved glycemic control, treatment adherence, and diabetes-related family conflict following 6 months of treatment [48]. There were also demonstrated long-term effects of this intervention on glycemic control as well as improved family communication and problem solving [49, 50].

*Problem-Solving Treatments* Problem-solving-based interventions have also been implemented with children and adolescents and have demonstrated significant reduction in A1C as well as improvement in adherence to self-management behaviors, problem-solving ability, and parent–child communication around diabetes management [30, 31]. Specifically, Nansel and colleagues [51, 52] conducted an RCT to test the feasibility and effect of integrating a problem-solving-based intervention called “WE-CAN manage diabetes” into routine clinical care for families with a child or adolescent with type 1 diabetes. There was a significant intervention effect (0.44% reduction in A1C for the intervention group overall) with noted glycemic control improvement primarily among older adolescents aged 12–14 [52].

*Coping Skills Training* Coping skills training is a cognitive behavioral intervention that is designed to help children and adolescents manage diabetes. Coping skills training includes focus on social problem solving, communication skills training, cognitive-behavioral modification, stress management, and conflict resolution [53]. Coping skills training attempts to improve competence and mastery of self-management behavior by helping youth to develop more adaptive coping styles. Grey and colleagues [54] conducted an RCT to examine the effects of coping skills training on glycemic control and psychosocial outcomes in adolescents with type 1 diabetes. At the 3-month follow-up, coping skills training, as an adjunct to intensive diabetes

management, resulted in lower A1C, better diabetes self-efficacy, and less distress about coping with diabetes compared with enhanced education as an adjunct to intensive diabetes management. These effects persisted at the 1-year follow-up. Additionally, in female subjects, coping skills training resulted in less weight gain and fewer episodes of hypoglycemia [55].

### Psychosocial and Behavioral Assessments in Diabetes Care

The ADA has set a number of recommendations regarding psychosocial assessment and care of patients living with diabetes; however, these recommendations are generally based on expert consensus or clinical experience rather than clear research-based evidence. ADA recommends that providers assess patients' psychological and social context as a routine part of diabetes management. ADA further provides guidance on areas for closer evaluation: attitudes about the illness, expectations for medical management and outcomes, affect/mood, general and diabetes-related quality of life, resources (financial, social, and emotional), and psychiatric history. In the context of poor self-management, ADA recommends screening for depression, diabetes-related distress, anxiety, eating disorders, and cognitive impairment [1]. When patients endorse problems in any of the areas above, a psychologist should be included as a member of the clinical care team whose role is to conduct further assessments and assist with treatment planning.

### Assessment of Health Behaviors and Diabetes Self-Management Behaviors

To augment a structured initial interview, there are a number of assessment tools psychologists can include in their work with patients with diabetes to assess key domains including knowledge, self-management behaviors, diabetes-specific distress, mood and adjustment disorders, empowerment, problem-solving skills, and quality of life (Table 17.3). Disease-related knowledge and engagement in self-management behaviors should be assessed to determine behavioral and/or knowledge barriers impacting diabetes management. A brief, reliable, and valid self-report measure commonly used to assess diabetes-related self-care behaviors is the Summary of Diabetes Self-Care Activities Measure (SDSCA) [56]. The SDSCA is recommended for use in clinical practice and assesses the following areas of self-management: general diet, specific diet, exercise, blood glucose testing, foot care, and smoking [56]. To obtain additional information about patient diet, the psychologist may also administer a 24-hour dietary recall, the gold standard for dietary assessment. The Medication Adherence Questionnaire [57] can be administered to assess medication adherence. In addition to using formal questionnaires, psychologists should encourage patients to track self-management behaviors using blood glucose monitoring logs, medication adherence logs, as well as food and activity records. Self-monitoring not only helps to inform the psychologist and the patient about areas of success and need for improvement, but there is also evidence that self-monitoring increases engagement in healthy behaviors and improves health outcomes [58].



**Table 17.3** Selected evidence-based measures for diabetes-related behavioral assessment

Domains	Assessment tools
<i>Disease knowledge</i>	Diabetes Knowledge Test (DKT) Diabetes and cardiovascular disease knowledge test Heart disease fact questionnaire
<i>Diabetes regimen behavior frequency and adherence</i>	
Summary scale	Summary of Diabetes Self-Care Activities (SDSCA) (nutrition, exercise, self-monitoring of blood glucose, medication taking, foot care, smoking)
Medication nonadherence	Morisky medication adherence measure
<i>Diabetes-related distress</i>	
Global diabetes distress	Problem Areas in Diabetes (PAID)
Specific diabetes fears	Diabetes Distress Scale (DSS) Fear of Hypoglycemia Survey (FHS) Fear of hypoglycemia (children) Diabetes Fear of Injecting and Self-Testing Questionnaire (D-FISQ)
<i>Mood and adjustment</i>	
Depression	Patient Health Questionnaire (PHQ-9)
Anxiety	Beck Depression Inventory-II (BDI-II) Beck Anxiety Inventory (BAI) State-Trait Anxiety Inventory (STAI)
Diabetes empowerment	Diabetes Empowerment Scale (DES)
<i>Problem solving<sup>a</sup></i>	
Generic/standardized scale	Social Problem-Solving Inventory (SPSI-R)
Diabetes specific	Social Problem Solving for Diabetic Youth (SPSDY) Diabetes Problem-Solving Measure for Adolescents (DPSMA) Diabetes Problem-Solving Scale (DPSS) (Hill-Briggs et al.)
Health related	Health Problem-Solving Scale (HPSS; Hill-Briggs et al.)
<i>Health-related quality of life</i>	
Generic	Medical Outcomes Study (MOS) SF-36, SF-12
Diabetes specific	Diabetes Quality of Life (DQOL) Rand Diabetes Items (Davidson 2005)
<i>Other assessment resources</i>	
Diabetes-specific and health-related scales (and language translations)	Health Psychology Research Group Ltd. <a href="http://www.healthpsychologyresearch.com">www.healthpsychologyresearch.com</a>
Michigan Diabetes Research and Training Center (DRTC) website	<a href="http://www.med.umich.edu/mdrtc/profs/survey.html#dkt">http://www.med.umich.edu/mdrtc/profs/survey.html#dkt</a>
General health behavior scales	Patient Reported Outcomes Measurement Information System (PROMIS) ([94] <a href="http://www.nihpromis.org">http://www.nihpromis.org</a> )

<sup>a</sup> For a full description of available problem-solving measures in diabetes research, see Hill-Briggs and Gemmell [30]

There are a number of validated depression screening tools available. Most depression screening questionnaires can be completed by patients in less than 5 min and scored by providers in less than 2 min. Commonly used depression screening

tools in the diabetes research literature include the nine-item Patient Health Questionnaire-9 (PHQ-9) [59, 60] and the 21-item BDI-II [61, 62]. The PHQ-9 can be used to evaluate depression severity and to diagnose major depressive disorder. The PHQ-9 is particularly useful in that the items map on to the DSM-IV diagnostic criteria for depression. The BDI-II yields categorical scores to identify mild, moderate, and severe depression. The 20-item Center for Epidemiologic Studies Depression Depression Scale (CES-D) [63, 64] is commonly used in diabetes research; however, this tool is not designed to yield clinically diagnostic depressive symptoms. It is useful for identifying distress and degree of nonclinical depressive symptoms in population-based studies; however, it is not appropriate for diagnostic purposes in the clinical setting. The 21-item Beck Anxiety Index (BAI) [65] is a valid screening tool for anxiety.

Although these measures are useful in identifying depressive symptomology, they are less useful in identifying diabetes-specific distress [66]. Fisher and colleagues [67] developed a brief, two-item, diabetes distress screening instrument. This very brief questionnaire is useful in identifying patients who may be experiencing diabetes distress. It is recommended that patients who screen positive on this two-item questionnaire be given the 17-item Diabetes Distress Scale, which clinicians can use to identify the content of the patient's distress and to inform intervention [68]. Several measures assess diabetes-specific fears and anxiety, including fear of hypoglycemia and fear of injecting (Table 17.3).

In addition to the instruments specifically mentioned in the diabetes literature, there are several reliable and well-validated health-related patient-reported outcome (PRO) measures for general health behaviors; these measures can be administered prior to, during, and after behavioral treatment to examine the effect of the intervention on outcomes such as social-ecological support [69] and health-related quality of life (Medical Outcomes Study SF-36) [70]. The Health Psychology Research Group ([www.healthpsychologyresearch.com](http://www.healthpsychologyresearch.com)) [71] has developed more than 289 disease-specific PRO measures, many of which are diabetes related, that have been translated and validated in more than 50 countries and 70 languages. Furthermore, although not chronic disease specific, the Patient Reported Outcomes Measure Information System (PROMIS) is also a great resource for reliable, valid PRO measures to be administered in a clinical setting (<http://www.nihpromis.org>) [72].

## Neuropsychological Assessment

Psychologists and neuropsychologists in medical settings are often consulted for cognitive or dementia screenings, neurobehavioral evaluations, or neuropsychological assessment to determine acute or chronic cognitive status in patients with diabetes. Diabetes is associated with higher prevalence of cognitive impairment and dementia in older adults [73–77], and a substantive body of literature elucidates vascular, biochemical, and metabolic mechanisms linking diabetes with increased risk of cognitive impairment across the life span [73, 78–80]. Moreover, patients with diabetes experience acute, transient changes in cognition associated with fluctuations in blood glucose and with hypoglycemic [73–77] states. Deficits in execu-

**Table 17.4** Measures of neuropsychological function with demonstrated sensitivity to diabetes-related dysfunction

Domain	Neuropsychological tests
Cognitive screening	Mini Mental State Examination (MMSE) [162]
Executive function	Stroop test [163] Trail making test, Parts A and B [164]
Motor function	Grooved Pegboard test [162]
Verbal and visual memory	California Verbal Learning Test (CVLT) [165] Rey Auditory Verbal Learning Test (RAVLT) [166] Rey–Osterrieth complex figure test immediate and delayed recall [167]
Attention and concentration	Wechsler Adult Intelligence Scales (WAIS) Digit span [168] WAIS digit symbol substitution test [168]

tive function, motor speed, and memory are the most commonly reported performance decrements found in adult diabetic samples relative to nondiabetic samples, although there are some differences found for type 1 as compared to type 2 diabetes samples [73, 76, 78]. Neuropsychological tests that have been found to be sensitive in differentiating cognitive performance of persons with and without diabetes are listed in Table 17.4. The reader is referred elsewhere for detailed descriptions of these domains and tests [81]. In persons with diabetes who have advanced complications, it is important to incorporate guidelines for neuropsychological assessment of persons with functional impairment and disabilities that may adversely impact neuropsychological test administration and performance [82].

### Inpatient Setting

Psychologists will often encounter patients with diabetes in inpatient settings because patients with diabetes are more likely to be hospitalized, to have longer lengths of stay, and to experience greater complications while hospitalized than patients without diabetes [83–87]. Additionally, reasons for admission are often related to diabetes complications (e.g., 21% of patients admitted with stroke have concurrent diagnoses of diabetes) [87]. Therefore, inpatient hospitalization provides a unique time in which there is a “teachable moment” to address difficulties the patient may have in coping with and/or managing his/her diabetes. Schumann, Touradji, and Hill-Briggs [88] described an Inpatient Rehabilitation Diabetes Consult Service, which offered brief assessment and intervention to inpatients with comorbid diagnoses of diabetes. Psychologists can assess a variety of areas, including: coping, health beliefs, experiences of hypo/hyperglycemia, barriers to self-management, self-efficacy for self-management, importance of engaging in self-management behaviors, motivation for self-management, and social support. Psychologists can also provide brief intervention, referral to outpatient follow-up treatment, and treatment recommendations to the interdisciplinary team [88].

## Evidenced-Based Practice/Practice-Based Evidence

As previously described, there are a number of behavioral and psychosocial aspects to assess during an encounter with a patient with diabetes. Data obtained from the structured interview and assessment tools in combination with clinical measurements allow both the psychologist and other members of the medical care team to take a more holistic approach to treatment planning. Specifically, assessment of self-management behaviors helps the medical care team and the patient identify what behaviors are contributing to poor glucose control. For example, the patient may be experiencing hyperglycemia on a daily basis due to eating a high carbohydrate diet, lack of exercise, or poor adherence to medication regimen. After establishing the problem behaviors, psychosocial assessments can be used to understand the barriers to engaging in health self-management behaviors. Depressive symptoms or chronic stress can lead to overeating and to increased time spent in sedentary behavior. Also, lack of health knowledge and/or health literacy can unfortunately result in patients implementing unhealthy practices to manage their diabetes (i.e., skipping meals or not taking medication as prescribed). Treatment planning should be individualized and tailored to address the specific barriers presented by the patient in order to promote optimal diabetes control. Although patients may present with several barriers and areas of improvement, in order not to overburden the patient, work with the patient on identifying one health behavior and barrier to establish treatment goals and focus on initially. Then as treatment proceeds and is deemed successful (i.e., increased engagement in healthy self-management behaviors and improved clinical outcomes such as fasting glucose or A1C) start to address additional behaviors and barriers.

Although there are evidence-based established behavioral treatment guidelines for diabetes, a psychologist must be aware of barriers patients may face in obtaining these targets. For example, regular self-monitoring of glucose, eating a healthy diet, and adhering to medication regimens can be difficult for patients with few resources. Consequently, it is important to translate the evidence-based self-management goals into doable targets for the patient, while assisting the patient in securing social work or case management services to maximize resource support. Use of problem-solving-based self-management training is an evidence-based approach for helping low-resource patients identify strategies, addressing their needs or barriers, for making health behavior changes and improving diabetes outcomes [32].

Patients with severe mental illness are more likely to develop type 2 diabetes than the general population. Although this relation is not fully understood, it is thought that antipsychotic medications can cause weight gain and obesity and raise plasma glucose and cholesterol levels, all of which may influence the onset of diabetes [89, 90]. Consequently, psychologists may be called upon to assess and intervene on comorbid mental health and diabetes diagnoses. Patients with severe mental illness may have increased challenges in maintaining self-management regimens that warrant closer attention and supportive counseling [91]. Psychologists should provide education and behavioral intervention aimed at improving adherence to

diabetes self-management behaviors within psychiatric settings where individuals with schizophrenia receive their mental health care. Additionally, medical providers should routinely monitor glycemic control in individuals with schizophrenia who are being treated with antipsychotic medications.

### In Practice

In summary, psychologists interact with persons with diabetes routinely in outpatient and inpatient medical settings. Diabetes management may be the reason for referral or consult, or diabetes may be a secondary condition impacting the primary reason for referral. Because of the heavy influence of behavior on diabetes care and outcomes, as well as the prevalence of mood and cognition-related symptomatology, psychologists have a breadth of roles in treating patients with diabetes. The diabetes literature provides evidence to support CBT to improve emotional distress in diabetes patients. PST approaches and MI can be effective for improving self-management behaviors and improving clinical outcomes. Collaborative team models have been found most effective for improving diabetes clinical outcomes and depression concurrently.

Psychological services can be billed using traditional CPT codes or health and behavior (H&B) codes. Traditional psychotherapy codes (90804–90809) are appropriate for patients with diabetes and comorbid psychiatric diagnoses. H&B codes (96150–96154) are appropriate for a broader set of patients (without psychiatric diagnoses), with whom the psychologist is addressing adjustment and/or self-management difficulties. Psychological assessment, neurobehavioral assessment, and neuropsychological assessment billing codes are appropriate for services rendered by psychologists for diabetes referrals that meet those code specifications. See Leichter and colleagues [92] for a comprehensive review of use of billing codes for psychologists working with diabetes patients.

In medical settings, psychologists treating patients with diabetes may work with interdisciplinary treatment teams. Whether a regular member of a treatment team or a consultant to a treatment team, there are a number of strategies psychologists can use to work effectively with teams and complex patients with diabetes.

1. Attend regular team meetings to identify yourself as an integral part of the treatment team. Get to know other providers in more casual ways as well (e.g., leave your office door open, eat lunch in the common break room, chat with providers in the hallway).
2. Whenever possible, colocate your office within the clinic. This helps providers remain aware of your services and makes it easier for them to refer patients. It also removes barriers for patients who may find it difficult/unacceptable to travel to another clinic to meet with the psychologist.
3. Educate providers on the role of clinical psychologists in health care and help them to identify appropriate referral questions (e.g., mood disorders, poor treatment adherence, assistance with behavioral change, motivational enhancement, etc.).

4. Collaborate with other members of the treatment team through co-treatment sessions when possible. This will communicate to the patient that the providers are working as a unified team to deliver a consistent treatment plan.
5. Stay in close communication with both patients and other providers regarding treatment planning and outcome.
6. Communicate to patients that the psychologist is one member of the treatment team and explain to the patient how health psychology differs from more traditional psychotherapy (e.g., problem focused, emphasis on functioning as it relates to a specific health condition).

In conclusion, psychologists play a key role in the care of patients with diabetes and their families, including addressing diabetes-related distress, coping and adjustment, and comorbid depression; in facilitating health behavior change and effective disease self-management; and in diagnosing and intervening upon cognitive dysfunction. The importance of behavioral intervention in diabetes care is well accepted, and psychologists serve as members of diabetes treatment teams in many specialty clinics. Incorporation of evidence-based intervention approaches, however, is key for optimal effectiveness.

## **Obesity**

Obesity is a major risk factor for chronic diseases including diabetes, CVD, and some cancers. In addition, obesity is often associated with the experience of stigmatization, psychological distress, and reduced health-related quality of life [93]. Because of the obesity epidemic, a psychologist's encounter with an obese individual within a medical setting is inevitable; thus, it is important to be aware of the evidence regarding this condition.

### ***Definition***

Table 17.5 presents the Center for Disease Control (CDC) definition for child and adolescent overweight and obesity based on BMI percentiles [94] as well as the World Health Organization (WHO) definition for adult overweight and obesity based on BMI [95]. Determination of child and adolescent BMI percentiles involves use of CDC Growth Charts (<http://www.cdc.gov/growthcharts/>) to account for child sex, age, and height.

**Table 17.5** Weight status classification based on Center for Disease Control (CDC) [94] and World Health Organization (WHO) criteria [95]

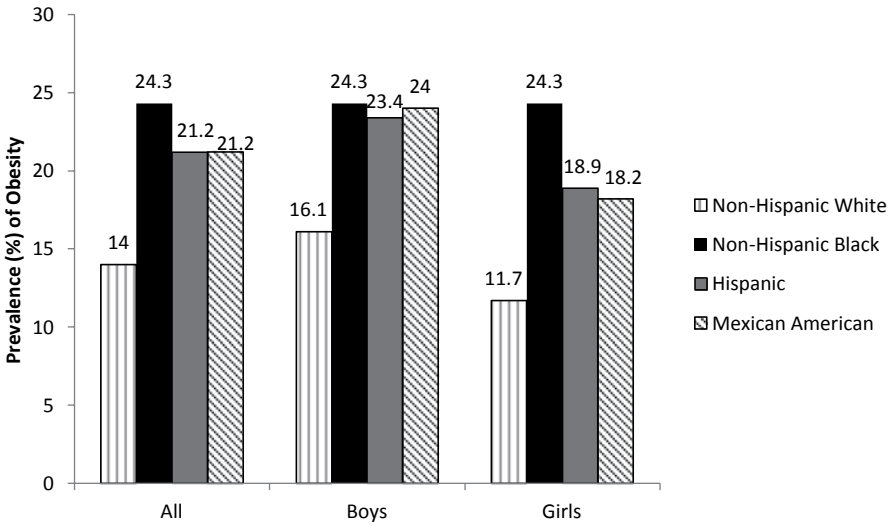
Child criteria (2–19 years old)		Adult criteria	
BMI percentile	CDC classification	BMI (kg/m <sup>2</sup> )	WHO classification
<5th percentile	Underweight	<18.5	Underweight
5th to <85th percentile	Healthy weight	18.5–24.9	Normal range
85th to <95th percentile	Overweight	25–29.9	Overweight
≥95th percentile	Obese	30–34.9	Obese class I (mild)
		35–39.9	Obese class II (moderate)
		≥40	Obese class III (morbid/ severe/extreme)

## *Pathophysiology*

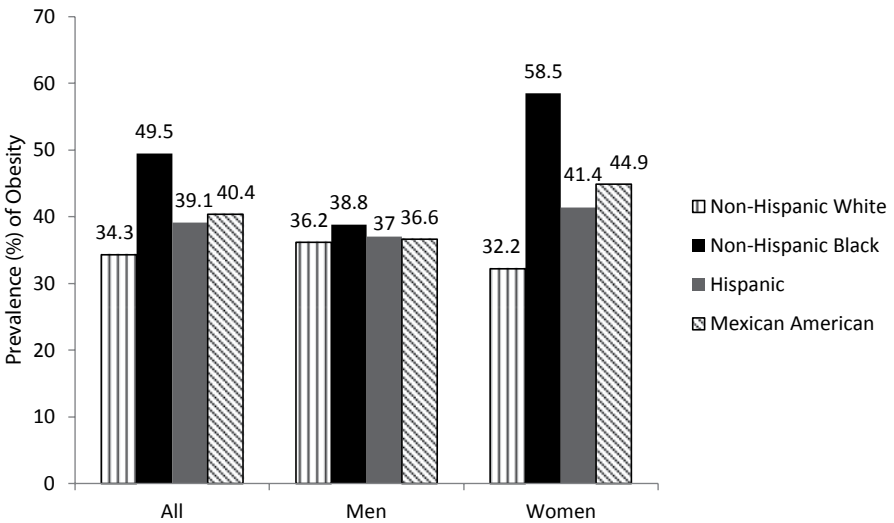
Previous twin and adoptee studies have provided evidence for genetic contributions to obesity [96, 97] with some studies suggesting a heritability of 50–90% [96]. However, recent studies would suggest that the rapid increase in obesity prevalence is not all due to genetics because the gene pool has not changed substantially in the last two decades. Rather, the rapid increase in obesity is more likely due to a complex gene–environment interaction, hormonal influences, and increase in unhealthy behaviors [98, 99]. Those predisposed genetically to obesity are more likely to be obese if living in an obesogenic environment (i.e., environment that promotes a high fat diet and low physical activity) [96, 97]. Unfortunately, an environment with readily available high fat foods and increased accessibility to sedentary activities (e.g., TV watching, using the computer) has become the norm in the USA. A behavioral explanation for obesity involves the consumption of calories (i.e., energy) outweighing energy expended through physical activity and resting metabolic rate [97]. However, the role of substances such as leptin and ghrelin further complicates the behavioral process as they directly impact food consumption. Leptin is a polypeptide released by adipose tissue that inhibits food intake, whereas ghrelin is a gut hormone that stimulates food intake [96]. Therefore, the pathophysiology of obesity involves a complex interaction among genes, environment, hormones, and behaviors [99], all components that should be considered when developing prevention and intervention strategies.

## *Prevalence*

In 2010, approximately 16.9% of 2–19-year-olds and 35.7% of adults met criteria for obesity [100, 101]. This represents about a 3% and 8% increase in prevalence for children/adolescents and adults, respectively, over the past 10 years [100, 101]. Data suggest (Figs. 17.2 and 17.3) that this increase is mostly due to the rise in prevalence of obesity among boys and men, whereas the prevalence among women and girls over the last decade appears to have stabilized [101]. Obesity is a grow-



**Fig. 17.2** Prevalence of obesity among 2–19-year-olds by sex and race/ethnicity: USA, 2009–2010. (Source: [101])



**Fig. 17.3** Prevalence of obesity among adults, aged 20 and older, by sex and race/ethnicity: USA, 2009–2010. (Source: [100])



ing problem for older adults as adults aged 60 and over are more likely to be obese than younger adults [101]. Furthermore, obesity is not just a problem among low-income individuals, but is highly prevalent among high-income individuals as well [102]. There are significant racial/ethnic differences in prevalence of obesity with non-Hispanic Blacks having the highest prevalence at 49.5% (adults) and 24.3% (children/adolescents) in 2010. It should be noted that obesity is most common among non-Hispanic Black women (currently 58.5%). However, over the past two decades there has been a 12% increase and 14% increase in obesity prevalence among non-Hispanic Black boys (currently 24.3% obese) and Mexican American boys (currently 24% obese), respectively, making the current prevalence equivalent to those of non-Hispanic Black girls (i.e., 24.3%) [101].

## *Clinical Care*

### **Behavioral Treatment**

Behavioral interventions are the first line of treatment for obesity [103]. In this chapter, we define behavioral interventions as treatment with three main components: (1) diet; (2) physical activity; and (3) behavioral management. Obese patients may be referred to a registered dietitian for “behavioral counseling,” which may consist of dietary education, counseling, and advice on lifestyle modifications. In addition, patients may be referred to a psychologist for “behavioral management,” which involves more extensive training in cognitive-behavioral principles to implement nutrition and exercise education and successfully achieve diet and exercise goals [104]. Cognitive-behavioral skills taught during a behavioral intervention for obesity include: goal setting, stimulus control strategies, self-monitoring, problem solving, cognitive restructuring, and relapse prevention [105, 106]. Behavioral interventions may be delivered in an individual or group format [103]. For obese children and adolescents, treatment typically involves parents and caregivers [104]. There are several manualized behavioral treatments for obesity that can be implemented by practicing psychologists in medical settings including:

- *The LEARN Program for Weight Control* [107]
- *Cognitive Behavioral Treatment for Obesity* [108]
- *The Beck Diet Solution: Train Your Brain to Think Like a Thin Person* [109]

### **Pharmacotherapy**

Weight loss medications are sometimes prescribed in conjunction with behavioral treatment. The two Food and Drug Administration (FDA)-approved and most commonly prescribed medications in clinical practice include Xenical (orlistat) and phentermine. Xenical works by blocking the absorption of fat in the diet [110] and is the only FDA-approved weight loss medication for long-term use [111]. Xenical

is available at a low dose over the counter as Alli. Phentermine is an appetite suppressant [110]. Clinical psychologists may be asked to provide behavioral treatment to enhance medication adherence [112] or to teach behavioral lifestyle modification skills to compliment the pharmacotherapy treatment.

## **Bariatric Surgery**

Individuals with a BMI  $\geq 40$  kg/m<sup>2</sup> (i.e., extreme or morbid obesity) or with a BMI of 35–39.9 kg/m<sup>2</sup> and a diagnosis of a serious weight-related medical condition (e.g., type 2 diabetes, hypertension, or severe sleep apnea) may be referred for bariatric surgery. The field of bariatric surgery has evolved over the last decade [113, 114]. Currently, the most commonly performed surgeries in the USA and Europe include: Roux-en-Y gastric bypass, duodenal switch, laparoscopic adjustable gastric banding or lap band, and sleeve gastrectomy [114, 115]. Today, it is common and in some cases mandatory for patients to undergo a psychological evaluation prior to approval to receive bariatric surgery. Psychologists may also provide cognitive-behavioral treatment and/or supportive counseling before or after surgery to address behavioral issues, binge eating, body image disturbance, or any mood or anxiety disorders that may interfere with initiation or maintenance of healthy behaviors necessary for successful surgery outcomes.

## ***Review of the Evidence***

### **Practice Guidelines and Recommendations for Obesity Treatment**

In 1998, the National Heart, Lung, and Blood Institute (NHLBI) in conjunction with the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) convened a panel of experts to establish guidelines on the identification and treatment of obesity for adults ([http://www.nhlbi.nih.gov/guidelines/obesity/ob\\_home.htm](http://www.nhlbi.nih.gov/guidelines/obesity/ob_home.htm)) [116] based on previous research. These guidelines are intended for use by primary care practitioners, dietitians, psychologists, and any other health professional that may deliver care to overweight and obese patients. An update to the NHLBI obesity guidelines is currently under development (<http://www.nhlbi.nih.gov/guidelines/obesity/index.htm>) and the American Psychological Association has also recently convened a panel to establish obesity treatment guidelines for psychologists (<http://www.apa.org/science/about/psa/2012/04/obesity-ptsd.aspx>). Additional treatment recommendations are provided in the *Handbook of Obesity Treatment* [117]. Similar to adults, an expert committee convened in 2005 to revise the 1998 established practice guidelines, recommendations, and assessment strategies for childhood obesity [118]. This section will summarize these guidelines and highlight the role of clinical psychologists.

## Treatment Guidelines for Adult Obesity

Based on the NHLBI treatment algorithm for obesity [116], history of elevated BMI, current BMI category, and patient goals/motivation must be accounted for when making treatment decisions. Treatment for overweight and obesity includes dietary counseling, behavioral management, and physical activity [116], which may occur in a primary care, outpatient psychology, or medical specialty clinical setting. Goals of a comprehensive weight management program include 10% loss of initial weight after 6 months of treatment (Evidence Category A) [116]. Patients should expect to lose ½ to 2 lbs per week (Evidence Category B) if adhering to a low-calorie diet, regular physical activity, and practice of behavioral strategies to achieve dietary and exercise goals.

### Dietary and Physical Activity

Dietary counseling should be individualized and take into account the patient's current BMI. NHLBI guidelines [116] recommend that a patient with BMI of 27–35 kg/m<sup>2</sup> should decrease daily total calorie consumption by 300–500 kcal/day whereas a patient with a BMI > 35 should decrease by 500–1,000 kcal/day in order to achieve 10% weight loss in 6 months (Evidence Category A). Dietary plans are typically revisited and adjusted with the provider after the initial 6 months depending on weight outcomes. Ideally, a registered dietitian is directly or closely involved in the dietary counseling, and frequent treatment sessions during the initial 6 months are highly recommended. A long-term physical activity goal for weight management and overall well-being for adults consists of engagement in moderate to vigorous intensity physical activity most, if not all, days per week for at least 30 min (Evidence Category B) [116]. The physical activity goals including activities, frequency, and duration are also individualized and may be decided along with a physician or health professional trained in exercise physiology.

### Behavioral Management

Any comprehensive weight management program should include a behavioral management intervention (Evidence Category B) [116, 119]. The purpose of a behavioral management intervention is to teach patients behavioral strategies that will help them adhere to their dietary and physical activity regimen and therefore optimize weight loss [116]. Key behavioral components taught during treatment include: goal setting, self-monitoring, stimulus control, problem solving, cognitive restructuring, stress management, and relapse prevention [103, 105, 106, 116].

## Pharmacotherapy and Bariatric Surgery

Pharmacotherapy can be used to augment behavioral treatment if 10% weight loss has not been achieved in the first 6 months or if the patient is seeking greater than 10% weight loss [116]. Furthermore, patients who have a BMI > 40 or BMI > 35 with another chronic comorbidity may opt to have bariatric surgery. However, behavioral treatment before and after surgery is still considered appropriate and may help to improve weight loss success and maintenance post surgery. Behavioral treatment before bariatric and/or after bariatric surgery may consist of CBT for binge eating. Approximately, 20–50% of patients seeking obesity treatment have experienced episodes of binge eating [116]. CBT for binge eating may include the use of self-monitoring of eating patterns, regular daily meal intake (three meals and two snacks), cognitive restructuring, and relapse prevention [116].

## Guidelines for Children and Adolescents

Treatment recommendations for childhood obesity include a more staged approach that increases in intensity with each stage [118]. The early stages of the treatment recommendations involve care within the primary care provider office while later stages consist of involvement of other specialties such as psychologists. However, all the stages of treatment consist of a number of behavioral management recommendations (i.e., goal setting, self-monitoring, stimulus control, and problem solving) in which psychologists can ideally be involved in care. Parents are expected to be involved in all stages of treatment to a more or lesser degree depending on the child's age. The first stage is described as *Prevention Plus*, which consists of a focus on specific healthy eating and activity habits for the child to follow to improve BMI status [118]. If the child has not made improvements in BMI status or health behaviors after 3–6 months, then they are referred to stage 2, *Structured Weight Management*. This stage builds upon the treatment provided in stage 1, but with additional structure including a planned diet and scheduled physical activity [118]. Stage 3, *Comprehensive Multidisciplinary Intervention*, consists of a multidisciplinary team approach to maximize support for behavior changes. Finally, stage 4, *Tertiary Care Intervention*, consists of pharmacotherapy, very low-calorie diet (VLCD), or bariatric surgery for older, severely obese adolescents who were not successful in stage 3.

## Behavioral Weight Management Interventions

As previously stated, for this chapter, behavioral interventions for obesity consist of a multicomponent lifestyle modification program focused on diet, physical activity, and behavioral management. Meta-analyses suggest that behavioral interventions are effective treatments of obesity in that they produce modest weight loss among children, adolescents, and adults [104, 105, 111, 120–123]. Specifically, adults participating in behavioral interventions for obesity lose an average of 7–10% of their

initial weight [105, 111, 120], which meets the WHO criteria of successful treatment—from 5 to 10% loss of initial weight [95].

In a recent meta-analysis based on 13,495 participants, LeBlanc et al. [122] found that those who underwent a behavioral intervention lost 3 kg (6.6 lbs) more than those in a control group after 12–18 months of intervention. Those in the intervention groups lost on average 4% of their baseline weight, whereas the control groups had minimal or no weight change [122]. There is limited evidence for treatment of obesity among young adults (i.e., 18–25 years old), but meta-analysis indicated an average loss of 2.96 kg for those participating in a comprehensive behavioral intervention [123]. For children and adolescents aged 4–18 years old (1,099 participants included in meta-analysis), BMI change was 1.9–3.3 kg/m<sup>2</sup> greater in comprehensive behavioral interventions compared to control conditions [104].

The majority of weight loss resulting from a behavioral intervention happens during the intensive phase of treatment, typically considered to be the first 3–6 months when intervention sessions occurred on a weekly or biweekly schedule [104, 111, 120]. In regard to treatment utilization, meta-analysis indicated that patients who attended 12–26 sessions tended to lose more weight (i.e., 6% of initial weight) than those who attended less than 12 sessions (2.8% loss of initial weight) [122]. Currently, there is not enough evidence to indicate the intensity or number of sessions needed to effectively treat obesity among children and adolescents [104].

Evidence of the effectiveness of teaching specific behavioral strategies during a behavioral intervention (i.e., goal setting, stimulus control, problem solving, cognitive restructuring, and relapse prevention) is also limited [104, 122]; however, there is growing support for the instruction on and use of self-monitoring. Self-monitoring is considered a key behavioral strategy for adherence to dietary and physical activity recommendations and thus indirectly leads to weight loss [111]. Previous studies demonstrated that self-monitoring of weight, diet, and/or physical activity is associated with weight loss, weight loss maintenance, healthier dietary intake, and increased physical activity [58, 124–127]. Parental involvement including teaching behavioral strategies to both children and their parents appears to be effective for treating or preventing childhood obesity [104, 128, 129].

Outcomes of behavioral interventions for obesity extend beyond weight loss. Behavioral interventions that promote modest weight loss (7–10% loss of initial weight) have been associated with reduction in blood pressure, fasting glucose, lipids, and the metabolic syndrome among adults [122, 130, 131]. In terms of behavioral outcomes, research suggests that behavioral interventions are effective in reducing total fat (7.3% reduction in calories from fat), saturated fat intake, and increasing fruit and vegetable intake (average increase of 0.6 servings per day), particularly among adult populations with elevated disease risk [132]. Among overweight and obese children and adolescents, there is some evidence for the effect of behavioral interventions on reducing adiposity, LDL cholesterol, and insulin resistance as well as increasing HDL cholesterol and physical fitness [104].

One of the major limitations of behavioral interventions for obesity across all age groups is the short-term effectiveness. Patients tend to regain about 30–35% of their lost weight 1 year post treatment, and by 5 years 50% of patients return to their

initial weight [133]. Research suggests that weight regain is due to biological, physiological, psychological, and environmental barriers including discontinued practice of behavioral strategies [115, 134]. However, to combat weight regain, the extended care model for treatment of obesity has been recommended [135]. Continued, significant weight loss (2–4 kg) in the long term has been demonstrated within interventions lasting 24–54 months [122]. Furthermore, research suggests that weight loss can be maintained for an additional year with ongoing support [111, 122]. Typically, this ongoing support may consist of monthly face-to-face meetings, contact by phone, e-mail, or text message, or use of an interactive Internet Web site [104, 134].

### Behavioral Weight Loss Treatment with Racial/Ethnic Minorities

Although African Americans and Hispanics have the highest prevalence of obesity, there is still no clear evidence on the best approach for weight reduction in these racial/ethnic groups. A consistent finding across large multiethnic RCTs for weight reduction is that racial/ethnic minorities lose less weight and are more likely to experience weight regain compared to non-Hispanic Whites [136–139]. Previous literature suggests a need to culturally tailor and adapt behavioral interventions in order to see larger effects and sustained outcomes, particularly by acknowledging the environmental (home and neighborhood), cultural, and policy factors that influence obesity within this group [140–142]. Refer to the *Handbook of Obesity Treatment*, Chap. 20 for additional information on obesity treatment in minorities [143].

## Psychosocial and Behavioral Assessments for Obesity Treatment

### Adults

BMI has been deemed the primary measure used to determine weight status in adults [116]. BMI is calculated by dividing weight measured in kilograms by height in meters squared. As shown in Table 17.5, a BMI of 25–29.9 kg/m<sup>2</sup> indicates overweight and a BMI  $\geq 30$  kg/m<sup>2</sup> indicates obesity. These values are typically obtained by the primary care physician; however, psychologists who have access to a scale and stadiometer may also calculate BMI during the initial assessment and periodically throughout treatment. An overweight or obese weight status and a patient's expressed interest in losing weight constitute a need for the inclusion of psychology prior to and during treatment planning.

In addition to conducting a physical examination to determine the patient's BMI status and other CVD risks, patient readiness and behaviors should also be assessed prior to starting treatment [116]. Behavioral assessments can be conducted by the psychologist with an objective to examine the biological, behavioral, psychosocial, and environmental contributions to obesity as well as the patient's weight loss goals [144]. In addition to a clinical interview, several questionnaires have been suggest-

**Table 17.6** Domains to address during initial interview and behavioral assessment prior to obesity treatment [144, 145]

Domains	Specific content area
Biological factors	Age of onset of obesity Family history
Environmental factors	Weight gain and weight loss history Number of meals and snacks per day Calorie intake Diet composition Environmental cues Appetite Problem eating
Physical activity	Type Duration Frequency
Psychosocial factors	Environmental and/or physical barriers Social context of weight loss Quality of life (physical, mental, and social functioning) as it relates to obesity Mood disorder (history or current) History of substance abuse History of physical/sexual abuse
Temporal factors	Timing of weight loss Weight loss expectations

ed for use in treatment planning and outcomes including the BDI-II and the Weight and Lifestyle Inventory (WALI) [144].

Clinical interview domains are presented in Table 17.6. During the initial interview, first, it is important to establish the biological or heritable factors such as age of onset of obesity, family history of obesity, and weight history. At times, it is helpful to create a weight gain/loss timeline with patients to understand fluctuations in weight over time, triggers of weight gain or loss, and the consequences. Second, a thorough examination of the patient's diet and physical activity behaviors needs to be assessed given that treatment planning and goal setting will be focused in these two areas. Psychologists may work with a registered dietitian to obtain information on diet and physical activity or on their own ask a few questions regarding eating patterns, environmental and emotional cues for eating, as well as the type, frequency, and duration of physical activity. To assess diet composition, in lieu of a 24-hour dietary recall or food record, clinicians can ask patients to describe their typical weekday and typical weekend day in terms of food and beverage consumption. This type of questioning allows the psychologist to understand more about the patient's eating habits including frequency of consumption of high-fat/ high-calorie foods and beverages. Occurrence of binge eating or night eating should also be assessed in order to determine if there is a need for specialized treatment (e.g., CBT for binge eating). Finally, psychosocial factors should be assessed including level of social support for weight loss (family, friends, coworkers), history of mood

disorders, history of substance, physical, or sexual abuse, and current life stressors. Also, the psychologist should inquire about the impact of obesity on the patient's emotional, social, and physical functioning as well as how weight loss may change these psychosocial factors as these may be key motivators for the patient to use during treatment. Refer to Kushner and Sarwar [145] as well as Chap. 10 in the *Handbook of Obesity Treatment* [144] for further details on domains and specific content areas recommended to be discussed during the initial interview and behavioral assessment.

Assessment of patient's readiness and motivation to lose weight and make behavioral changes is key for developing a tailored treatment plan and treatment success. The NHLBI [116] suggests several important questions that clinicians should ask patients to evaluate readiness for obesity treatment including the following:

- *What are your reasons and motivation for weight loss at this time?*
- *What factors contributed to previous failed or successful weight loss attempts?*
- *What is the level of social support in your life at this time and can you identify those who may help facilitate versus inhibit weight loss efforts?*
- *What is your attitude about physical activity?*
- *Do you have time to commit to a weight loss program now?*
- *What are the barriers that may prevent you from engaging fully in treatment?*

MI [34] has been used in both RCTs and clinical practice as a technique to help patient's resolve their ambivalence and increase their readiness to make behavioral lifestyle changes that promote weight loss [146, 147]. Previous research suggests that implementation of MI in combination with standard behavioral treatment promotes significant weight loss [146, 147].

## **Bariatric Surgery Evaluations**

A multidisciplinary team approach for evaluation, preoperative treatment, and post-operative treatment has been recommended for patients seeking bariatric surgery [148]. Typically, bariatric patients are required to complete a psychological evaluation with a clinical psychologist or other mental health professional prior to being approved for surgery. Most psychologists will conduct a clinical interview to assess the following key areas:

- *Knowledge and understanding of the surgery.* Patients should have a good understanding of what they are getting into including what will be removed or rerouted during the surgical procedure and the specific nutrition regimen that needs to be followed postoperatively.
- *Purpose for seeking surgery.* Psychologists should gather information to understand why the patient is seeking bariatric surgery at this time. For instance, some patients seek surgery to manage or reverse medical conditions such as diabetes, to increase physical functioning, or to improve appearance and self-esteem.
- *Family history of obesity, other chronic illnesses, and mental illnesses.*



- *Medical history.*
- *Current and past psychological health including mental hospitalizations, suicide attempts, and use of psychotropic medications. It is particularly important for the psychologist, surgeon, and/or medical doctor to be aware of the patient's use of psychotropic medications as some are not absorbed in the digestive system the same way after surgery. Also, mental illnesses may become exacerbated post surgery.*
- *Weight loss history.*
- *Behavioral assessment of past and present eating, activity, and substance use behaviors. Psychologists should be aware of any behaviors that may be contraindications for surgery such as current binge eating, regular consumption of caffeine, or substance abuse including smoking, alcohol, or other drugs.*
- *Preparation for surgery including dietary changes and changes in eating habits and physical activity.*
- *Level of social support regarding the decision to have surgery as well as postoperative care.*

However, there is no consensus on the assessment measures used in conjunction with the clinical interview. Below is a list of measures that have been cited in the literature as useful tools for the psychological evaluation before bariatric surgery:

- Beck Depression Inventory-II (BDI-II) [61]
- Binge Eating Scale (BES) [149–151]
- Revised Masters Questionnaire (MQR) [152]
- Personality Assessment Inventory (PAI) [153]
- Cleveland Clinic Behavioral Rating System (CCBRs) [154]

### **Assessments for Children and Adolescents**

As previously stated, BMI percentile is used to determine the weight status of children and adolescents, 2–18 years of age. A BMI between the 85th and 94th percentile indicates overweight status, and a BMI  $\geq$  95th percentile represents obesity. Psychologists can use the CDC Growth Charts (<http://www.cdc.gov/growthcharts/>) to determine and track BMI percentile over the course of treatment.

In addition to a medical assessment typically administered by the physician, a behavioral assessment should also be conducted with the child and his/her parents [118]. The primary goals of the behavioral assessment are to identify the child's diet-related and activity-related behaviors that promote obesity as well as the child and family's readiness and capability to make behavioral changes. Key information to obtain during the assessment includes the following:

- Number of meals and snacks consumed per day
- Frequency of eating food prepared outside the home
- Amount of sugar-sweetened beverages consumed per day
- Frequency and quality of breakfast

- Consumption of high-fat/ high-calorie foods
- Number of fruit and vegetable servings consumed per day
- Type, frequency, and duration of physical activity, specifically moderate physical activity to determine if the child is obtaining 60 min or more each day as recommended [118]
- Amount of time spent in sedentary behavior (e.g., TV watching, video games, or computer use) to determine if less than 2 h per day as recommended [118]

### **Evidence-Based Practice/Practice-Based Evidence**

It should be noted that most of the evidence for behavioral interventions for treatment of obesity are based on RCTs, which has its benefits in terms of efficacy, but has also presented challenges in terms of effectiveness and translation. Interestingly, clinical psychologists or psychology trainees often serve as the interventionists in behavioral clinical trials for obesity, but psychologists are currently not routinely represented in primary care practices or specialty medical clinics where treatment for obesity is often received. Exceptions are psychologists who perform presurgical assessments, and psychologists who treat obese patients within eating disorders clinics. Generally, psychologists encounter patients who are overweight or obese in the course of service provision in medical settings (e.g., treatment of patients with diabetes, hypertension, chronic pain, functional impairment and disability, psychological disorder); however, patients are often not referred for overweight or obesity as the primary presenting problem. Providers may not be aware of the role a psychologist can play in terms of behavioral assessment and treatment. Furthermore, some psychologists may not feel comfortable treating obese patients beyond providing therapy for the associated psychological distress or mental illness because they view it as a medical condition only to be addressed by medical providers [155]. Another major barrier is the evidence supporting the extended care model. Although long-term care of obese patients may be ideal, the current health care delivery model does not support extended behavioral medicine care for obesity management, due to time, space, and financial constraints. Consequently, use of remote approaches (i.e., phone, text messaging, and Internet) have been suggested as ways to deliver long-term behavioral treatment, but current billing practices for psychologists generally do not allow billing for services rendered by telephone. Therefore, there remain barriers to psychologists implementing behavioral interventions for obesity in routine clinical practice at the individual, medical practice, and health care system level.

### **In Practice**

Psychologists are involved in the treatment of obesity by either providing behavioral interventions or by conducting psychological evaluations for bariatric surgery candidates. Close communication with all providers (e.g., primary care physician,

specialty provider, dietitian, etc.) involved in the patient's care is key for developing a clear, consistent, and individualized weight management plan for the patient. Communication can be enhanced through the use of electronic health records as it provides a way for each provider to be aware of the patient's progress in each area (disease management, weight management, and behavior change). When in communication with patients, the psychologist should be sure not to use terms such as fat, large, or morbidly obese, but rather terms such as BMI, unhealthy BMI, and weight problem [156].

A structured interview covering the domains listed in Table 17.6 along with several psychosocial and behavioral assessment measures is typically conducted during the first encounter. Treatment planning should occur with input from the patient and/or the patient's family in the context of children; use of MI can help facilitate this discussion. Behavioral treatment of obesity typically occurs on a weekly or biweekly basis consisting of individual or group sessions lasting between 60 and 90 min. Length of treatment can vary depending on the patient's needs, setting, and resources. Structured treatment of obesity (i.e., use of a structured curriculum such as the LEARN program) may consist of 16–26 sessions or, in other words, 3–6 months. However, some patients may require more long-term care such as 12–24 months. Sessions typically begin with a weigh-in and review of completed food and physical activity records since the previous session [105]. Content of the sessions includes, but is not limited to, education on nutrition (e.g., food groups and recommended serving sizes and how to reduce fat in the diet), physical activity recommendations, and instruction in the key behavioral strategies (goal setting, self-monitoring, stimulus control, problem solving, cognitive restructuring, and stress management) [103, 105]. More specific therapies such as CBT and PST may also be incorporated into treatment delivery. The goals of treatment are to help patients improve their eating habits and increase exercise in order to achieve 5–10% weight loss in 3–6 months of treatment.

Psychologists are able to bill H&B codes for reimbursement when the behavioral treatment is delivered under the context of an obesity-related medical condition, such as diabetes. However, psychologists cannot be reimbursed for providing behavioral treatment for obesity alone. Recently, the Center for Medicare and Medicaid Services (CMS) instituted a policy to cover intensive behavioral interventions for obesity, but this policy currently only covers primary care practitioners (<http://www.cms.gov/medicare-coverage-database/details/nca-decision-memo.aspx>) [157].

Translation of research evidence regarding behavioral treatment for obesity into clinical practice has been difficult given the barriers stated earlier (e.g., few psychologists integrated into clinical care, uncertainty about role of psychologists, and logistics regarding multiple session/ long-term care). However, the Veterans Affairs (VA) has instituted a national program that provides a model for a patient-centered medical home approach for obesity treatment [158]. The national program is referred to as MOVE! (Managing Overweight/Obesity for Veterans Everywhere) and was first rolled out as a pilot program in 2005. MOVE! is an evidenced-based patient-centered weight management intervention delivered by an interdisciplin-

ary team (e.g., primary care, psychology, endocrinology, nutrition, physical therapy, recreational therapy, and patient education). Patients are typically referred to MOVE! by their primary care physician if they have a  $\text{BMI} \geq 25$  or if they are of normal weight, but hypertensive. Implementation and structure of MOVE! depends on the staffing and resources available at the VA facility, but most facilities have taken a multidisciplinary team approach as it appears to be most effective [159]. See Dahn and colleagues [160] as well as Rosenberger and colleagues [161] for additional details on site-specific implementation and effectiveness.

## Summary

Diabetes and obesity are endocrine disorders that are increasing rapidly in prevalence in the US among both youth and adults. These are commonly presenting conditions in medical settings, and psychologists encounter patients with these conditions frequently, either as primary or as secondary presenting problems. Both conditions have an evidence base supporting effective psychological and behavioral assessment tools and behavioral intervention approaches for helping patients reach treatment targets. Psychologists should be aware of barriers (e.g., time allocated for evidence-based services, maintenance, billing practices, consult service vs. integrated team member) that remain within current health care system delivery models that can serve as challenges to the conduct of routine and optimally effective behavioral treatments for endocrine disorders. Integration of psychologists into routine practice settings, and psychologists functioning as members of interdisciplinary treatment teams, are optimal for accessing patients with these endocrine disorders and contributing to the attainment of psychological, behavioral, and medical treatment goals.

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# Chapter 18

## Gastrointestinal Conditions

Tiffany Taft and Megan Riehl

### Introduction

In this chapter, we focus on chronic gastrointestinal (GI) conditions commonly seen both in primary care and specialty gastroenterology clinics. In the past decade, much advancement into the understanding of psychosocial factors of both functional and organic GI conditions has been made. Most of these changes have occurred in our understanding of the irritable bowel syndrome (IBS), which is now firmly rooted in the biopsychosocial model and replaces the previous psychosomatic paradigm. Advances in cognitive neuroscience have highlighted the cognitive-affective processes that affect pain and digestive functioning, which in turn have informed psychological interventions. Advances in the understanding of functional GI conditions have led to a dramatic increase in the quality of research into the psychological aspects of chronic organic conditions, such as inflammatory bowel diseases (IBDs) and esophageal conditions.

### Functional Gastrointestinal Disorders

The majority of psychosocial research in gastroenterology has focused on functional GI disorders, with most attention given to the irritable bowel syndrome (IBS). Other functional GI conditions include functional dyspepsia, globus, functional heartburn, functional abdominal pain, functional diarrhea, and functional constipation. The

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**Table 18.1** Rome III diagnostic criteria for irritable bowel syndrome [5]

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Recurrent<sup>a</sup> abdominal pain or discomfort<sup>b</sup> at least 3 days per month in the last 3 months associated with two or more of the following:

1. Improvement with defecation
  2. Onset associated with a change in frequency of stool
  3. Onset associated with a change in the form (appearance) of stool
- 

<sup>a</sup> Criterion should be fulfilled for the past 3 months with symptom onset at least 6 months before diagnosis

<sup>b</sup> “Discomfort” refers to an uncomfortable sensation and not described as pain

overarching characteristic of these syndromes is how the digestive tract normally operates is impaired in some way, and that traditional medical testing for organic pathology will appear normal. Therefore, functional GI disorders are diagnosed based on symptom presentation and typically via the Rome III diagnostic criteria.

### *Irritable Bowel Syndrome*

Of the functional GI conditions, the most widely researched is IBS. Affecting between 7 and 10% of the global population, IBS accounts for a majority of missed work days (second only to the common cold), and creates an economic burden that parallels cardiovascular disease and diabetes [1, 2]. Health care utilization, both direct and indirect through lost work productivity, in IBS patients is 50% higher than matched controls and results in a 20-billion-dollar annual societal burden. This may be related to comorbid somatization, which is present in up to 30% of people with IBS, but is more likely associated with the current lack of effective treatments especially for those with the most severe symptoms and poorest health-related quality of life.

IBS is generally diagnosed in people under the age of 50, but may occur at any point in the life span. It affects women 1.5 times more frequently than men, although recent studies have found a rise in IBS rates among male veterans with comorbid Gulf War syndrome [3]. Global prevalence rates are quite similar across various ethnic groups; however, some differences may be attributable to differences in access to health care and should be interpreted with caution [4].

*Diagnostic Criteria.* The benchmark for diagnosis of IBS is the Rome III criteria, outlined in Table 18.1. In classic IBS, symptoms are present at least 3 days per month for 3 consecutive months with abdominal pain being relieved or improved by a bowel movement at least 25% of the time [3, 5]. It should be noted that only Rome I criteria, first published in 1988, have been evaluated for specificity (85%) and sensitivity (71%) [6, 7]. Other diagnostic criteria for IBS are used, albeit not as widely as the Rome III. These include the Kruis symptom score [8] which sets a cutoff score of 44 to predict the presence of IBS, and the American College of Gastroenterology (ACG) clinical criteria [3] that states IBS is present when “abdominal

pain or discomfort that occurs in association with altered bowel habits over a period of at least 3 months” (p. S2).

In addition to abdominal pain associated with altered bowel habits, 76% of IBS patients report symptoms of abdominal bloating, which includes both a subjective feeling of abdominal distention and an actual visible swelling of the abdomen [9, 10]. Bloating is not considered part of the diagnostic criteria for IBS but is important for clinicians to understand because of its high correlation with psychological distress [10]. This is especially true for women, who report bloating more often than men [9], as this may be related to body image and cultural association of thinness with attractiveness. In some women with IBS, this may lead to compensatory behaviors, such as restricting their diets or frequency of meals which can, in turn, exacerbate their IBS symptoms [11].

Recently, the diagnostic focus for IBS has shifted from one of exclusion to one of a positive diagnosis based on established criteria. This is an important step in reducing patient risks, as well as the economic burden of IBS, by eliminating unnecessary testing. Only in the presence of “alarm symptoms” such as rectal bleeding, weight loss, iron deficiency anemia, family history of organic disease (e.g., inflammatory bowel disease (IBD), celiac sprue, colorectal cancer), or nocturnal awakening is further diagnostic testing considered in most cases [3]. Unfortunately, in some IBS patients this may contribute to heightened disease-specific anxiety that a more serious medical condition has been missed, which we discuss later in this chapter.

*Irritable Bowel Syndrome Subtypes.* After the diagnosis of IBS is done, the patient’s physician can determine which IBS subtype is present, of which there are four possibilities: diarrhea predominant (IBS-D), constipation predominant (IBS-C), mixed (IBS-M), or unspecified (IBS-U) [5]. A patient’s subtype is determined by what type of bowel movement is present greater than 75% of the time, but it is not uncommon for a patient to switch between subtypes over the course of their condition [3]. In terms of prevalence, IBS-D and IBS-M are slightly more prevalent than IBS-C. While clinically important, IBS subtyping may be limiting research to a symptom-relief focus rather than treating underlying pathophysiology as clinical trials usually limit enrollment to either IBS-D or IBS-C.

*Pathophysiology of Irritable Bowel Syndrome.* Recent adoption of the biopsychosocial model of IBS into both clinical and research practice has revealed some of the physiological and psychological processes that influence the onset and maintenance of IBS. This represents a major shift in the conceptualization of IBS, from a psychosomatic paradigm to one that includes genetics, cognitive processes, autonomic nervous system (ANS) function, early life experiences, and patient behavior.

A major advancement in the understanding of IBS is research into the role of *visceral hypersensitivity*, which involves a heightened awareness or exaggerated perception of normal physical sensations within the digestive tract [12, 13]. In other words, patients with IBS feel to a greater degree normal processes such as hunger, fullness, passage of food, and bowel sounds than those without the condition, and this hypersensitivity is thought to be a main contributor to abdominal pain in IBS [14]. Patients with high visceral sensitivity often become preoccupied with these

normal GI sensations, especially when comorbid anxiety is present. This leads to a vicious cycle of attention to symptoms and the contexts in which they occur, attributing them to be dangerous, and increased anxiety with compensatory behaviors that may then alienate them from others [15, 16].

Two main physiological systems are implicated in visceral hypersensitivity: the brain–gut axis and ANS. The brain–gut axis is an important concept in understanding IBS, as well as other functional GI conditions, and involves the mucosa and submucosa of the digestive tract, spinal cord, cerebral cortex, and limbic system. Included in the brain–gut axis is the ANS, which regulates visceral functions in the body which should operate largely below the level of consciousness. In patients with IBS, regulation of sensitivity to normal processes is disrupted and is associated with increased activity in the sympathetic branch and decreased activity in the parasympathetic branch of the ANS [12].

Brain imaging studies, including functional magnetic resonance imaging (fMRI) and positron emission tomography (PET), comparing IBS patients to healthy controls or other GI diseases demonstrate this heightened visceral response to various GI stimuli [15, 17, 18]. However, results are mixed at identifying specific areas of the brain implicated in IBS symptoms [19]. Rather, several areas of the brain communicate with the enteric nervous system (i.e. the nervous system surrounding the gut) including the hypothalamo–pituitary–adrenal (HPA) axis, thalamus, and several cortices including the cingulate, somatosensory, insula, and prefrontal [20]. People with IBS show greater neural activity in these areas, but researchers have been unable to pinpoint single areas in the brain due to inconsistent study results [15].

The role of neurotransmitters in the presentation of IBS has also garnered greater attention in recent years. Specifically, serotonin is implicated in the impairment of normal gut functioning [21]. Overproduction of serotonin is associated with IBS-D and underproduction with IBS-C. Other symptoms such as nausea, vomiting, and motility are modulated by serotonin levels in the enteric nervous system of the gut [22]. Logically, the prescription of psychotropic medications that act on serotonin levels has increased in recent years as an off-label treatment of IBS. There are important distinctions in how these medications work, as some are helpful in alleviating abdominal pain and diarrhea (e.g., amitriptyline, imipramine, sertraline, paroxetine) and others may help constipation (e.g., citalopram, fluoxetine, escitalopram). As these medications are commonly prescribed for depression, their GI side effects should be considered in IBS patients so as to not exacerbate symptoms [23, 24].

Visceral hypersensitivity is predicted by symptom severity [25] and may normalize over time [26]. This normalization raises questions about what other factors may also maintain IBS symptom reporting, including the role of psychological stress. Data on this are mixed, with some studies suggesting a direct relationship with visceral hypersensitivity and psychological distress [27, 28] and others finding no such relationship [25, 29]. Interestingly, one small pilot study evaluated changes in brain function via PET after cognitive-behavioral therapy (CBT) treatment for IBS and found that changes occurred within the limbic system and anterior cingulate cortex, resulting in altered pain perception [30] and supporting the role of psychological stress in IBS.



Regardless of IBS diagnosis, GI symptoms are common during moments of stress and anxiety—from a feeling of butterflies in your stomach to abdominal cramping and diarrhea. It should be noted that patients are often sensitive to the notion that stress *caused* their IBS, but it is important to understand the role stress plays in the perpetuation and even possible development of the condition via physiological and psychological pathways.

Acute and/or chronic stress is associated with physiological arousal that impacts the ANS and HPA axis, both of which play a role in IBS [31]. The release of stress hormones such as cortisol mediate autonomic, immunological, visceral, and behavioral responses [32, 33], and some evidence exists that people with IBS are more physiologically susceptible to the negative effects of stress [34–36] especially through peripheral processes that contribute to gut inflammation, motility, and sensation [37]. People with IBS may be coined “gut responders” in that when they experience stressful life events, effects are felt most prominently in their digestive tract.

It is difficult to say if people with IBS experience more stressful life events and daily hassles than those without IBS [38]. We do know that the effects of stress on the body are mediated by several factors including cognitive appraisals, coping behaviors, social supports, and core beliefs which, of course, vary widely across individuals. A main area of research focus in IBS patients has been the effects of early adverse life experiences. Stress associated with traumatic childhood events can predispose a person to developing IBS later in life [39]. Rates of reported childhood physical and sexual abuse range from 20 to 60% in IBS patients [40, 41]. This abuse is associated with more severe symptoms, increased health care use, and poorer sleep quality [42].

Early childhood abuse is not unique to IBS patients, but is found in roughly half of patients with other chronic pain disorders such as fibromyalgia, headache, and chronic pelvic pain [43, 44]. Therefore, it is not likely that abuse forms a direct pathway to an IBS diagnosis, rather sets in motion several predisposing traits that may lead to its later development. Maladjusted attachment to a caregiver can cause long-term brain dysregulation [39] and chronic hyperarousal of the central nervous system [42], both of which are implicated in GI functioning. Childhood abuse may contribute to deficits in communication and help-seeking, leading to behaviors such as gaining attention via a “safe domain” of physical symptoms [45]. Some studies suggest that the presence of trauma, rather than specifically childhood abuse, predisposes a person to IBS [37]. Increases in the prevalence of IBS among female veterans with post-traumatic stress disorder, between 10 and 30%, support this notion [46, 47].

Finally, some cases of IBS occur after an episode of acute gastroenteritis where symptoms of abdominal discomfort, bloating, and diarrhea continue to be present after the infection has resolved. Research into this phenomenon includes understanding the potential inflammatory and/or bacterial correlates of IBS, although results remain preliminary. This post-infectious IBS (PI-IBS) occurs in 5–32% of new cases [48]. Premorbid psychological functioning has been implicated in the development of PI-IBS, including the presence of anxiety, depression, somatization,

and neuroticism. Cognitive and behavioral processes may also perpetuate PI-IBS, as stress within a year of the infection and negative illness beliefs are often reported by these patients. Compared with idiopathic IBS, patients with PI-IBS have a better prognosis and may respond better to pharmacological treatment [49].

*Psychological Comorbidity.* Patients with IBS often present with comorbid psychiatric conditions [50]. The most common comorbidities are anxiety disorders (58%) and mood disorders (34%), with 12–28% experiencing a major depressive disorder and 7% dysthymic disorder [51–54]. These rates appear to be relatively consistent across cultures [55], indicating that psychological comorbidity plays a central role in IBS. Generally, a comorbid Axis I diagnosis precedes an IBS diagnosis [56] and is stable over time even after IBS symptoms have improved [56, 57].

Somatization disorder rates in IBS patients range from 15 to 48% [53, 58]. It is important to understand that IBS is not considered a somatoform condition [59] and some IBS patients may be sensitive to this implication. However, changes to the *Diagnostic and Statistical Manual for Mental Disorders-5th Edition (DSM-5)* and the inclusion of somatic symptom disorder have raised some concerns about how conditions like IBS will be understood going forward [60]. Some patients with IBS will seek multiple opinions from physicians, including specialists, to try to ease anxiety about their diagnosis and ensure that a more serious condition is not being missed. It is not uncommon for these patients to report having seen five or six physicians, having undergone repeated and unnecessary medical testing, all yielding very little satisfactory information to ease their anxiety. When other chronic symptoms are present, multiple medical visits to multiple providers lead to a series of cumulative diagnoses as the physicians attempt to explain the patient's symptoms. It is not uncommon for an IBS patient to present with comorbid diagnoses of fibromyalgia, chronic fatigue syndrome, headache, or chronic pelvic pain [59]. Unfortunately, these diagnoses do little to alleviate health-related anxiety and only serve to increase frustrations and degrade health-related quality of life. However, somatization disorder should be thoroughly assessed in the polysymptomatic IBS patient and should not be assumed to explain the overlap in these chronic functional syndromes, as an overlap exists in the physiological mechanisms that underlie many of these disorders.

Of the anxiety disorders, generalized anxiety disorder (GAD) and panic disorder (PD) are most common in IBS patients. As many as one third of IBS patients have GAD [50, 61, 62] and underlying GAD results in the person dedicating substantial amounts of time worrying about their IBS symptoms and functioning of their digestive tract. These worries are related to their subtype, so patients with IBS-D may ruminate over not being able to find a bathroom in time and those with IBS-C may worry about long periods of time between bowel movements. Other concerns include that their symptoms are caused by a missed serious medical condition [63], as well as focus on their inability to control their IBS symptoms effectively. Regardless of the presence of GAD, worry and intolerance of uncertainty are significant predictors in the development and maintenance of IBS [38].

PD, with or without agoraphobia, affects between 15 and 41 % of IBS patients [53], with a direct positive relationship between symptom severities of both conditions. IBS patients with PD exhibit the greatest negative impacts to quality of life due to their extreme anxiety over having symptoms [64]. These patients also tend to catastrophize normal GI sensations, creating a cycle of IBS symptoms, anxiety, and panic. Compensatory behaviors include avoidance and social withdrawal which do little to alleviate their panic and worsening IBS symptoms [65–67]. Beyond GAD and PD, other anxiety disorders found in patients with IBS include obsessive compulsive disorder (35%), specific phobia (13%), social phobia (7–26%), and post-traumatic stress disorder (10–12%) [50, 68, 69].

Finally, eating disorders such as anorexia and bulimia nervosa can occur in 4–8% of IBS patients [70–72]. It is unclear whether IBS may be preceded by or initiate disordered eating; however, one study found that 87% of participants developed an eating disorder prior to their IBS diagnosis [73]. Many patients believe that diet plays a role in their symptoms and will use a variety of dietary strategies to treat their condition. These behavior changes may lead to selective reinforcement of certain maladaptive eating habits that are part of the diagnostic criteria for an Axis I eating disorder. Additional research in this area is needed to understand the relationship between IBS and eating behaviors, and when IBS-related eating behaviors may become pathological.

*Psychological Assessment.* Careful assessment of initiating and maintaining factors of IBS symptoms is critical to treatment planning. A comprehensive clinical interview should evaluate the degree to which a patient experiences psychological distress, particularly anxiety, depression, and somatization, impacts on health-related quality of life, symptom severity, and the cognitive-affective processes that may be perpetuating symptoms. Several IBS-specific measures are available to evaluate symptom severity and quality of life specific to IBS (Table 18.2). Because the ANS plays an important role in the presentation and maintenance of IBS, understanding the relationship of IBS symptoms to stressful events is also an important part of a comprehensive assessment to guide potential interventions targeted at reducing ANS arousal (e.g., relaxation training).

Understanding the cognitive-affective processes that may be contributing to an IBS patient's experience is critical to effective intervention. To date, CBT specifically tailored for IBS is the preferred psychological treatment. It is an effective intervention that targets overly negative cognitive appraisals, suppression of emotions, and alexithymia [74–76] as well as changing confrontational, escape avoidance, and self-controlling coping strategies [77]. CBT for IBS also identifies core beliefs related to need for approval, over-responsibility and/or perfectionism, often found in a subset of IBS patients [78].

As we have previously mentioned, extreme thoughts and reactions to daily stressors or toward IBS symptoms themselves can lead to a self-perpetuating cycle of symptoms and psychological distress. A major cognitive dysfunction in IBS patients is catastrophizing, or blowing things out of proportion, especially as it relates to their IBS symptoms and the impact they have on their life. They also tend to

**Table 18.2** Select validated assessment instruments for gastroenterology

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<i>General GI</i>
Functional digestive disorders quality of life questionnaire
Visceral sensitivity index
University of California, Los Angeles (UCLA) global severity of gastrointestinal symptoms scale
<i>IBS</i>
IBS quality of life (IBS-QOL)
IBS-36 (HRQOL)
IBS-symptom severity scale
IBS stigma scale
<i>GERD</i>
Reflux disease questionnaire (RDQ)
Gastrointestinal quality of life index (GIQLI)
Gastroesophageal reflux disease health-related quality-of-life scale (GERD-HRQL)
Quality of life in reflux and dyspepsia (QOL-RAD)
Heartburn specific quality of life (HBQOL)
GERDQ [194]
<i>IBD</i>
Inflammatory bowel disease questionnaire (IBDQ; short form available)
IBD self-efficacy scale (IBD-SES)
Rating form of IBD patient concerns (RFIPC)
<i>EGID</i>
Adult eosinophilic esophagitis quality of life scale (EoE-QOL)

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*GI* chronic gastrointestinal, *IBS* irritable bowel syndrome, *GERD* gastroesophageal reflux disease, *IBD* inflammatory bowel disease, *EGID* eosinophilic GI disorders

underestimate their ability to effectively cope with symptoms when they do occur, which contributes to behavioral avoidance [79]. Catastrophic thinking increases if comorbid depression is present, which often leads to more severe abdominal pain [79, 80]. Problem-solving deficits unique to IBS and unhelpful worry about situations that are beyond their control can also exacerbate IBS symptoms; in essence, people with IBS tend to attempt to solve all problems, regardless of if a solution is available, rather than using emotion-focused coping to weather the storm [81, 82]. This coping style is also seen in patients with functional dyspepsia, which is further discussed later in this chapter [83].

*Management of Irritable Bowel Syndrome.* Unfortunately, the current treatment options for IBS are largely ineffective in alleviating its full range of symptoms [26, 84, 85]. This often contributes to frustrations and fears that IBS patients experience in that they feel that there are few effective medical options to alleviate the physical distress. Of the possible pharmacological treatments, antispasmodics (e.g., Hyoscyamine), antidiarrheals (loperamide), nonabsorbable antibiotics (rifaximin), tricyclic antidepressants (e.g., amitriptyline, imipramine), and peppermint oil show modest efficacy in controlling a variety of IBS symptoms [85–88]. These are not without side effects, which can lead to poor tolerance and discontinuation. There is

no evidence to support the use of laxatives in managing IBS [89] which should be avoided due to potential adverse events and addictive qualities.

Dietary management has gained much attention among patients, with several diets touted as treatments for IBS. However, there are still no recommended dietary guidelines for IBS. Previously believed to be effective in treating IBS, fiber has been found to have no evidence to support its use [85, 86]. Other diets with limited information on their effectiveness in treating IBS include elimination strategies for gluten, short chain carbohydrates, and monosaccharides—fermentable oligosaccharides, disaccharides, monosaccharides and polyol (FODMAP), and dairy. Often patients will report having tried several dietary strategies with limited success, and some may have severely limited their food choices due to anxiety related to eating and IBS symptoms. The use of probiotics in treating IBS shows some promise, specifically *Bifidobacterium infantis* 35624 which demonstrates superiority to placebo in five randomized controlled trials [90]. Other probiotics have not shown sufficient evidence to support their use in the treatment of IBS [91–94], but research in this area is emerging.

### ***Functional Esophageal Disorders***

Like functional bowel disorders, functional esophageal disorders are not evidenced by organic pathology. Chronic or recurrent complaints in the esophageal region that are not explained by biochemical or structural abnormalities are typically classified in this category. The functional diagnosis can be given through the combination of high-resolution manometry, failed response to proton pump inhibitor (PPI) therapy, ambulatory pH monitoring, and upper endoscopy [95]. It is important for patients to receive a proper diagnosis by a gastroenterologist to ensure and inform proper treatment.

Upper GI complaints are typically first addressed in primary care centers and make up a significant proportion of health care utilization in adult men and women in the USA [96]. Individuals with esophageal disorders account for 17.5% of all digestive system diagnoses and approximately 7,000,000 visits to ambulatory care per year [97]. Upper GI symptoms, for example, abdominal pain, nausea, and vomiting, account for significant rates of work loss, impaired quality of life [96], and significant economic impact on the US health care system [98].

The comorbidity of pathophysiological and functional problems requires careful diagnosis and examination. For example, esophageal hypersensitivity and gastroesophageal reflux disease (GERD) may have the same presentation by a patient in a health care setting [99]. Patients with esophageal hypersensitivity experience their symptoms more frequently and intensely than individuals without a hypersensitive esophagus. The experience of emotional, mechanical, and/or chemical stimuli can impact the presentation of symptoms experienced by this population of patients. Esophageal hypersensitivity causes patients to have a lower threshold for symptoms and should be considered for patients who continue to show up in GI and primary

care clinics believing their diagnosis has been missed [99]. Clinical judgment, careful collection of medical and social history, and appropriate testing must be utilized to determine whether an individual is presenting with an organic disorder. In a health psychology practice, the most common functional esophageal disorders are functional heartburn, functional dysphagia, and globus. Like IBS, psychiatric diagnoses, such as anxiety disorders, depression, and somatization disorder are common comorbidities in patients with functional chest pain (FCP)/non-cardiac chest pain (NCCP) as well as functional heartburn [100].

*Functional Heartburn.* Functional heartburn is defined by Rome III as retrosternal burning in the absence of GERD and any other histopathology-based esophageal motility disorders [100]. Upper endoscopy to rule out esophagitis, lack of response to PPI therapy, impedance and pH monitoring to measure acid reflux are required to make the diagnosis. Functional heartburn is a beneficial disease model to demonstrate the impact of esophageal hypersensitivity on symptom presentation in the esophagus. Esophageal hypervigilance is a learned behavior which develops over time in response to symptoms [101]. Accidental reinforcement of a person's sustained awareness to environmental and interoceptive cues can result in a cognitive-affective shift that the cues alone become equivalent to heartburn, creating a "self-fulfilling prophecy" for the experience of heartburn. It has been shown that 75% of patients with functional heartburn demonstrate esophageal hypersensitivity on balloon distention and experience decreased thresholds for the perception, discomfort, and pain when compared to controls [102]. Additionally, cognitive-affective processes such as catastrophizing, body vigilance, and somatization are also observed in this population [103].

Limited treatment options have been a long-standing problem for functional heartburn. Lifestyle modifications include dietary changes (eliminating spicy or fatty foods), smoking cessation, elevating the head of the bed for sleep, and reducing stress-inducing activities that are practical starting points for patients [104]. Also, relaxation techniques such as diaphragmatic breathing and psychological therapies aimed at decreasing hypersensitivity have proven effective [95, 105, 106]. PPI therapy is typically ineffective for this population and further research into pharmacologic approaches is necessary [105]. It has been suggested that a short course of medication such as low-dose tricyclic antidepressants [95], prokinetics, or histamine<sub>2</sub> blockers may produce symptoms reduction [207].

*Functional Chest Pain or Non-Cardiac Chest Pain.* FCP or NCCP has no clear etiology and is typically described as debilitating, recurrent chest pain not of burning quality [102]. The pain is explained as extreme pressure posterior to the breastbone, radiating outwards toward the neck and extremities causing concern and emergency room visits with fears of a heart attack. This pain may also be confused with pain from GERD or achalasia [95]. After an extensive cardiac workup to rule out cardiac disease, the use of endoscopy, pH monitoring, and a brief trial of high-dose PPI therapy are cost- and time-efficient steps in ruling out GERD to give a diagnosis of FCP/NCCP [95]. Despite a diagnosis, individuals may allow fear to drive continued health care utilization and symptoms cause significant impact on the patient's qual-

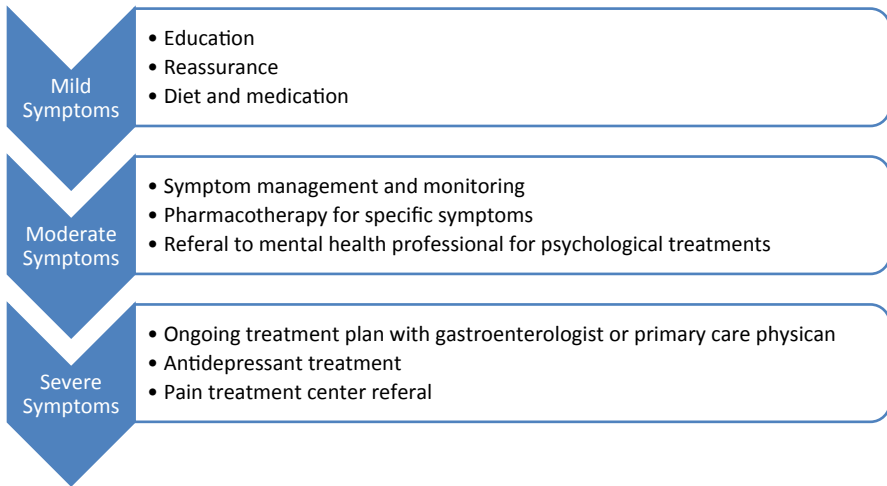
ity of life [102]. FCP/NCCP varies only slightly from functional heartburn, with esophageal hypersensitivity likely playing a role in the presentation of symptoms [101, 102, 107]. Controlled trials have shown efficacy for tricyclic antidepressants and selective serotonin reuptake inhibitors [108] and psychological therapies have been utilized in patients with high-intensity pain [95].

*Functional Dysphagia.* Functional dysphagia is characterized by “a sensation of abnormal bolus transit” down the esophagus [95]. Of the functional esophageal disorders, functional dysphagia is the least prevalent; in spite of this, one incident can cause a patient significant psychological distress in the form of fears of choking which can lead to food avoidance. Patients may arrive in the emergency room or primary care clinic describing a feeling of food or liquid sticking, lodging, or passing abnormally through their esophagus. An upper endoscopy and esophageal barium swallow test should be performed to rule out eosinophilic esophagitis, while achalasia and GERD should also be considered possible differential diagnoses [95]. Once a diagnosis is made, behavioral modifications can be implemented which should include slowing down the pace of eating and chewing food carefully. Reassurance by a physician, avoiding precipitating factors, and addressing any psychological stressors relevant to the patient’s symptoms should be considered. Finally, smooth muscle relaxants, botulin toxin injection, and dilation may prove beneficial.

*Globus.* Globus is described as a nonpainful, tightness or “lump in the throat” sensation that can be recurrent, difficult to treat, and persistent [109]. Equal in prevalence across genders, up to 46% of the general population may report an episode of globus sensation, typically associated with visceral hypersensitivity, upper esophageal sphincter dysfunction, and GERD [110]. Historically, globus has been a difficult disorder to treat due to unknown etiology; recent studies suggest GERD as the major etiology for 23–68% of globus patients [109]. Therefore, antireflux treatment may be indicated as a first line of treatment. Individuals who do not respond to antireflux therapy may benefit from relaxation therapy, CBT, speech and language therapy [109], or esophageal-directed hypnotherapy [110].

### ***Psychological Considerations and Management of Functional Chronic Gastrointestinal Disorders***

When patients are informed of a functional diagnosis, they may present as frustrated, overwhelmed, or apathetic, due to perceived lack of a plan or answer for their symptom presentation. A health psychologist should use empathy to ensure that the patient feels heard and validated. A primary feature of functional disorders is the increased motor and sensory reactivity to environmental stimuli which leads to greater physiologic reactions to stress [111]. Based on the severity of symptoms, collaboration between patient, physician, and mental health professional can be tailored (see Fig. 18.1). Psychological treatment should be focused on addressing illness-related thoughts and behaviors. Therapy goals may center on the reduction



**Fig. 18.1** Treatment planning for functional gastrointestinal disorders [111]

of pain catastrophizing and preoccupation of symptoms, improvement in the ability to cope, improving patient self-efficacy and control, and increases in healthy behaviors [112]. Basic psychoeducation on GI hypersensitivity and sensory perception in patients with functional GI symptoms can serve to validate their symptom presentation as well as build therapeutic rapport.

Psychological treatment may be a favorable option for patients who want to decrease medication reliance or who have not benefitted from medication regimens. The majority of studies on psychological treatments for functional GI disorders are for IBS, with some treatments showing significant promise [113]. However, a great deal of growth and research is warranted as defining the mechanism by which psychological treatments work for many functional GI disorders has not been easily established [112]. Thus far, sample sizes have been small, control groups or control treatments have lacked, sample sizes contain bias, and follow-up has been difficult for studies focused on the use of psychological treatment for the management of functional GI disorders outside of IBS. Of the possible psychological treatments for functional GI disorders, the use of interpersonal psychotherapy, gut-directed hypnotherapy (GDH), and CBT have the most empirical support.

Interpersonal therapy (IPT) is a form of brief psychodynamic psychotherapy that has been applied to refractory IBS and focuses on helping patients develop insight into their feelings about IBS, experiences with the illness, and how IBS impacts their relationships [113–115]. IPT has consistently demonstrated positive results, and works especially well in cases where IBS is related to or causes interpersonal difficulties [115] or a history of sexual abuse is present [116]. When compared to paroxetine, IPT was equivalent in reducing IBS symptoms and superior to placebo [117].



GDH has sustained empirical support for its effectiveness in treating IBS symptoms, especially in refractory cases [118]. Hypnotherapy has been shown to regulate reflux symptoms by decreasing anxiety, visceral sensitivity, and body vigilance [103]. It has been effective in patients with globus [110], NCCP [119, 120], and functional dyspepsia [121] and current research is addressing the potential use for patients with functional heartburn. Patients report feeling very satisfied with GDH as a treatment, and the degree of satisfaction appears to be independent of treatment efficacy [122].

Two validated models of GDH are available for clinical use: the Manchester Model [123] and the North Carolina Protocol [124]. Response rates are typically above 85%, which is greater than any other current medical therapy available for IBS [118, 122, 125, 126]. Typical GDH treatment involves 7–12 biweekly sessions with optional home practice via CD or digital recordings, and its effects may last as long as 5 [127] to 7 years posttreatment, especially when patients continue to practice GDH on their own [125]. While the exact mechanisms of GDH are not known, hypnotherapy reduces abdominal pain, bloating/distention, and alleviates altered bowel habits [118]. One concern about the use of GDH is lower effectiveness rates may occur when the treatment is administered in the community versus specialized treatment centers [126].

CBT has the most support as a psychological intervention for IBS and other functional GI disorders to date. A 2004 meta-analysis provides a thorough evaluation of the quality of studies evaluating CBT for IBS as well as their overall efficacy [79]. Early CBT trials for IBS emphasized reducing psychological distress [128, 129], unhelpful self-talk [130], avoidance behaviors [131], and health-related anxiety [132]. The positive effects of these CBT trials were present up to 4 years posttreatment [113] and were equivalent if not superior to standard medical therapies at the time [79].

The effectiveness of individual psychotherapy using CBT for IBS may translate well to small group formats, although results are mixed. In one study, CBT group therapy was associated with improvements in abdominal pain, improved adaptive coping strategies, and reduced maladaptive behaviors through long-term follow-up [133]. However, another randomized controlled trial found that group CBT for IBS was not superior to a psychoeducational control group [134], suggesting that individualized treatment may be more effective for IBS patients.

Current CBT trials for IBS focus on symptom-based outcomes, self-management, and minimal contact techniques to improve accessibility to psychological treatments. A 2010 study found that most IBS patients will respond to CBT interventions within the first 4 weeks of treatment [135]. A landmark, National Institutes of Health (NIH)-funded multisite clinical trial called the IBS Outcome Study (IB-SOS) [136] is underway and compares traditional CBT to a four-session, minimal therapist contact condition and to an educational supportive control condition. Pilot data for this study indicate that participants in the minimal contact condition felt equally satisfied with treatment as those in the traditional 10-week CBT condition [78]. Similar studies evaluating the effectiveness of minimal contact CBT techniques have yielded promising results. In one study, both telephone and in-person

interventions demonstrated comparable and significant improvement in GI symptom scores and health-related quality of life compared to controls [137]. A study evaluating a self-management program, where participants visited with a health psychologist for 1 hour, completed weekly readings and homework assignments, and had two 1 hour telephone contacts at treatment mid- and end-points found significant improvements in overall IBS symptoms. Most participants reported feeling highly satisfied with the treatment compared with previous IBS treatments, and rated it as either “effective” or “highly effective.”

In addition to minimal contact and self-management CBT treatments, Internet-based interventions show promise. A 2009 study evaluated a five-module web-based treatment for IBS and found that both GI symptoms and quality of life improved for the treatment condition as compared to wait-list control [138]. However, significant attrition occurred in both study groups and may be attributed to a lack of a client–therapist relationship and a lack of acceptability by IBS patients [139]. Further research in this area is warranted to determine if Internet-based CBT interventions are a viable option for treatment of IBS.

Patient education groups may be a positive intervention for IBS patients and offer an alternative to more intensive, specialized psychological treatments. Generally led by nurses with 8–10 patients, groups are a cost-effective strategy to reduce IBS symptoms through improved social support and accurate information regarding the legitimacy of IBS. The latter may be particularly important as patients with IBS report feeling stigmatized because of their condition from family, friends, employers, and even their physicians [140–142], [208], and that the diagnosis is considered a “catch all” diagnosis with little societal legitimacy.

Finally, some studies exist supporting the efficacy of other psychological interventions such as biofeedback [143], which when compared to hypnotherapy demonstrated similar results in improving symptoms in a cohort of refractory IBS patients. Meditation, exercise, and herbal remedies have limited data on their efficacy, but do show some effectiveness for some functional GI patients [144, 145]. Many functional GI patients report the use of complementary and alternative (CAM) therapies, even though sound data from randomized controlled trials are lacking [148, 149].

Psychological and behavioral interventions for functional GI conditions have produced promising outcomes especially for patients with frequent and intense pain who describe quality-of-life limitations [95]. The treatment of major depression, PDs, and other comorbid psychiatric disorders should be acknowledged by the health psychologist as contributing factors to their illness and that by addressing these symptoms, overall health and well-being may improve. Relaxation techniques aimed at reducing sympathetic nervous system activity can include progressive muscle relaxation, diaphragmatic breathing, meditation, and guided imagery; all serve to strengthen self-mastery and reduce physiological arousal [112].

## Organic Chronic Gastrointestinal Conditions

Organic GI conditions result from an identified pathophysiological process that leads to a variety of symptoms that are identified via diagnostic testing including inflammation, ulceration, and other visible damage to the digestive tract. Blood tests may also indicate systemic processes such as increases in immune system functioning, anemias, and inflammatory markers. Historically, organic GI diseases have not received nearly as much attention as functional conditions in regard to psychosocial issues. In the last decade, significant advancements have been made but there is much room for improvement.

### *Inflammatory Bowel Disease*

Inflammatory bowel disease (IBDs), which include Crohn's disease (CD) and ulcerative colitis (UC), are chronic, relapsing, and remitting autoimmune conditions with persistent and chronic inflammation of the GI tract. It is estimated that up to 1.4 million people in the US are affected by IBD, and this most commonly presents in adolescence to early adulthood at a time when many significant life decisions and changes may be occurring [150]. Patients with IBD are more likely to be unemployed or underemployed, take more sick days, and report a significantly poorer quality of life than those without [151].

There are some differences between UC and CD that should be understood. UC is the most common form of IBD and involves mucosal inflammation that is limited to the colon, typically affecting the rectum (ulcerative proctitis). Inflammation is continuous and, depending on the area of the colon affected, will spread back from the rectum to affect the sigmoid colon (proctosigmoiditis) to the entire colon (pancolitis) [152]. Symptoms will vacillate between quiescence (remission) and active (flare-up), and typically include bloody diarrhea with urgency sometimes with accompanying abdominal pain. These flare-ups can last for several weeks to several months, and some patients will require hospitalization and/or surgery [153]. When UC is in remission, patients are typically asymptomatic and their quality of life markedly improves [154]. It is not surprising that a common concern among UC patients is when their next flare may occur, as well the possibility of surgery and the long-term effects of medications. Flare-ups may be random or in response to an environmental trigger such as secondary illness, nonsteroidal anti-inflammatory drug (NSAID) use, sleep disturbance, smoking cessation (smoking is a protective factor in UC), and psychological stress [155–159]. For patients with UC, surgical removal of the colon is curative of the condition. Advancements in IBD surgery allow some UC patients undergoing total colectomy to have reconstructive surgery (J pouch) that allows for normal bowel function rather than lifelong use of an ostomy.

CD differs from UC in that it may affect any part of the digestive tract, from the mouth to the anus. However, the most common area of occurrence in CD is in the last part of the small intestine (terminal ileum) and first part of the colon. Unlike

UC, inflammation in CD may skip areas so that there are parts of the bowel that are healthy and parts that are inflamed and damaged [160]. Symptoms also alternate between remission and flare-up in CD, but in remission some patients struggle with the consequences of intestinal damage from disease flare-ups including intestinal blockage, abdominal pain, discomfort, and bloating [161]. During a flare-up, CD patients often experience bloody diarrhea, abdominal pain, weight loss, fatigue, and fever. Patients with CD are also more prone to extraintestinal symptoms (those outside the GI tract) such as joint pains, insomnia, and skin lesions [160]. Like UC, flare-ups may be random or in response to an environmental trigger. It is important to distinguish that while smoking has a protective factor in UC, it is considered a significant trigger of CD symptoms. For CD, surgery is a relatively common medical treatment where the diseased portion of the bowel is removed. However, unlike UC, surgery for CD is not curative and it often recurs next to the previous surgery site.

People with IBD have normal life expectancies, but disease-related concerns, psychological distress, and poor health-related quality of life are major issues, especially for those with CD. Subsequently, patients with CD are also more likely to seek psychosocial support than those with UC [162]. These differences between CD and UC are attributed to the more complicated and aggressive nature of CD [150, 163] and the more powerful (and risky) medical therapies typically used for CD (e.g., biological medications, immunomodulators). In a 2010 study, 84% of patients with CD reported significant worry about disease complications, 62% experienced depression, and 70% reported feeling embarrassed about their condition [164].

*Diagnosis and Medical Management.* IBD is diagnosed via a thorough clinical workup that includes endoscopic, radiological, or histological examination. Colonoscopy with biopsy, barium studies, capsule endoscopy, and specialized blood tests all can provide an IBD diagnosis [165]. However, the average time to receive an accurate IBD diagnosis ranges from 13 months [166] to 11 years [167], which has the potential for a significant psychological impact due to uncertainty, repeated testing, missed work, and declining health.

Currently, the aim of medical management of IBD is to reduce the inflammatory response in the body during flare-ups and maintaining remission once it is achieved through a regular medication regimen [168]. Medical therapies for IBD are not without risk or significant side effects, and even when treatment is optimal, patients still flare. There is some debate among gastroenterologists at the present time about the optimal way to manage IBD, with some arguing for a “top-down” approach where the more powerful medications, typically reserved for more severe cases when other treatments have failed, should be implemented early in treatment [161, 169]. Others contend that a more conservative approach, which has been historically taken, is the preferred treatment strategy. The following are the more commonly prescribed medications for IBD, which may be given alone or in combination with other medication types.

Corticosteroids (e.g., prednisone, budesonide) are a first-line treatment during an IBD flare-up [170, 171]. They may be taken orally or used topically through

suppositories, foams, and enemas. Around half of steroid users will experience significant side effects, which may include acne, insomnia, mood disturbances, edema, and glucose intolerance [34]. An uncommon side effect is steroid psychosis, where the patient may experience extreme changes in mood, irritability, delusions, and hallucinations [172]. Steroids are not considered a long-term solution for IBD treatment, rather are used to bring an active disease flare under control. Long-term steroid use may lead to cataracts, osteoporosis, osteonecrosis, myopathy, and increased risk for infections. Some IBD patients who use steroids for treatment have difficulty tapering off of the medication without a subsequent increase in disease activity, and are considered steroid dependent.

Aminosalicylates (mesalazine, 5-aminosalicylic acid) are commonly used to maintain remission in IBD patients [171] and are considered more benign medications due to their lower-risk profiles. However, up to 45% of patients experience side effects that include headache, nausea, epigastric pain, and diarrhea. While considered safe, aminosalicylates have the potential for serious side effects including pancreatitis, Stevens Johnson syndrome (skin blistering), and alveolitis [171]. These medications are typically taken orally several times per day.

Immune modulators (e.g., azathioprine, mercaptopurine) are used both during active flare-up and to maintain remission. As their name implies, these medications modulate the immune system response believed to be the cause of IBD. Unlike biological agents, which are described next, immune modulators broadly target the immune system with the goal to achieve an optimal dose (based on weight) that will maintain remission without overly compromising the patient's immune system [171, 173]. Side effects include flu-like symptoms, leucopenia, hepatotoxicity, and pancreatitis. Because of the risk of liver effects, patients on immune modulators are advised not to consume alcohol in excess.

Biological therapies (e.g., adalimumab, infliximab, certalizumab pegol) are the newest IBD medications and show great promise in treatment and maintenance of remission. Generally considered for moderate to severe cases that do not respond to other medications, biological therapies target specific parts of the immune system (e.g., tumor necrosis factor alpha) identified in the inflammatory processes of IBD. These medications are delivered either via intravenous infusion or self-administered injection. Side effects include nausea, fatigue, tremor, joint pain and stiffness, and fever. Patients have reported significant concerns in using these agents [174], mostly related to rare but serious side effects such as cancers, rare opportunistic infections, and even death. Often called “the big guns” by patients, some report that these are medications of last resort due to the aforementioned risks, treatment costs (in the thousands of dollars per dose), and perceived severity of disease necessary for their use.

*Psychological Considerations.* Recent advances in the understanding of the role of stress in IBD have demonstrated a complex interplay between environmental stress, gut physiology, and neuroendocrine functioning [157]. Significant life events do appear to be a trigger for relapse in UC patients [158, 175]. Regardless of the literature, 75% of IBD patients report psychological stress being a direct trigger for their

disease flare-ups. One potential source of stress for IBD patients is disease-related stigma, which has been linked to poorer disease outcomes, increased depression and anxiety, and poorer health-related quality of life [176].

Patients with IBD may experience comorbid anxiety and depression, which is associated with poorer disease outcomes [157, 177, 178] with the exception of one 2008 study that failed to find this relationship [179]. The chances of developing anxiety or depression seem to be greater during a disease flare-up [178], and patients who become psychologically distressed are more susceptible to relapse within an 18-month period than those who are not distressed [157].

As previously mentioned, anxiety related to IBD treatments is common and is second only to worry about having an ostomy [180]. The biological therapies are of most concern to IBD patients due to their Food and Drug Administration (FDA) black box warnings for adverse events, with patients questioning the risk–benefit ratio of using these medications [181]. These worries are heightened among pregnant women with IBD, where 84% express significant concerns about negative effects of medication on pregnancy outcomes even though research reports that most IBD medications are safe to use during pregnancy [182]. These concerns may influence patient decisions to use or adhere to IBD medications, so it is important to ask patients about factors influencing their treatment decisions.

Other sources of psychological distress for IBD patients include the diagnosis itself, symptom experience, and the demands of disease management. Patients who have difficulty in adapting to their diagnosis report more IBD symptoms, less engagement in activities, higher perceived stress, higher health care utilization, and an emotional representation of their condition [183]. Patient health behaviors are directly related to disease outcomes, including risk to flare and the efficacy of the prescribed medication regimen [184, 185]. Up to 50% of IBD patients report regularly missing doses of their medication and 12% are completely nonadherent, making medication adherence in IBD quite poor [184]. This poor adherence contributes to an expected annual relapse rate between 58 and 89% for patients who do not follow their prescribed regimen. Research suggests that these poor adherence rates are related to many IBD patients not feeling involved in their treatment planning, perceptions of significant stress and beliefs that their health is too poor. Other factors that may contribute to poor adherence include the physician–patient relationship [185] and knowledge about their disease [183].

*Psychological Treatments for Inflammatory Bowel Disease.* Some IBD patients identify a need for psychological support to cope with disease-related concerns and anxiety [162]. Research to date has yielded mixed results as to the efficacy of psychological interventions with IBD patients, especially if these treatments can directly influence disease course [186]. The use of CBT and GDH appear to show the most promise.

CBT for IBD has only been investigated in a handful of controlled trials, with the majority focusing on improving coping and stress management skills [186]. In a 12-week CBT group therapy trial for IBD, disease-specific anxiety was reduced for both UC and CD patients, and depression decreased significantly for women but not men. Another small study found that CBT was efficacious in treating depression

symptoms in adolescents with IBD, with the results replicated in a support group for teen girls with IBD and their mothers. A 6-week CBT trial that aimed to improve self-efficacy related to disease self-management showed promising results for patients with CD [187]. Psychoeducation alone may provide some benefit, but is not as robust as when incorporated into a CBT framework.

One potential intervention point for CBT for IBD is treatment-related anxiety. Many IBD patients report insufficient information and education about their disease [181, 188] which can increase anxiety, influence treatment-making decisions, and adherence. However, about one third of patients report that knowledge about the potential severity of IBD would increase their anxiety levels. Psychological interventions like CBT can aid with IBD patient psychoeducation while mitigating the potential anxiety this information may produce through cognitive monitoring and restructuring of negative or catastrophic thinking.

GDH, earlier described in the functional GI disorders section of this chapter, has been applied to IBD with some promising results [186, 189]. A one-session trial of hypnotherapy found that GDH reduced heart rate and blood flow, as well as several immune system components implicated in IBD including interleukin-6, substance P, histamine, and interleukin-13 [156]. A seven-session hypnotherapy randomized controlled trial demonstrated that GDH has the potential to improve IBD symptoms by reducing bowel and systemic symptoms (medium effect sizes observed) [187] and alter the disease course by reducing the likelihood of flare at 1-year follow-up by 57% compared to active controls [187]. While these results are preliminary, additional research into the potential beneficial effects of GDH for organic bowel diseases is warranted.

## ***Pathophysiological Esophageal Conditions***

In this section, we outline common organic conditions of the esophagus and stomach: GERD, Barrett's esophagus (BE), esophageal motility disorders, and eosinophilic GI disorders (EGIDs). Some of these conditions are relatively common phenomena both in primary care and specialty clinics (e.g., GERD) while others are more rare and poorly understood (e.g., EGIDs, achalasia).

*Gastroesophageal Reflux Disease.* Gastroesophageal refers to the stomach and the esophagus, while reflux is best characterized as the buildup of acidic or nonacidic contents from the stomach into the esophagus. Reflux can occur in adults who do not meet criteria for GERD; however, when a person has GERD the reflux may cause damage to their esophagus. GERD is described as a condition that results from the reflux of gastric material through the lower esophageal sphincter (LES) into the esophagus causing symptoms and/or damage to the esophageal tissue [190].

GERD is a chronic, often treatable disease, with the presence of heartburn and regurgitation of acid. Other symptoms include dysphagia (difficulty swallowing), chest pain, chronic cough, chronic hoarseness, dental problems, experiencing a bitter taste in the mouth [98, 190, 191], and esophageal hypersensitivity [99]. Esopha-

geal complications can include esophagitis, esophageal ulcers, peptic stricture, asthma, adenocarcinoma, and BE [98]. It has been suggested that GERD can be a temporary condition when triggered by a specific factor, such as pregnancy [190].

Nonerosive reflux disease (NERD) and erosive esophagitis are the two main categories of GERD. NERD is typically defined as the presence of typical GERD symptoms with no mucosal injury in the esophagus when examined by upper endoscopy [192]. Patients with NERD are typically more difficult to treat due to the nonpredictable and varied response to PPI treatment. Further, NERD patients may have esophageal hypersensitivity which may present as functional esophageal problems including heartburn, chest pain, dysphagia, and globus [99, 193].

In the USA, GERD is the most common diagnosis in outpatient gastroenterology, with a prevalence ranging from 10 to 28% [96, 98, 107]. Given the complexities of the pathophysiology of GERD, there are several definitions used to make the diagnosis. The use of a patient-administered questionnaire, such as the GerdQ, can be a complementary assessment measure for patients with symptoms associated with GERD [194]. Despite the creation of multiple questionnaires, limitations prevent them from routine use and should never be the sole diagnostic tool [107].

While a diagnosis of GERD can sometimes be made by a symptom report, medical tests are often necessary to confirm a diagnosis, rule out other diseases, and determine the extent of esophageal damage. Physicians can perform an upper endoscopy (allows for observation of inflammation, stricture, ulcers, or signs of cancer in the esophagus), high-resolution manometry (measures the pressure in the esophagus), ambulatory pH monitoring (measures the amount of acid in the esophagus), or combined impedance-pH monitoring (measures acid in the esophagus and reflux) [191].

*Treatment of Gastroesophageal Reflux Disease.* A number of lifestyle modifications can be implemented into the treatment of GERD. Recent literature has added to the importance of addressing the obesity epidemic in the USA by linking obesity to increased rates of reflux symptoms, frequency, and severity of esophagitis, as well as the frequency of BE and adenocarcinoma of the esophagus [195]. Weight loss (for patients with a body mass index >25), elevating the head of the bed approximately 6 inches to alleviate heartburn and acid exposure throughout the night, smoking cessation, and decreased alcohol consumption have already been accepted as standards of care for individuals with GERD [191, 196].

Dietary changes may include the restriction of acidic foods such as tomatoes, onions, garlic, citrus fruits, spicy foods, and carbonated beverages [191]. Foods found to weaken the lower esophageal sphincter such as fatty foods, peppermint, caffeine, and chocolate should also be avoided. Patient's will learn which foods are irritants by flare-ups in their symptoms; working with a registered dietitian to modify their diet in a way that decreases the risk of reflux and heartburn while eating balanced and healthy meals can be beneficial. Lifestyle modifications and the use of over-the-counter (OTC) medications can be effective for a large proportion of people with GERD.



**Table 18.3** Medications approved by the FDA for the treatment of GERD [191, 199]

	Brand name	Standard dose	Most common side effects
Histamine <sub>2</sub> blockers			Headache, diarrhea, fatigue, confusion
Cimetidine	Tagamet	400 mg twice daily	
Famotidine	Pepcid	20 mg twice daily	
Nizatidine	Axid	150 mg twice daily	
Ranitidine	Zantac	150 mg twice daily	
Proton pump inhibitors			Headache, diarrhea, constipation, abdominal pain
Omeprazole	Prilosec	20 mg daily	
Omeprazole with sodium bicarbonate	Zegerid	40 mg daily	
Pantoprazole	Protonix	40 mg daily	
Esomeprazole	Nexium	40 mg daily	
Lansoprazole	Prevacid	40 mg daily	
Rabeprazole	Aciphex	20 mg daily	
Dexlansoprazole	Dexilant	30 mg daily	

While lifestyle modifications are encouraged, people with more severe symptoms will require medical management. GERD is commonly treated with PPIs or histamine<sub>2</sub> blockers with the primary goals of symptom alleviation, decrease in reflux, and to heal the esophagus. In the USA, OTC and prescription PPI's account for \$ 11 billion in sales; worldwide, 80% of PPI's are purchased OTC [197]. Prescription strength PPIs and histamine<sub>2</sub> blockers offer a higher dosage than OTC medications. PPI medications are similar to histamine<sub>2</sub> blockers in that they both stop acid secretion in the stomach; however, PPI's are more powerful.

More recent literature highlights the overutilization of PPIs in clinical practice and the potential for adverse side effects and preventable cost expenditures [197]. Not all patients with GERD will respond to PPI therapy. A study in Asia reported that as many as 50% of patients with NERD and reflux esophagitis (RE) had no response [198]. With more research needed in this area of treatment, physicians should make informed clinical judgments when prescribing these medications. See Table 18.3 for a list of common medications currently approved by the FDA [191, 199]. For patients with more severe forms of GERD, fundoplication may be warranted. This is a surgical procedure which involves wrapping a portion of the stomach around the esophagus to create a tighter antireflux barrier [191].

*Barrett's Esophagus.* BE is a precancerous condition with obvious esophageal mucosal injury identified by an upper endoscopy. It is a less common esophageal disorder with risk factors that include a history of chronic GERD, male gender, tobacco use, older age, and central obesity [200]. With an estimated prevalence of 5–15% in patients with GERD symptomology, once diagnosed with BE, a routine

**Table 18.4** Example therapy script for de-catastrophizing with an esophageal patient

<i>Description of the event</i>	<i>Clinician:</i> Tell me what brought you in today <i>Patient:</i> I had a very serious event happen the other day during lunch. I was eating a piece of steak and I choked. It was terrible <i>C:</i> That must have been scary for you! What happened as you were choking?
Validation that the event was not ideal, and gathering information to aid in giving the patient evidence that the event was not dangerous	
<i>Description of the bodily and psychological reactions of the event. Patient's thoughts multiply the intensity of the fears</i>	<i>P:</i> Well, I couldn't breathe and thought I was going to die. I was coughing very hard, gasping for air, my heart was pounding, and I started to sweat. I felt out of control. I had my co-worker take me to the emergency room
Ofentimes emergency room visits will be costly, time consuming, and will not provide the patient with answers they want. However, testing may be done to give evidence that the esophagus is functioning efficiently	<i>C:</i> What did they do for you in the emergency room?
<i>Patient remains anxious and interprets bodily sensations in a catastrophic way</i>	<i>P:</i> They didn't do much. They did some tests and told me that my esophagus was perfectly fine. The doctor encouraged me to eat slower and take smaller bites. But, I haven't been eating much because my heart begins to pound before I eat and I am afraid I'll choke again
Use of psychoeducation and deflating the situation	<i>C:</i> I have some good news for you! It does not appear as though you actually choked. When you choke your airway is completely constricted or blocked and you would not have been able to receive air to breathe. You definitely would not have been able to converse with your co-worker and taken your time getting to the hospital. It sounds like what happened was something that was uncomfortable and scary, however, not as dangerous as you perceived
<i>Anxiety begins to decrease</i>	<i>P:</i> Yes, I was afraid I was going to die. So I wasn't choking!
Facilitate the development of coping skills to aid in controlling the patient's fears of choking in the future with cognitive restructuring, positive self-talk, coping statements, and distraction	<i>C:</i> No, and I think now that you know the difference between choking and having something uncomfortable happen while eating, you can remind yourself that your worst fear is not coming true and this is not a dangerous situation. Over time, the uncomfortable sensation will subside and you will be okay. As long as you are able to talk or cough, you are not choking. Maybe you could count to ten and tell yourself, "I am not choking, this is temporary discomfort." Or you could distract yourself by chatting with your co-worker about a project you are working on
<i>Patient feels more confident with skills to use</i>	<i>P:</i> I feel a lot better knowing that I didn't choke

**Table 18.4** (continued)

Implementing a plan to maintain patient's health and nutrition	C: Yes, and I think it is important to continue to eat on a regular basis. Think about all the meals you have consumed in your life! Have you ever had a true choking incident when your airway was blocked?
Probability versus possibility technique <i>Patient has data/facts to support the fact that they have skills and the ability to cope with stressful, uncomfortable situations</i>	P: No, I have not. That's a good point! I am going to work on slowing down during my meals, not talking so much while I eat, and taking smaller bites
Patient may benefit from some eating habit modification	C: Those sound like healthy behavior modifications!

examination with endoscopy is required to ensure it has not advanced to esophageal carcinoma [98].

*Esophageal Motility Disorders.* Esophageal motility disorders, comprised of achalasia, diffuse esophageal spasm, nutcracker esophagus, and hypertensive lower esophageal sphincter are less common upper GI conditions [201]. High-resolution manometry is used to diagnose these disorders, while increased sensitivity to esophageal distention, acid and bile, and psychological issues such as anxiety, panic, or depression often exacerbate symptoms.

Though there are no current cures for achalasia, successful medical therapies include pneumatic dilation, laparoscopic Heller myotomy, and peroral endoscopic myotomy (POEM) [201]. POEM is a minimally invasive surgery with early research showing a promising future in the management of achalasia. Wide use of POEM will require large clinical trials to demonstrate long-term effectiveness and safety of the procedure. The medical treatment of motility disorders includes the use of PPIs, nitrates, calcium channel blockers, phosphodiesterase inhibitors, tricyclic antidepressants, and serotonin-reuptake inhibitors [202].

*Eosinophilic Gastrointestinal Diseases.* Eosinophilic GI diseases (EGIDs) are a group of relatively newly understood chronic conditions of the GI tract [203]. Initially considered as a predominantly pediatric condition, EGID is increasingly recognized in adults. Increases in infiltration of eosinophilia, a type of white blood cell, lead to adverse physiological changes in the part of the GI tract affected: rings, furrows, and potential stenosis in the esophagus (eosinophilic esophagitis, EoE), or inflammation in the stomach (eosinophilic gastritis), intestines (eosinophilic gastroenteritis), and colon (eosinophilic colitis). Symptoms of EGIDs are also related to the affected area and include food impactions, abdominal pain, vomiting, nausea, and diarrhea. Treatment options for EGIDs are limited and include both pharmacological and dietary interventions.

While EGIDs may affect the small and large intestines, these subtypes currently comprise a very small percentage of EGIDs; thus, we focus attention on the most common EGID, EoE. Even EoE is a rare condition, affecting 1 in 2,000 individuals in the USA; however, these rates appear to be steadily rising as recognition and diagnosis of the condition improves [204]. Current EGID treatments are intensive and are not always satisfactorily effective. These aim to reduce exposure to antigens that would disrupt the GI environment and cause eosinophils to proliferate. Given the high incidence of food sensitivities in EGID patients, dietary interventions are often used to target inflammatory reactions to food antigens and include food elimination, formula-based diets, and gastric tube feedings [204]. Food introduction trials involve elimination of the top eight allergy-producing foods (dairy, soy, eggs, wheat/gluten, peanuts, tree nuts, fish, and shellfish) for a period of several weeks followed by a systematic reintroduction of a single food at a time to the patient's diet. In some individuals, additional foods are involved in invoking inflammatory responses, creating a longer and more complicated reintroduction trial. At the end of the trial, patients may be faced with having to eliminate several common foods from their diets indefinitely.

Only a few studies exist evaluating the psychosocial impact of EGIDs. A 2011 qualitative study identified five major concerns that patients with EoE experience: concerns about EoE as a new disease, concerns about symptom episodes, concerns about available treatments, impact on eating, and impact on social relationships [205, 206]. Interestingly, 74% of patients reported relief at receiving a diagnosis, highlighting the difficulties in obtaining an accurate diagnosis for their symptoms, which are sometimes present for years before their source is identified. In the same study, the average time that symptoms were present prior to a diagnosis was 11.5 years. Further research into the psychosocial impact of these conditions is warranted and forthcoming.

*Psychological Considerations.* The management of GERD and other organic esophageal conditions has centered on the use of medical therapies and behavior modification. Despite the high prevalence as well as economic and quality of life impacts, additional therapeutic approaches, aside from examining any comorbidities which could exacerbate symptoms, have shown little benefit and this is an area of growth for the field [108]. Psychosocial factors, such as emotional and/or physical stress, have been shown to impact esophageal sensation; therefore, consultation with a health psychologist can be beneficial [100, 108]. Working from a biopsychosocial model to address aspects of the patient's life that may be impacting the onset and maintenance of symptoms has proven advantageous for pathophysiological and functional disorders [112]. Treatment may focus on equipping patients with adaptive coping skills and social support for symptoms, as well as how to cope with the psychosocial responses of family, friends, coworkers, and society [111]. Patients with insight, understanding, and acceptance for the role of psychosocial factors in their illness tend to be more open to integrating mental health interventions into their treatment plan.

## Conclusions and Future Directions

In this chapter, we highlighted the most relevant and highest quality psychological research that has influenced conceptualization of functional and organic GI conditions. Of these conditions, IBS has received the most attention and subsequently has seen the greatest improvements in patient care. Unfortunately, while our understanding has improved, medical treatments remain largely ineffective for patients with IBS. Over the next decade, we expect the focus of research in IBS will likely shift to that of integrated dietary, medical, and psychological interventions. For the health psychologist, dissemination of evidence-based behavioral therapies for IBS is most relevant, with attempts to understand how these treatments work, for whom, and how these treatments can be integrated into medical decision making.

Psychological research into the remaining functional GI disorders is much less developed. However, parallels are emerging between these conditions and research on IBS indicating that findings from IBS studies may readily be translated to other

functional conditions. CBT and GDH have already demonstrated efficacy among other functional, and even organic, GI illness groups.

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# Chapter 19

## Cardiovascular Disease

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### Introduction

One American dies approximately every 39 s due to cardiovascular disease and one third of all deaths in the USA are due to cardiovascular disease [1]. According to the World Health Organization, cardiovascular disease is the most frequent cause of death in the world, except in low-income countries where it is the fourth leading cause of death. Despite a 30.6% drop in the rate of deaths attributable to cardiovascular disease between 1998 and 2008, cardiovascular disease continues to be the leading cause of death in the USA and accounts for 17% of national health expenditures [1, 2]. It is expected that by 2030, more than 40% of adults in the USA will have some form of cardiovascular disease and total direct medical costs will triple from US\$ 275.5 billion in 2010 to US\$ 818.1 billion [2].

To understand the antecedents of cardiovascular disease and what can be done to manage and treat the consequences of cardiovascular disease requires a biopsychosocial framework. In his 2005 American Heart Association Presidential Address, Robert Eckel, MD, highlighted the need to go beyond traditional physical interventions:

In our lifetimes, we have witnessed extraordinary advances in our ability to prevent cardiovascular diseases. These gains have been based on the basic, clinical, and population science that all of you in this broad international audience have produced. We have an unprecedented arsenal of weapons, including many potent medications. However, this power is not enough, and, in fact, in some cases, it has led us to ignore some very simple, effective, and human measures...We cannot simply rely on technological advances and

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medications to defeat cardiovascular disease. Unhealthy lifestyles threaten to undo all the progress we have made. What can we do? [3]

Regardless of whether a psychologist is working in a primary care setting or a cardiology clinic, psychologists need to be aware of how they can impact the development and management of cardiovascular disease. The focus of this chapter is on the physical, behavioral, cognitive, emotional, and environmental factors that contribute to cardiovascular disease. We review these biopsychosocial factors and provide practical, evidence-based recommendations for preventing, treating, and managing cardiovascular disease.

## **Physiology and Pathophysiology of the Cardiovascular System**

When working with patients at risk for or who have experienced a cardiac event, it is important for clinical psychologists to understand the normal and pathological functioning of the cardiovascular system. On the most basic level, the cardiovascular system is composed of the heart, the central blood vessels (large arteries and veins like the aorta and the pulmonary vein), and the peripheral blood vessels (arteries, veins, and capillaries). The heart is a muscle that functions to pump blood to the lungs to be oxygenated, and then to the body via the peripheral blood vessels. The heart supplies blood to itself through the coronary arteries. When functioning normally, the heart muscle pumps synchronously and continuously to provide oxygen and nutrients to all other organs and tissues in the body to meet the metabolic demands of the organism. In a well-regulated manner, the heart muscle contracts just enough to get the blood where it needs to go, without straining itself or the blood vessels. Additionally, optimal health of the cardiovascular system means central vessels and coronary arteries are free from occlusions, so that blood flows smoothly and responds to variations in blood flow by contracting or dilating. Similar rules apply to the peripheral vasculature; the healthiest vessels respond to variations in arterial pressure, are not stiff, and are not strained by the amount of blood flowing through them.

Unfortunately, due to the breadth of the cardiovascular system that reaches every living cellular structure in the body, there are many places where functioning can be disrupted. The vast majority of medical conditions caused by problems within the cardiovascular system can be attributed to the underlying process of atherosclerosis. Briefly, fatty streaks begin to line vascular walls early in life among humans who consume diets rich in fat, and within a relatively short period of time, these streaks begin to harden into plaques. The rate at which plaques are formed is influenced by genetic factors as well as the amount of fat content in one's diet. Because arteries are designed to dilate and constrict in response to changes in blood flow, these rigid plaques are prone to crack or rupture, stimulating the body's healing response to this type of cellular injury. The inflammatory healing response, in conjunction with

**Table 19.1** Most common forms of cardiovascular diseases, examples of clinical presentations, and their prevalence

<i>Disease</i>	<i>Clinical presentations</i>	<i>Description</i>	<i>Prevalence</i>
<b>Cardiovascular diseases associated with atherosclerosis</b>			
Coronary (ischemic) heart disease or coronary artery disease	<ul style="list-style-type: none"> <li>• Myocardial infarction (heart attack)</li> <li>• Angina pectoris (cardiac chest pain)</li> </ul>	Blockage of blood flow in the coronary arteries	4.1
Cerebrovascular disease	<ul style="list-style-type: none"> <li>• Cerebrovascular accident (stroke)</li> <li>• Transient ischemic attack</li> </ul>	Blockage of blood flow in the cerebrovasculature	2.6
Renal artery disease	<ul style="list-style-type: none"> <li>• Renal artery stenosis</li> <li>• Renovascular hypertension</li> </ul>	Blockage of blood flow in the kidneys	5–42% (≥64 years)
Peripheral vascular disease	<ul style="list-style-type: none"> <li>• Claudication</li> </ul>	Blockage of blood flow in peripheral arteries or veins	12%
<i>Cardiovascular disorders and diseases associated with processes other than atherosclerosis</i>			
Cardiac valvular disease	<ul style="list-style-type: none"> <li>• Stenosis</li> <li>• Mitral valve prolapse</li> </ul>	Leakage or narrowing of cardiac valves	25% (≥65 years)
Arrhythmic disorders	<ul style="list-style-type: none"> <li>• Ventricular tachycardia</li> <li>• Ventricular fibrillation</li> <li>• Sudden cardiac death</li> </ul>	Disturbance of electrical activity of the heart muscle	10% (≥80 years)
Cardiomyopathy	Congestive heart failure	Heart muscle dysfunction or weakness	1–17% <sup>a</sup>
Essential hypertension	High blood pressure	Increased cardiac output of blood accompanied by peripheral resistance to blood flow	26.5
Hypercholesterolemia	High blood cholesterol	High levels of lipids in the blood	16.2%

<sup>a</sup> Estimate; difficult to determine due to lack of strict diagnostic criteria

the deposit of lipid-rich calcifications (scabs), begins to occlude the artery, making it more vulnerable to subsequent plaque injuries. Over time, this injury–healing–injury cycle can lead to serious restrictions in blood flow (ischemia) or even complete blockage (infarction). As seen in Table 19.1, the process of atherosclerosis underlies several of the leading causes of death and disability in industrialized countries.

There are also several disorders of the cardiovascular system depicted in Table 19.1 not directly caused by atherosclerosis (e.g., valvular diseases, arrhythmias); however, even among these diseases, the process of atherosclerosis may play a contributing or complicating role. For example, myocardial infarctions (MIs) caused by atherosclerosis can damage the cardiac muscle, increasing risk for cardiomyopathy and/or congestive heart failure. The term “sudden cardiac death” is not tied to any specific cardiovascular disorder; rather, it refers to death occurring in response to any type of cardiovascular events within 1 h. Although the majority of patients who experience sudden cardiac death show evidence of atherosclerosis, deaths are more commonly caused by cardiac rhythmic dysfunctions than infarctions [4].

## **Medical Approaches to Assessing and Treating Cardiovascular Diseases**

Clinical psychologists need to possess a basic understanding of the assessment and intervention approaches used by other medical professionals for evaluating and treating patients with the full range of cardiovascular diseases and disorders. Although lifesaving, many of these medical procedures are stressful for patients and families to endure, and in some cases can lead to the development of significant psychological problems. In addition to the history and physical examination and laboratory tests that characterize any medical evaluation, the medical tests shown in Table 19.2 are commonly administered to patients with cardiovascular diseases or those suspected of having cardiovascular disease.

Patients typically encounter cardiology specialists in one of two ways. They are either referred by primary health care providers once cardiac problems are detected or suspected, or they encounter them following an emergent medical event (e.g., heart attack). In the former, patients are likely to receive a comprehensive evaluation of cardiac functioning that occurs over the course of several outpatient appointments before the appropriate intervention or prevention plans are developed. In contrast, in emergent situations, it is critical that intervention begins immediately and evaluations of heart functioning can be conducted in a much shorter time period. Normally, pharmacologic interventions begin immediately while necessary assessments of cardiac functioning are obtained. Following assessment, patients with lower risk of cardiovascular events are typically treated pharmacologically, those with significant coronary artery blockage typically proceed to one of the percutaneous coronary interventions, and those with the most severe cardiovascular disease may require bypass surgery.

### **Assessment of Risk for Cardiovascular Disease**

The role of clinical psychologists for evaluating the cardiac functioning of patients referred to cardiac treatment services using the assessments listed in Table 19.2 is fairly limited. However, clinical psychologists can be very helpful in evaluating behavioral or psychosocial risk factors among both patients at risk for developing cardiovascular disease and those recovering from cardiac events. It is widely recognized that there are several risk factors known to be associated with cardiovascular disease that should be monitored in all patients, especially those at risk for or with a history of a cardiovascular event. Table 19.3 depicts these established risk factors, several of which involve lifestyle behaviors amenable to routine assessment by clinical psychologists.

**Table 19.2** Common medical procedures for assessing and treating cardiovascular disease

<i>Procedure</i>	<i>Description</i>
<b>Assessment procedures</b>	
Electrocardiogram (ECG)	Assessment of electrical activity of the heart via surface electrodes
Ambulatory ECG (Holter) monitoring	Assessment of electrical activity of the heart via surface electrodes over a 24-h period using portable instrumentation
Stress test	Assessment of electrical activity of the heart via surface electrodes during physical exertion
Nuclear stress test	Assessment of blood flow during stress (typically induced by physical exertion or injection of a vasoactive drug). A radioactive isotope (e.g., thallium) that attaches to red blood cells is injected and flow is monitored using a scintillation camera
Cardiac PET scan	Assessment of blood flow to identify coronary artery stenosis. A radioactive blood flow tracer is injected and monitored using positron emission tomography scanning
Echocardiography	Noninvasive assessment of heart functioning using sound waves (ultrasonography). Can be conducted with or without “stress” testing
Computerized tomography	Noninvasive assessment of plaque type and volume using electron-beam scanning
Coronary angiography	Direct assessment of coronary artery functioning using a cardiac catheter inserted under local anesthesia. A radioactive dye is injected into the left ventricle and coronary arteries imaged to assess blockages in blood flow
<i>Intervention procedures and strategies</i>	
Pharmacologic interventions	Administration of antianginal (e.g., nitrates), antithrombotic (e.g., aspirin), antihypertensive (e.g., diuretics), antiarrhythmic (e.g., amiodarone), anticoagulant (e.g., heparin), and lipid-regulating (e.g., statins) agents
Pacemaker implantation	Surgical insertion of a device in the chest connected to the heart that emits an electrical signal to pace heart pump action
Implantable cardioverter defibrillator (ICD)	Surgical insertion of a pacemaker-like device that paces heart rhythm and “shocks” the heart into synchronous heart function when dangerous heart rhythms are detected
Percutaneous transluminal coronary angioplasty (PCTA)	Insertion of a catheter to the site of the blockage where a tiny “balloon” is inflated briefly to crush plaques against the vessel wall to increase blood flow
Coronary atherectomy	Insertion of a catheter to the site of the blockage where plaque is cut away, retrieved, and removed
Stent placement	Following PCTA or atherectomy, a tiny metal tube (stent) is placed at the site of the original blockage to reduce risk of restenosis
Coronary artery bypass graft (CABG)	Removing a nonessential arterial segment and grafting it between the aorta and downstream coronary artery bypassing the site of the blocked artery
Heart transplantation	Surgical removal of a defective heart and replacement with a donor heart

*PET* positron emission tomography

**Table 19.3** Established risk factors for cardiovascular disease

<i>Risk factor</i>	<i>Criteria for increased risk</i>	<i>Criteria for significant elevated risk</i>
<b>Modifiable risk factors</b>		
High blood pressure <sup>a</sup>	Systolic blood pressure $\geq 120$ mm Hg, or diastolic blood pressure $\geq 80$ mm Hg	Systolic blood pressure $\geq 140$ mm Hg, or diastolic blood pressure $\geq 90$ mm Hg
High blood cholesterol and triglyceride <sup>b</sup>	Total cholesterol $\geq 200$ mg/DL Low-density lipoprotein (LDL) $< 100$ mg/DL High-density lipoprotein (HDL) $< 60$ mg/DL Triglycerides $\geq 150$ mg/DL	Total cholesterol $\geq 240$ mg/DL LDL $\geq 160$ mg/DL HDL $< 40$ mg/DL (men) or 50 mg/DL (women) Triglycerides $\geq 200$ mg/DL
Diabetes and pre-diabetes <sup>c</sup>	Fasting plasma glucose $> 100$ mg/DL 2-h oral glucose tolerance test $> 140$ mg/DL	Fasting plasma glucose $> 126$ mg/DL 2-h oral glucose tolerance test $> 200$ mg/DL
Overweight/obesity <sup>d</sup>	Body mass index $> 25$ (overweight)	Body mass index $> 30$ (obese)
Physical inactivity <sup>e</sup>	No activity $>$ moderate activity $>$ high/vigorous activity	
Unhealthy diet <sup>d</sup>	High saturated/trans fat diet $>$ low-fat diet High-sodium diet $>$ low-sodium diet High sugar consumption $>$ low sugar consumption	
Tobacco smoking <sup>d</sup>	Exposure to tobacco smoke $>$ no exposure to tobacco smoke	
<i>Risk factors not amenable to behavior change</i>		
Age <sup>d</sup>	Age $\geq 45$ (men) and age $\geq 55$ (women)	
Gender <sup>d</sup>	Before age 55: men $>$ women After age 55: men = women	
Family history of heart disease <sup>d</sup>	Father/brother diagnosed with CHD before age 55 or Mother/sister diagnosed with CHD before age 65 $>$ no family CHD	

<sup>a</sup> National High Blood Pressure Education Program [5]

<sup>b</sup> National Cholesterol Education Program [6]

<sup>c</sup> National Institute of Diabetes and Digestive and Kidney Diseases [7]

<sup>d</sup> National Heart Lung and Blood Institute [8]

<sup>e</sup> Physical Activity Guidelines Advisory Committee [9]

## ***Assessment of Blood Pressure***

Although medically trained personnel are responsible for the routine assessment of blood pressure in clinic and hospital settings, clinical psychologists working in these settings can contribute to the interpretation of these medical assessments. Optimally, blood pressure determinations are made under conditions of quiet rest, a state not always obtained in medical environments. In busy clinic or hospital settings or with patients exhibiting uncertainty about the severity of their medical conditions, blood pressure values may be higher than measures of typical blood pressure, a condition termed “white coat” hypertension. Conversely, some patient’s blood pressures in clinic or hospital environments are lower than their average pressures

occurring during daily life, a condition termed “masked” hypertension [10]. To remedy the inaccuracy in blood pressure measurements in these types of patients, many medical clinics have turned to employing 24-h ambulatory blood pressure monitoring. Data from these assessments have consistently shown ambulatory measures of blood pressure to be better predictors of hypertensive target organ pathology and cardiovascular disease consequences than clinic-based assessments of blood pressure [11, 12]. In fact, a recent economic analysis recommends ambulatory blood pressure monitoring for the routine assessment of blood pressure [13]. Interpretation of ambulatory blood pressure data, however, requires a careful assessment of daily activities that occur during the monitoring period, data that can be generated through development of a good self-monitoring system.

### ***Assessment of Behaviors Associated With Diet and Activity***

Several modifiable risk factors for cardiovascular disease can be clustered together as they are all associated with lifestyle choices pertaining to energy consumption and expenditure. In brief, the sorts of foods an individual consumes, coupled with the amount of daily physical activity in which he or she engages, directly influence body weight, blood lipid profiles, and the propensity for developing diabetes. Although most cardiac service providers have access to nutritionists and exercise physiologists to carry out comprehensive assessments of a patient’s caloric intakes and levels of physical fitness, these assessments can be complemented with behavioral assessments of eating behaviors and physical activity, with special attention paid to personal and environmental impediments to adhering to the dietary and physical activity behaviors prescribed by the cardiac treatment team. In primary care settings, access to nutritionists and exercise physiologists may be more limited, thus providing a potentially larger role for clinical psychologists, within their scope of expertise. There is convincing evidence that adopting healthy eating and exercise behaviors leads to reduced risk for developing cardiovascular diseases and for having subsequent cardiac events among patients already diagnosed with cardiovascular disease. Mead and colleagues [14], for example, reported that changing diet by reducing saturated fats and substituting them with unsaturated fats was one of the most robust ways to reduce the number of cardiovascular events through dietary change. On the energy expenditure side of the equation, a recent review of several meta-analyses supports the widely held belief that engaging in exercise improves one’s risk factor status for heart disease, including lowering systolic blood pressure (SBP), cholesterol, and body mass index [15]. A summary of the evidence suggests that exercise may impart these benefits by changing activation within the central nervous system, which thereby reduces activation of the sympathetic nervous system [16]. Additional studies indicate that increased physical activity decreases the risk for cardiovascular disease more than altering some of the other risk factors [17].

## *Assessment of Substance Use and Abuse*

Although use of numerous substances has been linked with cardiovascular diseases, tobacco use stands out as one of the best-known risk factors for cardiovascular disease [18]. Research also suggests that second-hand smoke exposure increases risk for coronary heart disease (CHD) by 25–30% [19]. It is also recognized that reductions in risk for cardiovascular diseases accompany successful efforts at smoking cessation [20]. There is a health advantage to quitting smoking among healthy persons as well as those who have already suffered a cardiovascular event.

The consensus among cardiologists at this time is that low to moderate alcohol use confers a protective effect against cardiovascular disease, whereas high levels of daily use and binge drinking both increase risk. This results in a J-shaped risk curve, with the lowest risk associated with about one drink per day [21, 22]. It is difficult to suggest daily moderate alcohol use as one method of prevention of cardiovascular disease, however, because of the potential that problem drinking may arise or the increased health consequences associated with consumption of alcohol and other organ systems. Additionally, consumption of alcohol is also associated with elevated blood pressures, so whatever health benefit might exist for drinking small amounts of alcohol is partly offset by its negative effects on blood pressure. Certainly, patients with essential hypertension should be advised to decrease alcohol intake.

## **Psychosocial Risk Factors for Cardiovascular Disease**

Although clinical psychologists can greatly assist in evaluating lifestyle factors associated with increased risk for cardiovascular disease, they also play a central role in assessing psychological and social factors that may contribute to the etiology, presentation, and treatment of cardiovascular disease. In contrast to the recognized risk factors for cardiovascular disease depicted in Table 19.3, exact criteria for assessing psychosocial risk factors have yet to be established. Whereas we know that risk for cardiovascular disease increases somewhat as low-density lipoprotein (LDL) exceeds 100 mg/dl and to a greater extent when LDLs exceed 160 mg/dl, we do not have comparable criteria for stress, depression, or anger, nor are there uniform methods for using them. Despite these measurement challenges, there are several psychosocial factors clearly associated with cardiovascular disease. In a review of the literature in this area, Rozanski and colleagues [23] found evidence linking heightened levels of depression, anxiety, anger/hostility, social isolation, and psychological stress with cardiovascular disease. In this section, we summarize the most recent evidence regarding the relation between each of these factors and cardiovascular disease.

## ***Depression***

In their review of the impact of psychosocial factors on cardiovascular disease, Rozanski and colleagues [23] reported that depressive episodes as well as subclinical symptoms of depression were associated with more cardiac events among healthy controls as well as patients with coronary artery disease. Additionally, a dose response relation was observed, such that more severe depression was linked with the highest incidence of cardiac events, with moderate levels of depression conferring some risk, but to a lesser extent. The authors suggested that depression led to an increased risk for cardiovascular disease through several hypothesized mechanisms, including hypercholesterolemia, impaired platelet function, and reduced heart rate variability.

Research since that time widely supports the assertion that depression is associated with the increased risk for the development of CHD, and is also associated with subsequent cardiac events and mortality among patients with CHD [24, 25]. In fact, 15–45% of patients with cardiovascular disease have been reported to exhibit symptoms of depression [26]. These results have been demonstrated consistently among psychiatric, community, and cardiac populations [27]. In fact, the association between depression and cardiovascular disease is so robust that it is recognized by many to be as important as tobacco use and high blood pressure in establishing estimates of disease risk. Extending the conceptualizations of Rozanski and colleagues [23] a decade earlier, Brown, Barton, and Lambert [28] proposed that the increased risk for depression among cardiac patients involved common disturbances of the sympathetic nervous system and hypothalamic–pituitary–adrenal axis.

In contrast to the typical symptoms of depression of sadness, hopelessness, and low self-esteem observed in psychiatric populations, symptoms of depression observed among cardiac patients more commonly center on fatigue and lack of energy [29, 30]. Observations regarding specific depressive symptom profiles detected among cardiac patients have led some to focus on the pathological consequences associated with *vital exhaustion*, a psychological construct characterized by a constellation of tiredness, irritability, and demoralization appearing without a depressed mood [31]. Like depression, vital exhaustion has been shown to be prospectively associated with the onset of CHD [31].

Based upon consistent observations linking depression with CHD over several decades, it is not surprising that several intervention trials were devised in which cardiac patients with depression were treated using a variety of evidence-based intervention approaches. The Sertraline Antidepressant Heart Attack Randomized Trial (SADHART) [32] employed a pharmacologic intervention, the Enhancing Recovery in Coronary Heart Disease (ENRICHD) [33] employed cognitive behavior therapy, and the Canadian Cardiac Randomized Evaluation of Antidepressant and Psychotherapy Efficacy (CREATE) [34] employed both pharmacological and interpersonal psychotherapy interventions. In addition, the Randomized Exhaustion Intervention Trial (EXIT) [35] examined a specialized treatment approach targeting symptoms of vital exhaustion. Not surprisingly, the severity of depressive symptoms observed among cardiac patient participants lessened following treatment with each



**Table 19.4** Commonly employed methods for assessing psychosocial risk for heart disease

Psychosocial parameter	Typical scales used for measurement
Depression	Beck Depression Inventory [39] Center for Epidemiologic Studies Depression Scale [40] Patient Health Questionnaire [41]
Vital exhaustion	Maastricht Questionnaire [42]
Anxiety	State-Trait Anxiety Inventory [43] Brief Symptom Inventory [44]
Anger	State-Trait Anger Expression Inventory [45]
Hostility	Cook Medley Hostility Scale [46]
Social isolation	Social Network Index [47] Interpersonal Support Evaluation List [48]
Psychological stress	Perceived Stress Scale [49] Job Content Questionnaire [50] Effort Reward Imbalance Questionnaire [51]
Type D personality	Type D Scale [52]
Quality of life	Minnesota Living with Heart Failure [53] MacNew Heart Disease HRQL [MacNew] [54, 55]

of these intervention approaches. Despite the strong evidence that depression can be treated in patients with cardiovascular disease, in none of these trials was there evidence that frequency of future cardiac events declined among patients treated for depression. Through post hoc analyses of data from the ENRICH trial, there was some evidence that patients receiving cognitive behavior therapy *and* antidepressant medications exhibited lower rates of cardiac events, and those who engaged in group therapy exhibited lower rates of cardiac events than those who received individual therapy only [36].

Recent studies have examined the use of increased physical activity to improve depressive symptoms in patients with CHD [37] and chronic heart failure [38]. Increased activity reduced depressive symptoms while improving cardiovascular functioning; however, the short duration of these studies limits conclusions about whether the risk of cardiovascular disease was successfully reduced.

Findings from studies linking depression and cardiovascular disease suggest that much more needs to be learned about the association between depression and heart disease before it can be concluded that depression plays a causal role with respect to heart disease. However, given the consistent prospective support for an association between depression and heart disease, it should be assessed routinely in cardiac clinics (see Table 19.4 for common methods for measuring depression and other psychological variables associated with heart disease).

## *Anxiety*

In contrast to depression, anxiety represents an emotional state associated with increased arousal and sympathetic activation. Although evidence linking it to heart disease is not as convincing as evidence associating depression and heart disease, there is enough to warrant consideration. Based on the few studies available in 1999, Rozanski and colleagues [23] concluded that although no association was apparent between anxiety and MI, a dose-dependent relation was observed between anxiety and sudden cardiac death. In this regard, anxiety had less of a relation with the process of atherosclerosis and was more closely linked with conditions caused by arrhythmic disturbances. More recent meta-analyses confirm the increased risk for onset of cardiovascular disease and sudden cardiac death among anxious but otherwise healthy persons [56] and the increased risk for new cardiac events among post-MI patients [57].

## *Anger and Hostility*

Although solid evidence linking both depression and anxiety to various forms of cardiovascular disease exists, the emotional experience of anger has been associated with various cardiovascular conditions for the longest time. Based upon early psychosomatic hypotheses [58], suppression of anger was hypothesized as a psychological pathogen associated with essential hypertension. Although this hypothesis has been replaced with more comprehensive etiologic models based on advances in genetics and environmental science, the role of anger in cardiovascular diseases persists. Certainly, the exploration of the type A behavior pattern, popular in the 1960s and 1970s, was partly developed based upon observations that cardiac patients handled anger and frustration differently than other patients [59]. Early prospective work showed that type A behavior pattern, typified by strong competitive strivings, a chronic sense of time urgency, and easily evoked hostility, was predictive of cardiovascular disease outcomes [60]. Subsequent empirical work [61, 62], however, was less promising, leading to an overall decline in support for considering type A behavior pattern as an established risk factor for cardiovascular disease. It should be noted, however, that the Recurrent Coronary Prevention Project [63] showed significant reductions in recurrent MI and sudden cardiac death among patients randomly assigned to a type A behavior modification group, suggesting that reducing type A behaviors influenced medical outcomes, something we cannot state convincingly based on attempts to reduce depression via the ENRICHD, CREATE, and EXIT trials.

Despite the inconsistent support for the type A behavior pattern as a risk factor for cardiovascular disease, considerable research has examined one of its components—hostility. In contrast to anger, which is an emotional state, hostility refers to an attitude comprised of cynicism, a mistrust of others' motives, and the tendency to perceive actions of others as threatening. Not surprisingly, hostile individuals

experience anger more frequently than their non-hostile counterparts and struggle with developing and maintaining trusting relationships with others. In their review of the literature on hostility and risk for cardiovascular disease, Rozanski and colleagues [23] reported that while hostile heart patients were more likely than non-hostile patients to experience subsequent cardiac events, the relation between hostility and cardiovascular disease onset among healthy individuals was less convincing. However, a more recent meta-analysis of more than 25 prospective studies [64] concluded that a robust association existed between anger and hostility and coronary disease outcomes among both healthy and cardiac patient samples.

### ***Social Isolation***

It has been well established that individuals with effective social relationships exhibit better health outcomes across a range of medical conditions, including cardiovascular disorders, in contrast to those who are socially isolated [65]. Social isolation can occur because persons have few people in their social network (a structural support problem) *or* because the individuals comprising one's social networks are limited in the type of support they can provide (a functional support problem). Rozanski and colleagues [23] reviewed studies that evaluated the relation between social isolation and cardiovascular disease end points and concluded that greater social isolation was associated with higher incidence of cardiovascular disease onset among healthy persons and subsequent cardiac events among patients with heart disease. Dose-response relations were observed across studies that used both structural and functional measures of social integration and support. In contrast to the findings from earlier studies, a more recent meta-analysis revealed that the increased risk for cardiovascular disease associated with low social support was only significant when functional measures of social support were employed [66]. In this regard, these findings suggest that interventions designed to increase social support should focus on the qualitative aspects of social relationships rather than increasing social network size. However, the promise of reducing risk for cardiovascular disease through interventions aimed at improving social support is tenuous. Although interventions aimed at improving social support clearly result in less social isolation, the evidence for improved cardiovascular health is lacking [47, 67].

### ***Psychological Stress***

Exposure to life stress has long been known to be associated with occurrence of cardiovascular events like MIs and sudden cardiac death. Increased incidence of cardiovascular events has been observed following exposure to a broad range of life events, including earthquakes [68], acts of terrorism [69], stressful work environments [70], and even watching exciting sporting events [71]. Additionally, the notable inverse relation between socioeconomic status and incidence of cardiovascular

disease is often attributed to the increased levels of life stress confronting persons of lower socioeconomic status [72].

Based upon the correspondence between stress and increased incidence for cardiovascular events, several trials have been conducted examining the effect of stress management upon cardiac outcomes. When Rozanski and colleagues [23] reviewed this literature in 1999, several of these trials resulted in significant reductions in measures of psychosocial functioning, but only a few resulted in significant improvement in cardiovascular risk status.

In a more recent meta-analysis of stress management interventions by Linden and colleagues [73], positive outcomes were observed for both mortality and long-term cardiac event recurrence for men, but not women. Most recently, however, findings from the Stockholm Women's Intervention Trial for Coronary Heart Disease (SWITCHD) have been reported; in this study, Orth-Gomér and colleagues [74] showed that survival rate for women with cardiovascular disease increased by threefold over a 7-year period among those randomized to participate in a stress management program. Results from the Secondary Prevention in Uppsala Primary Health Care Project (SUPRIM) also yielded reductions in fatal and nonfatal cardiovascular events among both male and female cardiac patients randomized to a cognitive-behavioral stress management program [75].

### ***“Clustering” of Psychosocial Risk Factors***

The psychosocial risk factors presented in the previous sections do not represent orthogonal constructs. Individuals who are depressed often experience symptoms of anxiety, report encountering significant stress in their lives, and receive limited social support from those around them. Using the terminology introduced by Rozanski et al. [23], psychosocial risk factors “cluster” together and quite likely share common pathological pathways. Recognizing the importance of negative affect (i.e., depression, anxiety, and anger) and social inhibition (i.e., social isolation) among the recognized psychosocial risk factors, Denollet [52] advocated combining them into what he referred to as the type D (“distressed”) personality. Indeed, there is evidence linking persons with type D personalities (i.e., high negative affect and high social inhibition) with increased risk for cardiovascular disease [76, 77]. However, not all studies have shown an association between these personality characteristics and cardiac mortality [78, 79]

In perhaps one of the largest trials examining modifiable risk factors, the INTERHEART study [80] gathered risk factor information on more than 15,000 MI patients and their controls from more than 50 different countries. Because of the enormity of the data collection effort, psychosocial stress was measured briefly using a few questions pertaining to stress levels at work and home, financial stress, major life events, depression, and locus of control. Responses to these questions were summed to create a psychosocial stress index. Risk attributed to psychosocial stress was equivalent to presence of diabetes, obesity, or hypertension worldwide, slightly below the population attributable risk associated with smoking and abnormal lipids.

No discussion of modification of risk for CHD is complete without mentioning the Lifestyle Heart Trial [81]. As the Cadillac of intervention trials, the Lifestyle Heart Trial involved adopting a low-fat vegetarian diet, a moderate exercise program, smoking cessation, stress management training, and participation in supportive group meetings with other cardiac patients. Outcome measures of cardiovascular functioning (e.g., coronary artery stenosis, ischemia, subsequent cardiac events) have been impressive, particularly among those patients who adhered best to the program [81, 82]. The program, under the name the Multisite Cardiac Lifestyle Intervention Program, is offered at many health science centers and hospitals around the USA.

## *Quality of Life*

In addition to measuring disease outcomes, researchers have often examined quality of life as a primary outcome of interventions. Measures assessing quality of life among those with cardiovascular disease have been shown to be valid and reliable measures of functioning across multiple cultures and nations. Two commonly used measures are the MacNew Heart Disease Health-related Quality of Life (MacNew) and the Minnesota Living with Heart Failure questionnaire (MLHFQ). The MacNew [54, 55] measures physical, emotional, and social functioning, and scores have been shown to be related to health outcomes across a range of cardiovascular diseases [83, 84]. The MLHFQ [53] assesses the impact of heart failure and its associated treatments on perceived functioning and has been associated with outcomes of a variety of heart failure treatments [85, 86], as well as morbidity and mortality [87].

## *Summary*

Conducting an appraisal of risk for cardiovascular disease among healthy persons or of risk for subsequent cardiac events among patients with diagnosed cardiovascular disease would be incomplete without consideration of psychosocial factors. Unfortunately, most primary care clinics and cardiac treatment teams are not often staffed to conduct appropriate analyses of psychosocial risk among patients seeking care in their facilities. Clinical psychologists are optimally positioned to provide the desired expertise to conduct these assessments and assist in providing treatment recommendations the team might consider. Certainly, appropriate consideration should be given to the assessment of symptoms of depression, anxiety, anger/hostility, and psychological stress as well as to the presence of available social support. Although the evidence supports dose–response associations for many of these psychological risk factors in predicting risk for cardiovascular disease events, there are no standard methods for assessing them, nor are there established cutoff scores associated with various levels of risk. Until such parameters are established, clinical psychologists should at least inquire about these symptoms during patient evaluations and consultations, making good use of valid questionnaires (see Table 19.4) to assist in confirming one’s psychosocial risk factor status.

There is some emerging evidence that stress management interventions, largely based on cognitive behavior therapeutic techniques, may have some value in working with cardiac patients, not only for improving psychological functioning but also for improving cardiovascular health [73]. To the extent that these interventions continue to result in salubrious effects on the cardiovascular system, they can be offered to patients identified as having some degree of risk associated with psychosocial factors.

## Evidence-Based Practice

Given the breath and ubiquity of cardiovascular diseases, there are no all-encompassing evidence-based care standards of care. Rather, depending on where the clinical psychologist is practicing and the purpose of the assessment and treatment, there are multiple clinical guidelines to consider, particularly those targeting health behaviors and hypertension as well as implementing cardiac rehabilitation programs. These guidelines were constructed based upon careful consideration of the empirical evidence and assist clinical psychologists in developing the most effective intervention plans to help cardiac patients alter health behaviors to promote improved cardiovascular health and adhere to their prescribed cardiac rehabilitation regimens.

*Health Behaviors* Clinical guidelines have been developed to guide the assessment and treatment of many of the health behaviors associated with cardiovascular disease. It goes beyond the scope of this single chapter to discuss the evidence for all of these health behaviors, but we have summarized many of them in Table 19.5, including relevant guidelines from the USA as well as from the National Institute for Health and Clinical Excellence in England. In practice, these guidelines need to be adapted to patient's priorities and willingness to make changes, a hallmark of evidence-based practice. There may be benefits to targeting multiple behaviors simultaneously, but there are limited data supporting the effectiveness of such interventions [95]. The evidence-based treatment of hypertension is primarily guided by the Joint National Committee on the Prevention, Detection, Evaluation and Treatment of High Blood Pressure (JNC-7) [5] and relies on changing many of the same health behaviors. Reducing SBP by 12 mm Hg for 10 years among those in stage 1 hypertension will prevent 1 death for every 11 patients treated [5]. Lifestyle modification is recommended for patients exhibiting all levels of hypertension, including prehypertension. In addition to other behavior changes, the JNC-7 recommends the adoption of the Dietary Approaches to Stop Hypertension (DASH) eating plan to specifically target high blood pressure. Beyond these lifestyle changes, the primary treatment for hypertension includes the use of antihypertensive medications. Knowledge about common antihypertensive medications and their side effects, summarized in Table 19.6, is valuable for clinical psychologists as they are assessing and treating hypertensive patients.

**Table 19.5** Goals, treatment methods, and clinical guidelines for targeting health behaviors and psychosocial factors associated with the development and progression of cardiovascular disease

<i>Health behavior or psychosocial factor</i>	<i>Goal</i>	<i>Method</i>	<i>Resources</i>
Tobacco	No tobacco use	Set a quit date. Target physical, psychological, and habits associated with tobacco use. Use nicotine replacement and medications as necessary	HHS Clinical Guideline Treating Tobacco Use/Dependence <a href="http://www.ahrq.gov/clinic/tobacco/treating_tobacco_use08.pdf">http://www.ahrq.gov/clinic/tobacco/treating_tobacco_use08.pdf</a>
Weight	BMI < 25; 10% weight loss over 6 months, sustain weight loss for 6 months	Monitor eating and calories. Reduce calories consumed through environmental and behavioral changes	NIH Clinical Guidelines Overweight and Obesity in Adults <a href="http://www.nhlbi.nih.gov/guidelines/obesity/ob_gdlns.pdf">http://www.nhlbi.nih.gov/guidelines/obesity/ob_gdlns.pdf</a>
Diet	Limit sodium to 1,500 mg/day; limit saturated fat to less than 7% of kcal; limit dietary cholesterol to 200 mg/day; increase soluble fiber to 5–10 g/day; increase plant sterols/stanols to 2 g/day	Identify foods that patients should eliminate, increase, or add. Consider recommendations for standardized diet plan, such as the Mediterranean diet, which has been shown to improve CVD risk [88] (Walker & Reamy, 2009)	CDC Sodium Fact Sheet: <a href="http://www.cdc.gov/salt/pdfs/Sodium_Fact_Sheet.pdf">http://www.cdc.gov/salt/pdfs/Sodium_Fact_Sheet.pdf</a> NIH Lowering Your Blood Pressure with DASH <a href="http://www.nhlbi.nih.gov/health/public/heart/hbp/dash/new_dash.pdf">http://www.nhlbi.nih.gov/health/public/heart/hbp/dash/new_dash.pdf</a> NIH Lowering Cholesterol with TLC <a href="http://www.nhlbi.nih.gov/health/public/heart/cholesterol_tlc.pdf">http://www.nhlbi.nih.gov/health/public/heart/cholesterol_tlc.pdf</a> USDA & HHS Dietary Guidelines <a href="http://health.gov/dietaryguidelines/dga2010/DietaryGuidelines2010.pdf">http://health.gov/dietaryguidelines/dga2010/DietaryGuidelines2010.pdf</a>
Physical activity	30 min, moderate intensity activity 5 days/wk, OR 20 min, vigorous intensity activity 3 days/wk, AND muscle strengthening exercises 2 days/wk	Set specific goals for engaging in activity (days of the week, time of day); monitor daily activity (e.g., log, pedometer)	Physical Activity Guidelines <a href="http://www.health.gov/paguidelines/pdf/paguide.pdf">http://www.health.gov/paguidelines/pdf/paguide.pdf</a>
Medication adherence	Taking medications as prescribed	Clear verbal and written directions and treatment rationale, simplify regimen, planning when and where medication will be taken, using pill box and reminders/prompts, enlist social support [89, 90] (Hayman 2009, Murdaugh & Insel, 2009)	NICE Medicine Adherence <a href="http://www.nice.org.uk/nicemedia/live/11766/43042/43042.pdf">http://www.nice.org.uk/nicemedia/live/11766/43042/43042.pdf</a>

Table 19.5 (continued)

<i>Health behavior or psychosocial factor</i>	<i>Goal</i>	<i>Method</i>	<i>Resources</i>
Alcohol Moderation	Men: $\leq 4$ drinks/day, $\leq 14$ drinks/wk; women: $\leq 3$ drinks/day, $\leq 7$ drinks/wk Age and medication use may require lower goals	Determine whether goal is reduction or abstinence; track drinks per day, pace drinking, avoid/manage situations with increased drinking; assertiveness with others	Helping Patients Who Drink Too Much <a href="http://pubs.niaaa.nih.gov/publications/Practitioner/CliniciansGuide2005/guide.pdf">http://pubs.niaaa.nih.gov/publications/Practitioner/CliniciansGuide2005/guide.pdf</a>
Depression	Minimal depressive symptoms; no significant functional impairment	Increasing physical activity and participation in enjoyable activities, decreasing frequency and intensity of negative thinking (behavioral activation, cognitive therapy, acceptance and commitment therapy); consider discussing appropriate medications (e.g., SSRIs) with medical provider	NICE: Depression <a href="http://www.nice.org.uk/nicemedia/pdf/CG90NICEguideline.pdf">http://www.nice.org.uk/nicemedia/pdf/CG90NICEguideline.pdf</a> NICE: Depression in adults with a chronic physical health problem <a href="http://www.nice.org.uk/nicemedia/live/12327/45909/45909.pdf">http://www.nice.org.uk/nicemedia/live/12327/45909/45909.pdf</a> Stress Proof the Heart [91] Psychotherapy with Cardiac Patients [92] Acceptance and Commitment Therapy [93] Stress Proof the Heart [91] Psychotherapy with Cardiac Patients [92] Acceptance and Commitment Therapy [93] Stress Proof the Heart [91] Psychotherapy with Cardiac Patients [92] Acceptance and Commitment Therapy [93] Social Support Measurement and Intervention [94]
Anxiety	Minimal anxiety symptoms; no significant functional impairment	Acceptance of physiological arousal, distinguishing between cardiac pain and other sympathetic arousal	
Stress		Mindfulness, relaxation strategies, adjunctive biofeedback	
Social Support		Increase perceived social support using family, friends, and community resources	

SSRIs selective serotonin reuptake inhibitors

<sup>a</sup> National Institute for Health and Clinical Excellence in England



**Table 19.6** Common types of blood pressure medications. (Adapted from [http://www.nlm.nih.gov/hbp/treat/bpd\\_type.htm](http://www.nlm.nih.gov/hbp/treat/bpd_type.htm) and Larkin [96])

Type	Action	Generic names	Trade names	Side effects
Diuretics	“Water pills” that reduce water and sodium in the body	Amiloride Bumetamide Chlorothiazide Chlorthalidone Ethacrynic acid Furosemide Hydrochlorothiazide Indapamide	Midamor Bumex Diuril Hygroton; Thalitone Edecrin Lasix Esidrix, HydroDIURIL, Microzide Lozol	Frequent urination, extreme tiredness or weakness, muscle cramps or weakness, dizziness, headaches, dehydration, loss of appetite, nausea
Beta blocker	Reduce nerve impulses to the heart and blood vessels	Atenolol Metoprolol Propranolol Nadolol	Tenormin Lopressor; Toprol XL Inderal Corgard	Fatigue, cold extremities, dizziness
Angiotensin-converting enzyme (ACE) inhibitors	Causes vessels to relax	Captopril Enalapril Lisinopril	Capoten Vasotec Prinivil, Zestril	Cough, dizziness, headaches, drowsiness, weakness
Angiotensin II receptor blockers	Vessels become wider	Candesartan Losartan	Atacand Cozaar	Cough, dizziness, headache, drowsiness, diarrhea, metallic or salty taste
Calcium channel blockers	Keeps calcium from entering heart and blood vessel cells	Amlodipine Diltiazem Nifedipine	Norvasc Cardizem, Dilacor, Tiazac Procardia XL; Adalat CC	Swelling, constipation or diarrhea, dizziness, feeling warm
Alpha blockers	Reduce nerve impulses to blood vessels	Verapamil Doxazosin Prazosin	Isoptin SR, Calan SR Cadura Minipress	Weakness, fatigue, lightheadness, dizziness, headaches
Alpha-beta blockers	Reduce nerve impulses to blood vessels and heart	Carvedilol Labetalol	Coreg Normodyne, Trandate	Dizziness, diarrhea, scalp tingling, tiredness, extremity swelling, sexual problems
Centrally acting drugs	Reduce nerve impulses	Clonidine Methyldopa	Catapres Aldomet	Dizziness, drowsiness, dry mouth, anxiety, depression
Direct vasodilators	Causes muscle vessels to relax	Hydralazine Minoxidil	Apresoline Loniten	Lightheadness, dizziness, headache

*Cardiac Rehabilitation* The American Association of Cardiovascular and Pulmonary Rehabilitation and the American Heart Association (AHA) has defined cardiac rehabilitation as “coordinated, multifaceted interventions designed to optimize a cardiac patient’s physical, psychological, and social functioning, in addition to stabilizing, slowing, or even reversing the progression of the underlying atherosclerotic processes, thereby reducing morbidity and mortality” (p. 369) [97]. Core components for cardiac rehabilitation published by the AHA [98] recommend attending to nutritional and physical activity counseling, tobacco cessation, and monitoring and managing blood pressure, lipids, diabetes, and any existing psychosocial factors (e.g., depression, anxiety, anger or hostility, social isolation, family distress, sexual dysfunction/adjustment, substance abuse). Detailed cardiac rehabilitation guidelines have been published [99] and there is a national certification process ([www.aacvpr.org/Certification](http://www.aacvpr.org/Certification)) for programs. Exercise-based cardiac rehabilitation has been shown to decrease risk of all-cause and cardiac mortality when compared to those receiving usual medical care [97, 100], and attending more sessions of cardiac rehabilitation is associated with better long-term outcomes [101]. In medical practice, cardiac rehabilitation is recommended for a variety of patients, including those with atherosclerotic coronary artery disease (e.g., MI, angina pectoris), peripheral artery disease, and heart failure, as well as those recovering from a range of cardiac interventions, including coronary artery bypass grafting, percutaneous transluminal coronary angioplasty (PCTA), valvular surgery, placement of ventricular assist devices, and heart transplantation [102].

Despite the evidence supporting its effectiveness, cardiac rehabilitation programs are significantly underutilized [103]. Clinical psychologists have important roles in collaborating with their medical colleagues to promote patient’s participation in cardiac rehabilitation programs as well as contributing to the delivery of these programs.

## **In-Practice**

The biopsychosocial changes required to reduce morbidity and mortality associated with cardiovascular disease require lifelong adherence to behavior changes and management of risk factors. In most cases, cardiovascular disease prevention and treatment require a chronic care framework across primary and tertiary medical settings. One method of organizing how clinicians approach cardiovascular disease, regardless of the patient’s age or the medical setting, is by tracking how the joint treatment goals or the patient and care provider shift over the course of intervention, as advocated by Whitlock and colleagues [104]. The components of this approach, called the 5 As model, create a framework for guiding biopsychosocial assessments and interventions for the prevention and treatment of those with cardiovascular disease (see Table 19.7 for a summary). In the remainder of this section, we will examine how the 5 As model assists clinical psychologist in applying their clinical skills

**Table 19.7** The 5 As and related goals [104]

5 As	Goal during 5A stage
Assess	Conduct a functional analysis on physical symptoms, behaviors, thoughts, emotions, and environmental variables (e.g., physical living and working environment, family, friends, work interactions) contributing to cardiovascular disease
Advise	Based on gathered information, specify personalized options for treatment and expected functional changes
Agree	Collaboratively set goals based on patient interest and motivation for change
Assist	Provide information, teach skills, implement plans, to help patient reach goals
Arrange	Develop follow-up plans, refer to other specialists/services, implement stepped-care approach

with patients with cardiovascular diseases. It should be noted that whether a patient is seen in primary care or tertiary care settings (e.g., cardiac rehabilitation) will dictate the standard of care that is followed; however, the fundamental approaches of this model of care will be similar. Primary care settings will likely provide less time within each appointment than patients seen in hospital or tertiary care settings and, thus, limit the use of in-depth assessments and complex interventions. However, it is also quite likely that most individuals with some form of cardiovascular disease will be managed in primary care settings.

For patients seen in tertiary care facilities, like cardiac rehabilitation programs, contact with a clinical psychologist can be more extensive. Depending on the condition of the patient and the available resources, cardiac rehabilitation programs may last weeks, months, or even years. Some programs focus entirely on increasing physical activity, as aerobic and resistance exercise training is the foundation of all cardiac rehabilitation programs [97]. In collaboration with the medical team, however, the clinical psychologist can play a critical role in a cardiac rehabilitation program by assessing biopsychosocial factors contributing to cardiovascular disease risk and offering group sessions targeting motivational enhancement, stress management, mindfulness, behavioral activation, methods for managing negative thinking and developing psychological flexibility, improving communication, managing diet and weight, and improving sleep. Such classes provide an integrated approach to targeting the biopsychosocial antecedents and consequences of cardiovascular disease.

## *Assess*

During the Assess phase, information is gathered from the patient as well as from the medical chart and referring provider. If possible, gathering information from family members, particularly if the patient's functioning has significantly changed as the result of the cardiac event (e.g., post-MI), can provide valuable information

about the impact of the cardiac event on not just the individual, but the family as well. The standardized measures reviewed earlier and presented in Table 19.4 can facilitate these assessments, although longer assessments may not be practical in primary care settings. There are several domains that should be considered when conducting a proper functional assessment: (a) physical functioning, (b) health behaviors, (c) cognitive understanding of the disease/treatment process, (d) emotional functioning, (e) the degree of social connectedness, and (f) environmental factors that contribute to the problem.

*Assessment of Physical Functioning* The clinical psychologist should review relevant laboratory values (e.g., cholesterol levels), physiological assessments (e.g., blood pressure, cardiac output), and the patient's body mass index. If the patient has had a significant major cardiac event or surgery, information about physical problems with the heart and circulatory system should be gathered. Additionally, it is important for the provider to learn how the medical procedure the patient is confronting (if any) is expected to affect the patient's functioning and to consult with medical providers to understand what, if any, limitations there are on physical activity. Assessing presence of other medical conditions (e.g., diabetes, chronic pain, chronic obstructive pulmonary disease, COPD) that may also affect functioning is important.

When working with patients with cardiovascular disease, it is important to assess for problems associated with sleep and sexual functioning. Screening for sleep-related problems through questions about difficulty falling asleep, staying asleep, and waking up earlier than planned should be done as well as screening for sleep apnea by asking whether patients feel rested when they wake up, if they experience headaches when they awaken, and whether they snore at night and/or bed partners have noticed them gasping for air. Among men in the early stages of atherosclerosis, decreased sexual functioning may be an early sign of decreased systemic blood flow [105]. There are limited data supporting relations between female sexual functioning and vascular risk factors [106]. Concerns about sexual functioning can occur after learning one has cardiovascular disease, a cardiac event, or after cardiac surgery and should be addressed later in the Assist phase. Specifically targeting sexual functioning among patients with cardiovascular disease has demonstrated improved sexual activity [107].

*Assessment of Health Behaviors* Because adoption of a healthy lifestyle is critical in preventing first and subsequent cardiac events, it is essential that the clinical psychologist assesses relevant health behaviors, including tobacco use, diet, frequency and duration of physical activity, and use of alcohol and other substances. Reviewing the medications patients are taking and assessing medication adherence are also important. It can be helpful to ask about a typical day to compare the activities reported to what the patient did before a cardiac event. Given the importance of engaging in goal-directed activity to maintain mental health, it is important to assess the activities in which the patient engages at home, work, and for recreation, and whether there have been significant changes in participation in these activities.

*Cognitive Understanding of the Disease/Treatment Process* Because cardiovascular diseases affect both patients who have considerable knowledge of medical diseases and those who have none, it is essential to determine the patients' understanding of their cardiovascular disease, their expectations for the course of the condition, and what they believe that they can control. Negative thinking patterns about one's self, unrealistic expectations about what they can and cannot do, worry about the progression and/or recurrence of a cardiac event (e.g., "physical activity/sexual activity will cause a heart attack"), and concerns related to distinguishing between "anxiety" and "a heart attack" are common thoughts in those with cardiovascular diseases. Patients with high cholesterol or blood pressure often will not "feel sick," but the prescribed medications will result in undesirable side effects, which may contribute to poor medication adherence. Asking about perceptions of medications and the expected impact of the prescribed medical treatments can be valuable for promoting adherence. Patients may also demonstrate body image concerns due to scars and implantation of devices (e.g., pacemakers, implantable cardioverter defibrillators), and these issues should be explored.

*Emotional Functioning* Given the preponderance of evidence supporting the association between numerous emotional states and onset of cardiovascular disease, it is important to assess the patient for significant symptoms of depression, anxiety (including post-traumatic stress disorder, PTSD), anger, and stress. To conduct a proper functional analysis, it is important to determine the duration, frequency, and intensity of these emotional responses, as well as determine the contexts in which they occur. Given the high co-occurrence of depressive symptoms and cardiovascular disease, it is particularly important to screen for suicidal thoughts and behaviors. Those who have suffered an MI, particularly within the 1st month following discharge from the hospital, have been found to be at a significantly higher risk of suicide compared to matched controls [108].

*Social Connectedness* Because social isolation has such detrimental effects on health, it is important to determine upon whom the patient relies for social support as well as the valued organizations or support systems in which the patient engages with some degree of regularity (e.g., community groups, religious/spiritual groups). For example, it is good to ask whether patients believe that there are people to whom they can turn to if necessary to help them. Ethnic and cultural factors that may contribute to functioning and the course of care need to be considered. Additionally, the socioeconomic status of the patient and how this status may affect access to care and/or the ability to make recommended changes in their behaviors or environments should be assessed.

*Environmental Factors* Because life stressors, both acute and chronic, are associated with increased physiological arousal that may influence cardiovascular functioning, it is important to determine whether any contextual factors are contributing to the problem. These include relationship problems, work-related stress, financial problems, and other significant life events (e.g., job changes, death of a family member), but also account for the safety of the living environment (e.g., homelessness) and exposure to environmental pathogens. The presence of caregivers who

agree to be involved with the patient and the degree of stress experienced by those caregivers could affect clinical outcomes and should be evaluated, along with the financial impact of the cardiovascular disease or cardiac event on the patient.

### *Advise*

In the Advise phase, it is important to personalize the treatment options for the patient based upon the comprehensive assessment conducted in the previous phase. Realistic expectations and options for the patient should be considered and presented, including an explanation of how biopsychosocial factors could affect the risk of cardiovascular disease or a cardiac event, what behavioral changes would result in improved functioning, and what factors will likely contribute to the patient's quality of life. Quitting smoking, increasing physical activity, and losing weight have the most robust influence on cardiovascular disease risk, and should be considered as high-priority targets in devising a behavioral treatment plan. Advising patients of the need to make these changes remains essential for working with patients with cardiovascular disease and promoting cardiac risk reduction. However, cognitive and emotional factors, lack of social support, and environmental barriers may interfere with a patient's effort to initiate and sustain an effective behavior change program. Therefore, it may be necessary to target these factors before patients can be successful in implementing a sustainable behavior change program.

### *Agree*

If advising patients to engage in behavior change reliably resulted in significant improvement in health behaviors, the job of the clinical psychologist would be fairly easy. However, we know from decades of experience and considerable empirical support, behavior change will not occur unless care providers can get the patients to commit to changing their behavior. During the Agree phase, the clinical psychologist collaborates with patients to determine priorities for treatment, discuss the expected outcomes, and agree on goals for treatment. Some patients may demonstrate resistance or poor adherence to proposed changes. The transtheoretical model of behavior change [109], along with the motivational interviewing strategies to promote making a commitment to behavior change [110, 111], can assist the clinical psychologist in discussing behavior change plans openly and promoting cardiovascular disease health-related behavior changes [112, 113].

### *Assist*

Once the patient agrees to engage in any type of treatment, it is the role of the health care provider to Assist him or her in making the agreed-upon changes. Although

it is beyond the scope of this chapter to describe all of the practical approaches that have been used for targeting health behaviors associated with cardiovascular disease, a sample of common goals and evidence-based methods for improving factors related to cardiovascular health are summarized in Table 19.5. Choosing what behaviors to target and which skill to teach naturally flows from the earlier review of health behaviors and psychosocial factors risk factors for cardiovascular disease. The goals and methods used to attain them should be individualized to the needs of the patient and made in collaboration with medical providers. In cases where multiple health behaviors or psychosocial risk factors exist, it can be helpful to identify what the patient is most interested in changing rather than targeting all of the behaviors at once. Improving health behavior (i.e., smoking, physical inactivity, diet, and alcohol use) has the potential to reduce early mortality among coronary artery disease patients 20–45%, and 15–50% among the general population [114]. The goals that are presented in Table 19.5 are ideal goals and may not be realistic for many patients; however, working towards these goals can still have dramatic impacts on reducing risk for cardiac events.

Current data suggest that reducing depressive, anxiety, anger, and hostility symptoms as well as decreasing social isolation and psychological stress have a limited effect on decreasing risk for cardiovascular disease and cardiac events, but are important for improving quality of life. Clinical psychologists should collaborate with patients' medical providers to consider whether referrals for antidepressants and/or anxiolytic medications are appropriate in addition to psychosocial interventions that the clinical psychologist can provide.

Increasingly, there are online sites and applications that can be quite useful for assisting patients in monitoring cardiovascular disease-related health conditions and related behaviors. One example is the AHA's free application ([www.heart360.org](http://www.heart360.org)) that allows patients to track cardiovascular disease health status (e.g., blood pressure, cholesterol, blood glucose) and health behaviors (e.g., weight, physical activity, medications), and provides health status feedback. This application also allows providers to access patients' information to enhance collaborative care. Other websites that may provide helpful information for patients are listed in Table 19.8.

## *Arrange*

Once someone has been diagnosed with a cardiovascular disease, and even risk factors for cardiovascular disease (e.g., obesity), the problem needs to be treated as a chronic health problem. In the final phase of the 5 As model, the health care professional Arranges regular appointments or contacts with primary care personnel through phone calls or secure email, to assess the maintenance of behavior changes, once the patient has adopted them. Patients who demonstrate continued difficulty starting behavior change programs or regulating emotional responses may benefit from more specialized assistance in a tertiary care environment. When working with a high volume of cardiovascular disease patients, it is essential to collaborate

**Table 19.8** Websites with cardiovascular disease-related information for patients

Organization	Website
Agency for Healthcare Research and Quality	<a href="http://www.ahrq.gov/clinic/cvd/">http://www.ahrq.gov/clinic/cvd/</a>
American Academy of Family Physicians <sup>a</sup>	<a href="http://familydoctor.org/">http://familydoctor.org/</a>
American Heart Association	<a href="http://www.heart.org/">http://www.heart.org/</a> <a href="http://www.hearthub.org/">http://www.hearthub.org/</a> <a href="https://www.heart360.org/">https://www.heart360.org/</a>
Centers for Disease Control	<a href="http://www.cdc.gov/heartdisease/">http://www.cdc.gov/heartdisease/</a>
Cleveland Clinic	<a href="http://my.clevelandclinic.org/heart/guide.aspx">http://my.clevelandclinic.org/heart/guide.aspx</a>
Mayo Clinic <sup>a</sup>	<a href="http://www.mayoclinic.com/">http://www.mayoclinic.com/</a>
U.S. Department of Health and Human Services <sup>a</sup>	<a href="http://www.healthfinder.gov/">http://www.healthfinder.gov/</a>
Mended Little Hearts (Congenital heart defects)	<a href="http://www.mendedlittlehearts.org/">http://www.mendedlittlehearts.org/</a>
National Heart Lung & Blood Institute	<a href="http://www.nhlbi.nih.gov/">http://www.nhlbi.nih.gov/</a> <a href="http://www.nhlbi.nih.gov/educational/hearttruth">http://www.nhlbi.nih.gov/educational/hearttruth</a>
Up-To-Date <sup>a</sup>	<a href="http://www.uptodate.com/home/uptodate-benefits-patients">http://www.uptodate.com/home/uptodate-benefits-patients</a>
WomenHeart	<a href="http://www.womenheart.org/">http://www.womenheart.org/</a>

<sup>a</sup> Enter cardiovascular condition/disease of interest into search box

with nurses, dietitians, physical therapists, and social workers who can enhance the complexity of care and assist the patient in accessing community resources. For example, community-based and/or online support groups for patients as well as families and caregivers could be useful tools to add to the treatment plan.

## Summary

The pervasiveness of cardiovascular disease ensures that every psychologist, regardless of where they provide care, will encounter patients regularly who demonstrate risk factors for developing cardiovascular disease, who have a cardiovascular disease, and/or who have had a cardiac event. Current data suggest that improving health behaviors remains the most important target for reducing disease risk; however, a complete biopsychosocial approach to assessment, prevention, and treatment is needed to maximize physical, emotional, and social functioning. Relying on the 5 As model, psychological assessments can be used to identify underlying biopsychosocial factors contributing to the onset and manifestation of cardiovascular disease, and behavior change interventions employed to improve quality of life among these patients. It is important to recognize that patients with cardiovascular diseases, whether seen in primary care settings or tertiary settings like cardiac rehabilitation programs, can benefit from the services of clinical psychologists who practice in



these settings. To move beyond relying on “technological advances and medications to defeat cardiovascular disease,” as Dr. Eckel urged, clinical psychologists need to continue to develop and implement evidence-based biopsychosocial care for those at risk and who demonstrate cardiovascular disease.

### ***Key Points to Consider***

- Changing health behaviors (e.g., smoking, eating, weight, and physical activity) has the most significant impact on reducing the risk and progression of cardiovascular disease.
- Psychosocial factors including depression, anxiety, and social isolation are related to the development and progression of cardiovascular disease, but changing these factors has not been shown to substantially reduce the risk or progression of cardiovascular disease. These factors should be targeted to improve quality of life and to improve daily functioning.
- Cardiac rehabilitation programs are underutilized, but are effective for improving functioning and reducing cardiovascular disease risk.

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# Chapter 20

## Chronic Pulmonary Diseases Across the Life Span

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Chronic diseases of the pulmonary system affect both children and adults and can range in severity from mild to life-threatening. They may affect multiple aspects of functioning from time spent in treatment activities, physical limitations, emotional/behavioral functioning, and overall quality of life. As pulmonary disorders are prevalent conditions, clinicians working in health care settings need to develop an understanding of the major conditions and their associated challenges. This chapter will review three predominant, chronic pulmonary disorders that affect individuals across the life span: asthma, chronic obstructive pulmonary disease (COPD), and cystic fibrosis. A review of the physiological/medical factors, relevant psychological and social factors, and evidence-based assessment and treatment strategies will be presented for each condition.

### Asthma

#### *Disease Pathophysiology and Medical Treatment*

Asthma is a chronic condition in which the airways become inflamed and narrowed, thus affecting pulmonary functioning and resulting in difficulties in breathing

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(wheezing, shortness of breath), chest tightness, and coughing. The condition accounts for approximately 1 in every 250 deaths worldwide [1]. Individuals with asthma have chronic underlying inflammation, as well as periods of exacerbation (asthma attacks). During asthma attacks, which may last from minutes to days, the amount of air that can pass through the airways is reduced because the muscles around the airways tighten and the lining of the airway passages becomes inflamed. Attacks may be triggered by irritants in the environment, respiratory infections, allergens, and/or seasonal changes; these triggers vary across individuals and the course of the condition. In most people, asthma is characterized by intermittent attacks, separated by periods of normal, symptom-free breathing. The period of time between attacks may be days to years. Attacks may be reversible with medication or symptoms sometimes spontaneously remit. However, among some individuals with asthma, there are prolonged periods of coughing or wheezing, with intermittent periods of increased shortness of breath without full attacks. Asthma can be present at birth (congenital) or be acquired later in life, with early onset (prior to 12 years) or late onset (12 years or after) [2, 3].

According to a 2004 report on international prevalence of asthma, approximately 300 million people worldwide have asthma, and this number is on the rise due to increasing sensitivity to allergens in both children and adults that comes with urbanization [1]. Multiple genes appear to be involved in symptom expression and there appears to be a gene–environment interaction that is continuing to be a topic of clinical investigation [4]. In addition to genetic constitution and exposure to environmental pollutants, lifestyle factors also are implicated in the expression of asthma. Specifically, obesity and sedentary lifestyle have been shown to precede the manifestation of asthma symptom onset [5], as well as exacerbate symptoms in individuals already diagnosed with asthma [3].

With appropriate medical intervention and adherence to medications, the experience of daily symptoms and flare-ups are typically extinguished. For persistent asthma, inhaled corticosteroids (also called maintenance medication) are prescribed daily to treat the chronic, underlying airway inflammation. Additionally, medications such as rapid-acting inhaled  $\beta_2$ -agonists (called reliever medications) are prescribed often to provide quick relief of airway constriction during an acute flare-up. Medications are typically delivered through inhalation (e.g., metered dose inhalers, nebulizers), though they may also be administered orally or via injection. Training and skill development is needed for the appropriate delivery of inhaled medications, particularly in children. For a comprehensive review of controller and reliever medication types, methods of delivery, and side effects, see Global Initiative for Asthma (GINA) [6].

Patients with asthma may be followed by their primary care physicians or specialists in pulmonary medicine or allergy. During clinic visits, laboratory tests may include assessment of pulmonary function and reversibility of lung function abnormalities. These are measured via spirometry, the most common forms being the forced expiratory volume in one second ( $FEV_1$ ) and forced vital capacity (FVC). The  $FEV_1$  value indicates the volume of air that a person exhales in the first second following a full inhalation, while FVC values indicate the maximum volume of air



that a person can forcibly exhale following a full inhalation. Reversibility is measured by assessing changes in lung functioning, usually FEV<sub>1</sub> before and after use of a rapid-acting bronchodilator [7]. Additionally, measurement of peak expiratory flow (PEF), with an ambulatory device used by patients, also may be used in the diagnosis and monitoring of asthma symptoms.

Spirometry readings, along with other indicators of functioning (e.g., presence of symptoms, use of medications), are used to classify asthma control. According to guidelines set forth by GINA [6], clinical control of asthma is characterized by the following: (a) no or infrequent (less than two times per week) daytime symptoms, (b) no restriction of activity, (c) no disrupted sleep due to asthma, (d) infrequent (less than two times per week) or no need for reliever treatment, (e) normal or almost normal spirometry readings, and (f) no flare-ups or exacerbations. Alternatively, patients may have partial control or uncontrolled asthma, which is characterized by failure to meet at least three of the aforementioned guidelines [6]. Asthma control is increasingly replacing asthma severity as a descriptor of a patient's condition, as it is suggested to be of greater clinical utility when making treatment decisions [6]. However, severity of asthma is considered a useful classification for patients not yet receiving medical treatment for their asthma (i.e., initial diagnosis) and may be described as mild, moderate, or severe. Many health professionals argue that although interrelated, asthma severity and asthma control are distinct concepts and further argue that indications of severity may be helpful in research on the etiology and mechanisms of asthma [8].

## Common Psychosocial Issues

**Psychosocial Functioning.** Psychosocial difficulties associated with asthma are present across the life span and include increased rates of anxiety disorders and depression [9, 10], as well as absenteeism from work and school [11]. In a worldwide survey of adults in 17 countries, adults with asthma were 1.5 times more likely to experience depressive disorders, 1.5 times more likely to experience anxiety disorders, and 1.7 times more likely to experience alcohol use disorders than adults without asthma [12]. Panic attacks and panic disorder are the most common forms of anxiety among adults with asthma [13] and clinicians must take care to distinguish symptoms of asthma attacks from panic attacks, as there is often symptom overlap (e.g., difficulty breathing, tachycardia). Furthermore, the presence of anxiety is associated with a high frequency of emergency room visits, regardless of asthma severity [14].

**Tobacco Exposure.** As previously discussed, environmental irritants (e.g., second-hand smoke, pet dander) can contribute to asthma symptoms and flare-ups. Therefore, a significant psychosocial issue that health psychologists must address when working with patients with asthma is reducing sources of environmental irritants in the home. Among many patients and their families, reducing environmental irritants, particularly direct or indirect tobacco exposure, involves difficult behavior

change. Additionally, nearly half of patients with asthma report that their diagnosis preceded smoking onset [15, 16]. Therefore, smoking prevention and cessation are critical aspects of patient care in asthma, as the effects of smoking are additive and lead to significantly reduced lung functioning over time [17].

**Adherence to Treatment Regimen.** Adherence to treatment regimen, particularly maintenance medications, is strongly related to asthma control and subsequent symptom severity, health care use, and degree of functional impairment/quality of life [18]. However, adherence tends to be low for many children and adults with asthma, particularly among minorities and those from socioeconomically disadvantaged backgrounds [19, 20]. In one study following adherence to controller medications over 1 year in a sample of African-American children from socioeconomically disadvantaged backgrounds, average adherence was 50% of daily recommended doses at the start of the study and decreased to 20% 1 year later [21]. Similar rates have been found in other pediatric samples [20, 22]. Among pediatric populations, adherence may shift over the developmental life span as parents transition responsibility of treatment from the caregivers to the children. Rates of non-adherence have also been found to be high among adults. Estimates of deviation from prescribed treatment regimen among adult populations with asthma, gathered via self-report, electronic monitoring, or pill counts, range from 24 to 70% [23, 24].

Emerging research is focusing on the cognitive aspects of medication adherence to identify individual factors that may be targeted with intervention efforts [25, 26]. Beliefs about the utility of maintenance medications are related to adherence [19], and account for far more variance in adherence than do sociodemographic factors [27]. Additionally, not understanding the preventive nature of maintenance medications is prominent among families and related to reduced adherence [28, 29]. Finally, lack of perceived symptoms and need for medication also has been associated with adherence [24], which is paradoxical, as the absence of symptoms is typically indicative of the maintenance medication working.

### ***Evidence-Based Assessment of Psychosocial Concerns***

Several measures exist for assessing psychosocial factors (e.g., depression), quality of life, and asthma control and factors related to it among pediatric and adult populations. Methods used to assess anxiety are the same as those used in the general population of children and adults, and so a brief review of some common screening measures is presented in Table 20.1. Of course, any positive screening results should be followed with a full clinical diagnostic interview. However, clinicians should be cautious to distinguish physical symptoms of anxiety and depression from physical symptoms of asthma and may need to rely on the presence of cognitive and behavioral symptoms when determining whether a psychological disorder is present.

**Adherence.** For a comprehensive review of validated measures in assessment of asthma control, see Halbert, Tinkelman, Globe, and Lin [30]. However, assessment

**Table 20.1** Generic measures of psychosocial functioning for use with patients with chronic obstructive lung disease**General Screening**

- *General Health Questionnaire* (GHQ-12)
  - Self-report measure (ages 11–65+) assessing anxiety, depression, stress, and sleep problems
  - 12 items, each rated on 4-point Likert-type scale, over the past few weeks
  - Total score ranges from 0 to 36; higher score indicates worse health

**Anxiety**

- *Beck Anxiety Inventory* (BAI)
  - Self-report measure (ages 17–80) assessing two factors of anxiety: cognitive and somatic symptoms; note that 15 items measure physiological symptoms, which are highly relevant to panic disorder
  - 21 items, each with 4 multiple choice options, rated over past week
  - Total score interpretation: 0–7= minimal anxiety; 8–15= mild anxiety; 16–25= moderate anxiety; 26–63= severe anxiety
- *Anxiety Sensitivity Index-3* (ASI-3)
  - Self-report measure assessing somatic, cognitive, and social aspects of fear of harm from anxiety-related sensations
  - 18 items, each rated on a 5-point Likert-type scale
  - An 18-item child’s version (ages 6–18 years) has been developed: *Childhood Anxiety Sensitivity Index (CASI)*
- *Multidimensional Scale of Anxiety in Children* (MASC)
  - Self-report (ages 8–19 years) questionnaire measuring anxiety symptoms
  - 39 items, rated on a Likert-type scale
  - Yields a variety of scales and indexes (e.g., social anxiety, separation/panic) in addition to a validity scale (i.e., inconsistency index)
  - 10-item brief version available for repeated testing

**Depression**

- *Brief Assessment Schedule Depression Cards* (BASDEC)
  - Designed to measure depression in older adults in medical settings
  - Clinical interview (2–8 min) involving patients reviewing 19 statements relating to depression symptoms; items appear on a card in large font and patients sort cards by “True,” “False,” and “Don’t Know” responses
  - Total score ranges from 0 to 21 (higher scores indicate greater depressive symptomatology)
- *Geriatric Depression Scale* (GDS)
  - Self-report questionnaire designed to measure depression in the elderly
  - 30 items, rated on a “yes/no” format
  - Shorter, 15-item version has been devised and validated
- *Center for Epidemiological Studies Depression Scale* (CES-D)
  - Self-report (age 18+) questionnaire measuring depressive symptoms
  - Respondents rate each of 20 items by frequency during the past week on a 4-point Likert-type scale
  - Cut off score of 16 indicates significant depressive symptoms
  - 10-item version available (cut off score = 10)
  - A child’s version (ages 6–17 years) exists: *Center for Epidemiological Studies Depression Scale for Children* (CES-DC)
- *Beck Depression Inventory* (BDI-II)
  - Self-report (age 13+) inventory measuring the severity of depression symptoms
  - 21 items, rated in a multiple-choice format (0–3), over the previous 2 weeks
  - Consists of two subscales: Affective and Somatic

**Table 20.1** (continued)

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– <b>Total score interpretation:</b> 0–13 = minimal depression; 14–19 = mild depression; 20–28 = moderate depression; 29–63 = severe depression
• <i>Children's Depression Inventory-2</i> (CDI-2)
– Self-, parent-, and teacher-report inventory for depressive symptoms in youth (ages 7–17 years)
– Consists of two scales (emotional problems and functional problems) and four subscales (negative mood, negative self-esteem, ineffectiveness, and interpersonal problems)
– 28 items, rated in a multiple-choice format, over the previous 2 weeks; 12-item short, self-report version also available
<b>Activities of Daily Living</b>
• <i>Barthel Index of Activities of Daily Living</i>
– Assesses current level of ability and independence across ten activities of daily life, which can be grouped into self-care (e.g., grooming) and mobility (e.g., stair climbing)
– Self-report, other-report, or completed based on observation
– 10 items, each rated as 0-, 5-, or 10- points
– Total score ranges from 0 to 100, with lower scores suggestive of greater disability
<b>Family Functioning/Social Support</b>
• <i>Medical Outcomes Study (MOS) Social Support Survey</i>
– Self-report (age 18+) survey of functional social support across four dimensions: emotional/informational, tangible, affectionate, and positive social interaction
– Easy to administer to chronically ill patients
– 19 items, rated on a 5-point Likert-type scale (“none of the time” to “all of the time”); higher scores represent more frequent availability of social support
• <i>Family Assessment Device</i> (FAD)
– 60 items, rated on a 4-point format (“strongly agree” to “strongly disagree”)
– Measures how an individual interacts with and feels supported by his or her family
– Yields scores for six dimensions of family functioning (e.g., communication, affective responsiveness, problem solving); also provides a score for a “general functioning” scale

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of control alone does not provide information regarding regimen adherence, which can affect the presence and severity of symptoms as well as need for rescue medication. Therefore, assessment of treatment adherence, independent of symptom control, is critical. As with other chronic health conditions, multiple assessment methods are available for assessing adherence, including clinical interviews, self-report instruments (e.g., rating scales, computerized phone diaries), and objective assessments, such as electronic monitoring, laboratory indicators, and review of prescription refill records. Each technique has its strengths as weaknesses [31].

The unstructured clinical interview, although regularly used in practice, is the method most susceptible to social desirability bias and inaccurate assessment, as it relies on patient–provider rapport and clinical skill in asking an appropriate scope of questions [32]. Thus, semi-structured interviews may offer some benefits. One semi-structured interview for pediatric populations is the *Family Asthma Management System Scale* (FAMSS) [32, 33]. The purpose of the scale is to gather information regarding management of a child's asthma within a systems context, thus gathering information regarding knowledge, symptoms, medication adherence be-

haviors (by children, caregivers, and alternate caregivers), environmental control, rapport with the health care provider, and impact of asthma on family life. In assessing validity, low to moderate correlations were obtained between FAMSS scores and self-report measures of knowledge and self-efficacy, adherence data from electronic monitoring devices, and baseline morbidity factors. These findings indicate that although interviews may be beneficial, information regarding adherence behaviors should be collected using multiple sources of information.

Electronic monitoring of medication often is used in research as an objective measure of medication adherence. Electronic monitors can track and record data on the number of doses dispensed across a specified time period. Drawbacks to electronic monitoring include financial cost and potential for technical malfunctions [31]. Another limitation of electronic monitoring is that it focuses only on whether medication was administered but does not provide information about barriers to adherence (e.g., beliefs, knowledge) or adherence to other aspects of an asthma regimen (e.g., avoiding allergens and secondhand smoke) [32].

Several self and/or parent report scales specific to pediatric and adult asthma populations exist that provide information about adherence, as well as factors related to adherence (e.g., beliefs, knowledge, perception of symptoms, asthma control). For example, one commonly used measure of asthma control among children and adults is the *Asthma Therapy Assessment Questionnaire* (ATAQ) [34, 35]. The ATAQ is a validated self-report (or parent-report) measure of illness management designed specifically to identify patients with suboptimal adherence [34, 35]. It assesses four aspects of asthma control: (1) perceived asthma control, (2) impairment of daily activities, (3) symptom severity, and (4) use of rescue medications. It also assesses other aspects of illness management, such as satisfaction with treatment, patient-provider communication, and beliefs regarding medication [36]. The ATAQ for children and adolescents [34] is a 20-item, parent report measure that assesses control, attitudes, and behavior toward treatment, self-efficacy of management of treatment, and patient-provider communication. Scores derived from the ATAQ among both adolescents and adults predict future exacerbations [37], and scores also indicate perceived symptom severity in adults [38].

Another self-report instrument to assess illness management, particularly barriers to adherence, is the *Adherence Starts With Knowledge* 20-item survey (ASK-20) [39]. The survey was developed specifically to identify barriers to adherence to medical treatment among adults, including concerns regarding side effects, inconvenience, beliefs about efficacy of medication, and poor comprehension of physician instructions. Responses from the survey can inform the development of appropriate interventions for patients with suboptimal adherence. Among pediatric populations, the *Asthma Illness Representation Scale* (AIRS) [40] is a commonly used scale. It involves a parent-report questionnaire derived from qualitative interviews identifying barriers to maintenance medication adherence [41]. The AIRS assesses parental attitudes toward maintenance medications, perception of symptoms, knowledge, and beliefs/emotions regarding medication use. The AIRS has been validated with parents from high and low socioeconomic status groups and shown to be associated with caregiver education and perceived asthma severity [41, 42].

A final self-report measure of adherence among youth with asthma is the *Asthma Control Test* (ACT; ages 12–15) [43] and the associated measure for children, the *Childhood Asthma Control Test* (C-ACT; ages 9–11) [44]. These questionnaires assess asthma symptom activity, impact on daily functioning across environments (e.g., work, school), use of rescue medications, and overall perception of asthma control. The ACT consists of five items and information is gathered via self-report. The C-ACT consists of seven items and information is gathered via child and caregiver report. Scores obtained from the ACT and C-ACT appropriately coincide with physician reports of asthma control and percent-predicted FEV<sub>1</sub> values [43, 44].

**Health-Related Quality of Life.** Assessment of health-related quality of life (HRQOL) among individuals with asthma typically relies upon interview and/or rating scales (either electronic or paper and pencil) [45]. For adults, many measures of quality of life exist that are specific to asthma. Of the most commonly administered is the *Asthma Quality of Life Questionnaire* (AQLQ) [46]. The AQLQ is a 32-item questionnaire that can be administered via interview or as a rating scale. Patients are asked to indicate five areas of their lives most affected by asthma and then answer specific questions related to each area. HRQOL across four domains is then described: (1) activity limitations, (2) symptoms, (3) emotional functioning, and (4) exposure to environmental stimuli. The measure was later revised to a standardized version, the *Standardized AQLQ*, AQLQ(S), in which all patients are asked about HRQOL in the same areas of functioning, rather than being asked to select five [47]. A pediatric version of the standardized measure also has been developed, the *Pediatric AQLQ*, PAQLQ(S) [48]. The pediatric version is delivered via interview format that contains 23 items that load onto three domains of functioning: activity limitation, symptoms, and emotional. All variations of the AQLQ of the measure have been shown to have adequate reliability and are associated with generic quality-of-life measures, as well as clinical indicators of asthma control and severity [47, 48].

### ***Evidence-Based Interventions for Psychosocial Concerns***

**Psychosocial Functioning.** For patients exhibiting symptoms of anxiety and/or depression, in addition to their asthma, cognitive-behavioral therapy (CBT) may be an appropriate treatment [49]. CBT includes exposure to feared internal sensations and environmental triggers of exacerbations [50]; increasing pleasurable activities and reducing avoidance of situations associated with anxiety or mood concerns; problem solving; sleep management [51]; cognitive restructuring; coping skills; homework assignments [52]; introducing goal setting for lifestyle changes, such as smoking cessation and physical activity engagement; pacing of activity level, and mindfulness-based relaxation. One study involving random assignment to groups indicated that the implementation of a 15-session cognitive-behavioral treatment consisting of muscle relaxation, cognitive restructuring, behavior modification, and

asthma education was associated with reduced reports of low quality of life and symptoms of depression and anxiety, as well as decreased self-reported severity of asthma symptoms [53]. However, this study was conducted with a very small sample size and included asthma education as part of the CBT education, thus possibly confounding results. Other randomized controlled trials (RCTs) also support the use of anxiety management techniques, specifically relaxation-breathing training, in reducing anxiety and negative asthma outcomes among pediatric and adult populations [54–56].

**Adherence.** For patients who have suboptimal adherence or behaviors that negatively affect asthma outcomes (e.g., smoking), motivational interviewing may improve health-related behaviors. In an RCT involving adults with asthma, those who received a motivational interviewing intervention, in addition to asthma education, exhibited stable or improved adherence behaviors in comparison to those who only received asthma education and subsequently demonstrated a decline in adherence over time [57]. Additionally, motivational interviewing regarding parental smoking cessation has been effective when delivered in a home setting and paired with feedback regarding children’s secondhand smoke exposure [58] and is also beneficial when delivered in a school-based setting [59]. For caregivers and adolescents with poor adherence, more intensive interventions may be necessary. For example, some researchers have proposed using multisystemic therapy to promote adherence among families of adolescents with high-severity asthma and low adherence [60]; this approach has been effective at reducing hospital admissions and related costs with other adolescent populations with chronic illness (e.g., diabetes) [61].

Feedback regarding adherence to treatment regimen also is an important element of other interventions. In fact, emerging evidence indicates that simply providing feedback regarding adherence after measuring medication use with electronic monitoring may be associated with improved technique in dispersing inhaled medication and adherence [62, 63].

**Patient Education.** Finally, knowledge deficits and poor understanding of asthma treatment has been demonstrated to be a barrier to adherence; GINA recommends that patients receive written action plans that delineate individualized asthma treatment [6]. One systematic review of written asthma plans concluded that there is insufficient evidence to support the efficacy or effectiveness of written action plans on asthma outcomes (including emergency room visits and asthma control), regardless of whether the plan is coupled with peak flow monitoring [64]. However, the authors recommend that future research studies investigate whether written action plans are effective in subpopulations of individuals with asthma, such as those with high-severity and/or high-reliever medication use. Instead of (or in addition to) written action plans, there is emerging research support for interactive, face-to-face delivery of asthma education to patients and their families on adherence and outcomes [65].

## ***Critical Review of the State of Evidence-Based Care***

The current state of the research indicates that individuals with asthma may face numerous psychosocial challenges related to adjustment and illness management. There is a large body of research on evidence-based assessment of adherence. However, much research is needed on the assessment of panic, anxiety, and depression among patients with asthma [66]. Additionally, although several methods to assess illness management behaviors exist, most research involves very short time periods for assessment; thus, as a result of the Hawthorne effect, patients may demonstrate better adherence because they are participating in a research study. Longer studies are needed to more accurately reflect adherence rates in the community, particularly as they change across time [21].

In terms of intervention, several randomized controlled trials exist to assess various behavioral interventions (e.g., written action plans, motivational interviewing) targeting illness management behaviors; however, the quality of these studies do not typically meet high standards for clinical trials research and introduce several sources of bias into their designs [64, 67, 68]. There is a strong need for high-quality, randomized controlled trials to investigate the independent effects of the various intervention techniques to promote asthma knowledge, adherence, and outcomes. Additionally, it will be important for researchers to consider feasibility within an average clinic setting (e.g., pace of care, staff available, access to consultation) when devising and evaluating intervention approaches.

## ***In-Practice Tips***

Practitioners working with children and adults with asthma should be aware of the multiple psychosocial stressors that their patients may encounter. First, practitioners also need to be aware that throughout the life span, different challenges may present to patients with asthma. Therefore, the functioning and illness management behaviors of patients with asthma should be monitored at multiple time points across the life span. It is critical that practitioners understand that individuals with asthma are at significantly increased risk for experiencing psychosocial difficulties, particularly panic attacks and panic disorder. When assessing patients with asthma, it will be essential to attempt to distinguish the symptoms of asthma attacks from panic attacks. When comorbid anxiety and mood disorders are identified, the practitioner will need to implement appropriate cognitive-behavioral interventions (and other evidence-based intervention strategies) to address the symptoms of these psychological disorders.

Practitioners working in pulmonary settings should focus on assessing patients' (or parents') understanding and knowledge of asthma medications. Misperceptions of symptoms or lack of knowledge of reasons for medication may affect adherence, particularly to maintenance medication; psychoeducation may be needed to pro-



**Table 20.2** Initial screening questions for evaluating asthma adherence**For All Patients (and Parents):**

- *Please walk me through your (your child's) medication schedule.*
  - *What medications do you take?*
  - *What is the purpose of each medication?*
  - *Show me how you take the medication. (Inhaler technique)*
  - *When do you take them?*
  - *How much do you take of each?*
  - *Where do you keep your medications?*
  - *How do you know when you need to refill your medication?*
- *How often do you use your rescue inhaler?*
- *Everyone has times when they miss taking their medications. In a given week, how many days do you miss one or more doses?*
  - *What are the situations that make it most difficult to take or remember your medications?*
- *Do you ever avoid taking your medication because you don't think they're working or you think you don't need them?*
- *Do you ever avoid taking your medication to reduce the amount of money you need to spend?*
- *Do you ever avoid taking your medication because you don't like the way it tastes or makes you feel?*
- *What strategies do you use to remind yourself to take your medications?*

**For Children:**

- *Do children at school ever tease you or pick on you because of your asthma?*
- *Have you ever stopped taking your medication so you wouldn't be teased?*
- *Who is responsible for your remembering to take your medications?*
- *Does your asthma cause problems in how you get along with your parents?*

mote adherence. A sample list of screening questions for both children/parents and adults with asthma is listed in Table 20.2. However, when assessing adherence, the practitioner should be aware that relying on clinical interviews alone may lead to an overestimation of adherence. Therefore, it is strongly recommended that clinicians also adopt measures with better validity, either self-report questionnaires and/or objective indicators, to support self- or parent report. Assessment should also include identification of risk factors for maladaptive behaviors, particularly smoking. Research has demonstrated that individuals with asthma with depression, anxiety, poor quality of life, noncompliance, and peers who smoke are at increased risk for tobacco use [69, 70].

Finally, practitioners working in pulmonary clinics may support physicians' communication of treatment plans to patients and families. Specifically, they should encourage the communication of individualized action plans (preferably orally, as well as in writing). When providing written asthma plans, it is critical that clinicians consider the reading level of the patient/caregiver. Some adults from socioeconomically disadvantaged backgrounds or those with cognitive delays may not be able to comprehend written action plans. In such cases, pictures should be used instead to indicate treatment plans [71].

## Chronic Obstructive Pulmonary Disease

### *Disease Pathophysiology and Medical Treatment*

COPD is a heterogeneous group of preventable and irreversible diseases, which includes emphysema, bronchitis, and chronic obstructive airway disease, which often occurs after prolonged exposure to cigarette smoke or other environmental toxins [72]. Like asthma, COPD is an inflammatory disease that restricts the amount of expiratory airflow; however, COPD is progressive in nature, whereas asthma has an episodic course. Severe asthma and COPD have similar effects on the lungs that make it difficult to distinguish between the diseases when a patient presents in a medical setting, though the causes and medical treatment of these diseases are generally quite different. COPD is characterized by exacerbations that typically occur one to four times per year [73] and may be triggered by exposure to illness (e.g., influenza) and air pollution. As an individual's COPD progresses, increases in shortness of breath, coughing, sputum production, and fatigue are expected, as well as increases in the frequency and severity of exacerbations, with subsequent decreases expected in the individual's exercise capacity and overall HRQOL [73].

Prevalence of COPD among the general population of US adults is approximately 4%, with higher rates in females (5.4%) than males (2.8%) [74]. Estimates indicate that in 2005, COPD was responsible for approximately 64.3 deaths per 100,000 people in the population aged 25 and above [75]. With advances in medical care, average life expectancy for individuals with COPD is increasing [76]; however, the number of COPD-related hospitalizations is also on the rise [77], as is number of COPD-related deaths, particularly among women [78]. Although history of smoking is a risk factor for COPD-related death, approximately 16% of individuals who die from COPD do not have a history of smoking [79].

Diagnostic recommendations for COPD dictate that, among patients at least 40 years of age, symptoms that warrant assessment for COPD include dyspnea (i.e., shortness of breath), chronic cough, chronic sputum production, and exposure to tobacco smoke or other hazards (e.g., chemicals) [80]. According to the Global Initiative for Chronic Obstructive Lung Disease (GOLD) [80], there are four levels of severity in COPD: mild, moderate, severe, and very severe. These levels are based on the spirometry reading for the patient. Specifically, the criteria are based on the ratio of FEV<sub>1</sub> to FVC. FEV<sub>1</sub> to FVC ratios will be lower for individuals with obstructive diseases such as COPD (i.e., less than 0.7) than for healthy individuals, due to COPD's effect on limiting expiratory airflow.

Among individuals already symptomatic with COPD, prevention of exacerbations involves immunizations for infectious diseases (e.g., influenza) [81], regular doctor visits, adherence to the treatment regimen, keeping the air clean, exercising regularly, and maintaining a healthy diet [82]. Additionally, guidelines for medical management of COPD vary depending on severity and presenting symptoms, but may include medication (e.g., bronchodilators, inhaled glucocorticosteroids), respiratory therapy, and, in severe cases, surgery (e.g., lung volume reduction, lung

transplantation) [80, 83]. Other interventions for managing symptoms of COPD include pulmonary rehabilitation (PR), endurance exercise therapy [84], and nutritional supplementation therapy (i.e., for patients with weight loss and muscle atrophy [85]; for a comprehensive review of COPD treatment, see GOLD) [83].

### ***Common Psychosocial Issues***

**Psychosocial Functioning.** The progressive and irreversible nature of COPD, frequent exacerbations and hospitalizations, treatment burden, and its corresponding effect on activities of daily living can cause significant distress among patients. Clinicians therefore need to be knowledgeable about associated psychosocial difficulties. Among individuals with COPD, prevalence of depression is as high as 40%, higher than observed among patients with other chronic illnesses (e.g., diabetes, cancer) [86]. Kunik et al. [87] found the prevalence of anxiety disorders among individuals with COPD to be 51%, with a 26% prevalence rate of comorbid anxiety and depression among these individuals [87]. It is important to understand that some of the pharmacological treatments for COPD (i.e., bronchodilators) can result in symptoms that mimic psychological symptoms. Specifically, these medications can result in increases in anxiety and changes in mood and sleep [88]. Therefore, it is important to obtain a history of medication use in relation to the onset of psychological symptoms when considering treating depression and anxiety in a patient with COPD. Depression more likely accounts for symptoms such as sadness and suicidal ideation, whereas COPD is more likely the cause of changes in sleep, weight, and exercise tolerance [88]. Comorbid COPD and depression is associated with decreased quality of life, reduced time spent outdoors, and increased mortality (even when differences in severity are not present) [89, 90]. Similarly, comorbid COPD and anxiety is associated with decreased quality of life [91] and increased hospitalizations [92].

**Social Support, Coping, and HRQOL.** Due to stigma of COPD symptoms and treatment (e.g., coughing, oxygen use) and physical limitations of COPD that prevent involvement in daily activities (e.g., going to work), individuals with COPD are at risk of social isolation. Individuals with progressing disease symptoms will miss work frequently or will not be able to work, losing another potential source of social support (e.g., coworkers) and leading to more social isolation [93]. Additionally, patients with COPD tend not to use coping styles that are associated with seeking social support [94] and may adopt other coping styles, such as rational or problem-focused coping, which has been associated with a poorer HRQOL [95]. In comparison to adults without COPD, adults with COPD report twice as many physical and/or mental “unhealthy” days that restricted performance of activities of daily living [96]. As COPD symptoms progress and hospitalizations become more frequent and lengthy [97], quality of life decreases because symptoms often lead to deficits in self-care, mobility, and social activities [93].

**End-of-Life Issues.** As COPD symptoms worsen, it is important for health care providers to have honest discussions with patients regarding end-of-life issues, such

as patients' beliefs and values about what treatment they desire up until the time of their death. For example, where does the patient want to die? Does the patient want to receive mechanical ventilation? Despite the importance of having answers to these questions, such conversations do not occur regularly. In one study [98], approximately 67% of COPD patients reported that they wanted to discuss end-of-life issues with their physicians; however, less than 15% of those patients reported actually having this discussion. When individuals engaged in end-of-life discussions with their physicians, they reported better quality of and satisfaction with their care [98]. Knowing the benefit of these discussions, it is important to examine the reasons why they occur or do not occur.

Noted physician-related barriers to end-of-life discussions include: (1) belief there is not enough time during an appointment to discuss these issues, (2) concern that it will decrease the patient's hope, and (3) belief the patient is not ready to discuss these issues [99]. End-of-life discussions can also be affected by patient characteristics. Noted patient barriers include: (1) desire to focus on life, (2) confusion over which physician will care for the patient in the end, and (3) difficulty choosing treatment options for end of life. Alternatively, noted patient catalysts include: (1) knowing individuals who have died, (2) trust in the physician, and (3) satisfaction with the physician's disease management [99]. In sum, end-of-life discussions allow patients to make informed decisions about their future treatment while they are still able to communicate. Physician- and patient-related barriers to end-of-life discussions should be identified and addressed on an individual basis.

**Adherence.** COPD is a progressive disease that requires an extensive treatment regimen and is associated with comorbid psychological issues. Not surprisingly, treatment adherence rates in COPD patients are typically poor [100, 101] and are associated with more frequent hospitalizations and worse clinical outcomes [102]. Because COPD is a symptomatic disease, adherence may vary as a function of symptom severity. For example, patients with COPD who demonstrate poor adherence report increased confusion regarding their complex medical regimens and base their treatment decisions on how they feel and on their lifestyles [103]. In contrast, high levels of patient self-efficacy and strong patient beliefs in the effectiveness of medications to manage symptoms are significantly associated with better adherence [104]. Moreover, individuals with COPD with a caregiver (often a source of social support) have higher levels of adherence with antihypertensive medication use, long-acting  $\beta_2$ -agonist use, and smoking cessation [105].

### *Evidence-Based Assessment of Psychosocial Concerns*

To provide optimal care, clinicians should monitor for psychosocial difficulties that may further complicate symptom presentation and treatment in COPD. Important areas to assess are psychosocial functioning (especially anxiety and depression, given its high rate of comorbidity with COPD), HRQOL, and adherence. There are numerous assessment tools available for use with the general population, which also

have been used successfully in studies with patients with COPD. These measures have been summarized in Table 20.1. A few measures have been specifically validated with COPD patients and are summarized below.

**Psychosocial Functioning.** Because COPD and anxiety have overlapping symptoms (e.g., breathlessness, increased heart rate, catastrophic thinking) [106], it is helpful to assess for anxiety in the context of COPD. One anxiety measure specifically used with COPD patients is the *Interpretation of Breathing Problems Questionnaire* (IBPQ) [107]. This measure was developed with patients in the UK and assesses for the presence and strength of catastrophic thoughts related to COPD symptoms using 14 scenarios depicting the occurrence of symptoms in either a safe or unsafe setting. Respondents read the scenarios and indicate cognitive and behavioral responses, as well as an anxiety rating, for each one. This measure has high inter-rater reliability, internal consistency, and moderate test-retest reliability. A short form of the measure also is available (IBPQ-S); it uses 8 scenarios in the same manner as the 14 scenarios on the IBPQ, and offers the advantage of reduced administration and scoring time.

Another important psychological aspect to assess is family functioning. Because COPD frequently is caused by a history of prolonged cigarette smoking, individuals may perceive that their support systems blame them for acquiring COPD. One measure that assesses family functioning is the perceived criticism (PC) subscale of the *Family Emotional Involvement and Criticism Scale* (FEICS) [108]. High scores on this indicate unsupportive family relationships and can be utilized as a rationale for including the COPD patient's family in treatment. Reliability and validity for the PC subscale of the FEICS are adequate among patients in a medical center (not specifically those with COPD) [109].

**Adherence.** Similar to asthma, assessment of adherence among patients with COPD can be completed with multiple methodologies, including clinical interviews, rating scales, and more objective measures (e.g., electronic monitoring) of adherence. Also, similar to asthma, self-report measures of adherence show higher rates of adherence in patients with COPD than other forms of adherence measurement, such as inhaler weights [110] and electronic monitoring [111], suggesting that self-report measures should not be used as the only measure of adherence. Although electronic monitoring is the gold standard measure of adherence, it can only reveal non-adherence, but not the cause of it (e.g., intentional vs. unintentional) [112]. Drawbacks to electronic monitoring are cost [112] and susceptibility to deception via medication dumping [111].

Other measures of adherence assessment each have their strengths and weaknesses. For instance, clinical interviews [100] allow for discovery of reasons for non-adherence, but also are time consuming and subject to patient deception, thereby requiring training to be adept at obtaining honest responses [112]. Pharmacy refill data is another method for measuring adherence [113]; however, it is possible for patients to refill their prescriptions without taking their medication [112]. Finally, biological measures of adherence, such as plasma levels [114], are objective but can be influenced by drug interactions and can be invasive for the patient [112].

In sum, it is recommended to use multiple methods of adherence assessment while considering each option's advantages and disadvantages [112].

**Cognitive Functioning.** Considering that COPD is more prevalent among individuals from older age groups, it is important to assess patients' cognitive functioning as a possible barrier to treatment adherence. Screening tools to detect cognitive deficits that may affect care may be helpful to identify individuals who should receive further assessment. One measure that screens cognitive functioning has several versions available: the 30-item *Mini Mental State Exam-2: Standard Version* (MMSE-2: SV) and the 16-item *Mini Mental State Exam-2: Brief Version* (MMSE-2: BV) [115]. The MMSE-2 can be used for individuals from 18 to 100 years of age and the second edition has been broadened to include assessment for mild forms of cognitive impairment. Administration time is approximately 10–15 min for the MMSE-2 and 5 min for the MMSE-2: BV. The MMSE-2 (standard and brief versions) assesses registration (i.e., repeating named prompts), orientation to time and place, and memory recall tasks and has been used in both research and clinical settings. The psychometric properties across the various versions of the MMSE are strong [115].

The *Short Portable Mental Status Questionnaire* (SPMSQ) [116] is another brief (i.e., ten items) and easy-to-administer (i.e., no testing stimuli) tool for elderly patients [117] and has been used with COPD patients to assess for mild cognitive impairment [118]. This SPMSQ has acceptable psychometric properties [116]. Both of these measures (i.e., MMSE, SPMSQ) can be utilized in primary care and emergency care settings by any clinician, as they do not require specialized training in psychological assessment.

### ***Evidence-Based Interventions for Psychosocial Concerns***

**Psychosocial Functioning.** Psychological difficulties (i.e., depression, anxiety) and COPD negatively impact each other and both need to be addressed in treatment. There are pharmacological and psychological options to treat symptoms of depression and anxiety among patients with COPD. However, elderly individuals using pharmacological interventions should begin at a low dose and have their medication usage monitored closely. This is due to the increased risk of complications associated with the multiple health problems commonly experienced by this age group [87].

Antidepressants are sometimes used when major depression is present [119]; however, it has been reported that health care providers underutilize antidepressants [87], possibly as a result of a belief that depression is inevitable in patients with COPD [120], in part due to decreased quality of life [89]. On the other hand, more research is needed on the effects of antidepressants in patients with COPD and comorbid depression [88]. Selective serotonin reuptake inhibitors (SSRIs) have been shown to result in decreases in symptoms of both depression and anxiety in patients with COPD [121]. Tricyclic antidepressants are sometimes used with this

population, but the negative side effects of these medications have led to their use only after other medications have been shown to be ineffective [120]. As another example, it has been found that benzodiazepines decrease lung functioning, making it an undesirable treatment for anxiety in individuals with COPD [122]. It is important to note that approximately 50% of individuals with COPD do not adhere to their psychotropic medication regimen, either taking less or more medication than prescribed [88]. Adherence is particularly important to monitor, as having COPD and depression increases the risk for suicide, especially among older adults [88].

Psychological interventions are recommended for use with patients with COPD who have minimal to moderate levels of psychological distress [50]. However, research on the efficacy of interventions has produced mixed findings. In particular, Coventry and Gellatly [123] conducted a systematic review of CBT for mild to moderate anxiety and depression in patients with COPD. They defined CBT as “psychological treatments that attempted to modify patients’ negative thoughts and beliefs about symptoms (e.g., breathlessness and panic) and illness (e.g., irreversibility), and attempted to modify patients’ behavioral responses to symptoms and illness, such as through the use of breathing exercises and relaxation techniques” (p. 384). They concluded that one small RCT of moderate quality resulted in significantly reduced anxiety and depression, while a larger and higher-quality RCT resulted only in significantly reduced depression, and all remaining RCTs did not report significant reductions in either anxiety or depression [123]. Therefore, it is unclear to what extent CBT is efficacious in reducing these psychological concerns in patients with COPD.

An alternative to the time- and resource-intensive CBT is the five-phase minimal psychological intervention (MPI) [124]. MPI includes components of CBT (e.g., explore feelings, thoughts, and behaviors) and self-management (e.g., develop a plan to alter behavior and monitor progress) and can be implemented by a trained nurse [125]. The phases occur over ten or fewer sessions and begin with the interventionist assessing for patient thoughts on the causes of their symptoms and how those thoughts are associated with their behavior and limitations. The patients then monitor and record their symptoms, thoughts, worries, and behaviors so that the interventionist can assist the patients with associating their thoughts, moods, and behaviors to the course of their chronic illness. The interventionist then encourages patients to consider methods of changing their behavior, problem solving, and goal setting. In the final phase, the interventionist assesses patients’ progress in reaching their goals [125]. Through an RCT, this intervention has led to significant decreases in symptoms of anxiety and depression and improvements in HRQOL in older adults with COPD [125]. Given that this approach was designed for use in clinics (e.g., narrower focus, fewer sessions, nurses as interventionists) and it demonstrates efficacy, this intervention seems to have great promise for addressing psychosocial concerns.

Another intervention that may be beneficial in managing symptoms of anxiety and depression among individuals with COPD is physical rehabilitation (PR) [126]. PR is a multidisciplinary, comprehensive intervention for patients with respiratory difficulties that aims to reduce physical symptoms, obtain optimal functional status,

and reduce health care costs [127]. The program involves training in exercise and nutrition, as well as using biofeedback and stress management techniques [127]. Biofeedback techniques may involve practicing physical activities, such as walking, while receiving indicators of pulmonary functioning (e.g., oximetry feedback, heart rate variability) [128]. Although PR is not solely a psychological intervention, it involves multiple components of psychosocial interventions (e.g., relaxation) and a review of the literature shows that it is effective in improving certain areas of quality of life (e.g., dyspnea, fatigue, emotional functioning) [129].

**Adherence.** A few recent studies report the development of interventions aimed at promoting regimen adherence in patients with COPD. One intervention, the adherence-enhancement approach (AEA), involves a problem-solving therapy (PST) component for patients with COPD and depression [130]. This intervention examines barriers to adherence, provides education on how to reduce these barriers and increase adherence to both COPD treatment and antidepressant medication, reduces symptoms of depression, and teaches problem solving to address issues. AEA involves ten weekly sessions delivered in the medical or home setting, followed by four monthly sessions to reinforce skills and behaviors discussed in previous sessions. Another intervention addresses motivational aspects (e.g., beliefs, behavior), cognitive components (e.g., disease information), and skills (e.g., inhaler technique) relevant to adherence in patients with COPD [131]. Though these interventions incorporate techniques that have proven successful in improving adherence with other chronically ill populations, their efficacy has not yet been reported.

**Patient Education.** A recent RCT compared CBT to COPD education [51]. Participants in the education group reviewed the following topics: description of the disease, rationale for the use for oxygen, exacerbation prevention tips, methods to stop smoking, treatment options, and planning for end-of-life issues. Both groups led to improvements in quality of life and mental health symptoms (i.e., anxiety, depression), which were maintained through 1-year follow-up. These authors also suggested that psychoeducation on anxiety and depression is beneficial, as these are highly comorbid conditions with COPD and providing this information may increase patient self-efficacy [51]. In general, it appears that a thorough, accurate psychoeducation of both COPD and psychological symptoms is associated with positive patient outcomes.

### ***Critical Review of the Current State of Evidence-Based Practice***

One of the major issues with research on anxiety and depression in COPD patients is the sparse information on validity of specific measures with this population. For example, the *Panic Attack Questionnaire* [132] has been revised for use in individuals with respiratory problems and is commonly reported throughout the literature, but information on its validity with this population is lacking [133]. Additionally, some generic measures of depression and anxiety contain items related to COPD



symptoms [134]. Therefore, the overlapping constructs could make it difficult to determine which symptoms result from COPD and which result from psychological issues. Future research needs to examine the validity of measures of anxiety and depression specifically for use with COPD patients.

Multiple methodological issues exist in the literature examining the assessment and treatment of depression and anxiety in patients with COPD. A recent meta-analysis revealed the limited research on efficacious psychological treatments for depression, anxiety, and quality of life in COPD patients and noted the following limitations of previous research including a lack of: (a) randomization, (b) statistical control for interventionists who were not blind to the study purpose, (c) statistical analysis for differences between groups as a result of attrition, (d) a priori power analyses, and (e) effect sizes reported [134]. Additional limitations are the use of small sample sizes [135], insufficient follow-up, reliance on self-report measures to detect reduction in depression and anxiety [136], and lack of direct comparison of treatments. Future studies with larger sample sizes, random assignment, and comparison of interventions are needed. Additionally, the studies need long-term follow-up to determine whether effects are sustained, and subgroup analyses to determine individual factors that may predict response to treatment will be important. It also was recommended that future studies should expand to include patients with minimal to moderate disease severity and should examine the overall cost effectiveness of psychosocial treatments [134]. Finally, given significant barriers in a standard clinic setting, such as availability of staff, billing issues, and logistical concerns (e.g., clinic space), research is needed to identify assessment and treatment approaches that are feasible and practical in this environment.

### ***In Practice Tips/Application***

Health psychologists working with patients having COPD are likely to encounter a multitude of psychosocial difficulties. Individuals with COPD are facing a progressive and irreversible disease that adversely affects activities of daily living and overall quality of life. COPD involves high medical treatment demands and is associated with difficulties for the individual and his/her family due to associated functional limitations (e.g., inability to work, restricted mobility). Anxiety and depression are common psychosocial reactions to this disease. Thus, practitioners need to screen for psychosocial comorbidities, as well as be able to differentiate between physical symptoms of COPD and symptoms of psychosocial distress. Ongoing follow-up assessment for individuals with COPD is a critical aspect of their overall care, as psychosocial difficulties affect symptom presentation and disease course. Interventions to treat symptoms of depression and anxiety are CBT and MPI [124].

Given the demandingness of the COPD medical regimen and comorbid psychological concerns, it is likely that treatment adherence issues will arise with patients. For medical regimen adherence, it is important to comprehensively address a patient's individual beliefs and experiences related to COPD and associated

**Table 20.3** Areas of functioning to evaluate when working with patients with chronic obstructive pulmonary disease (COPD)

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**Psychosocial Functioning**

- *On a scale of 1 (very low) to 10 (very high), what has your average mood been like over the past week?*
- *What aspects of your COPD and its care seem to contribute to this rating?*
- *When you are feeling down, what are the things you do to make yourself feel better?*
- *Are there times when you feel worried or anxious?*
- *Have you had any changes in your sleep, such as feeling overly tired or not being able to fall or stay asleep?*
- *Tell me about the people who provide support to you and how they help you.*

**Quality of Life**

- *Are you working?*
- *In what ways does COPD affect your ability to do your job?*
- *In what ways does COPD affect your ability to carry out activities around the house or activities you enjoy?*
- *In what ways does your COPD affect your relationships?*
- *What activities do you do for fun or enjoyment? How often do you do them?*
- *Does your COPD interfere with your doing these activities?*

**Adherence**

- *What does your treatment routine involve?*
  - *Everyone has problems remembering their medication at times. In an average week, how many days do you miss one or more doses of your medication?*
  - *What are the things that make it most difficult to carry out your treatments on a daily basis?*
  - *What strategies do you use to remember to take your medications?*
  - *Does anyone help you with your treatments?*
  - *Do you ever avoid some parts of your treatment because you don't think they're helpful?*
  - *Do you ever avoid some parts of your treatment because it costs too much money?*
- 

treatments, build rapport with the patient, listen to all of the patient's questions and concerns, and engage in joint goal setting to tailor the patient's regimen to the disease stage and to accommodate the patient's particular life circumstances. Collaborative problem solving between physicians and patients to resolve barriers to adherence also is likely to increase adherence rates. It is likely that exerting extra effort with patients who are not regular appointment attendees by calling the patient and including the patient's family members in the treatment will improve attendance [137]. Specific to psychological regimens, it has been determined that approximately 50% of patients who are referred out of their primary care physician's office to mental health treatment do not go. It was noted that some patients preferred to address their mental health functioning in their primary care setting [138]. Therefore, when feasible, it is important to include a mental health professional in the patient's usual care to improve adherence to psychological treatment. The clinician is referred to Table 20.3 for a sample list of questions to include in a clinical interview with patients with COPD.

As noted previously, there are certain predictors of disengagement in psychological treatment among patients with COPD and research has resulted in several suggestions. For example, one recommendation was to describe mental health in terms

of “behavioral medicine” to clients to reduce the stigma associated with psychological services. Similarly, clinicians can frame the patient’s psychological symptoms in terms of how they might be expected or normative for someone with COPD [120]. Another recommendation was to frame the psychological symptoms in terms of the patient’s quality of life and how the symptoms relate to their COPD symptoms [91]. In addition to improving treatment adherence, it is also likely that including the client in treatment decisions (e.g., choice of treatment method) and eliminating barriers to treatment would promote engagement in psychological treatment.

Finally, it is essential to discuss and plan for end-of-life issues with COPD patients. Many of the COPD patients in one study reported that they were not informed that they could die from their disease, but the patients who reported that they were knowledgeable of their disease-related mortality reported that discussing the process of dying and planning for end of life was particularly important to them [139]. Yet, medical staff often struggle in having these particular conversations with their patients [120, 140]. Nonetheless, accuracy and clarity is important when discussing end-of-life issues with COPD patients to minimize confusion on the part of the patient. In terms of preparing a patient in the late stage of COPD, it has been suggested that health care providers visit the patient at home, discuss the patient’s preferences on treatment, and possibly even put the patient’s preferences in writing, so the patient can point to a decision if he suddenly becomes unable to communicate verbally [141].

## Cystic Fibrosis

### *Disease Pathophysiology and Medical Treatment*

Cystic fibrosis (CF) is a congenital and life-limiting condition caused by a recessive gene that affects the lungs and digestive system (for a comprehensive review, see Stark, Mackner, Patton, and Acton [142]). The genetic variation disrupts normal transport of sodium and chloride across cell membranes, resulting in the production of thick, sticky mucus that clog the lungs and obstruct pancreatic activity to produce enzymes. In the lungs, the mucus interferes with pulmonary functioning and significantly increases risk for bacterial growth and infection, which ultimately leads to the formation of scar tissue in the lungs. Impaired pancreatic production of enzymes that are essential for the digestion and absorption of nutrients leads to difficulty gaining and maintaining a healthy weight, particularly in adolescence and adulthood, and other digestive concerns (e.g., bowel obstruction; large, greasy stools).

Identification of individuals with CF has significantly improved and as a result of newborn screening for symptoms, early detection of CF has skyrocketed, with now 55% of patients diagnosed as newborns (up from 15% in 2004) [143]. Nearly 70% of patients with CF are diagnosed prior to the age of 2 years. The Cystic Fibrosis Foundation has set forth guidelines for promoting newborn screening and early intervention, as early treatment is associated with better weight and healthier lungs

later in life [144]. If a child has a positive screen for symptoms of CF, a sweat test (the gold standard in CF assessment) is typically conducted, which involves attaching a small electrode into the skin to stimulate sweat glands. Sweat is then tested for amount of chloride (increased levels indicate CF). Alternatively, genetic testing may also occur if the results of the sweat test are inconclusive.

Early identification and intervention and advances in treatment approaches have significantly improved both quality and length of life among individuals living with CF. Prognosis of individuals with CF has drastically improved over the past several decades. In the 1950s, children diagnosed with CF were not expected to live beyond school age; in contrast, the median life expectancy in the late 1980s was the mid-20's; and in 2010, the median predicted life expectancy was 38.3 years [143]. Current epidemiological estimates indicate that CF is present in approximately 70,000 individuals worldwide and in 1 in 3,000 births [143]. In 2011, the vast majority of individuals in the CF Foundation Patient Registry were Caucasian (94.3%), with roughly equal proportions of males and females [145].

There is no cure for CF; thus, treatment focuses on promoting nutrient absorption and reducing the thick mucus in the lungs to decrease risk for infection and decline in pulmonary functioning. Treatment protocols vary depending on the individual, but typically involve multiple elements. For a comprehensive overview of care guidelines, see the Cystic Fibrosis Foundation *CF Care Guidelines* [146]. Treatment may include ingestion of pancreatic enzymes during times of food intake to promote breakdown of food and nutrient absorption. Even with enzymes, individuals with CF typically also need to increase their caloric intake in contrast to typically developing individuals. Additionally, some require supplemental feeding via tube. Airway clearance therapy (e.g., vest; rhythmic clapping on the patient's back or chest physiotherapy (CPT); flutter device) is used multiple times per day to expel the thick, sticky mucus from the lungs. It is recommended that airway clearance therapy be coupled with exercise to promote further expulsion of mucus from the lungs [147]. Additionally, to improve breathing quality and treat frequent pulmonary infections, oral and/or nebulized antibiotics are administered. Because the effects of scar tissue buildup in the lungs are cumulative, many individuals with CF eventually require lung transplants.

Depending on severity of the disease, engagement in the various aspects of treatment may range from approximately 30 min to 5 h per day. The majority of treatments, such as airway clearance, nebulized medications, and oral medication and enzyme intake, can be completed in the home. There exists debate regarding whether more intensive delivery of intravenous antibiotics to treat infections also should be completed in the home setting or whether it should occur in the hospital. On one side, arguments are made regarding equivalent effectiveness of home-based versus hospital-based treatment, whereas others argue that at-home administration dangerously "normalizes" CF and may lead to lower quality of care over time [148].

Patients with CF are followed closely by pulmonologists, usually at quarterly visits. During visits, typical laboratory tests include sputum cultures to assess for the presence of bacteria and infection and pulmonary function tests (PFTs) to

measure pulmonary functioning. Body weight, or body mass index (BMI), is another objective indicator physical well-being.

### ***Common Psychosocial Issues***

**Psychosocial Functioning.** CF is a lifelong condition and therefore the psychosocial difficulties that may be related to the condition vary across the life span. For a comprehensive review of the developmental course of psychosocial difficulties across the life span and their association with various disease milestones, see the review paper by Ernst and colleagues [149]. Whereas various psychosocial challenges, which will be described in the ensuing paragraphs, present themselves to some individuals with CF, generally, individuals diagnosed with CF display remarkable resiliency. Many research studies have indicated that neither youth nor adults with CF exhibit increased rates of psychopathology diagnoses, such as depression or anxiety, in comparison to the general population [150–154]. However, other sources, such as the 2011 CF Patient Registry Report [145], indicate that 11.8% of the patients registered experience depression, a 5.7% increase since 2001. It is possible that individuals with CF do experience increased rates of depressive symptoms that fall within the subclinical range for a formal diagnosis, which may explain discrepancies in research findings. Consistent with this, elevated depressive symptoms that fall below cutoffs for depression have been reported in the research literature [155, 156]. Regardless of whether an increased risk exists, the presence of psychopathology, especially depression and/or oppositional behaviors, is of significant clinical concern because they can affect quality of life and adherence to treatment regimen [155].

**Health-Related Quality of Life.** Another area of clinical concern among individuals with CF is HRQOL. Individuals with CF are more likely to report decreased quality of life related to emotional functioning and other aspects of daily life (vitality, treatment burden, physical symptoms, and health perceptions) in comparison to individuals without CF [152]. Decreased quality of life is more likely to be present among patients with negative illness perceptions [157]. Social concerns also have been noted, particularly related to stigmatizing aspects of the disease, such as the severe and often phlegmy coughing, clubbing of the fingers and toes, and increased flatulence. Predictably, those who do experience symptoms of depression also endorse lower quality of life [152]. Although perceived quality of life may be lower among some individuals with CF, limitation of life activities is variable. In the 2011 CF Registry, approximately 67% of adults over the age of 18 reported their education as “some college” or beyond [145]. However, 15.9% of adults with CF indicated unemployment due to disability [145].

**Nutritional Intake.** As mentioned in the previous section, CF often interferes with proper nutrient absorption, making weight gain and maintenance challenging for patients. According to the 2011 CF Patient Registry Report, the goal BMI for indi-

viduals with CF is the 50th percentile, similar to individuals without chronic health conditions, as BMI is associated with lung functioning (FEV<sub>1</sub> values) [145] and survival [158]. A systematic review of research on nutritional intake among individuals with CF concluded that higher energy intake results in weight gain and led to the guidelines that state children aged 2 years and above and adults with CF should intake approximately 110–200% of the energy needs for individuals of similar age, size, and sex without CF [158]. Furthermore, the guidelines indicated that research evidence indicates that behavioral interventions coupled with nutritional counseling should be implemented in children aged 1–12 years with CF who exhibit growth deficits [158].

**Adherence.** Due to the significant demands of treatment regimen, adherence is a common behavioral health issue among the CF population. Problems with adherence have been described across different aspects of treatment, including airway clearance, oral medications (e.g., enzymes, antibiotics), nebulized medications, and attending regular clinic appointments, but is more pervasive for certain aspects of treatment versus others. Specifically, airway clearance is an aspect of treatment associated with significant adherence difficulties, possibly because it requires substantial daily time commitment [159]. In a multisite longitudinal study with patients ranging in age from 7 to 44 years, moderate non-adherence was present in nearly half the patients, with the average amount of time engaging in airway clearance only 36–58% of the prescribed treatment time [159]. Among a large sample of adults, less than 30% reported engaging in airway clearance even once per day [160].

Barriers to adherence may vary according to the patient's developmental level. Young children may exhibit disruptive or oppositional behaviors that preclude adherence to treatment regimen. Older children and adolescents often attempt to assert their independence by shaking off parental oversight of medical activities. Unfortunately, the drawback to the desire for the decreased supervision is associated problems with adherence [161]. Finally, in adulthood, adherence also can be problematic as patients struggle to balance rigorous treatment regimen demands with occupational, domestic, and social responsibilities [160].

**Transitioning Care.** Finally, additional psychosocial concerns may emerge in adolescence and adulthood. These include issues such as transitioning care, promoting independence, family planning, and end-of-life concerns [162]. Transitioning responsibility of care from the pediatric to adult pulmonary teams typically occurs in late adolescence or early adulthood [163]. This has been more challenging than with other medical conditions, as adult practitioners often do not have the level of training and experience of working with CF as do pediatric pulmonologists due to the more recent extended life span of patients with CF. In response to this physician shortage, the Cystic Fibrosis Foundation has focused on preparing a new generation of physicians for care of adults with CF by creating clinical fellowships and mandating the development of clinical programs for adults at CF centers across the USA [164].

**Fertility.** Another psychosocial concern that emerges in adulthood is family planning. CF often results in infertility, especially in males (for a thorough explanation, see the review paper by Rutherford [165]). However, with recent advances in fertility treatment, males are able to produce viable embryos in vitro [166]. In

individuals with childbearing capacity, additional stress may be elevated due to decisions regarding whether to conceive, as individuals with CF will pass the recessive gene on to their child, guaranteeing their child to be either a carrier of CF or possibly inherit the condition if the other parent also is a carrier. Moreover, family planning is complicated as females with CF must be aware of potential health risks to themselves, as well as possible teratogenic effects of medications on the fetus. Despite multiple aspects that contribute to difficulty in fertility and family planning decisions, patients often report feeling unknowledgeable [167] or exhibit knowledge deficits [168, 169] about the disease-specific aspects of fertility and family planning and state their desire for discussions related to reproductive health to be approached sooner by their health care providers [167, 170].

### ***Evidence-Based Assessment of Psychosocial Concerns***

**Psychosocial Functioning.** Although individuals with CF are not shown to be at increased risk for depression diagnosis, screening for depressive symptoms and other symptoms of psychopathology, such as anxiety and disruptive behavior disorders, is important due to possibly elevated, yet subclinical symptoms of depression [156] and associations with adherence to treatment and quality of life [152]. When assessing for depressive symptoms, it is imperative that clinicians differentiate physical symptoms due to low oxygen intake and difficulty with nutrient absorption from actual depressive symptoms. For example, a patient may present with decreased energy, weight loss, increased fatigue, feeling slowed down, and difficulties concentrating, which are all symptoms of depression but also could be complications stemming from physiological aspects of CF [171]. No disease-specific measures for depression or anxiety were identified for patients with CF, so clinicians are encouraged to adopt measures that assess for cognitive and behavioral (rather than physical) symptoms due to overlap among symptoms of anxiety and depression and symptoms of CF. One such questionnaire is the Hospital Depression and Anxiety Scale (HADS) [172], a brief, 14-item measure of cognitive symptoms of depression and anxiety for use with patients with chronic health conditions. The HADS has been used in previous research involving screening for depression and anxiety among adolescents and young adults with CF [156].

**Health-Related Quality of Life.** Quality of life in youth and adults with CF has been assessed using rating scales based on patient or caregiver report. Disease-specific instruments for measuring HRQOL in youth with CF are the *Cystic Fibrosis Quality of Life Scale—Revised* (CFR; previously the *Cystic Fibrosis Questionnaire*) [173]. The child-report and caregiver-report versions of the measure assess general HRQOL (physical symptoms, social functioning, emotional functioning) as well as CF-specific domains (body image, eating disturbances, treatment burden, respiratory symptoms, digestive symptoms) and the adult version measures four general domains (physical symptoms, emotional functioning, vitality, school functioning) and seven CF-specific domains (the five included in the child version, as well as

weight and overall health perception). Agreement between parent and child report on the seven overlapping domains is *moderate* for respiratory and digestive symptoms and body image, *strong* for eating disturbances, and *poor* for ratings of physical symptoms, emotional functioning, and treatment burden [174]. Disagreements among parents and youth in reports of HRQOL underscore the importance of gathering information from multiple sources/raters [174].

**Eating Habits.** As previously mentioned, the *CF Care Guidelines* indicate that behavioral intervention should be implemented for children who are below weight expectations [158]. To identify behaviors to target with intervention, it is critical to complete an assessment of mealtime behaviors. Although direct, systematic observation for mealtimes by a clinician would certainly yield valid information regarding mealtime behaviors, the clinical utility of such an approach is low due to the significant time and resources involved. Instead, parent report of eating behaviors is recommended in clinical settings. The *Behavior Pediatric Feeding Assessment Scale* (BFPAS) [175] is a 35-item, parent-report scale that assess children's mealtime behaviors, as well as parental attitudes and strategies for managing mealtime. The BFPAS has been shown to correlate with direct, systematic clinician observations of mealtime on length of the meal ( $r=0.53$ ), child delaying a meal by talking ( $r=0.55$ ), child leaving the table ( $r=0.58$ ), child negotiating ( $r=0.46$ ), parent feeding the child ( $r=0.65$ ), and parent commanding/coaxing the child to eat ( $r=0.46$ ) [176].

**Adherence.** Several methodologies exist for assessing adherence to prescribed treatment regimen, including rating scales, daily diaries, prescription refill records, and electronic monitoring. For a review of evidence-based assessment of adherence, including individuals with CF, see Quittner and colleagues [177]. Rating scales and/or patient/caregiver interviews of adherence assess adherence behaviors and knowledge of treatment regimen. When gathering subjective report of adherence, it is essential to assure respondents that experiencing barriers to adherence is normal and understandable to promote honesty in responding [178].

Daily diaries are another technique used to assess adherence. Daily diaries require that patients and/or caregivers monitor treatment activities; these data may be collected by clinicians daily via telephone or other electronic communication device, or during predetermined periods of time (e.g., every 2 weeks). Although relying on patient/caregiver recall and report, daily diaries maintained by patients and caregivers are more cost effective than electronic monitoring and have been demonstrated to have moderate to strong correlations with electronic monitoring devices [177]. However, they can be time consuming, especially if collected on a daily basis.

Finally, electronic monitoring devices are another tool for assessing adherence. This methodology is considered the most objective measure of adherence, but it is also subject to intended and accidental error, such as opening bottles and dumping medications without ingesting/inhaling as prescribed, turning on CPT vests without wearing them, or errors in properly using equipment. Due to discrepancies among raters of adherence and measurement approaches, it is always important to gather information from multiple sources and using multiple methodologies [179].



## ***Evidence-Based Interventions of Psychosocial Concerns***

**Psychosocial Functioning.** Individuals with CF may be at risk for experiencing symptoms of depression and/or anxiety, particularly in adolescence and beyond [156]. It is therefore imperative that clinicians be aware of potential treatment avenues for difficulties with psychosocial functioning. In a recent systematic Cochrane review of treatments for adolescents and adults with CF, research evidence supporting the use of various psychological treatment approaches was reviewed [180]. At the time, no high-quality CBT interventions using RCTs were found to evaluate their effectiveness among individuals with CF. However, several studies of behavioral interventions with cognitive components to treat eating behaviors (described below) were identified. Although more research is needed that is specific to patients with CBT, given the high response rates among other child and adolescent chronic illness populations to CBT [181], it is a recommended strategy for individuals with CF as well.

**Adherence.** As psychosocial concerns vary across the life span, so too does appropriateness of intervention strategies. For younger children, interventions based on family-centered, behavioral techniques targeting adherence to treatment regimens have promising research support. The interventions have been used to promote adherence to various aspects of treatment regimen, including caloric intake, engagement in exercise, and compliance with airway clearance. For example, using an ABAB design, a behavioral reinforcement approach (a token economy) was demonstrated to be effective to increasing exercise among three children with CF who were prescribed exercise as part of their treatment [182]. As part of the token economy, children received a small prize for engaging in a predetermined level of exercise and also earned a point for each 10 min of exercise that could be applied to a larger prize. All three children engaged in significantly more exercise, as measured by daily diaries of frequency and duration of exercise, during treatment phases than at baseline phases. These gains were maintained at 1 and 3-month follow-up. Another behavioral intervention study adopted single subject design methodology to demonstrate improvements in treatment compliance across treatment modalities (airway clearance, enzymes, medications) among two young children with oppositional behaviors related to treatment [183]. A negative punishment approach (time-out for noncompliance), coupled with differential reinforcement of alternative behavior (praising compliance), was adopted. Results indicated increase in compliance among one of the participants and a possible increase in the second (though time-out was never implemented with this child).

Behavioral interventions delivered in the hospital setting also have led to improvements in treatment compliance with airway clearance for adolescents with CF treated as inpatients [184]. CBTs may also be helpful for improving psychosocial and health outcomes for adolescents and adults with CF, though research on the effectiveness of such approaches are preliminary [185, 186].

**Eating Behaviors.** Behavioral approaches likewise are effective in promoting effective eating habits among children, as is recommended by the *CF Care Guidelines* [158]. A study using single subject design in an RCT examined effectiveness of

a combined nutritional counseling and behavioral intervention (i.e., praising appropriate mealtime behaviors and ignoring disruptive behaviors, parental limit setting, contingency management) at promoting adherence to prescribed caloric intake and pancreatic enzyme supplements among 14 children with CF [187]. Results clearly indicated significant increase in caloric intake at snacks and meals that were sustained at 3 months and 1 year.

### ***Critical Review of the State of Evidence-Based Care***

The lengthening life span and earlier detection of CF has expanded the diversity and presenting concerns of the identified patient population. Although evidence-based assessment and intervention strategies have been developed, there is significantly more research pertaining to children and adolescents with CF and less focusing older adolescents and adults [180]. Future research is needed to understand psychosocial concerns, develop assessment strategies, and implement interventions that are relevant for adolescents and adults with CF. This research also should involve use of validated measures of adherence and quality of life. Additional topics of exploration need to focus on adults with CF, particularly related to communication of fertility information [166, 167, 169, 170], as well as issues pertaining to transition of care [163]. Additionally, there exists a discrepancy among estimates of depressive symptoms and depressive diagnoses among individuals with CF [152, 156]. Research investigating this discrepancy is needed to determine whether elevated depressive symptoms are due to physiological/physical aspects of the disease (e.g., fatigue) or whether cognitive and behavioral symptoms are elevated as well.

Across all developmental levels, there is a strong need for RCTs to assess efficacy and effectiveness of interventions to address symptoms of depression and anxiety, particularly among adolescents and adults with CF [180]. This was called for nearly a decade ago in a 2003 Cochrane Review of psychological interventions for CF [188]. At the time this chapter was written, 78 intervention clinical trials were registered in the *clinicaltrials.gov* database that focused on either adherence or quality-of-life issues among individuals with CF. Approximately ten of these studies involved psychosocial interventions. Several strategies used with other chronic health populations, such as motivational interviewing, multisystemic therapy, and other family-based therapies, may have applications for clinicians working with patients with CF. These interventions should be one area of focus for further study. It will be particularly important to explore their applicability for promoting adherence and positive HRQOL in adolescents and adults.

### ***In-Practice Tips***

Clinicians working with patients with CF should be aware that psychosocial challenges may present themselves across the life span and therefore monitoring

psychosocial adjustment, quality of life, and barriers to adherence will be important at various developmental stages.

When assessing individuals with CF, several factors must be taken into account. First, when screening for psychosocial difficulties, such as depressive and anxiety symptoms, the clinician must be careful to distinguish physical symptoms from symptoms of a mental health condition. For example, increased fatigue, decreased appetite, and loss of interest in participating in activities may be associated with decreased pulmonary function or may be indicative of a depressive disorder. Therefore, it will be important for the clinician to attempt to identify cognitive symptoms of a mental health condition prior to making a diagnosis.

Additionally, assessment also should include a review of illness management behaviors. Treatment regimens may vary drastically across individuals and the clinician should take care to understand the unique demands of an individual's regimen and identify potential barriers and facilitators to adherence. To the extent possible, assessment of these issues should involve multiple informants and multiple methodologies.

Finally, as more research will be emerging (based on the registry of clinical trials of psychological/behavioral interventions for individuals with CF), clinicians will need to be careful consumers of knowledge to be aware of the newest evidence-based assessment and intervention strategies. This will be particularly true of research pertaining to adolescents and adults with CF, as the life expectancy of individuals with CF continues to increase and new challenges for care emerge.

## Conclusion

Chronic pulmonary disease is found in both pediatric and adult populations. Psychosocial concerns (e.g., regimen non-adherence, impaired HRQOL) and psychological disorders (e.g., depression, anxiety) are common to asthma, COPD, and CF. Both disease-specific and generic measures have been used to assess for psychological problems in youth and adults across disease groups. Interventions, particularly with a behavioral or cognitive-behavioral focus, have been successful in improving not only psychosocial difficulties but also other disease-related outcomes (e.g., health care utilization). Feasibility and practicality have been key obstacles in implementing routine screening, assessment, and intervention for psychosocial concerns in pulmonary patients given the fast-paced nature of clinic settings and limited resources (e.g., staff availability). Moreover, some studies have found that patients prefer to receive psychological care within the context of their health care clinic and subsequently may not show for psychological consultation at an outside setting. Consequently, it will be important for future research to develop and evaluate assessment measures and intervention approaches with feasibility within the clinic as a guiding factor.

Overall, the field of pulmonary medicine has advanced substantially over the past few decades, resulting in greater longevity for patients as well as more demanding

medical regimens. Because pulmonary disease is common in most health care settings, health psychologists need to have a basic understanding of these disorders as well as a solid grasp on evidence-based assessment and treatment strategies to address associated psychological concerns. Indeed, psychologists can play an important role in multidisciplinary health care teams in pulmonary medicine. Specifically, these psychologists can serve as consultants and train medical staff to screen effectively for psychosocial concerns, as well as to discern when these staff members can address such concerns through brief, targeted behavioral interventions or when a mental health referral may be necessary. Of course, in the ideal situation, a health psychologist would be integrated into the clinic and hospital setting and directly provide evidence-based assessment and treatment services to those patients and families in need.

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## Chapter 21

# Primary Insomnia and Sleep Apnea in Pediatric and Adult Populations

Stacey L. Simon, Christina L. Duncan and Janelle M. Mentrikoski

Daytime sleepiness can have debilitating effects on morbidity, quality of life, academic and work achievement, and health care costs, [1] yet most adolescents and adults obtain significantly less than the recommended amount of nightly sleep [2, 3]. The literature is filled with evidence that insufficient sleep is associated with a wide range of impairments, including mood problems, physical morbidity such as obesity, increased rate of motor vehicle accidents, and poor academic and occupational achievement [4–6]. Sleepiness in children is often manifested as oppositional or inattentive behavior and may place youth at risk for mood problems [7]. Alarmingly, more than 30% of adults report that they experience daytime sleepiness to the extent that it impairs daily activities several days per month or more [8].

Daytime sleepiness can be assessed subjectively via self-report or objectively based on overnight polysomnography (PSG). Other objective tests include the multiple sleep latency test (MLST) to assess the amount of time a patient takes to fall asleep during nap opportunities while the maintenance of wakefulness test (MWT) tests the ability to resist sleep [9]. The Epworth Sleepiness Scale [10] is a commonly used self-report questionnaire where patients rate how likely they are to fall asleep in various everyday situations (e.g., watching television, riding in a car). In youth, the parent-report Children's Sleep Habits Questionnaire (CSHQ) screens for a variety of sleep problems and includes a subscale on daytime sleepiness [11].

In addition to being prevalent in the general population, excessive daytime sleepiness is a defining feature of many primary sleep disorders. Yet, most family physicians do not inquire about sleep problems or symptoms as part of a routine health history [12]. The prevalence of daytime sleepiness coupled with this

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alarming statistic lends credence to the need for psychologists to be aware of and address sleep with patients in a variety of health care settings (not just sleep clinics). Psychologists can play a significant role in working with patients with a variety of sleep-related sequelae, ranging from screening for cognitive or psychiatric comorbidity to providing evidence-based therapies to improve sleep or increase adherence to health recommendations. This chapter reviews the current evidence base for assessment and intervention for two common sleep disorders, primary insomnia and obstructive sleep apnea (OSA), and discusses the ways that health psychologists can use these techniques to promote positive outcomes in patients.

## Primary Insomnia

Primary insomnia is the most common sleep disorder in the adult population, with an estimated 9.5–15% of individuals in the USA meeting criteria for the diagnosis, and as many as 33–55% of individuals experiencing at least some symptoms of insomnia [13–15]. The disorder is common in children as well, with prevalence rates for pediatric insomnia estimated around 10.7% [16]. Often, adult patients present with complaints of sleepiness, frustration with difficulties in falling and/or staying asleep, difficulties in daily functioning (e.g., difficulty sustaining attention), and/or increased irritability. If individuals indicate significant impairments in these areas, further assessment of their sleep disturbances is warranted to determine if they meet criteria for primary insomnia (see Table 21.1 for examples of initial screening questions for sleep complaints).

Primary insomnia, as defined by the *DSM-IV-TR*, is characterized by difficulty maintaining or initiating sleep for at least 1 month [17]. In order to be classified as primary insomnia, other causes for the sleep difficulties (i.e., medical, psychopathology, drug use) must be ruled out [17]. According to the *International Classification of Sleep Disorders, Second Edition (ICSD-2)*, insomnia is characterized by three conditions, including inadequate sleep opportunity, persistent sleep difficulty, and associated daytime dysfunction. In children, insomnia (also known as behavioral insomnia of childhood) is classified by the *ICSD-2* as either sleep-onset association type or limit-setting type. Criteria for sleep-onset association type include an extended and specific process/routine, object, or environment that is required for the child to fall asleep; inappropriate or demanding sleep associations which, if absent, delay sleep onset for the child; and nighttime awakenings that require a caregiver's involvement before the child is able to return to sleep [18]. Criteria for limit-setting type include difficulty maintaining or initiating sleep; bedtime stalling/refusal; and lack of or inappropriate limit setting by the caregiver which would establish appropriate bedtime routines [18].

A number of factors are thought to be responsible for the development of insomnia, including genetic risk, poor sleep stimulus control, physiological and cognitive hyperarousal, poor affect regulation, and daytime behaviors that can contribute to problematic night sleep [19]. Some studies suggest that a complex neural network

**Table 21.1** Initial screening questions for evaluating sleep complaints

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What time do you/your child usually go to bed? How long does it take for you/your child to fall asleep?
On average, how many times do you/your child wake up during the night?
How long does it take you/your child to fall back asleep after waking during the night?
What time do you/your child wake up in the morning? Any difficulties with waking up (e.g., irritability, defiance)?
How do you/your child feel when you wake up in the morning (e.g., mood, fatigue level)?
On average, how many hours of sleep do you/your child achieve each night?
How many naps do you/your child typically take during the day? How long do the naps last?
How long has sleep been a problem for you/your child? Any significant events occur around the same time the sleep problems occurred (e.g., starting new job/school, family stressors)?
Are you/your child experiencing any difficulties in daily functioning (e.g., school/work performance, difficulty concentrating)?
In general, how is your/your child's mood during the day?
How many caffeinated foods or beverages do you/your child consume during the day?
When do you/your child typically exercise (e.g., morning, afternoon, evening)? Do you/your child have any vigorous physical activity in the evening?
Do you/your child take any medications to help you/your child fall asleep? Do you/your child take any other medications regularly during the day?
What have you tried already to manage your/your child's sleep problems (e.g., get out of bed, watch television, comfort the child)?
What is your/your child's typical bedtime routine?

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in the brain explains the neurobiology of insomnia [20]. This complex neural network may include various systems (e.g., arousal and emotion-regulation systems) as well as involve multiple areas of the brain (e.g., prefrontal cortex, hippocampus, amygdala), suggesting that sleep is not linked to one specific area of the brain [18]. In particular, individuals with insomnia tend to have cortical and somatic hyperactivation during sleep onset compared to healthy sleepers [21]. Other precipitating factors that may be important to consider include health factors (e.g., pain), recent stressors (e.g., family stress such as divorce, work/academic stress), and psychopathology (e.g., anxiety) [22]. For example, patients presenting with chronic pain may also have difficulty sleeping and a thorough sleep evaluation would be warranted. Additionally, there may be high-risk developmental periods for insomnia, such as adolescence or late life (e.g., [23–25]). When a patient reports or presents with any of these risk factors, it should signal a need for further assessment of potential sleep difficulties.

### ***Evidence-Based Assessment of Insomnia***

*Sleep duration.* PSG and actigraphy are two objective measures that inform practitioners about sleep. PSG can be used to rule out potential medical causes for sleep disturbance (e.g., OSA), but does not directly measure markers of insomnia. In the absence of other indicators to suggest its necessity, PSG would not likely

be a first-line assessment method, given its expense and difficulties with access (e.g., performed in a sleep laboratory). Still, PSG is widely used in research and is a valuable tool. Actigraphy is a watch-like device worn on the individual's wrist throughout the night to measure motoric activity with an accelerometer. Advantages of actigraphy include being less obtrusive than PSG and ability to be used outside of a sleep lab (e.g., [26]). Additionally, actigraphy can provide an extended view of sleep in the home environment, which may be more indicative of typical sleep than a PSG, and more accurate than sleep diaries [27]. Despite its potential utility in medical settings, given the expense of the devices and time-intensive nature of interpreting the data, actigraphy is currently most commonly used as a research tool. As such, subjective measures such as sleep diaries and sleep questionnaires may be more cost-effective and practical.

A sleep diary is the most commonly used subjective measure of sleep complaints. Sleep diaries can be used easily for assessing sleep complaints in both pediatric and adult populations, with parents assisting their young children in completing the sleep diary if needed. Individuals using sleep diaries typically record when they fall asleep and when they wake up during the night and in the morning for at least a week in order to get a representative sample of both weekday and weekend sleep. Napping, consumption of coffee or alcohol, and exercise also can be recorded in sleep diaries. Clinicians then utilize the information obtained from the sleep diaries to diagnose insomnia and inform treatment. An example of a brief sleep diary that may be utilized in a clinic setting or as a method to monitor progress throughout treatment for insomnia is provided in Table 21.2.

Questionnaires may also be used to provide additional information on a variety of sleep factors (e.g., sleep quality). Two of the most common sleep questionnaires (*Pittsburgh Sleep Quality Index*, PSQI [28]; *Insomnia Severity Index*, ISI [29, 30]) have strong psychometrics and are quick to administer and relatively easy to score. These questionnaires may be beneficial in medical settings as measures of pre- and posttreatment outcomes, in addition to providing clinicians with more information on an individual's sleep difficulties. Other subjective and validated measures of sleep complaints that may be useful in medical settings are the *Sleep-Efficacy for Sleep Scale*, which assesses an individual's belief in his/her ability to fall asleep, [31] and the *Dysfunctional Beliefs and Attitudes about Sleep Scale*, which assesses factors such as an individual's beliefs, thinking errors, and unrealistic expectations related to sleep [30]. Although these questionnaires do not measure qualities (e.g., sleep onset latency) of sleep disorders per se, they nonetheless provide information on potentially relevant sleep-related variables that may be targeted through the course of treatment.

*Sleep quality.* The PSQI is used to determine sleep quality and has been shown to be sensitive enough to distinguish between "good" (i.e., individuals with no sleep complaints) and "poor" (i.e., individuals with sleep disturbances) sleepers [28]. The PSQI is a brief, 19-item self-report measure suitable for use in youth as young as 6 and with adults. It assesses seven components of sleep quality, including subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medications, and daytime functioning [28]. Testing



**Table 21.2** Sample sleep diary

	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7
Bedtime							
Time to fall asleep							
Number of night time awakenings							
Morning wake-up time							
Total sleep time							
Time spent napping during the day							
Fatigue during the day (0 = very energetic to 10 = very fatigued)							

Example of a brief sleep diary log that can be used by adults and older youth or completed by parents of young children. Sleep diaries are usually maintained for 1–2 weeks to ensure that a representative sample of information is collected regarding sleep complaints. This monitoring form can be modified to include additional information that may be relevant to collect, such as number of caffeinated drinks consumed, duration of exercise during the day, medications taken, and/or activities engaged in prior to bedtime

of the PSQI indicates strong psychometrics, including high reliability (Cronbach's alpha for individual component scores range from 0.46 to 0.83; test-retest reliability = 0.87 for the total score) and validity (found to significantly correlate with PSG) as a measure of sleep quality [28, 32]. However, this measure does not provide information on what type of sleep disorder may be present and thus may only be beneficial as a general screener for sleep disturbances. Nonetheless, the PSQI may be useful as a treatment outcome measure to use as a treatment outcome measure.

*Symptom severity.* The ISI is another brief (seven-item) self-report measure which assesses adult's perceptions of insomnia, including sleep onset and maintenance difficulties, interference with daily functioning, level of satisfaction with sleep, and distress and noticeability of the sleep problem [29, 30]. Psychometrics indicate that the ISI is reliable and valid, with adequate internal consistency (Cronbach's alpha = 0.74) and content validity ( $R^2=0.72$ ) [29]. Additionally, a study which assessed the concurrent validity between the ISI and sleep diaries and actigraphy before and after an insomnia intervention indicated that there were small but significant correlations between the ISI insomnia subtypes and sleep diary variables ( $r=0.32-0.55$  at baseline and  $0.50-0.91$  at posttreatment) and actigraphy data ( $r=0.07-0.45$  at baseline and  $0.23-0.45$  at posttreatment) [29]. The content of the ISI overlaps with the *DSM-IV* criteria for insomnia, and it yields a cutoff score to aid in the diagnosis of insomnia [29]. The ISI also has versions to be completed by a clinician or bed partner.

### ***Evidence-Based Interventions for Insomnia***

Psychological interventions are extremely effective for primary insomnia: 70–80% of patients diagnosed with insomnia benefit after undergoing treatment, and about

50% of individuals leave treatment with at least some clinically meaningful improvements in sleep [33]. Improvements are seen consistently in a variety of domains, including better sleep quality, decreased sleep onset latency, less wake after sleep onset, and longer sleep duration, with the majority of sleep improvements sustained over time for at least 6 months [33]. Cognitive-behavioral therapy for insomnia (CBT-I) is a well-established, multicomponent treatment for insomnia and is considered the first line of treatment for children and adults with insomnia [34]. A recent meta-analysis of randomized controlled trials concluded that CBT-I is an effective intervention, with benefits maintained after the conclusion of treatment on both objective and subjective sleep measures [35]. Multiple studies (including randomized controlled trials) have provided additional evidence in support of CBT-I in adult (e.g., [36–39]) and pediatric populations (e.g., [40]).

CBT-I for children and adults involves multiple components, and some studies have examined these individual constituents independently with positive results (e.g., [33, 41–44]). Components of CBT-I often include psycho-education (i.e., sleep hygiene education), stimulus control, relaxation training, sleep restriction, and cognitive therapy techniques, such as cognitive restructuring [45]. In pediatric populations, operant conditioning principles (e.g., graduated extinction, reinforcement of compliance to bedtime routines) may also be used as part of the CBT-I treatment package.

*Psycho-education.* The purpose of sleep hygiene education is to increase individuals' knowledge about appropriate sleep behaviors to promote better sleep. Educational recommendations may include avoiding caffeine and nicotine consumption before bed, limiting engagement in physical activity before bed, and restricting noise and light in the bedroom [33] (see Table 21.3 for more suggestions). Alone, sleep hygiene education has limited benefits [33]. However, providing this education at the outset of CBT-I may be beneficial for individuals with insomnia, particularly children and adolescents, as they may not be aware of behaviors which prevent them from achieving optimal sleep and benefitting maximally from CBT-I.

*Stimulus control.* Stimulus control typically involves instructing individuals to use their bedrooms only for sleep, leave their room if they do not fall asleep in approximately 15 minutes, set a regular awakening time, go to bed only when sleepy, and avoid napping during the day [42]. Few randomized control studies have examined stimulus control as an individual treatment component for insomnia, particularly in pediatric populations. Nonetheless, stimulus control is associated with significant improvements in sleep duration and reduced sleep onset latency compared to both a control group and an imagery group in a geriatric population [42]. In a sample of adults who were undergoing a sleep medication withdrawal program in addition to stimulus control found that the addition of stimulus control to the withdrawal program was associated with treatment gains in total sleep time, sleep quality, and sleep efficiency compared to control participations who did not receive stimulus control [46]. Other studies have demonstrated similar results in adult populations (e.g., [47, 48]) while a few small and uncontrolled studies have demonstrated positive

**Table 21.3** Sleep hygiene recommendations

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Maintain a consistent sleep–wake schedule, including on weekends and holidays
Avoid napping during the day
Avoid caffeine, particularly late in the day
Obtain regular exercise
Eat a light snack 1 h before bed
Avoid liquid consumption before bed
Avoid using alcohol as a sleep-aid
Restrict light and noise in the bedroom
Ensure a comfortable sleep environment (e.g., keep temperature cool)
Engage in a predictable and relaxing bedtime routine
Avoid television, computer, or video games before bed
Avoid engaging in activities (e.g., doing computer work) in bed other than sleep and sexual relations

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Note for practitioners: Rather than simply providing a handout with a list of all recommendations to a patient, it is recommended that you engage the patient and/or parent in a discussion around individualized recommendations. It also is suggested that you help the family problem solve around potential barriers to implementing a healthy sleep hygiene routine

results in children with bedtime tantrums (e.g., [49]) and other sleep complaints (see [50] for an overview).

*Relaxation training.* Biofeedback, progressive muscle relaxation, imagery, deep breathing, meditation, hypnosis, or cognitive distraction are all types of relaxation training used to address the hyperarousal typically associated with insomnia. A recent review of the literature suggested that progressive muscle relaxation can improve subjective reports of sleep quality as well as other sleep outcomes in adults compared to placebo, wait-list, or no-treatment control groups [33]. Again, studies examining the effectiveness of relaxation training as an individual treatment component for children and adolescents with insomnia are particularly scarce. In addition to progressive muscle relaxation, autogenic training (i.e., verbally inducing a relaxed state) may be used to treat insomnia. A relaxation procedure that included autogenic thinking in addition to other relaxation techniques (e.g., deep breathing, maintaining a relaxed attitude) was examined in a randomized controlled trial with older adults with primary insomnia, with results indicating that autogenic thinking subjectively (as assessed by sleep diaries) improved various sleep parameters (e.g., total sleep time, sleep latency) in the short term compared to a placebo-desensitization group which received systematic desensitization procedures prior to going to bed [51].

*Sleep restriction.* Sleep restriction therapy focuses on stabilizing sleep, which is defined as a reduction of excessive time spent in bed and an increase in sleep efficiency [44]. After tracking sleep for 2 weeks with a sleep diary, prescribed time in bed (TIB) is determined by averaging the individuals' subjective report of total sleep time. For example, if an individual believes they spent an average of 9 h in bed, but obtained a mean of 6 h of sleep per night, the prescribed TIB would be set at 6 h. Bedtimes and awakening times are then established to be in line with TIB.

If a patient has to get up at 6 a.m. for work and TIB is set at 6 h, bedtime would be 12 a.m. Each week, TIB is increased or decreased by 15–20-min intervals depending on sleep efficiency (the ratio of the amount of time spent sleeping compared to the amount of time spent in bed). If a patient demonstrates good sleep efficiency on average across 5 days (defined as greater than or equal to 90%), TIB is increased; if sleep efficiency is poor (defined as less than 80%), TIB is decreased [33]. If the mean sleep efficiency value across 5 days was between 80 and 90%, TIB did not change [33]. Few studies have examined the effectiveness of sleep restriction therapy as an intervention on its own, especially in pediatric populations. However, in Spielman's original study, which included 35 adults diagnosed with insomnia, results suggested improvements in total sleep time, sleep latency, total wake time, and sleep efficiency [44].

*Cognitive therapy techniques.* Cognitive therapy for insomnia typically focuses on challenging and changing an individual's cognitions regarding sleep and sleep behavior. According to Harvey's [52] cognitive conceptual model, insomnia is maintained by cognitive processes that occur both during the day and at night. Specific cognitive processes unique to insomnia include selective attention and monitoring of sleep behaviors, dysfunctional beliefs about amount of sleep obtained and daytime functioning with a lack of sleep, and safety behaviors which enable individuals to avoid their fears of not being able to sleep [52]. These cognitions tend to cause an increase in sleep-related worries, which in turn increases physiological arousal and emotional distress [52]. Thus, cognitive therapy seeks to decrease insomnia symptoms by reversing the maladaptive cognitive processes of insomnia. To do so, therapy typically uses various cognitive restructuring techniques, such as behavioral experiments, guided discovery, Socratic questioning, and assigning homework throughout treatment [53]. Studies examining the effectiveness of cognitive therapy in both children and adults have typically found moderate positive outcomes on insomnia symptoms (e.g., [41, 43]).

*Operant conditioning principles.* These behavioral techniques are particularly beneficial for pediatric insomnia, and, as such, these involve parent training. As outlined by Meltzer, [54] there are key elements in a behavioral treatment for insomnia, including setting a consistent bedtime schedule that is age-appropriate and maintained every day during the week; implementing a consistent bedtime routine (e.g., providing verbal warnings of upcoming bedtime, limiting activities before bed to quiet and non-stimulating ones, utilizing a bedtime chart to reinforce compliance to bedtime routine); and teaching the child to fall asleep independently (e.g., through graded extinction procedures). Extinction (i.e., ignoring crying or misbehavior of children), graduated extinction (i.e., ignoring crying or misbehavior with occasional checking by the parents), and parent education on proper sleep hygiene have been found to be effective in reducing bedtime refusal and night wakings in children, while scheduled awakenings (i.e., spontaneous nighttime awakenings) may also be effective [55]. When parents consistently apply these operant behavioral principles, clinically significant improvements in children's bedtime problems and/or night wakings are possible [56].

*Pharmacological treatments.* Pharmacological treatments for insomnia can provide immediate relief of insomnia symptoms; however, pharmacological treatments do not fix maladaptive sleep behaviors and may have significant side effects. The most commonly prescribed medication for adult insomnia are benzodiazepines, which have been shown to be effective in improving subjective sleep parameters such as sleep onset and sleep maintenance in adults (e.g., [57, 58]) and elderly patients (e.g., [59]) in the short term. Other effective medications used in the treatment of adult insomnia include antidepressants (e.g., doxepin) and non-benzodiazepines (e.g., zaleplon, zolpidem) [60, 61].

The majority of clinical trials examining the effects of various medications on sleep in individuals with insomnia have utilized samples of adults or elderly adults. Little research has examined the effectiveness of medications in children and adolescents with insomnia. In 2005, the American Academy of Sleep Medicine [62] initiated a task force to develop recommendations for prescribing medications in a pediatric population with primary insomnia. The task force recommended that medication should not be the first option for treatment of insomnia in a pediatric population; however, if deemed necessary, it was recommended that medication use should be short term [62]. The medications examined by the task force all had negative side effects, with some having the potential for developing tolerance and withdrawal symptoms [62]. The recommendations of this task force suggest that more clinical trials need to be conducted in a pediatric population with insomnia.

Melatonin is an over-the-counter supplement that is often used by children and adults with sleep difficulties in order to increase sleepiness and reduce sleep onset latency [63]. As a hormone naturally produced by the human body, melatonin helps regulate the sleep–wake cycle and signals the body to prepare for sleep [63]. Melatonin is typically recommended to be taken 30–60 min prior to bedtime. Of note, melatonin does not help with sleep maintenance. Melatonin appears to be safe, with only minor side effects [63]. However, the effectiveness of melatonin in treating individuals with insomnia has been contradictory (e.g., [63–65]), with some studies indicating that melatonin is effective in managing symptoms of insomnia while others suggest a lack of long-term benefits.

### ***Evaluation of Current Evidence Base and In-Practice Caveats***

Insomnia research has made great strides in recent years. In the area of assessment, multiple measures have been found to be reliable and valid estimates of sleep quality, dysfunctional beliefs about sleep, and severity of insomnia symptoms. In addition, objective measures provide accurate assessments of sleep and have the potential to become more accessible to practitioners in the future. In the area of interventions, much research has been conducted on psychological and pharmacological treatments. For adults, evidence suggests that psychological interventions generally are effective, with stronger evidence to support behavioral and cognitive-behavioral interventions. Fewer studies have examined psychological interventions for

childhood insomnia compared to the adult literature; however, there is evidence to support behavioral and cognitive-behavioral interventions as treatments for youth. It is generally recommended that psychological interventions be considered prior to considering pharmacological treatments.

Despite these strengths, insomnia research could still benefit from more randomized controlled studies. Future intervention studies should focus on clinically meaningful outcome measures besides sleep quality, such as quality of life and daytime functioning [33, 45]. Furthermore, it is still unclear what specific mechanisms of interventions are associated with treatment effects and so intervention studies should use attention control groups rather than wait-list control groups [33]. More studies are also needed that compare pharmacological treatments to psychological interventions as well as studies that compare single therapies to multicomponent therapies [45].

In practice, it is first necessary to recognize potential red flags which may indicate sleep problems in certain individuals, such as psychological diagnoses, developmental phases, environmental changes, or significant stressors. It is then essential to initially complete a thorough interview when assessing complaints of insomnia symptoms, focusing on the diagnostic criteria of insomnia as well as a functional assessment of the sleep problems (e.g., what environmental conditions may be maintaining the sleep problems?). In addition to a thorough clinical interview, self-report assessments and sleep diaries can be used to provide further information on sleep complaints. Treatment decisions should be based on the needs of the individual and should utilize the strong evidence base in support of the CBT-I treatment components. In pediatric insomnia, treatment will involve the parents and, as such, clinicians should be comfortable addressing any parental concerns they may have regarding the treatment. Common barriers to treatment in both children and adults may include inconsistently following recommendations and failure to complete sleep logs/sleep measures; in some cases, individuals may be resistant to change. In such cases of resistance and inconsistency in following treatment recommendations, clinicians should evaluate the individuals' investment in treatment and readiness to change, or possible alternative functions for maintaining sleep problem behaviors (e.g., child co-sleeping with parent helps one spouse cope with marital distress). By providing a strong rationale for the treatment of insomnia, clinicians can help individuals to be on board with therapy. Additionally, providing ongoing follow-up to monitor treatment progress during routine clinic appointments is imperative in order to ensure that treatment successes are maintained.

## **Obstructive Sleep Apnea**

OSA is a sleep disorder in which patients experience frequent episodes of upper airway obstruction that results in brief cessation of breathing and arousal from sleep. Estimates of prevalence are approximately 2–4% in adults and 1–3% in youth [66, 67]. Obesity is a significant risk factor for developing OSA in adults and adolescents, while young children more commonly develop the condition in response to

enlarged tonsils and adenoids. With rising rates of obesity in the USA, OSA is likely to become an increasingly significant source of morbidity and health care costs.

Patients with OSA may present with complaints of labored breathing during sleep and disturbed, less restorative sleep [68, 69]. The apneic episodes result in brief arousals from sleep and those with severe OSA may wake up as often as hundreds of times during the night. A patient's bed partner or a parent is typically the one to express concern about the restless sleep, loud snoring, or gasping during sleep as the patients themselves are often unaware of their symptoms. A variety of secondary symptoms are common, including mood fluctuations, behavior and attention difficulties, cognitive deficits, and academic problems [70]. Health consequences of OSA can be severe, and the disease puts patients at risk for other conditions including hypertension, type II diabetes, and stroke [67].

On a positive note, treatment of OSA can be extremely successful. Surgical removal of the tonsils and adenoids is curative in 70–90% of children [68, 69]. For others, positive airway pressure (PAP) is a palliative treatment. Attached to a mask worn on the face during bedtime, the PAP device emits a flow of air that maintains open airways during sleep. However, the device must be used consistently in order to sustain benefits and missing a single night's use will result in the return of symptoms. Unfortunately, non-adherence to the PAP regimen is common: In children, rates of use range from 3 to 7 h per night [71–75] while estimates of non-adherent adults are as high as 25–50% [67].

### ***Evidence-Based Assessment of OSA***

*Diagnosis.* PSG is the gold-standard diagnostic method for sleep disorders in youth and adults. It is recommended for the assessment and diagnosis of OSA given its ability to quantify the respiratory abnormalities found in the disorder [76]. Additionally, PSG can help diagnose or rule out multiple other sleep disorders, such as central sleep apnea or periodic limb movement disorder, and possibly identify physiological causes for complaints of insomnia [76]. PSG, also referred to as a “sleep study,” is traditionally an inpatient, overnight procedure that takes place in a specially equipped facility at approximately the patient's typical bedtime without sedation or sleep deprivation in order to replicate normal sleep. A variety of monitoring devices are used to obtain information on a number of variables, including sleep stage, respiratory effort, air entry, extremity movements, and snoring [77]. The information obtained is reviewed and scored by an experienced technician and interpreted by a qualified sleep medicine specialist. In particular, technicians review the patient's respiratory events, including apneas (a complete cessation of airflow) and hypopneas (a partial cessation of airflow). The apnea-hypopnea index (AHI) is a calculation of the number of apneic and hypopneic events per hour of sleep. Greater AHI is indicative of greater severity of disease; cutoff values of 10, 15, or 20 have been used to identify a diagnosis of OSA in adults, [76] while an AHI of more than 10 is considered severe OSA in children [69].

*Adherence.* As mentioned previously, non-adherence to the PAP regimen is common and this is the primary area where psychologists can intervene with patients with OSA. Many PAP devices are now equipped with technology to track usage data. This electronic monitoring allows for the real-time and long-term tracking of usage as it occurs and thus can be beneficial for treatment planning and as a valuable research tool. Depending on the manufacturer, adherence data are typically stored on a computer chip in the machine that can be removed and downloaded via special computer software that generates usage information, including graphical displays of hours of daily usage, level of daily pressure, and daily patterns of use (i.e., time of day used). Quantifying usage and providing feedback to the patient is an important first step in addressing adherence problems, though additional information is needed to understand adherence concerns fully. Studies examining factors related to non-adherence have found many possible contributors, including individual patient and disease characteristics, treatment titration procedures, PAP device-specific features, side effects, and psychosocial variables such as negative emotional reactions towards treatment and illness [74, 78]

### ***Factors Related to Adherence***

To promote adherence successfully, it is necessary to understand first the specific challenges patients and families are experiencing. Several studies have attempted to assess particular factors to investigate their relation to continuous PAP (CPAP) adherence. Treatment side effects, such as congestion and skin irritation, and feelings of claustrophobia have been reported as being negatively correlated with adherence in adult patients [67, 79]. Other studies, based on social cognitive theory and the health belief model, have attempted to find pretreatment factors that predict subsequent adherence. For example, treatment outcome expectancy and patient perceptions of risk and functional limitations prior to initiating CPAP were significant predictors of subsequent adherence in an adult population [67, 80]. Variables related to social cognitive theory (e.g., self-efficacy, knowledge) assessed after 1 week of trying CPAP significantly predicted adherence 1 month later in adults [81]. In a pediatric sample, greater barriers to treatment adherence as reported by youth and their parents were associated with poorer regimen adherence [74]. Specific barriers highlighted by families include a negative emotional reaction to PAP (e.g., feeling embarrassed) and daily hassle (e.g., forgetting). See Table 21.4 for examples of barriers that may be important to assess in patients and families. Several disease-specific measures have been developed to assess these variables as they relate to patient's prescribed CPAP treatment.

*Barriers.* The *Adherence Barriers to CPAP Questionnaire* (ABCQ) [74] assesses barriers via both parent- and youth self-report versions and has been used with children aged 9–17. The 31-item measure yields a total barriers score, with higher scores indicative of more barriers. Psychometric properties for the ABCQ are strong, with internal consistency values of 0.89 and 0.90 for the youth and parent



**Table 21.4** Potential barriers to PAP adherence

Barriers	Examples
Side effects	Congestion, discomfort; dry mouth
Financial concerns	Cost of PAP device; insurance coverage
Time management	Forgetting; lack of bedtime routine
Use when away from home	Vacation; sleepovers
Denial of illness	Desire to forget about having OSA; embarrassment about using PAP
Education	Lack of understanding of need to use PAP daily; uncertain how to use machine

form, respectively [74]. The measure demonstrated acceptable convergent validity, as supported by significant correlations between ABCQ scores and measures of objective adherence, health care satisfaction, and negative outcome expectancy. Test-retest reliability over a 2-week interval was adequate (0.73–0.81 for parent and youth versions) [74].

*Knowledge.* The *Apnea Knowledge Test* (AKT) was developed by Smith and colleagues [82] to assess adult patient’s understanding about OSA and PAP treatment. The measure consists of 15 items, 13 multiple choice and two open-ended, with higher scores revealing better knowledge. Participants with higher levels of education demonstrated greater levels of OSA-related knowledge, supporting the validity of the measure [82]. Cronbach’s alpha for the measure was 0.60, which indicates low-to-moderate internal consistency [82].

*Attitudes and beliefs.* The *Apnea Beliefs Scale* (ABS) [82] consists of 24 statements that evaluate adult’s beliefs about their illness and treatment across areas including perceived impact of OSA, trust in medical staff, outcome expectations, acceptance of PAP, openness to new experiences, commitment to change, willingness to ask for help, attitude to health, and self-confidence. Items are rated on a 5-point Likert-type scale ranging from “agree” to “disagree,” and those who score high on the measure demonstrate more accurate beliefs. With respect to validity, the measure successfully differentiated between adults with and without sleep apnea, such that patients with OSA had higher scores on the ABS [82]. Internal consistency was 0.75 for an adult sample [82].

*Self-efficacy.* The *Self-Efficacy Measure for Sleep Apnea* (SEMSA) [83] was developed based on the social cognitive model. The self-report questionnaire instructs adult patients to rate each item on a 4-point Likert-type scale (e.g., “not at all true” to “very true”). Mean-weighted scores take into account missing item responses. Three subscale scores are generated based on confirmatory factor analysis: risk perception, outcome expectancies, and treatment self-efficacy. The measure has demonstrated excellent internal consistency with Cronbach’s alpha = 0.92, and acceptable test-retest reliability at 1 week ranging from 0.68 to 0.77 across subscales [83].

*Summary.* While these measures all meet rigorous psychometric standards and have been evaluated and utilized within a research context, the degree to which

they are used in clinical settings is likely not as often. While there are clear benefits to assessing the above-mentioned factors in a clinical practice, there is often a perceived lack of time during a busy clinic day as well as difficulties with availability of the measures. Additionally, few measures exist specifically aimed at youth and families. Nonetheless, increased awareness of the potential clinical utility of these OSA-specific measures is important.

### ***Evidence-Based Treatment for OSA***

Recent research has focused on developing empirically supported interventions intended to improve regimen adherence specifically for adult patients with OSA. These interventions can be grouped into three categories: (1) education-based, (2) cognitive-behavioral therapeutic (CBT) techniques, and (3) telehealth interventions. Additionally, one pediatric behavioral intervention has been developed and tested.

*Education Interventions.* The earliest interventions aimed at improving adherence to PAP focused on education efforts. One study [84] investigated two interventions, with adult participants either receiving written information about OSA and the importance of treatment or weekly telephone calls to encourage PAP use. Adherence was monitored using a counter built into the PAP device. Both interventions resulted in improved rates of PAP use at 2-month follow-up compared to a standard care control group, with the best outcomes for the educational literature intervention, with that group using PAP 2.7 h per night more than the control group, and 1.4 h per night more than the telephone support group. This type of education intervention has the benefit of being easy to administer and requires minimal time, resources, and expense; however, it is unclear how long these effects will maintain with this long-term treatment regimen.

However, providing extra education may not be enough to improve adherence. One randomized clinical trial compared an “augmented support” intervention, in which adult patients received extra education, watched a video, received nurse support via telephone, and early return clinic appointments to a “basic support” control group who simply received written brochures and education provided by nurses [85]. The authors found no differences between groups in rates of PAP usage at either 1-month or 3-month follow-up. However, the group receiving additional support did endorse better quality of life during the intervention period, indicating that the intervention may have had a positive influence in patients’ perceptions of the process of initiating CPAP treatment. Similarly, another intervention provided individualized written feedback to patients including education about illness and treatment along with personal objective and subjective health data compared to normative data [86]. Compared to a control group that simply received three brochures about OSA and CPAP, there were no significant differences in regimen adherence at either short-term or long-term follow-up (2 weeks and 3 months).

Rather than just providing extra education and support, research has shown that altering the way that patients hear about the benefits of CPAP or negative consequences of OSA can influence adherence. Trupp and colleagues [87] randomized adult patients to watch one of two videos that used either positive or negative message framing to discuss illness and treatment. In addition, consistent with either the positive or negative messages, both groups listened to brief, recorded phone messages weekly and received a magnet to place in a prominent location. An example of the positive messages is “Using CPAP at least 4 h per night will reduce your daytime sleepiness and give you more energy,” while the negative messages included such statements as “If you don’t use your CPAP at least 4 h per night, you miss the chance to be less sleepy and have more energy.” At 30-day follow-up, the negatively framed message group had higher rates of CPAP usage compared to the positive framing group. While this intervention demonstrates that an extremely simple change in the way that educational information is conveyed to patients may influence their adherence, the study could not control for the variations in personal communication styles or educational messages received from the variety of health care providers with whom patients had interactions outside of the study. Still, clinicians may find success in providing educational materials highlighting the negative consequences of inadequate PAP use and using such negative examples in their discussions of PAP adherence with their patients.

*Cognitive-behavioral interventions.* Interventions utilizing CBT techniques also have been developed for OSA populations and have demonstrated efficacy. One such intervention is described by Aloia et al. [88, 89] in their series of articles on a motivational enhancement therapy for CPAP (ME-CPAP) and identified positive outcomes. The intervention utilized techniques from motivational interviewing and occurred over two 45-min clinic sessions and a 15-min follow-up phone call with a nurse therapist. Session components included assessing patients’ confidence in their ability to use CPAP, providing personalized information on the negative consequences of OSA, reviewing benefits of CPAP use, reviewing patients’ experiences with CPAP, identifying rewards, and setting goals. In a randomized clinical trial with 142 treatment-naïve adult patients, [89] participants were assigned to either the ME-CPAP, a traditional education comparison intervention receiving didactic educational information about OSA and treatment, or a standard care control condition. The ME-CPAP group had the lowest rates of patients prematurely discontinuing treatment. Participants were classified according to rates of adherence, and while there were no differences in the proportion of patients with “low” usage (on average, less than 4 h per night), almost half of the ME-CPAP and education intervention participants used their CPAP for an average of 6 or more hours per night at 13-week follow-up. While using motivational enhancement is somewhat more intensive than standard care, the intervention has the benefit of being able to use trained nurse therapists as the primary interventionists to reduce costs and psychologist burden. Overall, though long-term maintenance is as yet unknown, the studies show impressive support for brief interventions utilizing cognitive-behavioral

elements to improve two important domains for OSA patients: rates of discontinuation of treatment and adherence to therapy.

*Telehealth interventions.* Still, other studies have utilized technological advancements in order to intervene with patients to improve regimen adherence. The ME-CPAP intervention was modified for use with an interactive voice-response telephone communication system, such that participants heard digitized human speech and entered responses using a touch-tone phone [90]. Participant responses regarding amount of CPAP usage and its side effects as well as symptoms of OSA were monitored by physicians to allow for immediate intervention if necessary. After receiving weekly phone calls for 1 month and monthly calls thereafter, the intervention group demonstrated an hour more of use per night than an attention control group at 6-month follow-up, and 2 h more per night at 12-month follow-up. While these results are promising, overall rates of adherence for the population were extremely low, ranging from 2.4 to 2.98 for the intervention group and from 0.99 to 1.48 in the control group, which the authors hypothesize may be due to patients who believed they would require assistance using PAP and thus maybe more high risk for non-adherence were more likely to enroll in the study. Despite this, the intervention demonstrates an innovative use of technology to provide an intervention for minimal cost and resource utilization that allows for immediate notification and response by care providers to target issues.

*Pediatric interventions.* Only one intervention has been developed and tested thus far for youth with OSA. That study allowed 20 children (aged 1–17 years) and their families to self-select one of three conditions: consultation only, consultation plus behavior therapy, consultation and behavior therapy declined [91]. All families participated in a 90-min consultation consisting of an assessment with a structured interview and direct observation of families using CPAP equipment, and received individualized, behavioral recommendations for adherence-promoting strategies such as relaxation, distraction, and positive reinforcement. Families tried the strategies for 1 week and if they continued to report difficulties, a course of behavioral therapy taking place at either the hospital clinic or home was recommended for more intensive assistance with implementing behavioral strategies. Of the families that either achieved success after the consultation or who initiated behavior therapy upon recommendation, 75% of children successfully tolerated CPAP and increased their nightly usage significantly, by more than 5 h per night. In contrast, of the families who were recommended behavior therapy but declined, the children decreased their CPAP adherence according to device meter readings by more than 2 h per night. While this study should be interpreted with caution, given that a majority of the children had borderline or impaired cognitive functioning and families were not randomized to the intervention conditions, it can be suggested that further development of behaviorally focused interventions with pediatric populations may be beneficial in improving adherence.

## ***Evaluation of Current Evidence Base and In-Practice Caveats***

Significant progress has been made in developing psychometrically sound assessment measures specific to the OSA population aimed at investigating factors related to adherence to PAP treatment. Similarly, several promising intervention techniques have demonstrated success in improving adherence to the PAP regimen, primarily in adults. Work remains to be done, however, as much of the research base is characterized by small samples, male-only populations, and few pediatric studies. Additionally, the studies have brief follow-up periods, making it difficult to determine the long-term impact of the intervention on a very long-term treatment. The CBT-based ME-CPAP intervention appeared to be the most promising treatment, with the ability to be adapted for both in-person and telehealth provision. In addition to larger, randomized clinical trials to verify efficacy of behavioral interventions, the field needs to move into effectiveness research in order to make sure interventions are feasible for delivery in a busy sleep clinic setting.

For psychology practitioners working with patients with OSA struggling with adherence, significant benefits may be gained by using the techniques identified in the literature. Assessing specific factors that may be related to adherence (e.g., barriers, self-efficacy) can help practitioners understand patients and their families better and to provide individualized treatment. This can be accomplished via interview and augmented by validated questionnaires historically primarily used in research but which now are amenable for use in a fast-paced clinic setting. The adherence monitoring capabilities of the PAP device can be used to provide frequent feedback to patients and families and to troubleshoot difficulties they may be having in following CPAP use. Finally, cognitive-behavioral techniques such as identifying benefits of treatment as well as consequences of non-adherence and using goal setting appear promising for both adults and children. Rather than waiting for problems to be identified, psychologists should be integrated into an interdisciplinary sleep clinic team which will make it possible to intervene early, even before a patient begins PAP treatment, which is important for optimal response given that patterns of adherence are developed within the first week of use [79]. Additional opportunities exist for psychologists to consult with and train other health care providers to use techniques such as motivational interviewing or problem solving to promote adherence, or for health psychologists to consult within other medical clinics where patients with OSA may be seen (e.g., weight management clinics, primary care settings).

## **Conclusion**

Sleep disorders are a common problem in both pediatric and adult populations and such concerns can be related to psychological disorders (e.g., depression, anxiety) and often lead to decreased quality of life, impaired daily functioning (e.g., decreased academic and work performance), increased health care costs, and other

morbidity factors. Though PSG often has been considered the “gold standard” for assessment of sleep disorders, other methods of assessment also play a significant role in diagnosing and monitoring treatment effects with a variety of sleep disorders. Specifically, actigraphy, sleep diaries, and questionnaires are useful tools in a multi-method, multi-informant approach to assessment. Of these measures, sleep diaries are the most frequently used, given their low cost, flexibility, and ease of use in a fast-paced clinical setting. Because actigraphy is costly and requires considerable training to interpret data, it is not yet commonplace in clinic settings; however, there is considerable opportunity to build the use of questionnaires in the clinical care of patients with sleep disorders. Although most sleep questionnaires were developed and used specifically for research purposes, their relative brevity, ease in scoring and interpretation, and limited to no cost make them a relatively untapped assessment resource. Consequently, an important area of focus for psychologists treating sleep problems is increasing the use of validated sleep questionnaires for pediatric and adult patients.

Like assessment, the treatment of sleep disorders in youth and adults has benefited from substantial empirical research. CBT-I has a strong and consistent evidence base as a behavioral treatment for various sleep difficulties. This approach to treatment incorporates several strategies, including psycho-education (e.g., sleep hygiene), stimulus control, sleep restriction, and cognitive therapy. For children, operant conditioning strategies, namely extinction of maladaptive sleep behaviors and positive reinforcement of adaptive sleep behaviors, are an added component. Despite the effectiveness of CBT-I, patients and families often encounter barriers (e.g., readiness to change) that can impede progress, so it is important that these barriers be identified and addressed throughout the course of therapy. Pharmacological treatment for insomnia also has been the subject of randomized clinical trials, but primarily with adults and geriatric populations. It has been noted that although medication can provide immediate relief for many patients, it does not address the maladaptive sleep behavior patterns that often lead to and maintain many sleep disorders. For youth, it has been recommended that medication not be the first line of therapy, and, when used, it should be taken only on a short-term basis. In contrast, treatment of OSA often involves surgical procedures (e.g., tonsillectomy and adenoidectomy), particularly in children, weight management (when obesity is a complicating factor), and CPAP in both youth and adults. Psychological treatment still is an important component in the treatment of OSA, because adherence to CPAP use and weight loss procedures typically is low across age groups. Consequently, behavioral and cognitive-behavioral strategies have been found to be useful in identifying and addressing barriers to regimen adherence. Given the chronic nature of this health condition, future research needs to identify efficient and effective methods for monitoring and promoting long-term adherence, particularly within a primary care of sleep specialty clinic setting.

Taken together, the field of sleep medicine has advanced substantially over the past few decades regarding the assessment, diagnosis, and treatment of insomnia and OSA in individuals across the life span. Because sleep difficulties are a common problem in most health care settings, it is imperative that psychologists achieve

a basic understanding of these disorders as well as evidence-based assessment and treatment strategies to address them. Indeed, psychologists can fulfill an important role in assisting medical teams not only in the identification of these concerns via standard screening procedures but also by intervening with evidence-based treatment when such concerns are identified.

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# Chapter 22

## Managing Chronic Pain in Primary Care

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### Introduction and Background

Because pain is one of the primary reasons for an individual to visit their primary care provider (PCP; [77]), a great deal of work has been done to assess the efficacy of integrating pain management into primary care settings. This is especially true since musculoskeletal pain is the second leading symptom prompting all primary care visits [15]. The most common medical setting a clinical psychologist is likely to work with chronic pain patients is within primary care settings, which will be the focus of this chapter. However, many of the topics discussed in this chapter are applicable to any medical setting dealing with chronic pain patients. This chapter's recommendations are particularly well suited to a medical home model of primary care (covered in Chap. 14).

Defining “chronic” pain can be deceptively difficult and there are numerous inconsistencies in research and clinical domains regarding when pain actually becomes chronic. Researchers tend to define “chronicity” as a set duration of pain since the time of onset or expected wound healing. Some of the most commonly used durations defining chronic pain range from 3 to 6 months. Treatment providers seem to prefer either an absence of demonstrable pathophysiology or recalcitrance to medical interventions. Though rarely endorsed in the research, the most sensible way to identify a complex problem like chronic pain is to designate it as chronic as soon as symptom complexity is noted. For example, an individual with a broken arm will certainly experience some endured pain with fleeting emotional distress.

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However, if the arm eventually heals without significant emotional distress, cognitive distortions about the quality or meaning of the pain, or severe functional deactivation due to concerns about reinjury, then the pain was never really chronic regardless of how long it took the arm to set and the pain to remit. If, however, a person stubs a toe and has alarming emotional and cognitive responses to the injury resulting in quality-of-life impairment and functional limitations, then that could reasonably be called “chronic pain.”

There are various theories that try to elucidate pain chronicity by explaining how and why acute pain transitions into chronic pain. While the literature discusses many potential attributes for the transition of acute to chronic pain, none fully explains the complexities that lead to chronic pain. Regardless of how acute pain transitions into chronic pain, chronic pain continues to be a significant problem in primary care. Chronic pain is a complex phenomenon, and attempts to define chronic pain vary significantly. The primary requirement for a chronic pain condition is a patient’s subjective report of enduring pain. It is unclear, however, how long pain must persist before it is considered chronic. Research initiatives define chronic pain as pain lasting anywhere from 3 to 6 months, though more clinical definitions require pain lasting beyond the expected healing time for an injury. Unfortunately, none of these definitions adequately captures the true breadth of chronic pain, which can manifest through musculoskeletal, neuropathic, or inflammatory physical pathways. Examining the overlap and divergence of chronic versus acute pain can be a good starting point for better understanding chronic pain, especially for those who are unfamiliar with chronic pain. Acute pain is familiar to the vast majority of people, while chronic pain is familiar to only a few. Though some acute pain can last for weeks, it is reasonable to expect that the pain will completely ameliorate with medical intervention. Chronic pain, on the other hand, is less responsive to medical treatment and eventually begins to frustrate the patient who may lose hope in a cure. Acute pain is clearly tied to a specific etiology and patterns in the pain are reflective of aggravations of the pain associated with additional harm (e.g., overexertion of a strained muscle that causes additional pain). At times, there can be no clear etiology for the onset/maintenance of chronic pain and variations in chronic pain may not reflect additional harm at all. Finally, acute pain dissipates quickly enough for the patient to return to full functioning with minimal suffering while chronic pain endures long enough for psychosocial distress to set in and contribute to the pain experience.

The best clues for differentiating between chronic and acute pain may lie in theories underlying how pain transitions from acute to chronic. One of the earlier theories of physical factors contributing to chronic pain development focuses on the role of physical deconditioning in response to acute pain development [31]. According to this theory, an individual suffering from short-term pain responds to the pain by significantly decreasing physical activity in order to allow an injury to heal and to avoid the experience of pain related to the injury (a phenomenon closely tied to recommendations of bed rest after injury). When a person becomes overly reliant on rest to avoid pain and possible reinjury, they experience a decrease in muscle mass (i.e., atrophy), skeletal density, and connective tissue strength. All of these sequelae result in multiple physiological weak links that prevent the body from adequately

compensating for an injured part. Activity must be carefully balanced to ensure that the patient is active enough to maintain strength throughout the body but not so active that additional injury is incurred. Overexertion can complicate healing and perpetuate the experience of pain, while overreliance on rest may contribute to atrophy that weaken other support structures in the body that can help support an injury (e.g., deconditioning). Deconditioning will sometimes occur because an individual misattributes soreness and pain during healing as symptoms of additional injury and harm and responds through underactivity in order to minimize the perception of pain. This phenomenon, commonly referred to as kinesiphobia or fear avoidance, ultimately results in an acute pain sufferer who adopts an almost permanent patient role that disallows them from adequately rehabilitating an acute injury and progressing on to chronic pain [24].

Recent data suggest that acute pain conditions that are poorly treated and present with intense pain are significant risk indicators for the development of chronic pain. Sinatra [68] examined the consequences of inadequate acute pain management through a comprehensive literature review and found that poorly treated acute pain can have significant impacts that may contribute to the development of chronicity. He noted significant decrements in quality of life, sleep quality, and physical functioning as well as stressful economic costs associated with increased health care utilization among poorly treated acute pain sufferers. According to Sinatra, intense acute pain and the consequences of poor pain treatment are likely contributors to a transition to chronicity. Conversely, Sinatra found that effective acute pain control mitigates these risks and actually reduces the risk of chronic pain development.

Increased body weight (due to decreased physical activity) may contribute to chronic pain development. It makes sense that increased body weight can add to musculoskeletal burden that can impact orthopedic pain experience. Unfortunately, many pain sufferers may be at increased risk of gaining weight through decreased physical activity and the use of some pain treatment medications with a weight gain side effect (e.g., steroids). Though subtle weight gain has not yet been directly tied to chronic pain development (with the exception of heel pain, see [33]), obesity has been clearly linked to chronic pain development through various proposed mechanisms. Obesity commonly occurs in musculoskeletal pain with some prevalence estimates ranging up to 50% [54]. A study of fibromyalgia sufferers revealed that obesity contributes to increased tender point and visceral pain sensitivity [54]. The authors note that the relationship between pain and obesity is unclear but posit that physical deconditioning due to decreased physical exercise capacity and altered endocrine and endogenous opioid processes are likely contributors. Vincent et al. examined fear avoidance in obese and nonobese chronic low back pain sufferers and found that obese low back pain patients are more likely to experience decreased quality of life and increased fear avoidance that significantly predict self-reported disability compared to nonobese patients. Ray et al. [64] found that obesity doubled the risk of chronic pain development in an elderly sample, and they confirmed that the contribution of obesity to chronic pain is strong and independent of obesity-related conditions like insulin resistance, inflammation, osteoarthritis, and diabetic neuropathy.

Psychosocial factors like learning, emotional distress, and pain-related catastrophic beliefs have been implicated in the transition between acute and chronic pain. A comprehensive review of these factors is beyond the scope of this chapter, but recent data continue to support the significant role of psychosocial and behavioral contributors to chronic pain development. Some researchers posit that the roots of chronic pain begin well before acute pain is incurred. Goubert et al. [28] suggest that simply observing others responding to pain in an alarming or resilient fashion can make the observer vulnerable or resistant to developing chronic pain later. The authors suggest that a clear understanding of how observational learning contributes to development and maintenance of chronic pain would greatly add to pain management and prevention efforts. In support of this, operant conditioning models of pain in which pain report was punished or reinforced have shown an effect of learning on pain perception (see [36]).

Emotional distress is an undisputed consequence of pain, and some evidence seems to suggest that acute pain with comorbid emotional disturbance results in chronic pain development. McMahon et al. [47] emphasize a strong etiological role of psychosocial distress in chronic pain development, which is a significant concern due to estimates of comorbid pain and depression/anxiety ranging from 10 to 100% [57]. One hypothesis concerning the increased rates of psychopathology among chronic pain patients is based on a “diathesis-stress model” [75]. Dersh et al. [13] suggest that there may be a diathesis or substrate for the development of psychopathology for these individuals existing before their injury in which “semi-dormant psychological characteristics...are then activated by the stress (associated with chronic pain and disability)” (p. 466). Another hypothesis set forth by Gatchel [24] explains the high rate of psychiatric conditions among chronic pain patients as the result of “worn-down” defenses depleted by one’s ongoing struggle in coping with chronic pain and disability. The lack of emotional defenses makes the individual unusually susceptible to the development of psychopathology, including depression and anxiety, which can “overlay” or intensify one’s pain thereby depleting them further in a vicious cycle. To date, the true nature of the link between emotional distress and chronic pain has yet to be fully understood, and attempts to identify a “chronic pain personality” have been largely unsuccessful [70]. Despite the mysteries that remain about the exact nature of emotional distress in chronic pain, the patient’s reported suffering is real and should be taken seriously [58].

Recent evidence strongly supports the role of depression and anxiety in chronic pain development and maintenance. Depressive disorders are common among chronic pain sufferers with an estimated prevalence of up to 65% [60]. High chronic pain severity has been independently associated with increased levels of depressive symptoms [35], and the presence of chronic pain has been identified as a risk factor for higher symptom severity, suicide risk, and general psychosocial functioning among depressed individuals [59]. Poleshuck et al. [60] suggest that pain and depression impact one another reciprocally and note that comorbid pain and depression ultimately result in poor treatment outcomes for either condition, making treatment difficult for this population. Asmundson and Katz [2] offer a comprehensive review of the role of anxiety in chronic pain. The authors site multiple epidemio-

logical studies of anxiety disorder comorbidity in chronic pain with a prevalence of around 30%, though some estimates for specific anxiety disorder diagnoses are much higher (e.g., post-traumatic stress disorder, PTSD). They note that there is little evidence to support the theory that anxiety disorders cause chronic pain to occur; however, they do offer a description of a mutual maintenance model in which symptoms or characteristics of chronic pain and anxiety maintain and exacerbate symptoms between the two conditions.

## Review of the Evidence

Pain management services are frequently requested within primary care settings. Despite its frequency, PCPs often find pain management challenging and may not be as satisfied with their ability to treat chronic pain compared to other chronic health conditions [76]. Furthermore, despite the existence of several chronic pain practice guidelines, provider approaches to pain management appear to be variable with little consensus on which treatment options are best [56]. For example, Phelan et al. surveyed 382 general internal medicine physicians on their preference among multiple, specific clinical treatment options for chronic pain management. The investigators found wide variation in the preferred treatment for pain among the physicians surveyed including varying attitudes about the etiology of chronic pain symptoms, the role of opioid medications in pain treatment, the applicability of the biopsychosocial model to pain care, and the extent to which the physician needs to engage in treatment with the patient. Matthias et al. [44] interviewed 20 primary care physicians about their experiences treating chronic pain. They found that many providers found pain treatment (or the patients with chronic pain) difficult. The physicians indicated a need to better understand their pain patients and their treatment needs. Matthias et al. point out that chronic pain providers need help developing empathy for their patients and are vulnerable to burn out that can result in erosion of the quality of patient care. For these reasons, a clinical psychologist working in a primary care clinic is a strong resource for helping PCPs better understand their patients, manage their own work-related stress, and, ultimately, provide better pain care.

Studies examining patient attitudes about chronic pain management in primary care also paint a similarly distressing picture. Upshur et al. [76] note that most patients are dissatisfied with chronic pain management in primary care, citing a number of other studies in which fewer than 20% of patients treated rated their care as helpful or “excellent.” The investigators used focus groups of primary care non-malignant pain sufferers to more thoroughly assess patient perceptions of chronic pain treatment in an independent primary care environment. Most of the focus-group patient reported dissatisfaction with their pain treatment, citing provider-related barriers to care (i.e., not feeling respected by their provider, being labeled by providers as hypochondriacs, and being accused of drug seeking) and medical system barriers (i.e., limited provider access to comprehensive assessments of pain and the



perception that a pain sufferer is a “burden to the system”) as primary factors in poor care. This study emphasized the vital need for PCPs to gain a comprehensive understanding of the difficulties faced by chronic pain patients and the significant benefit potential of developing a stronger relationship with their patients allowing for clearer communication.

It is obvious that a transition to a patient-centered medical home (PCMH) model of primary care (see Chap. 14 for core principles of the PCMH) could allow for much needed improvements in medical management for most pain sufferers. Furthermore, a collaborative care environment in which multiple disciplines (including clinical psychology) are able to interact in developing a comprehensive assessment and treatment approach may offer the best solution to maximizing the benefit of primary care pain treatment. A number of collaborative care pain models have been examined and one of the best examples of these efforts is the Study of Effectiveness of a Collaborative Approach to Pain (SEACAP), undertaken to evaluate the integration of collaborative pain care in the veterans affairs primary care system. The SEACAP typically involves the integration of an internist and clinical psychologist pain care manager (and sometimes a physical therapist) into primary care as chronic pain management consultants. In this model, the psychologist pain care manager conducts initial and follow-up assessments, provides patient education and functional activation, gathers data for PCPs, helps develop treatment goals, and assists with referrals [17]. Preliminary studies of this collaborative model have shown moderate treatment effects [17, 18], while subsequent research has shown a significant improvement in the number of pain disability-free days for SEACAP patients compared to those who receive treatment as usual [16]. The SEACAP investigators aptly point out that maximizing the effectiveness of primary care pain treatment is vital not only to improve patient care but also limit the high costs associated with pain treatment. There is some cost increase attributable to introducing additional pain treatment resources into primary care, though these costs likely pale in comparison to relying on medical management alone. Turk [74] has noted that opioid medication management of chronic pain can cost more than US\$ 4,000 per year and surgeries can result in tens of thousands of dollars in additional costs. In contrast, the SEACAP intervention was found to add an additional US\$ 2,300 in treatment cost with the added benefit of decreased disability and improved health-related quality of life.

Other collaborative care programs have focused on providing multidisciplinary pain care to primary care patients in a group format. The Pain Day Program was developed as a single-session, 75-minute group medical visit focusing on psychoeducation and behavioral health consultation for chronic pain sufferers. Moitra et al. [50] developed the program in response to widespread complaints among primary care physicians about the difficulty of treating chronic pain patients. The Pain Day Program curriculum offers education about the physiological mechanisms of pain and medical pain treatment options as well as cognitive and behavioral interventions aimed at helping pain patients overcome dysfunctional thinking and behavior related to pain. Collection of outcome data is under way for this program, though the investigators do note that pain care providers appreciate the single-session pro-

gram and feel as though referring patients to the program lessens the burden they feel in caring for their complex patients.

A strong case can be made that the integration of clinical psychology pain management in any setting is beneficial for the patient as well as the medical provider. The skilled clinical psychologist should work closely with treating providers to develop a comprehensive understanding of the patient and to convey this understanding to the medical provider. This could be accomplished through assessments and working collaboratively (with the patient and provider) to develop treatment goals. When done correctly, this kind of collaboration can help providers gain a stronger understanding of factors contributing to the patient's pain experience and acquire greater empathy for the suffering of the patient (which is more noticeable in a comprehensive psychosocial evaluation versus a physical exam). Furthermore, close interaction with the medical pain care provider will allow the clinical psychologist ample opportunity to informally assess for provider burnout and offer intervention or advice when necessary. It also may be beneficial to develop treatment aims for the patient that include learning how to effectively communicate treatment needs to their providers in order to promote the best understanding of their needs, which ultimately allows for better clinical outcomes for the patient.

## Assessment

The evaluation of chronic pain conditions is a primary concern for all treatment practitioners, though the assessment of pain can pose unique challenges including inconsistency in how pain is defined. As noted, chronic pain has been linked to several etiological factors, including physical stress, psychosocial variables, job strain, social variables, and even smoking, all of which should be considered in assessment [6]. Accordingly, Price et al. [62] indicated that a "good" pain assessment strategy should target specific aspect(s) of the complex pain concept in a valid and reliable way. This strategy represented a significant change in the way in which pain assessment was conceptualized. The earliest measure of pain was based on the patient's subjective report upon presentation for medical treatment, often consisting of a simple and unidimensional assessment of the construct [37]. Because pain is one of the most common reasons people seek medical treatment, pain has been added as the fifth vital sign [51]. The fifth vital sign requires the use of a numerical rating scale (0=no pain, 10=worst pain possible) at clinical encounters. Any patient report of a 4 or higher should trigger an in-depth assessment and prompt intervention. The use of the fifth vital sign stresses the importance of assessment that leads to better pain treatment. Contemporary pain assessment strategies need to tap multiple domains that comprise a comprehensive biopsychosocial conceptualization. These domains should include demographics, emotional factors related to pain, self-report of pain quality and intensity, quality of life, cognitive factors, behavioral factors, and perceived disability.

## ***Demographics***

Although they are not generally modifiable, pain-related demographic factors are a foundational component of pain assessment. Chronic pain symptoms have shown systematic variance along demographic dimensions such as age, gender, race, and socioeconomic status (SES; [38]). The incidence of chronic pain increases with age, with older adults more likely to report musculoskeletal pain, and pain coping strategies seem to differ as one ages [69]. Studies of gender have shown systematic differences in low back pain prevalence across the two genders. For example, males have shown a higher rate of low back pain related to workman's compensation, likely due to a higher concentration of males in jobs requiring greater physical exertion [38]. Low SES and African American ethnicity have been correlated with an increased frequency of chronic pain symptoms (including disability), though the exact nature of this relationship seems to be complex and difficult to clearly discern [23, 27]. Racial differences, in particular, may impact chronic pain through racially based differences in health care utilization and attitudes toward health care. Green et al. [29] found that African American ethnicity may impact chronic pain treatment based on differences in health care coverage and the overall ability to pay for health care services for pain.

## ***Emotional Factors***

McMahon et al. [47] stress that psychological factors (depressed mood, anxiety, stress) play a major role in the development and maintenance of chronic pain and it has become evident that chronic pain assessment must include the assessment of comorbid or contributing emotional states or psychopathology [13]. Gatchel [24] explains that emotional disturbance is common, but may be a cause or maintenance rather than a by-product of pain. Research confirms that emotional factors are substantively implicated in chronic pain onset, maintenance, and course (to some extent), which is concerning based on reports that show an estimated comorbidity of emotional disturbance in the chronic pain ranging from 10 to 100% [57]. It can be difficult, however, to identify a single focus for emotional assessment in pain. The mere assessment of general emotional distress may not be enough to fully describe the complex relationship between emotions and pain due to differences in pain interference across emotional disturbances. For example, individuals with depression and anxiety diagnoses differ according to the amount and nature of intrusion the psychopathology has on pain. Polatin [57] states, "...patients with an anxiety neurosis tend to have a lower pain threshold, whereas depressed patients' thresholds may vary" (p. 152). Furthermore, some forms of psychopathology, notably anxiety, may deteriorate one's ability to cope with pain, thereby "greasing the wheels" for the development of chronic pain.

Assessment tools for emotional distress are plentiful and each scale offers unique advantages and drawbacks. A full review of emotional assessment is beyond the

scope of this chapter, so the reader is referred to Worzer et al. [84] for more information, though we will use the example of depression scales to illustrate how and why certain options may be used. Commonly used measures of depression in chronic pain include the Beck Depression Inventory (BDI-2; [4]), the Hamilton Depression Rating Scale [30], and the Center for Epidemiological Studies Depression Module (CES-D; [63]). Some prefer the CES-D over the BDI due to a decreased reliance of somatic items on the CES-D. However, alternative scoring and interpretation guidelines have been offered for the BDI-2 which limit the spurious impact of somatic items on depression assessment with pain patients [61]. Additionally, the CES-D lacks an item assessing suicide risk in pain, which is a particularly important factor to include in a medical setting where personnel, who do not routinely assess for suicide risk by interview, often carry out screening.

### ***Pain Quality and Intensity***

In clinical practice, the assessment of pain quality is an important assessment parameter and entails the words one uses to describe pain [83]. Self-report measures of pain intensity are among the most commonly used measures of pain quality and intensity and there a number of ways to measure the fifth vital sign. Scott and Huskisson [66] observed that “the measurement of pain must always be subjective since pain is a subjective phenomenon—only the patient can therefore measure its severity” (p. 184). In order to accomplish this, the majority of pain intensity measures utilize either a numeric rating scale (NRS) or visual analog scale (VAS). NRS, in which a pain sufferer is asked to rate his or her pain on a numerical scale (often ranging from 1 to 10 or 1 to 5), are widely used due to the possibility that they could generate interval or ratio data (which allows for a more sensitive measure). Some argue, however, that VAS for pain assessment, described as “a straight line, the ends of which are defined as the extreme limits of the sensation or response being measured” ([66] p. 175), allow for a more continuous, and therefore reliable, scale of pain intensity. A good VAS or NRS should specifically define the sensation being evaluated, with definite cutoff points at the median response thought to occur in the exact center of the line [66]. Captions at either end of the scale should be behaviorally worded (e.g., a pain rating of 10 on a 0–10 scale should be labeled “pain bad enough to seek treatment at the emergency room” instead of “extreme pain”), and descriptors should be short and easily understood. These guidelines allow for a more reliable measure.

### ***Health-Related Quality of Life and Cognitive Factors***

There are a number of social and cognitive variables to consider when assessing chronic pain. In the social domain, primary consideration is often given to the measurement of quality of life and approaches to coping with a chronic musculoskeletal

pain condition. Health-related quality of life is a significant concern for any individual struggling with a chronic health condition. Quality of life can be a difficult concept to assess and multiple options are available to capture this concept. The World Health Organization has developed a model of quality of life specifically for chronic pain with six major facets including physical health, psychological health, level of independence, social relationships, environmental concerns, and spirituality [43]. Most practitioners who work with patients with chronic pain choose to assess quality of life using the Medical Outcomes Survey, Short Form (SF-36; [82]), a comprehensive health survey of 36 items originally created for clinical and research use in the assessment of health-related quality of life. Mason et al. express some concerns that the SF-36 is a research tool that lacks sensitivity for some of the specific concerns associated with chronic pain (e.g., sleep concerns), so other options should be explored before settling on a quality-of-life measure (e.g., the World Health Organization Quality of Life-Pain, WHOQOL-Pain; [42]). Ultimately, the SF-36 is the most widely researched and consistently used tool for measuring health-related quality of life in chronic pain and its use is recommended in most cases due to the excellent access to scoring interpretations for numerous pain-related conditions.

Although a number of cognitive domains contribute to chronic pain experience, the concepts of fear avoidance, pain acceptance, and pain catastrophizing are starting to receive a great deal of attention. Briefly, the term “fear avoidance” refers to a purposeful decrease in functional activity due to concerns about harm that may result from the activity, even when these concerns are not substantiated. Fear avoidance accompanies a confusion regarding activity-related increases in pain intensity. Pain sufferers who experience an increase in pain during physical activity may confuse this pain increase as harmful, when, in fact, the pain increase represents natural muscle soreness due to physical deconditioning or other nonharmful activity-related pain. Activity may be unnecessarily decreased due to these concerns, further contributing to deconditioning and removing the pain sufferer from access to external coping resources that may help him better manage his pain. Commonly used measures of fear avoidance include the Fear Avoidance Beliefs Questionnaire (FABQ; [81]) and the Tampa Scale for Kinesiophobia (TSK; [39]).

Acceptance of chronic pain is described as living a meaningful life despite feeling sensations of pain [79]. Pain acceptance can play a significant role in how an individual responds to pain and engages in pain treatment. Those with a newly diagnosed chronic pain condition may experience initial difficulty accepting that the condition is chronic and focus on treatment with a short-term view, often with the hope of finding a “cure” or “fix.” This can result in a hesitancy to engage in chronic pain treatment modalities that are aimed at long-term management and improved quality of life, resulting in unnecessary suffering. There is growing evidence that failure to treat chronic pain adequately within 6 months after chronicity sets in leads to an increase in pain intensity and depression that may be attributable to maladjustment associated with poor pain acceptance [45]. The Chronic Pain Acceptance Questionnaire (CPAQ; [26]) is one of the most notable measures designed to assess the acceptance of chronic pain.

Pain catastrophizing is best defined as “an exaggerated negative mental set brought to bear during actual or anticipated painful experience” [72]. Sullivan et al. [73] suggest that there is a link between catastrophic thinking and the development of chronic pain. He stated that catastrophic thinking contributes to higher levels of pain and emotional distress, increasing the likelihood that a pain condition will persist over an extended period of time. The Pain Catastrophizing Scale (PCS) was developed in 1995 by Michael Sullivan et al. at the University Centre for Research on Pain and Disability [71]. It is one of the most widely administered scales to examine the impact of catastrophic thinking on pain symptoms. Developing a sense of pain acceptance contributes to motivation to engage in pain management treatment and may have an impact on catastrophic thinking about pain. Little is understood about the specific relationship between these phenomena, though studies are currently under way to explore the relationship between catastrophic thoughts about chronic acceptance of chronic pain.

### ***Behavioral Factors and Perceived Disability***

The assessment of behavioral symptoms associated with chronic musculoskeletal pain can add significantly to one’s understanding of how a chronic pain condition is developed and maintained [80]. Evidence of muscular bracing (evidenced through static postures or other purposeful limitations of movement) suggests increased muscle tension, which can add to pain intensity through pulling at a pain site. Though easy to spot, pain behaviors are difficult to interpret. Main and Waddell [41] suggest that pain-related behaviors (like changes in gait or posture) should be interpreted in light of subjective disability and functional ability data to best describe the impact of pain on functioning. Furthermore, these authors argue that some behaviors that are believed to be a sign of malingering or symptom exaggeration are actually evidence of real suffering. In other words, a patient who exaggerates a pain symptom may be doing so more to convince others about the severity of their pain rather than trying to achieve some other secondary gain. This kind of phenomenon is understandable in chronic pain because the primary symptom is subjective (i.e., not outwardly notable to others, especially if the patient is working hard to appear “normal”). Audible utterances in response to pain exacerbation may be a sign of distress or a way of eliciting help when it is needed. All pain behaviors are relevant to chronic pain assessment and should be documented. Some behaviors may even help a treating practitioner identify the role of emotional distress in functional impairment (cf [41]). Pain behaviors can be easily assessed through observation of the patient, though some formal scales do exist (e.g., The UAB Pain Behavior Scale; UAB, University of Alabama).

Pain disability can be quantified functionally (through an assessment of physical impairment) and behaviorally (through an assessment of psychological impairment), but assessing the subjective component is also important. De Souza and Oliver Frank [14] interviewed 11 chronic pain sufferers about the impact of chronic

pain on their daily functioning. They identified multiple themes associated with the impact of pain on daily functioning including concerns about being a burden to loved ones, the need to push through physical and emotional symptoms in order to function normally at work, as well as the ultimate fear of unemployment if unable to persist at work. The thorough assessment of these concepts can help to improve a behavioral health practitioner's understanding of the impact of pain on a patient's daily living and provide meaningful targets for treatment and treatment outcomes. Fortunately, there are good self-report measures available that can contribute to assessment of subjective disability. Two of the most commonly used measures include the Oswestry Disability Inventory (OSI; [20]) and the Million Visual Analog Scale (MVAS; [49]).

## **Evidence-Based Practice**

### ***Primary Care Treatment***

There is a vital need to enhance the quality of treatment provided in primary care [65]. Improved primary care treatment can reduce inequities in health care through more accessible treatment, greater accountability for care, and the integration of evidenced-based processes of care into practice [34]. DeGruy and Etz [12] caution, however, that adequately addressing psychosocial issues in primary care can be time consuming and, consequently, prohibitive. There are multiple models of primary care integration that may help overcome the time burden of addressing psychosocial concerns, including a transition in the role of the PCP to that of a multidisciplinary collaborator and care integrator. To emphasize the difficulty of accomplishing this, however, Hollingsworth et al. analyzed 2007 data from the National Ambulatory Medical Care Survey and found that PCPs who assume responsibility for specialty care of patients with chronic pain would need to work an additional 3 weeks per year in order to account for the extra time needed in treatment. Hollingsworth et al. suggest that care responsibilities can actually be offset to nonphysician clinicians (i.e., clinical psychologists) to help account for the additional treatment need in primary care and take treatment burden off of the beleaguered medical provider. Runyan provides a brief overview of data supporting the efficacy of providing behavioral health consultation in primary care as well as helpful guidance for transitioning nonmedical providers into a medical environment. For more detailed information about integration of psychologist in primary care, please see Chap. 14 in this book.

A number of variables influence how chronic pain patients access treatment in primary care and the eventual outcome of medical treatment. In a detailed analysis of cost associated with a multidisciplinary pain management consultation model, Dickinson et al. [16] note that age, depression, and chronic disease burden can all impact health care utilization and costs. They found that a 1-year increase in age

was associated with a 0.9% increase in treatment costs while one-unit increases in depression and disease burden were associated with 2.1 and 7.9% increases in treatment costs, respectively. An additional study by Dunn et al. [19] examined prognostic indicators for poor outcome in primary care treatment for low back pain. The investigators found that low back pain treatment failure was predicted by a number of factors including high levels of pain intensity, comorbid upper body pain, functional disability, pain episode duration, anxiety, self-rated health, and employment. Some of these factors are amenable to medical treatment (e.g., opioid management of severe pain intensity) while others require psychosocial intervention best provided by a clinical psychologist. Moitra et al. [50] found that depression is directly correlated with emergency department visits in the past 3 months. They also revealed that depression and general acceptance of pain were directly related to more severe symptoms as measured by numerous measures of pain.

### ***Relaxation***

There is also evidence to support the use of discrete, short-term pain self-management interventions in primary care [78, 7]. Relaxation has been widely supported as an effective chronic pain management tool for pain relief and decreased disability associated with relaxation for chronic pain [52] and is an intervention that is possible to implement in primary care in a single appointment. Austrian et al. [3] found that relaxation therapies are not frequently used by physicians in primary care due to barriers including time constraints and concerns about efficacy; however, relaxation therapies are ideal for use by a clinical psychologist in primary care. They suggest that relaxation should be introduced to primary care patients along with an assessment of potential barriers to relaxation practice. Identified barriers should be addressed to ensure that relaxation can and will be utilized to maximum benefit.

### ***Cognitive and Behavioral Therapies***

Cognitive and behavioral therapies (CBT) have also been widely supported in the successful management of chronic pain. Typically, CBT treatments take place in a behavioral health treatment environment and can require numerous sessions to obtain maximum benefit. These characteristics of CBT call into question the likelihood of successfully translating CBT interventions into primary care. Heapy et al. [32] examined the efficacy of a primary-care-based CBT treatment protocol for chronic pain (PRIME CBT) in a sample of 89 chronic pain sufferers with either neuropathic or musculoskeletal pain. Patients were asked to identify self-management goals to improve pain management and treatment adherence was compared to typical CBT treatment delivered in a behavioral health clinic, and a no-CBT treatment control. PRIME CBT was associated with significantly greater rates of treatment goal accomplishment compared to those who did not receive CBT, and there was



no difference in treatment adherence between the standard CBT and PRIME CBT treatments. The authors conclude that, regardless of the setting of treatment delivery, skill practice (i.e., homework) outside of the treatment session mediated the relationship between readiness to change and pain management outcomes.

## ***Exercise***

Exercise can be one of the most beneficial treatments for chronic pain management, especially for pain of musculoskeletal origin [52]. There are limited studies examining the efficacy of exercise-based interventions in primary care, though the few existing studies are encouraging. Angstrom et al. [1] examined a primary care-based exercise protocol delivered to 122 chronic musculoskeletal pain patients being treated in primary care. Participants with musculoskeletal pain received eight to ten sessions with a physical therapist that focused on structured physical exercise based upon exercises individually adapted for the participants based on physical impairment. The authors found significant improvement in pain-related disability for those who received the exercise intervention, and gains were maintained for at least 2 years. Additionally, those receiving the exercise intervention showed continued (though nonsignificant) improvement in symptoms for the 2 years after treatment concluded. However, when compared to a primary care-based tailored behavioral health treatment protocol, the exercise-alone intervention appeared to offer lesser benefit compared to behavioral health treatment.

## ***Enhancing Patient–Provider Communication***

Because of its subjective nature, communicating with others about chronic pain can be quite difficult. Nilsen and Elstad [53] found that patients with pain feel as though their pain experience is poorly understood by their health care providers, resulting in disappointment in care and poor treatment effectiveness. Similar results were found among women with chronic pelvic pain. McGowan et al. [46] surveyed 32 women seeking treatment for chronic pelvic pain. Some of the women expressed emotional distress in response to negative consultations with physicians, especially when the pain was difficult to explain through demonstrable pathophysiology. The authors explain that such negative consultations leave a patient with pain doubting her own understanding of her pain, which creates significant difficulties in communicating pain concerns and treatment needs to others. Furthermore, perceptions that others do not believe in one's pain can result in feelings of rejection and withdrawal from care. McGowan et al. emphasize the importance of instilling empowerment for chronic pain patients who do not feel as though they are being taken seriously in medical treatment. This can be accomplished through a thorough biopsychosocial assessment aimed at comprehensive assessment of pain experience as well as communication training in which a patient is taught how to assertively pursue treatment and avoid passive responses to perceived poor care.

## *Lifestyle*

Chronic pain conditions have been shown to have a high comorbidity with overweight and obesity [40]. The mechanisms underlying this comorbidity are not well understood, though existing research sheds some light on how overweight and chronic pain impact one another. Wright et al. [85] reviewed records from 3,645 twins in the University of Washington Twin Registry. Data analyses revealed a clear link between chronic pain and obesity that was greatly mediated by depression, though the authors acknowledge the likely role of inactivity and sedentary lifestyle that can exacerbate both pain and weight issues. Another study examined the impact of a weight loss intervention on pain symptoms using a sample of overweight and obese women diagnosed with fibromyalgia [67]. Women who received the weight loss intervention lost approximately 9 pounds over the 20-week intervention, and weight loss was associated with significant improvements in multiple pain outcomes including pain interference and quality of life. Based on these results, weight loss may be a promising adjunctive treatment to specialty medical care. Currently, there is no available research data exploring the chronic pain benefit of a brief weight loss intervention that could reasonably be implemented in primary care. However, there are data available to support the efficacy of brief weight loss interventions delivered in primary care (cf [11]), which supports the notion that primary care weight loss interventions could benefit chronic pain patients. Future research examining ways to deliver efficient weight loss interventions through primary care would be of benefit.

## **In Practice**

Most available evidence strongly supports the benefit of integrating clinical psychology services into primary care in order to best serve chronic pain patients. The following section includes practical tips for the clinical psychologist to succeed within a primary care setting. The evidence-based assessment and treatment options already covered in this chapter should serve as a framework for the use of the following recommendations.

For a number of reasons, the integration of the clinical psychologist into the medical practice can be perilous (e.g., it can be difficult to offer psychosocial services to a pain patient who did not expect to see a mental health provider during a medical visit). One of the best ways to begin this process is to collaborate closely with the treating medical professional (i.e., physician, nurse practitioner, physician's assistant) and clarify the role that the psychologist will have in pain treatment. Medical pain care providers may also vary in the extent to which they would like to interact with the clinical psychologist. For example, the psychologist could be asked to function as either an interdisciplinary collaborator (who works in unison with the medical provider to develop treatment plans) or a multidisciplinary consultant (who may independently manage a patient's psychosocial distress and self-management targets without collaborative input from a physician). Although a collaborative role is preferred, clarifying these roles can be beneficial for the provider (who gains the

desired level of access to the psychologist's services), the patient (who receives more integrated care), and the psychologist (who is able to function as a valued part of the team).

As the clinical psychologist becomes involved in the medical home environment, she should start to learn basic information about the various medical treatment options available to her pain patients. Common medication classes, pain relief injections, implantable devices, and even surgical options should be discussed with the medical provider. Understanding these options not only imbues the psychologist with a greater level of legitimacy in the eyes of the patient and the medical provider but also allows the psychologist to better understand the realistic benefits and limitations (i.e., side effects) associated with each treatment. Familiarity with medical treatments helps the psychologist serve as a valuable resource in determining a patient's psychosocial suitability for certain treatment options (especially implantable technologies and surgeries) and provides the patient with an accessible source of basic information as well as an advocate if more detailed information is desired. One of the pitfalls of increased knowledge about medical treatments is the possibility that the patient (and sometimes PCPs as well) may begin to rely on the psychologist as a medical consultant (i.e., ask for opinions or advice about medical treatment options). It is vital that the psychologist maintain clear boundaries with the medical team and function solely within the scope of her or his practice. One way to accomplish this is to try to maintain balance in the flow of information by exchanging medical information received from providers with psychosocial education to improve the doctor's understanding of pain. This allows both sides to improve their practical understanding of pain and continually emphasizes the psychosocial role of the clinical psychologist in conceptualization and treatment. It is also recommended that the psychologist maintain contact with professional organizations dedicated to clinical psychology and clinical health psychology practice in order to avoid feeling separated from their professional roots and to have easy access to colleagues who can provide guidance and consultation if difficulties arise.

Engaging in treatment for chronic pain can be difficult in the primary care setting because of the high pace of care, limited time for intervention, and likelihood that intervention may be limited to a few (or even a single) sessions. As a result, assessment and treatment should be as brief and organized as possible and the use of educational materials as supplements for self-care or emotional management interventions should be provided as often as possible. A common repertoire for brief pain management typically includes a short, multidimensional assessment, psychoeducation about mechanisms of pain, a review of the biopsychosocial model of pain, teaching relaxation and stress management interventions, brief CBTs to address emotional distress and cognitive factors contributing to pain experience, and/or communication skills training.

Due to the complexity of chronic pain, brief assessment of pain can be a significant challenge. A short battery of measures tapping multiple dimensions of the chronic pain experience is ideal, but a high number of self-report measures may deprive the clinical psychologist of time for a clinical interview. In order to balance the needs for interview and self-report assessment, the psychologist should

begin with an interview touching briefly on the multiple domains of chronic pain including demographics, emotional distress, pain course/severity/duration, modifiable behavioral factors contributing to pain experience, social support, perception of disability, and the patient's history of interactions with the health care system for pain management. Once the interview is complete, the clinical psychologist may select self-report measures that target specific domains of interest. It is highly recommended that a measure of depression and suicide risk be provided regardless of the perceived need based on the interview. There are ample data to support an increased risk of suicide in the chronic pain population, attributable to characteristics of pain experience per se as well as the relatively high frequency of known suicide risk factors among pain sufferers [21]. As measures are being selected, the clinical psychologist should keep in mind that measures may be simplified or abbreviated to save time as long as validity and reliability are maintained. Some data are available to support single-item assessment of concepts like depression, suicide, pain intensity, and occupational factors (see [55], for an example). A wealth of information can be gleaned from a single NRS measure of pain intensity [25], which may negate the need for a more comprehensive evaluation of pain-related disability and coping. Pain behaviors can be observed and documented throughout the course of interaction with the patient and the assessment of cognitive variables contributing to pain could be accomplished as part of CBT treatment. Finally, information from the medical provider and support staff should be solicited before meeting with the patient to save time and help focus the interview.

Regardless of the chosen assessment strategy, all assessment should be conducted against a biopsychosocial backdrop. Thus, the clinical psychologist would benefit from beginning treatment with a brief (i.e., 10 min or less) discussion of the biopsychosocial model of pain and how this model informs assessment and treatment. One way to accomplish this is to provide the patient with a "pain quiz" and a diagram illustrating the biopsychosocial model of pain (an example of each is provided in the Appendix). After allowing the patient to complete the pain quiz, the clinical psychologist should discuss the results and use the discussion as a way to illustrate the biopsychosocial model of pain. Once the model has been discussed, the patient and the psychologist can use it to identify aspects of the patient's own pain experience that fit into the model and review how those components interact with one another to contribute to pain experience. For example, if a patient mentions that a bad night's sleep results in waking up in a bad mood the next morning, the psychologist can help the patient trace how a bad mood leads to negative social interactions and increased physical stress to result in increased pain experience (which, in turn, contributes back to the bad mood). Tracing connections between the domains of the biopsychosocial model in this way is a vital step because it serves as a rationale for how modification of one domain (e.g., emotional) can result in beneficial changes in other domains (e.g., social and physical). When done well, this brief interaction not only provides a solid rationale for the interventions to follow but also offers rich opportunities for assessment and helps the patient feel "understood" by the psychologist.

Once assessment is complete, simple interventions focused on pain management can be used in any order the patient or psychologist prefers. Many pain psychologists begin with simple relaxation exercises. This is a good place to start because relaxation interventions promote an immediate benefit that can help the patient buy in to other treatments and relaxation is familiar enough to most patients to be readily approachable. Some common, empirically supported relaxation interventions for pain management include diaphragmatic breathing, autogenic relaxation, progressive muscle relaxation, and imagery (worksheets for each of these relaxation strategies are provided in the Appendix). Most patients will benefit from a short explanation of the myriad benefits associated with relaxation for chronic pain. Once again, this can be accomplished by using connections between the domains of the biopsychosocial model of pain or through a discussion of the “fight or flight” model of stress response (a supplemental handout for which is included in the Appendix). Once a solid rationale for relaxation is given, the clinical psychologist can lead the patient through a short relaxation exercise and allow the patient to try it once or twice on their own before ending the session. After practice, it is helpful to review the patient’s experience and identify benefits of relaxation and any difficulties the patient had in using relaxation. Because experience and aptitude for relaxation techniques vary across techniques and across patients, the clinical psychologist should be open to trying different techniques if one does not work well and to encourage the patient to practice the skill at home to improve its effectiveness and ease of use. A relaxation log can be helpful for promoting practice (see Appendix for an example).

Cognitive and behavioral interventions (CBT) for pain management can be difficult to implement in short-term therapy, but these should be used if behavioral and cognitive factors (e.g., catastrophic or unrealistic thoughts about pain or pain treatment) are strongly implicated in pain experience. It is highly recommended that CBT interventions wait until a strong rapport has been established between the patient and the clinical psychologist (i.e., after assessment and relaxation interventions). These techniques require a greater level of commitment from the patient and a greater openness to treatment suggestions, especially because cognitive restructuring focuses strongly on psychological concepts that may either be foreign or unwelcome to a patient seeking medical treatment in a medical environment. CBT should begin with another review of the biopsychosocial model of pain (with particular focus on cognitive, behavioral, and emotional components) along with a brief review of the gate control theory of pain [48], which provides a physical foundation for the role of emotional factors in pain experience and treatment. Because there may not be ample time for a thorough assessment of each patient’s unrealistic or alarming thoughts about pain, it is recommended that the clinical psychologist start with a review of some of the more common (and common sense) alarming and reassuring thoughts associated with pain (a handout reviewing some of these is included in the Appendix). A structured worksheet or dysfunctional thought record (similar to that used by [5]) can help the patient learn how to identify, interpret, and restructure troublesome cognitions and track the consequences of addressing these thoughts (an example worksheet can be found in the Appendix).

Communication skills training is a highly beneficial and often overlooked treatment option for chronic pain patients. There is ample evidence to suggest that interactions in one's social environment can have a significant impact on pain experience. For example, a husband who punishes expressions of pain-related distress in his wife can actually contribute to emotional distress and isolation that can worsen pain. This punishment may take the form of a spouse telling his wife who is experiencing pain that she needs to stop talking about her pain and move on while refusing to help her physically. Conversely, a husband who is overly solicitous when his wife expresses pain can reinforce her pain behaviors and make it difficult for her to become independently functional. Helping a pain patient learn how to effectively communicate their needs to others can improve the social support that they receive and help avoid distressing social interactions that can lead to emotional disruption, stress, and subsequent worsening of pain. An additional benefit of communication training is that a pain patient can use those tools to better communicate treatment needs to their medical providers. Not only does this open the door to more effective medical management, it also benefits the provider by helping a frustrated patient learn how to express treatment concerns to the provider in an assertive (instead of aggressive) manner. There are a number of ways to teach communication skills in the medical home, and a few worksheets are provided in the Appendix covering some brief methods focusing on the discrimination between aggressive, passive, and assertive communication and specific considerations when communicating with health care providers.

Exercise can be one of the most beneficial recommendations in chronic pain management. There are a number of ways in which a clinical psychologist can greatly contribute to the benefit of exercise including increased adherence to exercise activities, improving motivation to exercise, overcoming unrealistic thoughts or expectations about exercise, and tracking the benefits of exercise activity. Unfortunately, exercise interventions for chronic pain patients can be difficult because patients may have mobility restrictions based on the mechanism of their pain and deconditioning that may have occurred due to underuse. To complicate things further, cognitive constraints like fear avoidance can make it difficult for the patient and the psychologist to adequately identify a patient's true functional capacity. Fear avoidance causes a patient to avoid certain activities (such as social or physical activities) in fear that these activities will cause an increase in pain [10]. For example, a patient with low back pain whose health care providers have cleared them for light lifting may still avoid lifting at all costs if they erroneously interpret lifting-related back pain exacerbations as signs of harm to their back. The patient may need help to plan and adhere to an exercise program that is safe, effective, and designed to help them gradually increase functional activity without using pain as guide, which should only be done with input from a medical care provider to ensure that no true harm will befall the patient. Ideally, the exercise program should be developed in collaboration with the patient, PCP, and/or physical therapist (who is a good judge of which activities are likely to be safe and beneficial). If other options are not available, the patient may be able to identify exercise activities in which they are already engaged that can serve as a starting point for an exercise program. Care should be

taken, however, to ensure that the program is safe and medical consultation should be solicited before exercise begins. Interventions like exercise diaries (an example of one exercise diary is available in the Appendix) and motivational interviewing can help improve motivation and adherence for exercise. If activity pacing is difficult for the patient (i.e., either they have a hard time finding an activity level that does not result in significant increases in pain or they have difficulty increasing activity to achieve benefit), then a pacing model similar to that offered by Fordyce [22] can be very beneficial.

It is vital that the clinical psychologist discuss the circumstances under which each intervention tool is most likely to be beneficial. For most pain sufferers, chronic pain is a variable experience and the applicability of pain intervention strategies will likely vary as pain changes. For example, a cognitive restructuring exercise that helps decrease stress and improve pain may be very beneficial when pain is at a manageable level already and the patient is able to concentrate on the work of identifying and changing thoughts. When pain spikes, however, it can be difficult for the patient to engage in complex pain management strategies, so simpler strategies might be preferred. Helping the patient to best understand not only how but also when to use various pain management strategies can significantly improve the effectiveness of what is being taught. The pain experience should be broken down into various phases or stages and a separate plan for pain management should be developed for each stage. An example of the stages of pain is available in the appendix.

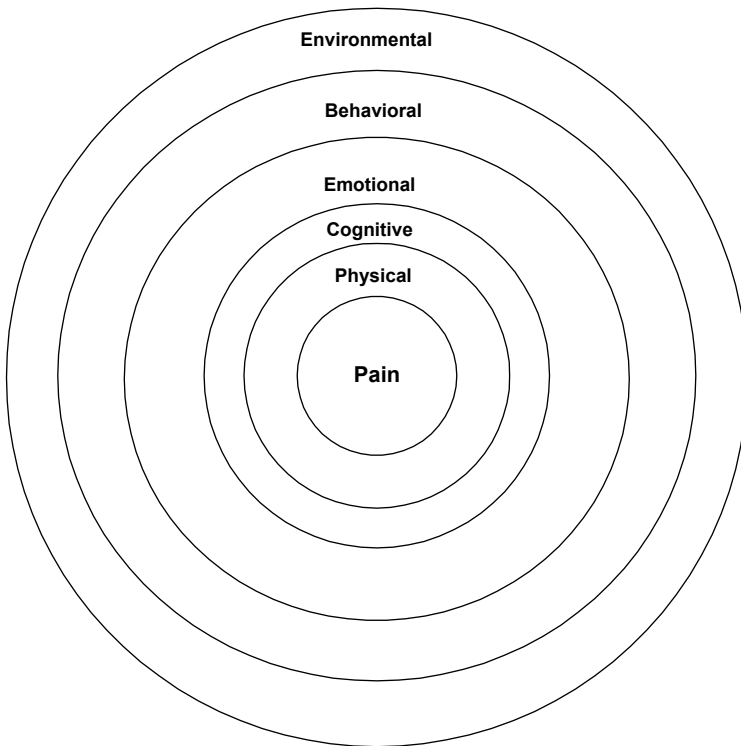
## Conclusion

Chronic pain is a significant concern in the USA, and the majority of individuals with chronic pain needs are seeking treatment in primary care clinics. PCPs, on the other hand, feel ill equipped to manage the tremendous burden of chronic pain care and experience significant frustration in their work with these suffering, complex individuals. As noted in Chap. 14, the medical home model of care is an attractive option for improving pain care and the consulting clinical psychologist has a vital role in maximizing the benefits of care. When done correctly, the patient feels more understood by providers, providers feel less frustrated in their care provision, and chronic pain symptoms improve. Though data supporting the role of behavioral health care treatment of chronic pain in standard primary care or the medical home are sparse, preliminary evidence provides some real hope that this can be achieved. There is ample evidence supporting the use of individual chronic pain management tools in a primary care environment, and treatment effects will likely grow as clinicians and researchers alike find more manageable ways to combine self-management and medical treatments into a primary care-based approach tailored to the needs of each patient. Clinical practice guidelines do exist for chronic pain care (targeted mostly for back pain, cf [9]), but guidelines describing the translation of care into the primary care settings are nonexistent. This chapter sought to highlight the

problem of treating chronic pain in the primary care setting, using many concepts of the medical home model, and shed light on possible solutions. Though not exhaustive (i.e., an entirely separate chapter could have been written about the role of the clinical psychologist in identifying and managing possible opioid dependence; see [8] for an excellent overview), it is hoped that the information and clinical guidance herein will aid clinical psychologists who have taken on the worthy challenge of collaborating in chronic pain management through primary care.

## Appendices

### INFLUENCES AND EFFECTS OF PAIN







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## PAIN MANAGEMENT QUIZ

1. As pain persists over time, it can easily affect and be affected by:
  - a. how we feel physically
  - b. how we think
  - c. how we feel emotionally
  - d. how we act - our lifestyle habits
  - e. how others treat us
  - f. all of the above
  
2. Most chronic pain problems seem to have no known physical explanation for their starting  
True or False
  
3. One physical way a person can complicate a muscle-related chronic pain problem is to  
\_\_\_\_\_
  
4. Which of the following do you think would be a healthy use of thinking to manage an ongoing pain?
  - a. Concentrate on exactly where and how it hurts.
  - b. Think the pain must mean it's cancerous.
  - c. Put mind onto a task like a card game or hobby.
  - d. Think "I can't do anything as long as I have this pain."
  
5. People who are experiencing an ongoing pain problem are at greater risk to develop feelings of:
  - a. depression?
  - b. worry?
  - c. guilt?
  - d. anger?
  - e. They're at no greater risk for any emotion.
  
6. Some ways we can change our lifestyle or habits to try to manage our chronic pain include  
\_\_\_\_\_
  
7. Others will only do and say things that will encourage us to go on with life in spite of pain.  
True or False

## Diaphragmatic Breathing

1. Sit in a comfortable position
2. Take 3 deep cleansing breaths
3. Place one hand on your stomach and the other on your chest
4. Try to breath so that only your stomach rises and falls.

As you inhale, concentrate on your chest remaining relatively still while your stomach rises. It may be helpful for you to imagine that your pants are too big and you need to push your stomach out to hold them up. When exhaling, allow your stomach to fall in and the air to fully escape.

5. Take some deep breaths, concentrating on only moving your stomach.
6. Return to regular breathing, continuing to breathe so that only your stomach moves.

Note: It is normal for this healthy method of breathing to feel a little awkward at first. With practice, it will feel more natural.



## Autogenic Phrases

- Step 1: Find a quiet place, away from distractions, and get into a relaxed posture, either sitting or lying down.
- Step 2: Close your eyes.
- Step 3: Imagine yourself in a comforting, pleasant environment.
- Step 4: Say each of these phrases to yourself, imagining the sensations as you focus on each phrase. Repeat each phrase 3 times and allow about 30 s between each repetition to give yourself time to experience the sensations.

1. My arms are heavy and warm  
(repeat 3 times)
2. My face is heavy and warm  
(repeat 3 times)
3. My chest is heavy and warm  
(repeat 3 times)
4. My legs are heavy and warm  
(repeat 3 times)

Step 5: End the exercise with this suggestion:

**When I open my eyes, I will feel refreshed and alert.**

### ***Progressive Muscle Relaxation (8 Muscle Groups)***

For each muscle group, tense the muscles involved about 1/3 to 2/3 of the maximum tension possible (enough to feel tension but not any pain). Hold in the tensed position for about 4 seconds, then let the muscles relax in their natural resting positions for about 40 seconds.

**Both Legs:** Lift both legs off of the ground, straighten your knees, and point your toes toward your head.

**Abdomen:** Tighten these muscles as if you were about to be hit in the stomach.

**Chest:** Take a very deep breath (through your upper chest, not your diaphragm) and hold it.

**Both Arms:** Turn your palms up, then make a fist. Bring your fists up to your shoulders while tensing the biceps.

**Shoulders:** Lift both shoulders up toward your ears.

**Back of Neck:** Tuck in and lower your chin toward your chest.

**Forehead:** Raise your eyebrows.

**Eyes:** Squint.



	<i>Planned day and time</i>	What I will do to relax	How relaxed I felt before after	Time spent	Comments/difficulties
-	-	-	-	-	-
-	-	-	-	-	-
-	-	-	-	-	-
-	-	-	-	-	-

**Rate how relaxed you feel:**

- 1 = Deeply and completely relaxed throughout my body
- 2 = Generally relaxed in most of my body
- 3 = Somewhat more relaxed than usual
- 4 = Neither tense nor relaxed. My usual resting state
- 5 = Somewhat tense in some areas of my body
- 6 = Very tense in some areas of my body
- 7 = Extremely tense throughout my body

**Types of Alarming Thoughts**

**Demandingness:** Thoughts or beliefs in which we expect ourselves, others, or life in general to live up to some type of standard, goal, or rule which is unrealistic

**Musts About Self**

- “I should be able to get rid of this pain!”
- “I must be pain free or my life will be miserable!”

**Musts About Others**

- “She should treat me better!”
- “He should understand I hurt!”

**Musts About the World/Conditions**

- “Improving my pain condition should be easier!”
- “It isn’t fair that my sleep is disrupted!”

**Hint**

Look for words such as “Should”, “Must”, “Ought”, and “Have to” in order to detect demandingness.

**Awfulizing:** Rating the quality of a person (ourselves or others) or events in extreme terms. Often involves words such as “awful” “terrible” or “disaster.”

- “My life has turned into a total disaster because of pain!”
- “I had a bad day yesterday, this program must not be working anymore!”

**I Can't Stand It Itus:** Convincing yourself that you will not be able to tolerate unfortunate or frustrating occurrences.

“If I don't get rid of this pain soon, I'll go crazy!”

“I hurt so bad, how can I be expected to work today?”

**Faulty Evidence/Assumptions:** You accept a belief without considering the evidence against that belief.

“I need to stay in bed until I feel better.”

“There has to be a pill that would help me.”

## Reassuring Thoughts

**Preferences** (even strong preferences), but with the realization things might not turn out like I'd prefer them. For example:

“I hope I don't hurt tonight, but if I do, I'll cope okay. No reason to make myself crazy about it.”

“I wish my boss was more understanding, but she isn't. That's the way she is going to act.”

“No one can prove that my life *has to be* hassle free and it is almost certain not to be.”

Reassuring thoughts avoid **AWFULIZING** and **I CAN'T STAND IT ITUS (LFT)**.

“Having pain is a real hassle, but it is not 101% bad.”

“This headache is difficult to manage, but I've gotten through many headaches in the past, I'll get through this one.”

Reassuring thoughts carefully examine the **evidence** for a belief.

“I may not have perfect control over my sleep, but there are things I can do.”

“Staying in bed when awake only leads to frustration.”

### **Remember, Reassuring Thoughts Are REALISTIC Thoughts.**

They are not unbelievable positive thoughts. Aiming for Positive Thinking places you at risk for constructing thoughts which are as unrealistic as alarming beliefs.

Examples of Unrealistic, Positive Thoughts:

“Life is fair, I'll always get what I deserve.”

“People will always look out after my best interests.”

“Soon I'll be pain free all the time.”

“My marriage will last forever.”

“I know I'll be able to alleviate my pain in seconds after this program.”

“Good things always happen to good people.”

“This treatment will finally get rid of my pain.”



## Healthy Thinking Leads to Better Pain Management

### *Types of Communication Responses*

#### **Assertive Response**

**H**onest

**A**ppropriate (time and place)

**R**espectful/Responsible

**D**irect

Assertive behavior promotes equality in human relationships, enabling us to act in our own best interests, to stand up for ourselves without undue anxiety, to express feelings honestly and comfortably, and to exercise personal rights without denying the rights of others.

#### **Non-Assertive Response**

Indirect

Dishonest

#### **Aggressive Response**

Inappropriate

Disrespectful

Important!! What is considered assertive, non-assertive or aggressive depends upon the persons involved and the circumstances of the situation.

### **Communicating Effectively with Physicians**

There are Two Types of Communication Styles Which Often Work Well With Physicians:

1. **Partnership Statements**—“How can we work together so that my blood pressure doesn’t go so high?”



2. **Simple Assertive Statements**—“When I take this medication my stomach becomes upset. Is there an alternative medication which does not have this side effect?”

### **Other Helpful Tips**

- Keep in mind your physician’s point of view. They are trained to “Fix” the problem—often they become very frustrated if they cannot figure out or fix a pain problem. Have some tolerance for their struggle.
- Keep a list of physical complaints to review with your physician. Remember they might have time to only concentrate on the one or two most important complaints. However, when they review your list they may put things together which you might not have thought of, so it’s good to list all the complaints you have. Just don’t expect your provider to be able to address all of them in one appointment.
- Write down anything important that you want to tell your provider. Sometimes patients can get anxious or flustered around physicians and forget what they wanted to say. This interferes with assertive communication.
- Remember you have your rights and that physicians are fallible humans. Express your concerns in an assertive or tactful manner. *Communicating Effectively with Physicians*

### **Exercise Summary Sheet**

1. Start by getting a baseline measure of your ability. On the baseline pay close attention to your body and any pain you feel. Count the repetitions or watch the time until you notice a “just noticeable difference” in (a) increase in pain, (b) fatigue, or (c) weakness.
2. Record your baseline time or number or repetitions.
3. Each day after the baseline very gradually increase your repetitions or time by no more than 5% (see example). Remember, you want to continue to build up your exercise even if there is pain, weakness, or fatigue. Only cut back if you experience an unfamiliar pain or are concerned you may fall. If increasing your exercise feels too much, stay at the same rate as the previous day and increase tomorrow.

Type of Exercise:				
Baseline Average:				
Goal to Increase:				
Date:				
Baseline				
Baseline				

### Stages of Pain and Healthy Thinking and Behaving

1. **Anticipating/Preparing for Pain Episode:** Come up with a plan and several alternatives for when the pain hits. Use diaphragmatic breathing.
  - Sitting and worrying about the pain doesn’t help. What else can I do that will help – let me do that now.
  - I’m not hurting as much now. By thinking about and doing other things I can make this good feeling last longer.
  - I don’t have to scare myself about the pain; I’ll get through the next episode whenever it comes.
  - I’m glad it’s not intense now; it does increase and decrease, doesn’t it?
  
2. **Confronting the Start of Pain Episode:** Begin to use tools that you can implement to manage pain while still going about your day. Try cue-control relaxation and IRMA.
  - Alright, I’m feeling tense. That reminds me to take some slow, deep breaths and relax.
  - I won’t get overwhelmed. I’ll just take it one step at a time.
  - It doesn’t help to lie here and hurt. Let me get involved in something.
  - Here’s the episode. It will be like the others and gradually decrease; I don’t need to be alarmed.
  
3. **Dealing with Pain at Its Peak:** Use your plan and alternatives, if necessary. Try combining IRMA strategies, PMR, and diaphragmatic breathing.
  - The episode is running its course like I expected. I can get through this.

- It will be decreasing before I know it, especially if I can put my concentration onto something else.
  - I don't want to make this worse for myself. Let me follow my plan – let me switch my activities.
  - Don't panic. I've been through this before.
4. **Reflections as Pain Decreases:** Review how well your plans worked. Give yourself credit where credit is due and revise plans, if necessary.
- Good, I did it. Next time I'll do even better in managing it.
  - I'm doing better at putting the pain in the back of my mind; I can use my attention and thinking to work for me.
  - I'm not hopeless and helpless with this. I can limit the effects the pain has on my life.

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# Chapter 23

## Evidence-Based Practice in Clinical Behavioral Oncology

Jamie L. Studts, Michael G. Mejia, Jennifer L. Kilkus and Brittany M. Brothers

### Introduction

Over the past few decades, psychologists, psychiatrists, and social workers have made substantial inroads in cancer care, joining interdisciplinary care teams as well as offering independent services designed to address psychological and social concerns of individuals diagnosed with cancer and their family and friends. With continued improvements in cancer care leading to longer survival and even cures, the number of cancer survivors will continue to grow [1]. With this increasing number comes a greater emphasis on survivorship care, and one of the major components of survivorship care involves the emotional and behavioral health of cancer survivors [2, 3].

Substantial research efforts have documented the psychosocial impact of cancer and demonstrated that a significant minority of individuals experience considerable psychological distress [4] and diagnosable mental health disorders following diagnosis, during treatment, as well as following completion of treatment [5, 6]. The most commonly noted diagnostic categories include adjustment disorders, depression, and anxiety disorders, but may also involve substance abuse and dependence. In addition to diagnosable disorders, another large proportion of individuals diagnosed with cancer experience significant behavioral or psychosocial issues and challenges along with physical symptoms and side effects that can be managed using psychological and social interventions [7]. It is important that these conditions

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are addressed as mental health and behavior issues can adversely affect treatment adherence, interfere with patient provider communication, and cause disruptions to social support within the individual's family or peer group that is an invaluable asset as the individual copes with the broad impact of cancer and its treatment.

This chapter fundamentally outlines key considerations and evidence-based interventions that have been developed for use by those providing psychological health care for individuals who have been diagnosed with cancer. The chapter aims to provide a general foundation of information to guide initial practice and resources for additional consideration, as an exhaustive review is not feasible. The chapter begins with a basic description of cancer, diagnostic considerations, and common treatments. The second section offers a general review of the evidence for psychosocial interventions in cancer. The third section addresses screening and assessment procedures commonly used by psychologists in oncology settings, and the fourth section presents some general guidelines and considerations regarding evidence-based practice in behavioral/psychosocial oncology. The fifth section covers specific information about a number of common cancers (e.g., breast, colorectal, lung, gynecologic, prostate, and hematologic malignancies). Within each of these areas, the chapter will provide brief epidemiologic information about each cancer, address the data pertaining to specific psychological concerns faced by individuals with the specific cancer, and conclude with a review of evidence-based interventions targeting individuals with this specific malignancy. Finally, the chapter concludes with some recommendations for future clinical efforts and areas where additional intervention development would be beneficial.

In any attempt to cover a domain of clinical practice as large as psychosocial care of individuals with cancer, it is important to acknowledge the limitations. This chapter will largely focus on cancer survivors, but there is a range of interventions that have been developed to address partners and family members of survivors. Additionally, this chapter focuses on adult survivors. There is an ample literature and support system that addresses psychosocial care in pediatric [8, 9] and adolescent oncology [10], but it is beyond the scope of this chapter. Finally, there are a wide range of additional clinical issues and scenarios that will not be addressed (e.g., pharmacotherapy, exercise interventions, end-of-life care, grief and loss), but the reader is encouraged to seek additional information about specific clinical issues from the literature or seek professional consultation from other practicing clinicians. There will be some mention of evidence-based interventions that target symptom management, but the predominant emphasis will focus on interventions designed to address behavioral and psychosocial sequelae of cancer that can be administered by a psychologist or mental health care provider. The American Psychosocial Oncology Society is an interdisciplinary professional society dedicated to advancing psychosocial care for individuals diagnosed with cancer and supporting the mental health care professionals who provide the care. They have many resources available on their website ([www.apos-society.org](http://www.apos-society.org)).



## Cancer

Rather than a single entity, cancer is likely more than 200 different types that share a common characteristic involving uncontrolled cell growth that adversely impacts health [11]. Cancer cells grow without the normal constraints of other cells, invading other tissues/organs, impairing necessary bodily functions, causing symptoms and death if not treated. Cancer can be detected by screening, the emergence of symptoms, or by circumstance. Occasionally, cancers are detected during the work-up for some other illness or injury. Regardless of how the cancer is detected, the first process oncologists pursue is staging the cancer to identify the most appropriate course of treatment. Cancer staging involves determining the location and volume of the cancer and is guided by the American Joint Committee on Cancer (AJCC) [12]. The AJCC system involves determining the location of the primary tumor, its size and number (occasionally multiple tumors are identified), and whether the malignancy has spread to lymph nodes or other areas of the body. Depending on the type of cancer, oncologists will use physical examination, imaging studies (X-rays, CT scans, and MRIs), laboratory tests, and pathology reports to stage the cancer. After determining the location, oncologists use the TNM staging system [12] to describe the extent (size) of the cancer (T=tumor size), whether the cancer has spread to the lymph nodes (N=nodal involvement), and whether the cancer has metastasized to other parts of the body (M=metastasis). It is important to note that each cancer type has its own classification system that provides the most accurate characterization in order to inform treatment decision making. After the TNM staging is complete, the cancer is given an overall stage of 0, I, II, III, and IV, which is often the classification system that is most familiar to individuals outside the oncology care community. Stage 0 commonly refers to cancers that remain in situ, within the cell, and there is ample debate as to whether or not this classification should really be considered cancer. Stage I disease generally means that a cancer is localized to the primary tissue/organ where it originated. Stage II disease commonly refers to a cancer that has grown larger but remains localized to the tissue or organ, whereas stage III disease usually reflects cancer that has spread to regional lymph nodes. Stage IV disease generally means that the cancer has metastasized to distant tissues or organs. Prognosis is best for earlier stage disease, but varies substantially by disease site and other pathologic features of the cancer. As research expands knowledge of cancer, the staging system and prognoses continue to evolve as well.

### *Cancer Therapies*

Once cancer staging is complete, oncologists and patients use this information to determine the best course of treatment; this might include single modality or multimodality treatments. Surgical removal of tumors generally applies to earlier stage disease and seeks to remove the tumor completely. Even if surgical removal of the tumor was successful, additional (referred to as adjuvant) regional or systemic

cancer treatments may be considered in order to destroy any tumor cells that may have remained after surgery or had previously entered the bloodstream. Radiation therapy delivers high-energy radiation to kill cancer cells by damaging their DNA. While radiation therapy does also kill healthy/noncancerous cells, it can be delivered locally, to limit the adverse impact on healthy cells. Chemotherapy is a systemic treatment approach that uses drugs to kill cancer cells throughout the body; however, it cannot specifically target cancer cells. Chemotherapy can also cause a range of familiar side effects (e.g., hair loss, nausea and vomiting, fatigue, anemia, etc.).

In addition to these three principal treatment modalities, there are a number of other treatment modalities that have emerged and are playing increasingly prominent roles in cancer care. These modalities include endocrine therapies that are appropriate for certain hormonally linked cancers (e.g., breast, prostate), cancer vaccines, biological therapies, angiogenesis inhibitors, and others. Each of these newer modalities can provide a more targeted approach to care and offer favorable outcomes while reducing symptoms and undesirable effects of treatment. Those interested in reviewing current treatment guidelines by cancer site are directed to the National Comprehensive Cancer Network ([www.nccn.org](http://www.nccn.org)), which publishes treatment guidelines that are updated at least once per year.

One other important aspect of describing a treatment approach involves where it occurs in the treatment trajectory relevant to surgery. Most regional and systemic treatments occur following surgery and are referred to as adjuvant therapies. However, sometimes these treatments occur prior to surgery, perhaps to shrink the size of the tumor before removing it; neoadjuvant therapy is the term used to describe these treatments.

Earlier diagnosis and more effective cancer treatments continue to create better options and improve the prognosis for individuals with a number of different types of cancers (regrettably, not all types). With these advances has come a greater emphasis on quality of life and survivorship following diagnosis and treatment along with a resurgence in interest in the psychological and emotional functioning of individuals diagnosed with cancer. A number of prominent public and private institutions have dedicated substantial research support to explore psychosocial aspects of cancer care and survivorship and to develop and evaluate interventions designed to address the psychosocial and emotional impact of cancer. The next section will transition to a focus on a general overview of the literature regarding psychosocial aspects of individuals diagnosed with cancer and the evidence supporting the utility of psychosocial interventions for cancer survivors.

## **Psychosocial Impact and Interventions**

The Early research exploring psychological factors in cancer focused on describing emotional reactions to a cancer diagnosis and the incidence of various diagnosable mental disorders that occurred following diagnosis. While these data must be

interpreted within the context of the time in which it was collected (i.e., prior to 1985), there emerged a notion that approximately one third of all individuals diagnosed with cancer might experience a diagnosable mental health disorder comorbid with their cancer diagnosis [13], and that these people will likely experience depression, anxiety, post-traumatic distress, or adjustment disorders. Some individuals will have premorbid mental health issues while others will experience mental health and emotional concerns in reaction to a cancer diagnosis and/or treatment. More recent research has continued to recognize the substantial incidence of psychological distress following a cancer diagnosis, and current standards recognize the importance of access to evidence-based approaches to addressing these concerns [14].

Along with recognition of the psychosocial impact of cancer diagnosis and treatment, a number of early investigators began to explore the utility of psychological interventions designed to help people cope with the psychosocial and emotional toll of cancer as well as manage various symptoms and side effects of cancer and its treatment. Some efforts also explored whether psychosocial interventions could reduce mortality in addition to improving quality of life and psychosocial well-being [15–17]. A body of intervention literature has emerged, and the general topic of psychosocial interventions for individuals diagnosed with cancer has become a very popularly reviewed and debated topic [18–21] with the general consensus showing a demonstrably positive effect of psychosocial interventions and their impact on psychosocial aspects of well-being as well as symptom management.

Psychosocial and behavioral interventions for individuals diagnosed with cancer is a popular topic of literature reviews, including a number of narrative [22–24], systematic [25, 26], and meta-analytic [27–29] summaries of the literature. The vast majority of the reviews conclude that psychosocial interventions (individual, couple, or group format) targeting psychological distress demonstrate moderate levels of efficacy [20–23, 25, 27, 29]. These reviews have generally included studies examining a broad mix of interventions, employing different formats (i.e., individual or group formats), varying theoretical frameworks (i.e., cognitive-behavioral therapies, support-expressive therapies, SETs), and intervention targets (i.e., distress, anxiety, depression). Further, the reviews have tended to include studies with broad methodological approaches, including rigorous randomized controlled trials in addition to quasi-experimental designs. Despite the range of methodological approaches to these reviews, reasonable evidence is found to conclude that patients diagnosed with cancer are likely to benefit from psychosocial intervention. In particular, those who are experiencing clinically significant levels of psychological distress are most likely to benefit from intervention.

Along with the emergence of what might be considered a general consensus supporting the utility of psychosocial interventions, there have also been some notable and important concerns raised in the literature that require additional consideration [18, 19] and some reviews that have questioned the conclusion that psychosocial interventions have adequately demonstrated broad efficacy and have recommended more cautious and conservative interpretations of the literature [24, 26, 30]. First, one of the notable limitations of much of the research has been the lack of a distress criterion for study entry [19]. Essentially, most intervention studies have enrolled

anyone who was eligible by virtue of a cancer diagnosis, regardless of whether or not they reported psychological distress. While this does potentially reduce the likelihood of reducing distress if participants do not report distress at baseline, it also affects the generalizability of the data to individuals who do experience clinically relevant levels of distress. Second, there has been a general concern about the methodological rigor and quality of the intervention studies [18, 19]. Many noteworthy studies have employed designs with methodological limitations, and other confounders have potentially influenced even well-designed studies. Third, the intervention literature has not adequately addressed several concerns about generalizability. Notably, accrual rates for many intervention studies are quite low, which could be due to strict eligibility criteria or might also be linked with volunteer bias [19]. Either way, important questions about generalizability of the data exist, specifically regarding general interest in these types of interventions or possible biased results by only accruing individuals who believe they will benefit from the intervention. Finally, questions about sample representativeness also raise questions about generalizability. Many studies report samples that consist of well-educated, higher socioeconomic status (SES), Caucasian women. Much less data are available regarding the efficacy and effectiveness of psychosocial interventions for cancer among more diverse samples, including men, individuals with varying economic resources, and heterogeneous racial/ethnic backgrounds.

Given these methodological issues as well as concerns about generalizability, there remains an ongoing need for additional research using rigorous designs as well as efforts to achieve high-quality reporting of clinical trials [18, 19, 21]. With increased quality, it is likely that the true signal regarding the ultimate clinical utility of psychosocial interventions for individuals diagnosed with cancer will become even more clear and hopefully support broader dissemination and implementation of the evidence-based approaches.

## **Distress Screening**

One of the most important aspects of developing a program or offering clinical psychosocial oncology services involves identifying appropriate referrals and/or identifying individuals who may warrant assessment and intervention. Research to date has highlighted the proportion of cancer patients that experience distress, as well as negative outcomes that occur when distress is not addressed [31, 32]. Beyond the negative consequences of not treating distress, research on distress in cancer care has noted improved outcomes when patients are screened for distress and provided appropriate referrals. The National Comprehensive Cancer Network (NCCN) first issued Clinical Practice Guidelines in Oncology for Distress Management in 1999 [33]. These guidelines were developed in large part to promote best practices in cancer care by addressing unmet psychosocial needs. In addition, as an effort to promote patient-centered care, the American College of Surgeons Commission on Cancer has also recently included distress management as part of their

patient-centered standards published in 2012, requiring distress screening and the provision of or referral to mental health professionals [34, 35].

Development and evaluation of various approaches to screening patients who might be appropriate for services has been a very active area of research in psychosocial oncology [36–38]. While initial research focused on identifying rates of mental health issues or diagnoses among individuals recently diagnosed with cancer, subsequent efforts evolved into the evaluation of different screening tools and approaches to identify individuals who may warrant a broader assessment and subsequent psychosocial intervention. Positively screened individuals provide an opportunity for additional assessment and the opportunity to offer available services.

In addition to the development and evaluation of screening instruments [38], there have been efforts to identify low-cost and efficient approaches to implementation of screening as well as studies examining the overall utility of screening [36]. These studies have examined a variety of technology-focused approaches and the use of a diverse range of professionals to administer, evaluate, and provide appropriate intervention or referral. The following section provides a summary of the measures that have been evaluated for the purpose of screening for psychosocial distress following a cancer diagnosis.

## *Screening Measures*

There are quite a number of measures that have been used to screen for emotional difficulty in cancer settings [32, 36]. These measures are designed to assess and screen for a variety of psychological symptoms, including depression, anxiety, and distress with the goal of identifying individuals who may warrant additional evaluation or referral for psychosocial services.

Vodermaier and colleagues have reported the results of a systematic review examining instruments designed to screen for emotional distress in cancer patients [38]. The review initially categorized measures into groups based on the number of items on the instrument: ultra-short (1–4 items), short, (5–20 items), and long (21–50 items). Of the 33 unique instruments included in the review, the authors indicated that Center for Epidemiologic Studies—Depression Scale [39] and the Hospital Anxiety and Depression Scale (HADS) [40] demonstrated the most appropriate psychometric properties within the short category. The authors also recommended use of the Beck Depression Inventory [41] and the General Health Questionnaire—28 [42] as quality instruments that met the evaluative psychometric criteria for longer instruments. Although brief, the authors raised some concerns about ultra-brief instruments, noting that the literature had not yet provided a substantial evaluation of this group of instruments, but also added that efforts to improve the utility of these instruments has been encouraging [38].

The most studied psychological measurement tool used in a cancer setting has been the HADS [32, 40]. In specific studies, the HADS has been found to perform better than the General Health Questionnaire-12 [43] as well as the Schedule for Affective Disorders and Schizophrenia, Beck Depression Inventory-II (BDI-II),

and the Center for Epidemiological Studies Depression Scale at identifying patients with depressive symptoms [44]. Other measures have been evaluated for accuracy of symptom identification, including the Patient Health Questionnaire (PHQ) and European Organization for Research and Treatment of Cancer Quality of Life Core Questionnaire. Depending on the study, the HADS [45] or the PHQ [46] has been described as the best measure to screen for depression symptoms accurately.

A more recent meta-analysis [47] evaluated the properties of a number of commonly used instruments to identify depression in cancer settings. The results of this meta-analysis pointed to the BDI-II and one- and two-stem questions (such as the Distress Thermometer, DT) to be the most accurate measures available to assess for depression in this population [47].

Although the Vodermaier and colleagues' review raised concerns about ultra-short instruments [38], the DT has received substantial clinical and empirical support and has been broadly implemented [48]. The DT is a one-item measure that has been used to screen for more broadly experienced emotional difficulties in the cancer setting. It was developed as a rough initial screening for emotional upset that could be from a number of sources, not only cancer [33]. It has been found to have adequate sensitivity and specificity and has good concordance with the HADS [33]. The NCCN Clinical Practice Guidelines for Oncology (NCCN Guidelines) for distress management recommend using the DT as an initial screening tool, with further follow-up and and/or referral for patients endorsing a 4 or higher score on the 0–10 scale [49].

## Summary

In summary, screening for distress has become a vital component of psychosocial oncology services and facilitates appropriate psychosocial referrals and should be incorporated as part of quality patient-focused cancer care [35, 37]. Implementing a screening program can help identify individuals who are appropriate for further evaluation and possible treatment. Although there is some contradictory evidence for the best screening measure to use, there have been number of brief measures that have been shown to have good utility for this purpose. Single-item approaches (e.g., DT) have the benefit of brevity and clinical efficiency in addition to being publically available, overcoming financial barriers to broad implementation. Traditional psychometric instruments such as the HADS and BDI-II have also been recommended based on their history and sound psychometric foundation across many different settings. However, these instruments are not without their limitations or criticisms. In particular, the HADS has come under increased scrutiny for its structure and terminology [50, 51]. In the end, it appears that there are a number of reasonable and clinically useful options for distress screening, and clinicians are encouraged to consider the tools that best fit their practice setting.



Fig. 23.1 Three circles model of evidence-based practice. (Satterfield et al. 2009)

## Evidence-Based Practice in Behavioral Oncology

Data to support implementation of psychosocial interventions for individuals with cancer have established a generally strong foundation of support as noted previously, indicating the importance of addressing psychosocial issues in order to maximize cancer survivorship [22]. As in any practice setting, it is important to have a strong foundation of empirical support to guide care. In addition to the evidence, it is also important to consider available resources and patient preferences in providing care. Indeed, models of evidence-based practice (EBP) have emerged from a sole focus on research data to incorporating important ecological and patient-focused considerations.

### *Three Circles Model of Evidence-Based Practice (EBP)*

While most clinicians recognize the importance of research evidence in practicing evidence-based care, there are other equally important aspects of the equation in terms of optimizing service delivery and achieving optimal outcomes. The Three Circles Model [52] of EBP describes how evidence fits with other key influences and provides an excellent foundation for integrating these important domains of evidence-based psychosocial care in oncology (see Fig. 23.1). This model involves three equally weighted components (e.g., evidence, preferences, and resources) that overlap and integrate in order to guide care decisions. Before addressing the three circles, it is fundamental to note that the model is grounded in an ecological framework that incorporates the environmental and organizational context in which a

service might be delivered. Further, the model emphasizes shared decision making, where providers and patients work collaboratively and synergistically to explore treatment options and determine a care plan. Clinicians and patients engage in a joint venture to determine which treatment would provide the best chance for the desired outcome given the patient's values and preferences and the resources available.

With regard to the three circles [52], one circle involves the best available research evidence, including the systematic organization of data from research and observation. Another circle incorporates the patient's characteristics, including status, needs, values, and personal preferences regarding treatment. A third circle addresses resources, including provider training and expertise. Specifically, provider resources comprise skills related to EBP process, assessment, communication, and intervention. Decision making overlaps with the research, resources, and client characteristics as a centralized component indicating that it is not only the clinician that is making decisions but also the patient who is ideally sharing equally in this process and conjointly evaluating the other sources of information to inform the treatment decision/plan.

This model seems particularly well suited for psychosocial care in oncology. Provider expertise in evidence-based interventions is expanding, particularly with the advent of National Cancer Institute (NCI)-funded training programs specifically designed to facilitate dissemination and implementation of evidence-based psychosocial cancer care interventions. It is well known that patients have varying preferences for care regarding psychosocial sources of distress. Engaging in a shared decision-making process using the three circles model as a guiding heuristic will ideally integrate those preferences and personal considerations into determining the best course of action.

### ***Distress Management Clinical Practice Guideline (DM-CPG)***

Using the evidence that has emerged regarding psychosocial care in cancer, one clinical practice guideline has been developed which addresses distress management for individuals diagnosed with cancer [53]. While not entirely evidence-based and targeted to a broader audience than only psychologists working in oncology, this clinical practice guideline is informed by both evidence and expert opinion and offers an excellent starting point for development and implementation of psychosocial interventions. Developed and disseminated by the NCCN, the Distress Management Clinical Practice Guideline (DM-CPG) addresses a range of relevant considerations for psychologists working with individuals diagnosed with cancer [14, 53, 54]. The DM-CPG specifically concerns the identification and treatment of psychosocial and emotional problems among individuals diagnosed with cancer. One foundational element of the DM-CPG involves its focus on distress, rather than other psychologically oriented terms like depression or anxiety. The NCCN specifically selected this term in hopes of destigmatizing psychosocial care for



cancer patients. Additionally, they have provided a thoughtful definition and simple clinical measurement tools (discussed previously). Per the DM-CPG, “Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.” While this definition extends into some areas psychologists typically do not address (spiritual crisis), it is important to note that the DM-CPG is an interdisciplinary effort that incorporates psychosocial services by various health care providers and emphasizes collaborative care (available from the NCCN website: [www.nccn.org/clinical.asp](http://www.nccn.org/clinical.asp)).

In addition to defining distress and emphasizing collaborative care, the DM-CPG proposes several key features of providing appropriate psychosocial services for cancer patients that are consistent with recommendations from the Institute of Medicine Report, *Cancer Care for the Whole Patient* [55] another key resource for individuals providing psychosocial care for individuals diagnosed with cancer. First, the DM-CPG proposes that screening for distress and psychosocial needs is a vital process for distress management. Second, screening results should guide the development and implementation of a specific treatment plan to address identified needs. Individuals scoring four or higher on the DT should be identified as warranting referral. Third, patients should be referred for psychosocial care if psychosocial concerns are specifically identified on the Problem Checklist (PC). The PC is a tool often used in conjunction with the DT to identify potential sources of distress. The major categories are framed as areas of concern or problems and include items pertaining to practical (e.g., childcare), family (e.g., dealing with partner), emotional (e.g., depression), spiritual, physical (e.g., breathing), and other problems (open-response format) [14]. Fourth, the treatment plan should be periodically reevaluated and adjusted. As noted in the DM-CPG, psychosocial care is rapidly becoming an integral aspect of quality cancer care and one of many important components of a cancer care plan [14]. Attending to psychosocial issues and providing appropriate services can not only benefit patients but also family and oncology providers.

### ***Biobehavioral Model of Cancer Stress and Disease Course***

While clinical practice guidelines provide a compelling starting point, it is similarly important to consider individual and environmental resources and patient preferences when developing programs and/or designing specific treatment plans for individual patients [52]. One aspect of understanding the patient perspective involves understanding risk factors for distress and other adverse psychosocial outcomes.

In considering factors that could contribute to the psychosocial burden of individuals diagnosed with cancer or the likelihood that they will experience psychosocial morbidity, Andersen et al. [56, 57] have developed frameworks that can help

clinicians conceptualize patient experience and plan for patient care. Andersen's biobehavioral model of cancer stress and disease course [57] provides a comprehensive framework for understanding biopsychosocial influences on morbidity and mortality following a cancer diagnosis, and the earlier model offers a cogent description of factors clinicians can use to understand risk for psychosocial concerns and help guide efforts to target psychosocial interventions [56]. In the earlier model, Andersen divides risk factors for adverse psychosocial outcomes into two categories: (1) preexisting psychosocial factors and (2) diagnosis and treatment factors [56].

With regard to preexisting psychosocial factors, the Andersen model draws on the literature to discuss four areas that engender risk for adverse psychosocial morbidity following a cancer diagnosis. The first area involves sociodemographic factors, including socioeconomic disadvantage, age, and race/ethnicity [56]. For example, while risk for cancer increases with age, the relationship between psychological distress and cancer diagnosis is the reverse. Data consistently show a relationship between younger age at diagnosis and greater distress and psychosocial morbidity among adults. The second area comprises poor health status, both mental and physical. Individuals with preexisting mental health conditions are likely to be living with some degree of distress, and cancer is likely to add to that burden. The third area involves social isolation and the lack of social support. Drawing on the extensive literature, it is well documented that social support can buffer the impact of illness and has been shown to be associated with longevity [58]. Cancer often creates a substantial emotional burden that can be partially mitigated by a strong and engaged social support network; the lack of such a network of relationships places an individual at heightened risk for distress. The final area includes the presence of other preexisting psychosocial stressors, including any other contextual factors that detract from the individual's ability to adhere to treatment recommendations or requires the patient to divert resources to cope with other stressful situations.

The second general domain involves factors that emerge following diagnosis and can include treatment factors [56]. Individuals who experience disruptive symptomatology are more likely to experience psychosocial concerns and distress. Second, there is a well-established relationship between the extent of disease and treatment and psychological distress. Individuals with a more dire prognosis are more likely to experience the existential crisis that cancer often engenders along with anticipated loss of life. Similarly, the more intensive and burdensome the treatment regimen, the more likely individuals will experience deflating side effects that can tax personal coping resources. Third, while many treatment side effects remit following completion of therapy, long-term and late effects of treatment also tax coping resources and make individuals vulnerable to adverse psychosocial outcomes. Long-term effects involve symptoms and side effects that persist following treatment, and late effects are symptoms and side effects that actually emerge after completing treatment, sometimes years or even decades after treatment. Finally, the model indicates that individuals who are diagnosed with cancers where there are no known risk-reducing options following treatment are also at higher risk for adverse psychosocial outcomes.

When combined, these preexisting psychosocial factors and disease and treatment factors provide a conceptual framework from which to evaluate patients and their likely need for psychosocial interventions. Preexisting psychosocial factors help clinicians evaluate the personal resources and background characteristics that each patient brings to the clinic when confronting cancer, and the diagnosis and treatment factors help the clinician understand the source and scope of impending challenges that an individual will likely face. Using this nomenclature, the provider can help anticipate the potential need for psychosocial services and work to identify appropriate evidence-based treatment options to review with the patient.

## **Evidence-Based Practices in Specific Malignancies**

The next section provides more specific evidence and guidance for practice in work with specific populations of individuals diagnosed with cancer. As discussed previously, individuals diagnosed with cancer vary substantially and do not constitute a homogeneous group. It is often advisable [4], if not necessary, to consider specific data regarding psychosocial considerations within specific cancer domains. This section addresses the psychosocial literature that has developed addressing several common cancers, including breast, gynecologic, prostate, colorectal, lung, and hematologic malignancies. Each section will provide some epidemiologic information about the specific cancer, review literature related to psychosocial aspects of the cancer, and close by providing information about psychosocial interventions specifically designed and targeted to address the concerns and needs of the given population.

### ***Breast Cancer***

#### **Epidemiology**

Breast cancer (BrCa) is the most prevalent form of malignancy among women in the USA with 232,340 new diagnoses expected in 2013 [59]. Despite the high incidence rates, the overall 5-year survival rate is encouraging (approximately 90%), and only 39,620 deaths are expected in 2013 [59]. In part due to screening efforts, BrCa is generally detected while still in early stages, greatly increasing the possibility of effective treatment and cure. Most women will be diagnosed with localized disease (61%), with only 7.6% presenting with distant or unstaged disease at the time of diagnosis [60]. Ninety-eight percent of women who are diagnosed with localized disease survive 5 years or beyond. Treatment options for localized disease comprise many different approaches and combinations of approaches, including surgery (breast conserving approaches or mastectomy) followed by adjuvant chemotherapy and/or radiation therapy. Depending on tumor pathology, some women

will be eligible for long-term hormonal therapies or targeted therapies that are appropriate for certain types of breast cancer. Primary treatment for metastatic disease involves systemic approaches, including chemotherapy, targeted therapy, and endocrine therapy, although local approaches (e.g., radiation therapy and surgery) may also be used with palliative intent.

## **Psychosocial Impact**

Despite improvements in treatment efficacy and survival, BrCa continues to be a significant source of psychosocial distress [61] that may affect several areas of functioning [62] and endure beyond the detection and treatment phases. Indeed, research suggests that among BrCa patients, the prevalence of general distress may approach 33% [4], and it has been estimated that clinically significant symptoms of post-traumatic stress may affect anywhere from 3 to 19% of BrCa patients [62]. While women over the age of 50 account for more than three quarters of the total yearly diagnoses of BrCa, [59] younger age at diagnosis has been found to be a risk factor for poorer adjustment and long-term challenges in both physical and psychosocial domains [63, 64]. In general, studies indicate that women diagnosed with BrCa under the age of 50 may experience unique challenges, increased symptoms, and lower quality of life compared to their older counterparts. Furthermore, younger women tend to experience BrCa-specific concerns and intrusive thoughts, heightened symptoms of depression and emotional distress, greater distress regarding treatment effects on their body and appearance, such as hair loss, surgical removal of the breast, sexuality, hot flashes, early onset of menopause, infertility, as well as the implications on their career or possibility of raising children [63–65].

The year following diagnosis has also been identified as a time in which women are at particular risk for distress [66, 67]. For example, Epping-Jordan et al. [68] found that shortly after diagnosis, approximately 40% of their sample reported experiencing anxiety and 34% reported symptoms of depression. These statistics represent rates that are three to four times what is expected of the general population. In a recent review, Fann et al. [66] found that rates of major depressive disorder (MDD) among women with BrCa span 10–25%, and other researchers have reported rates of depression among this population as high as 46% [5].

Beyond the first year, levels of depression and anxiety among women in remission have been reported to be similar to those seen in the general population, and studies suggest that this may be more dependent on factors associated with the patient rather than the disease or treatment itself [67]. For example, a 5-year observational study conducted by Burgess et al. [67] found that within a year of diagnosis, almost half of their sample reported either depression, anxiety, or both. However, in the second, third, and fourth year, this number went down to 25%, and in the fifth year it fell to 15%. The authors found that lack of social support, younger age at diagnosis, and having received previous psychological treatment were all factors predictive of longer episodes of depression. Furthermore, diagnosis before the age

of 65, history of depression, and having been treated with chemotherapy have all been identified as possible predictors of depression following treatment [66].

### **Psychosocial Interventions**

Much of the psychosocial oncology intervention literature has focused on development and evaluation of interventions for women diagnosed with breast cancer. Andersen et al. [69] developed a psychosocial intervention for women with BrCa targeting stress reduction, health behaviors, treatment adherence, and improvement of quality of life. This group-based intervention met weekly for 4 months and consisted of components such as psycho-education regarding the stress response and training in relaxation, coping, and communication skills. Furthermore, participants were encouraged to follow an exercise regimen and were provided with information regarding diet, as well as smoking cessation. This intervention has produced promising results including decreased symptoms, reduced smoking, and lowered levels of depression and distress. Furthermore, results indicated improved social support and dietary habits. Moreover, participants in the intervention also demonstrated improvements in general health, functional status, and other biobehavioral parameters as compared to the assessment-only condition [69–71].

The Breast Cancer Stress Management and Relaxation Training (B-SMART) program is another psychosocial intervention with a strong foundation in cognitive behavioral therapy for women with nonmetastatic BrCa [72, 73]. This intervention employs relaxation and coping skills training, cognitive reframing techniques, and addresses communication and social skill development. Participation in this intervention involved ten weekly meetings lasting approximately 2.5 h in which group leaders addressed structured topics during the first portion of the meeting. In the latter half of each session, participants were encouraged to discuss cancer-related issues and share personal accounts of facing or overcoming psychosocial barriers and role-play techniques they had developed to facilitate social support and positive social comparison. In addition to the in-session exercises, participants were also asked to practice the relaxation techniques and complete assigned exercises in the home between sessions. The intervention was compared to a control condition consisting of a one-day psycho-education module lasting approximately 5–6 h.

B-SMART has demonstrated several benefits to psychosocial functioning and quality of life for participants including evidence of increased optimism and benefit finding [72, 74]; a decrease in rates of moderate depression among more than 30% of the sample [72]; and reduction in general anxiety and cancer-related thought intrusion which was maintained for approximately 9 months following participation [75]. A follow-up study conducted by Antoni et al. [76] demonstrated not only the long-term efficacy of B-SMART on several aspects of quality of life but also identified a mechanism of action for these changes. Specifically, the authors noted lasting improvements among the treatment group in the areas of illness-related interpersonal disruption, emotional well-being, benefit finding, positive affect, and positive lifestyle change. Analyses indicated that confidence in one's ability to relax at will

mediated the intervention effects on these quality-of-life variables, thus serving as a possible mechanism of action [76].

SET is another group-based psychosocial intervention for women with BrCa developed by Spiegel et al. [77]. This intervention began as a randomized controlled trial targeting symptoms and psychological adjustment among women with metastatic BrCa. This intervention aimed to build bonds, express emotions, redefine life priorities, increase the support of family and friends, improve the doctor–patient relationship, develop coping skills, improve pain management, and detoxify issues of death and dying.

As the name implies, this intervention emphasized open interaction and expression of disease-related emotions among the group members [78]. The role of the therapist in SET is to provide the participants with an example of an open and accepting environment in the early stages and to display the types of behaviors and attitudes of support that can be modeled by the participants [78]. In this way, participants were able to focus on commonalities to reduce feelings of isolation. Furthermore, the interactive and cooperative nature of problem solving their common challenges allowed participants to gain self-efficacy and accept the assistance of others at the same time. The women were randomized to either a control or a treatment condition and those in the SET group met weekly for 1 year with assessments occurring at 4-month intervals. The authors reported improvements in the areas of health-related quality of life (affective factors), coping skills, general affect, confusion, fatigue, phobic ratings, anxiety, and improved pain management [77, 79].

The efficacy of SET is further supported by several studies that have either replicated or incorporated aspects of this intervention among samples with varying stages of disease [80–83]. These studies have demonstrated promising results such as improvements in family and social functioning, attitudinal coping, cancer-related knowledge, and reports of self-growth [80, 84]. Kissane et al. [80] noted possible protective effects of the intervention on the likelihood of developing depression. Indeed, out of the participants in either condition that were depression-free at baseline, those who were randomized to the control group had a higher probability of not developing depression. Moreover, investigators have reported reductions in anxiety, traumatic stress symptoms, perceptions of pain, total mood disturbance, and those participants who had a diagnosis of depression at baseline reported a reduction of intrusive thoughts [80, 82, 83].

## Summary

While survival rates have risen significantly over the past 40 years, BrCa continues to be the most commonly diagnosed malignancy among women. Furthermore, research indicates that a large proportion of those diagnosed with BrCa may experience late effects of treatment or face psychosocial challenges such as general psychological distress, MDD, or PTSD. Moreover, it is important to keep in mind that the year following diagnosis has been understood to be the period when survivors report experiencing the most distress, after which time research has shown that

levels of distress may tend to decline and return to near baseline levels within 3–5 years. However, there is evidence that this is not the case for women who are diagnosed at a younger age, among whom we tend to see unique and more pronounced psychosocial challenges, which may persist from the time of diagnosis through long-term survivorship. High survival rates for BrCa mean that women are living longer with this disease. Due to the prevalence of stressors faced by this population, several psychosocial interventions are available, some of which have been developed specifically for women of a certain age range or disease status, with cognitive-behavioral approaches demonstrating efficacy when targeting psychosocial distress among women with earlier stage disease [69, 72], and SETs demonstrating efficacy when targeting psychosocial issues and distress among women with metastatic or more advanced breast cancer [77, 80, 82, 83].

## ***Colorectal Cancer***

### **Epidemiology**

Colorectal cancer (CRC) is a cancer that occurs in the colon or rectum, and is the second leading cause of cancer death in the USA [59]. The American Cancer Society estimates that more than 100,000 new cases of colon cancer and more than 40,000 new cases of rectal cancer will be diagnosed in 2013 [59]. The lifetime risk for developing CRC is approximately 20% [85]. The overall 5-year survival rate for CRC is 64%, reducing to 58% at 10 years from diagnosis [59]. When detected at an early stage, CRC has a substantially higher 5-year survival rate at 90%. However, only slightly more than one third of CRC cancers are diagnosed at this stage, likely due to low screening uptake [59].

Treatment for colorectal cancer frequently involves surgery. If the cancer is diagnosed and removed at a localized stage, surgery may be sufficient for remission [59]. When the cancer is across a larger area and resection of the colon or rectum is required, a colostomy may be needed for the elimination of body waste [85]. Chemotherapy and radiation may be used prior to surgery in order to shrink the tumor or after the surgery to reduce the risk of recurrence [59, 85].

### **Psychosocial Impact**

The stage and site of the tumor have a significant influence on potential quality-of-life and psychosocial issues in CRC patients. Depending on the location of the tumor, resection may heavily impact daily functioning following recovery. In general, most patients with colon cancer report higher quality of life following treatment recovery than rectal cancer patients due to differences in tumor location and treatment [86–88].

While there are a number of psychosocial concerns that CRC patients share with other cancer patients, a diagnosis of CRC and the subsequent treatment also has a number of unique implications for psychosocial and quality-of-life issues. For example, the necessity of a temporary or permanent ostomy has significant implications for overall well-being and quality of life. Patients may also experience an increase in bowel movements or a change in bowel control [88]. This may substantially limit the ability of some patients to participate in their normal daily activities. In addition, intimacy and sexuality concerns may follow a diagnosis due to treatment side effects of surgery, radiation, or chemotherapy. Patients with an ostomy may experience more of an increase in sexual dysfunction as a result of poor body image, embarrassment, or their partner's reactions [88, 89].

A recent large cohort study of cancer survivors found that 8.6% of colon cancer patients reported clinically significant symptoms of depression, while 9.5% of patients reported clinically significant symptoms of anxiety. A further 11% of the sample reported mixed depression and anxiety symptoms [90]. CRC patients are more likely to experience depression if their social activities are limited and if they have low social support [91]. Advanced disease is also associated with greater symptoms of anxiety and depression [92].

CRC patients also experience high levels of these symptoms in survivorship with 26–44% of long-term CRC survivors continuing to have high levels of cancer-related health worries [93]. Greater incidence of cancer-related health concerns have been associated with higher reports of depression and anxiety symptoms [93]. High levels of overall distress have also been noted in CRC survivors [94]. In particular, patients with low social support, low education, and later stage disease were found to be more likely to experience high levels of distress [94].

## **Psychosocial Interventions**

There have been few psychosocial interventions developed specifically to target psychological outcomes in CRC survivors. Although several interventions were identified that have included CRC survivors, these sample sizes were often too small for subset analyses to examine differences in outcomes between those with CRC and other cancer diagnoses. Other studies including psychological outcomes as part of their intervention did not include statistics on pre and postintervention changes. Currently, few known intervention studies both investigated the impact of an intervention on psychological outcomes in CRC survivors and found significant changes to these outcomes post intervention. We present only studies that reported a statistically significant effect of a psychosocial intervention.

A 2003 study investigated the effect of progressive muscle relaxation on anxiety and quality of life in CRC patients compared to standard care [95]. Patients were provided two teaching sessions and then practiced progressive muscle relaxation at home for 10 weeks. The use of progressive muscle relaxation was found to significantly reduce state anxiety in study participants.



Livingston et al. [96] examined the impact of information and support on anxiety and depression symptoms in CRC patients. This study utilized cancer helpline nurses to screen CRC patients for distress using the Distress and Impact Thermometer. If patients scored five or higher on this measure, the nurses provided tailored information, support, and resources as well as referred patients to psycho-oncology services. Results of the intervention were measured by scores on the HADS. Following the intervention, HADS depression scores significantly decreased, while HADS anxiety scale scores were not significantly different between baseline and post intervention.

The only known group intervention examining psychological outcomes in colorectal cancer patients was an expressive-disclosure intervention designed by Carmack and colleagues [64]. This intervention consisted of twelve 1-hour group sessions that emphasized emotional expression of thoughts and feelings related to cancer and cancer treatment. Following the intervention, patients scored significantly lower on a depression scale.

While few studies have examined psychological outcomes, others have examined the impact of psychosocial interventions on quality-of-life and well-being factors among CRC survivors. The Cheung and colleagues study described above investigated the role of progressive muscle relaxation on quality of life as well as anxiety [95]. In addition to reducing anxiety, analyses showed that patients in the experimental group reported higher overall quality of life than those in the control group following the intervention.

Lee et al. [97] designed an intervention integrating meaning-making coping strategies. They examined the effect of meaning making on adjustment to cancer by measuring differences in self-esteem, optimism, and self-efficacy. Following the intervention, scores on these three constructs were found to be significantly higher. This study included both breast and CRC patients, and no differences were found between these groups on the impact of the intervention. This study is of particular interest in this population, as it has well documented that the unique location and treatment options for CRC patients negatively impacts self-esteem.

A 3-month intervention called “LiveWell” also demonstrated a significant impact on quality-of-life scores in a preliminary feasibility trial [98]. This lifestyle intervention included a personalized physical activity and diet plan, goal setting, personalized feedback, and social support. At the end of the intervention, 14 of the 17 participants reported improvements in quality of life based on a statistically significant increase in quality of life questionnaires.

## Summary

A diagnosis of CRC introduces a number of unique psychosocial concerns, including psychological distress but also unique psychosocial and physical concerns related to specific treatments and their sequelae (e.g., placement of an ostomy). Currently, the data on the efficacy and effectiveness of psychosocial interventions in this population is scarce. The evidence that does exist is varied and likely warrants

replication. Progressive muscle relaxation has been found to reduce state anxiety and increase quality of life in CRC patients [95], while a lifestyle intervention may improve quality of life [98]. The provision of information and support to those with higher levels of distress has also been shown to reduce depression in CRC patients [96]. Surprisingly, there have been few psychosocial interventions that emphasize emotional expression. The expressive-disclosure intervention designed by Carmack et al. [99] was found to be effective for reducing depressive symptoms in CRC patients. Using meaning-making as a coping strategy has also been found positively impact CRC patients through improvements in self-efficacy, self-esteem, and optimism [97].

The intervention literature targeting psychosocial issues among individuals diagnosed with CRC remains underdeveloped, and there is no conclusive evidence regarding efficacy or effectiveness. However, there are some potentially helpful interventions that clinicians can consider when treating patients with a CRC diagnosis, and clinicians should consider the distinctive challenges that are faced by CRC patients.

## *Lung Cancer*

### **Epidemiology**

Cancers of the lung and bronchus constitute approximately 14% of all cancers in men as well as 14% of all cancers among women in the USA [59] but account for 28% of all cancer deaths among men and 26% of cancer deaths among women. Fortunately, the annual incidence of lung cancer has been decreasing over the past several years (228,190 new cases expected in 2013), following tobacco-control efforts initiated decades ago. However, lung cancer remains the number one cause of cancer mortality. The high mortality rate is primarily linked to late-stage diagnosis, when the cancer has metastasized to other vital organs (e.g., brain). The 5-year survival rate for lung cancer is only 16%, but is 52% when lung cancer is diagnosed early. Recently, enthusiasm has increased for early diagnosis of lung cancer following publication of results from the National Lung Screening Study (NLST), which showed that high-risk individuals who participated in annual low-dose computed tomography screening (LDCT) experienced a 20% relative reduction in mortality compared against annual chest X-rays (CXR) [100]. If adopted and implemented broadly, this could result in greater focus on survivorship among individuals diagnosed with lung cancer.

Despite the incidence and mortality associated with lung cancer, there has been relatively less clinical psychosocial research focusing on this patient population, relative to other cancers. The research to provide a foundation for clinical psychosocial intervention has mostly described the psychosocial burden of lung cancer. While a few efforts have focused on developing psychosocial interventions to target this population, the majority of intervention work has sought to develop evidence-based

tobacco cessation efforts targeting individuals who continue to smoke cigarettes or use other forms of tobacco following diagnosis and treatment [101].

### **Psychosocial Impact**

A diagnosis of lung cancer carries with it a substantial psychosocial burden as noted by a number of investigators [4, 102, 103]. In fact, one study found that individuals diagnosed with lung cancer reported the highest rate of psychological distress as measured by the Brief Symptom Inventory (43.4%) [4], substantially above the overall prevalence rate among all cancers (35.1%), a finding supported by several studies [104, 105]. A more recent study focusing solely on individuals with lung cancer used the DT [106] to assess psychological distress among care recipients at a multidisciplinary lung cancer clinic by Graves et al. [102] found even higher levels of clinically significant psychological distress with 61.6% of 333 individuals reporting a score of 4 or higher on the DT [102]. Fewer studies have examined rates of diagnosable psychological disorders among individuals diagnosed with lung cancer, but have revealed high rates of nicotine dependence, adjustment disorders, alcohol dependence, as well as mood and anxiety disorders, [107] with a rather substantial rate of disorders persisting through early survivorship [108, 109].

In addition to the direct emotional impact of the disease, lung cancer and its treatment significantly impact many other aspects of quality of life and well-being [103]. Specifically, lung cancer treatments, including surgery, radiation, and chemotherapy for early-stage disease, and chemotherapy and radiation for later-stage disease, contribute to clinically significant fatigue, insomnia, pain, shortness of breath, and others among a substantial minority of individuals diagnosed with lung cancer [110]. These symptoms often exacerbate distress and reduce quality of life and well-being. While beyond the scope of this discussion, other psychosocial and behavioral interventions have targeted symptom management and related aspects of lung cancer, including palliative care [111].

As is well known, one of the unique aspects of lung cancer involves the link with tobacco use and nicotine dependence. Although a wide range of estimates are available in the literature, a substantial group of individuals diagnosed with lung cancer use tobacco at the time of diagnosis (~50 or higher%) and many of those continue to smoke or use tobacco following treatment (~35%) [112]. Thus, tobacco cessation interventions and treatment of nicotine dependence play important roles in psychosocial care for individuals diagnosed with lung cancer [113]. Indeed, motivation to quit is often very high among recently diagnosed individuals, potentially providing a teachable moment for intervention [114, 115].

### **Psychosocial Interventions**

Despite the demonstrated psychological burden and overall psychological morbidity associated with lung cancer diagnosis and treatment, there are very few

psychosocial or behavioral interventions that have specifically targeted lung cancer survivors [103]. While one trial specifically targeted spouses of individuals diagnosed with lung cancer, the trial itself did not achieve significant results [116]. With steadily improving rates of survivorship associated with early detection as well as advances in surgical care and adjuvant therapies, there will hopefully be greater opportunities to develop and test targeted psychosocial interventions in lung cancer. However, behaviorally oriented interventions targeting tobacco cessation among lung cancer survivors has drawn more attention from clinical researchers and has provided evidence to support care.

A growing body of research has addressed smoking cessation following a diagnosis of lung and other tobacco-related malignancies (e.g., head/neck) [101, 113]. Although the US Public Health Service's clinical practice guideline *Treating Tobacco Use and Dependence* [117] strongly recommends that every tobacco user who engages the health care system receive a basic cessation intervention based on the 5A's (Ask, Advise, Assess, Assist, Arrange) [118] individuals diagnosed with cancer are likely to benefit from interventions with greater intensity for several reasons [101, 112]. Individuals diagnosed with lung cancer who continue to smoke after diagnosis and treatment have a substantially higher rate of recurrence, potentially reduced efficacy of treatment, lower quality of life, greater symptomology, and shorter survival than individuals who stop smoking at the time of diagnosis [113].

These data have led to efforts to design and evaluate targeted tobacco cessation interventions for individuals who are using tobacco at the time of diagnosis [101, 113, 119]. Early efforts focused on brief clinician-delivered interventions, but subsequent research has examined more intensive interventions [112] that combine behavioral counseling strategies with pharmacologic intervention using nicotine replacement strategies as well as prescription pharmacologic agents that have proven efficacy in tobacco cessation.

Schnoll et al. [120] provide one example of a more structured and theoretically driven intervention. The investigators evaluated a cognitive-behavioral intervention (CBT) for tobacco cessation and compared it against a general health education (GHE) approach. The four-session intervention was partially delivered in person (one session), but the majority of the intervention was delivered by telephone (three sessions). This highlights one of the many challenges of delivering tobacco cessation intervention in an oncology setting; given the burden of the illness and treatment, patients are less likely to attend appointments outside of their scheduled oncology visits. Thus, clinicians often attempt to plan sessions in alignment with other clinic visits or deliver interventions by phone. Despite a theoretically derived intervention, the two treatment arms were not statistically different with regard to 30-day point prevalence estimates taken at 1-month (44.9 vs. 47.3%) or 3-month (43.2 vs. 39.2%) follow-up evaluation. Data favored the CBT arm, but both arms demonstrated rather high cessation rates when compared against interventions targeting smokers without cancer. While this research provides support for psychosocial interventions generally, the addition of pharmacologic intervention is often recommended to achieve even higher cessation rates.

A more recent quasi-experimental study examined the efficacy of a motivational interviewing (MI) and varenicline (V) intervention in a thoracic oncology clinic [121]. In this study, participants in the intervention arm received a 12-week motivational interviewing-based counseling intervention along with varenicline, a pharmacologic agent proven to be successful in supporting tobacco cessation in other settings. Results showed a substantial cessation rate at 12 weeks (34.4%) as measured by 7-day point prevalence; however, this outcome was not statistically different from the historical control group (14.3%). Technically, this study was underpowered to evaluate the efficacy outcome, but interpreting the effect size differential between the two arms (odds ratio = 3.14, 95% confidence interval 0.59–16.62) suggests that MI+V is an appropriate intervention for subsequent evaluation in a larger trial designed and powered to test efficacy.

Based on these promising results, several randomized controlled trials of behavioral and pharmacologic approaches of tobacco cessation interventions with recently diagnosed lung cancer patients are underway. Data from these trials will help provide additional direction to psychologists who work with individuals diagnosed with cancer, including examination of challenges and strategies to disseminating these interventions into community practice settings.

## Summary

When working with individuals diagnosed with lung cancer, there are several novel issues to consider. First, individuals diagnosed with lung cancer are likely to encounter a range of psychosocial challenges and are more likely than individuals diagnosed with other cancers to experience clinically significant psychosocial distress (e.g., depression, anxiety). Second, this elevated distress may be associated with late stage of diagnosis, given that the preponderance of disease is diagnosed at more advanced stages. Third, while relatively little data are available to guide psychosocial interventions targeting lung cancer (other than generalizing data from interventions developed for individuals facing other malignancies), addressing tobacco use is a critically important aspect of care. Although there are notable challenges to delivering tobacco cessation interventions in the oncology setting [113, 121, 122], there is evidence to support the efficacy of tobacco cessation [101, 119], and offering these interventions is consistent with an established clinical practice guideline [117] as well as recommendations from cancer organizations [113].

## *Gynecologic Cancer*

### Epidemiology

Gynecologic cancer is a broad category that includes cervical, ovarian, endometrial, vulvar, and vaginal cancers. In 2013, there were approximately 91,730 new cases of

gynecologic cancer and 28,080 deaths from this category of cancer in the USA [59]. Five-year survival rates for all gynecologic cancers are around 90% if diagnosed at a localized stage, with the 5-year survival estimates ranging from 16 to 27% for women with distant disease. The likelihood of diagnosis at an early stage is also determined by the location of the cancer and the types of screening tests available. For example, the majority of ovarian cancers are diagnosed at a late stage because there are typically no obvious symptoms and currently no evidence-based screening tests that identify the disease early and lead to effective treatment [59].

Treatment for gynecologic cancer typically involves surgery followed by chemotherapy or radiation [59, 123, 124]. However, treatment options vary widely depending on the site of the tumor and the stage at diagnosis. For example, in some gynecologic cancers such as vaginal intraepithelial neoplasia, treatment may include watchful waiting while others may include hormone therapy [124].

### **Psychosocial Impact**

Women diagnosed with gynecologic cancers have unique psychosocial concerns that follow diagnosis and treatment. Both diagnosis and treatment for gynecologic cancer have significant implications for fertility and femininity. The nature of the site of these cancers and the treatment options available introduce difficult quality-of-life and well-being choices at a time of vulnerability and distress [123]. For example, surgery involving a hysterectomy removes the possibility of conceiving children, while other therapies may induce early menopause [125]. These issues are of particular concern for younger women, who may experience a sense of loss, isolation, guilt, or anxiety as a result [123, 126]. Changes in function following diagnosis and treatment may also introduce sexual and physical challenges. Many women experience a decrease in libido and difficulty with pain during intercourse and must adapt to these changes in order to maintain sexual intimacy and satisfaction with their partners [123, 127, 128].

During and following treatment, women may experience side effects to a degree that they are unable to participate in childcare and management of the household, activities that are still performed primarily by women, even those that work full time [129, 130]. Gynecologic cancer survivors experience a reality of now having to care for themselves and their families without having the physical abilities they had in the past [129].

Not surprisingly, there are a substantial percentage of patients with gynecologic cancers that experience anxiety, depression, distress, and post-traumatic stress symptoms [90, 123, 131, 132]. A recent study estimates that between 1.2 and 4.6% of gynecologic cancer survivors report clinically significant rates of depression, while between 9.9 and 10.8% report clinically significant rates of anxiety. An additional 9.3–11% of these individuals report a mixed pattern of depression and anxiety symptoms [90]. Rates reported varied according to malignancy site, with cervical cancer survivors reporting the highest rates of depression and anxiety symptoms. Another study by Hodgkinson et al. [132] examining psychosocial

outcomes in this population estimated even higher figures, with 29% of survivors in this study reporting clinical levels of anxiety. Gynecologic cancer survivors have also been reported to experience high levels of overall distress. Johnson and colleagues administered the DT to a group of gynecologic cancer patients undergoing chemotherapy [131]. More than half (57%) of women in the study reported a “4” or higher on the DT, indicating a higher risk for clinically significant distress that requires further intervention. Finally, there is evidence that a significant portion of gynecologic cancer survivors experience symptoms of post-traumatic stress related to their diagnosis and treatment. The study mentioned above by Hodgkinson et al. [132] also screened for symptoms of post-traumatic stress disorder (PTSD) in gynecologic cancer survivors of varied disease stage. Nearly one third (29%) of advanced stage survivors met the criteria for PTSD, while a significant proportion (19%) of stage I and II survivors met the criteria.

### **Psychosocial Interventions**

Rates of psychological distress in this cancer population highlight the need for interventions designed to reduce these symptoms. Several individual and group interventions have examined the impact of psychosocial interventions on psychological outcomes in gynecologic cancer patients, including the following studies that reported a statistically significant effect of a psychosocial intervention in this population.

#### **Individual Interventions**

Only two interventions using an individual format with gynecologic cancer survivors were found to significantly improve psychological outcomes. A study conducted by Manne et al. [133] compared the effect of two different individual interventions on depressive symptoms and cancer-specific distress to usual care. The study examined the efficacy of a coping and communication-enhancing intervention as well as a supportive counseling intervention. Both interventions consisted of six 1-hour sessions with a follow-up telephone booster session. The coping and communication-enhancing intervention utilized cognitive-behavioral and educational techniques, while the supportive counseling intervention was less skill-based and was more reflective and supportive in nature. Participants in both interventions reported significantly lower depressive symptoms at 6- and 9-month follow-up, while depressive symptoms in the usual care group increased over time. There were no significant differences found between the two intervention arms. Neither intervention had a significant effect on reducing cancer-specific distress.

The remaining study utilized a one-time intervention. Petersen and Quinlivan [134] examined the effect of relaxation techniques in a group of postoperative gynecologic cancer patients. They compared a 1-hour relaxation and counseling interview provided by a senior treating doctor to usual postoperative care. The session

consisted of relaxation exercises and discussion of the patient's condition. Patients were provided an instruction sheet with a variety of relaxation exercises. Patients completed questionnaires assessing depression and anxiety symptoms 6 weeks after the session. At follow-up, scores on the HADS and the anxiety, somatization, and personality development subscales of the General Health Questionnaire-28 were significantly lower than the control group.

## Group Interventions

There have been two group interventions that have been found to significantly improve psychological outcomes in gynecologic cancer patients. A study by Cain et al. [135] examined the impact of an eight-session thematic counseling intervention on depression, anxiety, and psychosocial adjustment to illness. The eight sessions focused on a variety of topics including relaxation, diet and exercise, and negative emotions related to a cancer diagnosis. This intervention was provided in both individual and group formats and compared to standard care. Six months post intervention, patients that participated in either the individual or group counseling interventions reported significantly lower anxiety, depression, and adjustment to illness than patients in the standard care group.

A pilot study conducted by Caldwell et al. [136] investigated the impact of a 12-week group intervention for psychosexual problems on sexual functions and mood disturbance. The intervention focused on providing a supportive environment for women to explore body image and sexuality issues. Mood disturbance was measured by scores on the Profile of Mood States (POMS). Immediately following the intervention, POMS scores improved significantly. However, at the 3-month follow-up, these improvements did not remain significant and returned to baseline levels.

## Summary

A diagnosis of gynecologic cancer comes with a number of significant psychosocial concerns. To date, there is some evidence that interventions that include support, skills training, and discussion of cancer-specific concerns may significantly improve psychological outcomes. However, data are limited and requires replication. In addition, more extensive follow-up may be needed to assess the long-term effects of these interventions.

Encouragingly, a variety of interventions have been found to improve anxiety and depression symptoms, including skill-based and supportive interventions [133]. In addition, both individual [133–135] and group interventions have been found to benefit patients [134–136]. The results of the one-session relaxation intervention conducted by Petersen and Quinlivan [134] are particularly promising, and suggest the potential for a brief, cost-effective intervention that has positive outcomes for gynecologic patients. While there is a need for more conclusive evidence regarding



psychosocial interventions in gynecologic cancer, there is some promising evidence for a variety of individual and group interventions that clinicians can consider when working with this patient group.

## ***Prostate Cancer***

### **Epidemiology**

Prostate cancer (PrCa) is the most prevalent form of non-skin cancer among men in the USA with approximately 241,740 new cases diagnosed in 2012, a figure which constitutes nearly 29% of total cancer diagnoses [137]. Furthermore, the American Cancer Society (ACS) estimates that approximately one in six men will be diagnosed with PrCa during their lifetime [59]; however, this number is likely to decrease due to recent recommendations against use of regular prostate-cancer-screening procedures among older men [138].

While PrCa is the second leading cause of cancer-related mortality among American men [59], the 5- and 10-year survival rates remain high, at 99% and 98%, respectively. Moreover, PrCa is generally a disease of older age, as diagnosis in men over the age of 65 accounts for approximately 60% of new cases [124]. Decisions regarding PrCa treatment modalities are generally based on disease stage, tumor grade, and prostate-specific antigen (PSA) level, along with patient characteristics, such as their life expectancy, health status, and personal preference. For those diagnosed with localized disease, the decision is between active forms of treatment, such as radical prostatectomy, external beam radiotherapy, hormone therapy, and an observational approach known as active surveillance (AS; sometimes referred to as watchful waiting, or expectant monitoring). AS is an approach to cancer care that is used among several subsets of patients diagnosed with PrCa [139]. In this approach, the man forgoes active treatment and instead meets with his doctor for regular monitoring of the disease through digital rectal exams, PSA tests, and biopsies. By monitoring the tumor and only undergoing active therapy when it progresses, the man can: (a) avoid unnecessary treatment; (b) delay treatment-related side effects, which affect quality of life; and (c) possibly live the same amount of time as they would have lived with active treatment, but without the treatment-related side effects. Patients who choose AS retain the option to initiate active treatment at any time [139]. Active forms of treatment share an almost equally high survival rate, but generally result in treatment-related side effects including erectile dysfunction and urinary and bowel incontinence [140–142]. Despite the low proportion of early stage disease, which will progress to the point at which treatment is necessary, studies have found that nearly 90% of men diagnosed with early-stage disease will opt for active treatment [143]. Research has also indicated that up to 30% of men treated for PrCa may experience significant levels of psychological distress [144]. For this reason, it is suggested that decisions regarding treatment should incorporate the impact of treatment-related side effects on quality of life and emotional well-being

in addition to medical endpoints [145, 146]. Despite the high incidence rate, only 1 in 36 men will die from this disease [147]. Nevertheless, men who are diagnosed with PrCa may still face a host of difficulties, including psychosocial challenges as well as physical consequences of treatment [148, 149].

### **Psychosocial Impact**

As noted above, studies have identified a range of psychosocial concerns experienced by men diagnosed with and treated for PrCa, including depression and anxiety [144, 150–153], worry and uncertainty regarding choice of treatment or disease progression [143, 154], general cancer distress and severe distress [148, 155, 156], spousal discord or distress [155, 157–161], sense of threat to masculinity [162–164] and social isolation/withdrawal [151, 153, 165].

However, research examining quality of life among individuals diagnosed with PrCa is mixed with some studies indicating it returns to pretreatment levels within 1–2 years following PrCa treatment [140, 166–168], while others suggest more long-lasting decrements [141, 169–171]. This is important because many of the psychosocial challenges faced by men with PrCa are linked with treatment-related side effects [172–174]. For instance, sexual dysfunction has been identified as one of the most common disease-specific causes of distress among men treated for PrCa [175]. In fact, it has been suggested that up to 85% of men treated for PrCa may experience sexual side effects including erectile dysfunction, reduced libido, and orgasmic problems. Among one sample, nearly 61% of patients reported experiencing moderate to severe distress by this impaired level of sexual functioning more than 4 years after treatment [141]. Moreover, studies indicate that among treatment-related side effects, sexual dysfunction and urinary problems are the strongest predictors of marital problem development [174]. Bowel functioning is another area affected by PrCa treatment that can impact psychosocial well-being. For instance, Bacon et al. [174] found that bowel function proved to have the most severe impact on vitality and general health perceptions, physical functioning, and reduced role and social functioning, above and beyond the impact from both urinary and sexual dysfunction. Given the central role of social support in men's adjustment following PrCa treatment [157], as well as the relationship between marital status and survival [140, 176, 177], it is clear that relational factors must be considered when discussing psychosocial interventions for men diagnosed with PrCa.

### **Psychosocial Interventions**

Despite being the most commonly diagnosed non-skin cancer among men in the USA, there are still relatively few evidence-based psychosocial interventions available for those with PrCa [178]. In addition to the delivery approaches and components traditionally found in psychosocial interventions for patients who have been treated for cancer, many of the interventions for PrCa tend to include components

developed specifically to address common side effects. As such, interventions developed for men with PrCa tend to include multiple components and vary greatly in their approach to delivery of services. Studies investigating the patient's perspective regarding their need for psychosocial support indicate that approximately 65% expressed a need for psychological services [151], with approximately 30% reporting the need for psychological intervention to be moderate to high [179]. These statistics demonstrate that not only would men be willing to participate in programs were they made available, but also that they identify this as an unmet need in their care [154, 180].

## Psychoeducation

Among the components most commonly employed in psychosocial interventions is psychoeducation; in fact, among several interventions, psychoeducation is the one of the primary components [154, 181–183]. Previous literature indicates that the lack of general cancer information as well as information regarding treatment-related side effects, long-term outcomes, self-care strategies, patient–provider communication, and resources following treatment have been identified as unmet needs among PrCa survivors and their partners [154, 182]. Many studies have demonstrated that the provision of psychoeducation through various methods of delivery can improve several dimensions of quality of life for the PrCa survivor and their partner by alleviating the uncertainty associated with the cancer experience [154, 181], addressing distorted health beliefs and illness perception [181, 184], and promoting effective communication between patient–provider, family, and friends [146, 154].

For example, in a study comparing two telephone-based interventions, Badger et al. [185] found that patients and partners in a health education attention condition (HEAC) demonstrated improvements beyond those individuals who were randomized to an interpersonal counseling condition (TIP-C). The HEAC intervention provided materials with general information regarding PrCa diagnosis and treatment, nutrition throughout the cancer experience, methods of finding resources in the community, and smoking cessation. Authors noted that while both interventions managed to decrease depression, results were more pronounced in the participants of the HEAC condition. Other areas of improvement seen in the HEAC condition included decreased levels of fatigue, depression, negative affect, perceived stress, and spiritual well-being. It was suggested that HEAC might have shown greater improvements in comparison to the TIP-C due to the extensive length of time since treatment (186 weeks on average). Furthermore, they note that the results of this study are in line with research highlighting the importance of addressing unmet informational needs among PrCa survivors and partners, which may continue to impact their quality of life beyond the initial adjustment phases of diagnosis and treatment.

Lepore et al. [181] conducted a study investigating the influence of a group education (GE) and a group education + discussion (GED) intervention on general and disease-specific quality of life, PrCa knowledge, and health-related behaviors when

compared to standard medical care. In this study, the education-only condition consisted of six 1-hour psychosocial education lectures addressing topics such as biology and epidemiology of PrCa, physical side effects, nutrition and cancer, stress and coping, relationships and sexuality, follow-up care and future health concerns. Furthermore, participants received printed summaries of the topics covered following the lecture and were permitted a 10-minute question and answer session. The education-plus discussion condition differed from the education-only condition, in that instead of a 10-minute question and answer session, the participants were provided with a moderated group discussion lasting 45 min.

The 1-year follow-up results indicated that participants who received the GED intervention showed benefits in positive health behaviors, were less troubled by sexual dysfunction, and were more likely to remain steadily employed than either the GE or the control conditions. Furthermore, among noncollege graduates, both GE and GED interventions resulted in better physical functioning than the control condition and the participants who received the GED intervention demonstrated an increase in health behaviors compared to the control and GE conditions.

As previously noted, uncertainty regarding the cancer experience can be a significant source of distress for both the patient and their family members. In a study designed to address this issue, Mishel et al. [154] implemented a telephone-based psychoeducational intervention with conditions aimed at developing skills for managing uncertainty between both the patient and a close family member. This study compared a control condition to two intervention conditions, one that was directed at the patient only, and the other that included a close family member. Patients were encouraged to voice their specific concerns in order to tailor the intervention to their needs and provide information regarding these specific concerns, as well as assist the patient and family member to develop skills in cognitive reframing, problem solving, and assertive communication to address these concerns. Results demonstrated improvements in the coping strategies of cognitive reframing and problem solving among patients; however, these tended to plateau at 4 months post baseline and then decline by the 7-month follow-up. It is important to note that patients who received the intervention that included their family members reported that the most meaningful aspects of the intervention were the information they received regarding treatment side effects and their management. A strategy of the intervention was to encourage the spouse to discuss symptoms with the nurse and then to cooperatively identify methods to manage them. Finally, it is of note that by 7 months post intervention the retention rate remained at 95 %, indicating the willingness to participate in a psychosocial intervention.

### **Group-Based Interventions**

Group-based interventions developed for men with PrCa have shown evidence for positive outcomes in both psychosocial as well as physical well-being [164, 181, 186]. These interventions capitalize on the interactive nature of the group context to develop the patient's ability to identify and make use of systems of social support

[187]. Through training in adaptive coping skills and the encouragement of empathic sharing, group peers can learn from one another's experience, model adaptive behavior of other men in the group, and develop these important inter and intrapersonal resources necessary for adjustment [181, 187]. This is important because the development of appropriate coping strategies has been shown to predict less depression and anxiety, improved self-esteem, and improvements in mood as well, while maladaptive forms of coping have been shown to have an inverse association with positive affect and physical functioning [188].

Moreover, the group format may provide a safe environment for men to share their experiences, exchange information, and provide one another with social support. It has been suggested that this aspect of group-based interventions may facilitate cognitive processing, which has been identified as a possible pathway by which social support can enhance quality of life. For example, Roberts et al. [189] found that social support was negatively related to intrusive thoughts and an ongoing search for meaning; two factors associated with cognitive processing, such that patients who reported lower levels of social support at the baseline interview also demonstrated less likelihood of having cognitively processed their cancer experience 3 months later. Furthermore, the researchers also found that the influence of social support on cognitive processing might also promote improvements in mental functioning.

With this in mind, we can now look to specific evidence-based multimodal interventions that incorporate many of the components that we have discussed, such as psychoeducation, cognitive reframing, problem solving, coping skills, social support, and communication training.

Cognitive-behavioral stress management (CBSM) is a group-based manualized 10-week intervention adapted by Penedo et al. [190]. CBSM incorporates relaxation training and stress management approaches along with psychoeducation, development of adaptive coping techniques, and social skills training with the aim of improving quality of life among men diagnosed with localized PrCa. Similar to the B-SMART program for women with breast cancer, the 2–2.5-hour weekly sessions are composed of two segments, the first addresses relaxation exercises, such as diaphragmatic breathing and progressive muscle relaxation, and the second focuses on development of stress management skills including cognitive restructuring, coping skills, anger management, and utilization of social support [190, 191].

This approach has a strong evidence base as it has demonstrated improvements in various outcome measures. For instance, CBSM has shown benefits to participants such as improvements in general quality of life [187, 191], physical and emotional well-being [192], benefit finding [187], sexual dysfunction, and urinary incontinence [164], among others. Furthermore, the researchers have attempted to identify pathways by which the CBSM intervention brings about these improvements. For example, in a study examining the influence of social support on health-related quality of life, Zhou et al. [165] found that baseline levels of social support were positively associated with 2-year follow-up scores of health-related quality of life. The authors further demonstrated that this relationship was partially mediated by perceived stress. These results suggest that social support and perceived stress may

be important targets for psychosocial interventions, as social support may serve as a protective factor on health-related quality of life. In another study, Penedo et al. [193] demonstrated that perceived improvements in one's ability to manage stress was a strong predictor of improved quality of life, demonstrating that the intervention was not only able to influence the participants' ability to manage stress, but also that this skill was associated with quality-of-life benefits.

### **Couples Interventions**

Previous research indicates that psychosocial hardships associated with a chronic illness not only affect the patient, but the spouse as well [157, 158]. Moreover, spouse caregivers often report feeling that they have fewer sources of support as well as less confidence in their ability to manage the illness than their partner [156]. Indeed, the spouse caregiver of patients with chronic illness tend to report experiencing a great deal of distress, often surpassing the level of distress experienced by the patients themselves [155, 157, 158, 194]. In fact, general cancer distress among PrCa patients and their partners has been estimated to be 47 and 76%, respectively, with severe distress among patients to be 11%, while reaching 30% among partners [155]. Kim et al. [157] found that the level of psychological distress among spouses of men treated for PrCa was negatively related to the physical health of the survivor, above and beyond the survivor's own psychological distress, age, and stage of cancer. As studies have indicated that men tend to look to their spouse as their main source of social support [195], these findings of partner effects speak to the benefit of addressing the psychological needs of the couple, rather than the patient alone. Prior research has also demonstrated that there tends to be a discrepancy between the patient's and the spouse's accounts regarding changes that came about from the diagnosis and subsequent treatment of PrCa [196]. Furthermore, several studies have indicated that patient's accounts of marital distress due to treatment-related sexual side effects tend to be overreported in comparison to those of the spouse [155, 158]. Including the spouse in psychosocial interventions may influence relationship intimacy by promoting effective communication between the couple, facilitating discussion of uncomfortable topics, and through encouraging the exploration of alternative methods of sexual expression [154, 158, 160].

### **Summary**

PrCa is the most common non-skin cancer among men, but prognosis is generally quite optimistic. Despite this favorable perspective, men diagnosed with PrCa do experience significant rates of psychological distress as well as a broad range of side effects influencing quality of life and psychosocial well-being. In fact, because many of the quality-of-life-influencing factors involve the side effects of the treatment (e.g., erectile dysfunction, bladder and bowel incontinence) rather than the disease itself, providers often recommend AS in response to a diagnosis. This

approach involves close monitoring of the illness and treating only when the disease progresses or when a patient decides that the risk of potential side effects is more favorable than the risk of progression. Couples-based and group interventions have demonstrated efficacy at reducing distress and improving quality of life among men diagnosed with PrCa as well as their partners. In addition to addressing distress, many of the interventions promote coping strategies that help patients and their partners manage side effects of PrCa treatment.

## ***Hematologic Cancer and Blood/Marrow Transplantation***

### **Epidemiology**

Leukemia, lymphoma, and myeloma are forms of cancer known as hematologic or hematopoietic malignancies due to their relationship with the blood, bone marrow, and lymphoid system. In the USA, nearly 150,000 new cases of leukemia, lymphoma (Hodgkin's and non-Hodgkin's), or myeloma are expected in 2013 [197], constituting approximately 9% of all new cancer diagnoses. Leukemia can be broken down into four main types which are differentiated by the origin of the disease (mature or immature cells) and the cells affected (myeloid or lymphoid) [60]. Lifetime risk of developing leukemia is 1 in 63 for men and 1 in 88 for women and the overall 5-year survival rate is 56% [60]. As their name implies, lymphomas are forms of cancer of the lymphatic system and account for approximately 5% of all cancer diagnoses with the two most common being Hodgkin's lymphoma (HL) and non-Hodgkin's lymphoma (NHL) [197]. HL is a form of cancer that starts in the cells of the immune system called lymphocytes. The lifetime risk of being diagnosed with HL is 1 in 146, and it is considered to be one of the most curable forms of cancer, having an overall 5-year survival rate of 85% [60]. NHL is the name for a heterogeneous group of cancers that are similar in that they develop in the lymph nodes and lymphatic tissue. NHLs are further subtyped as either indolent or aggressive, describing the speed at which the cancer progresses. For men and women, the lifetime risk of being diagnosed with NHL is 1 in 47 [60], and the overall 5-year survival rate is 69% [60]. Myeloma is a form of cancer affecting plasma cells in the bone marrow. The lifetime risk of being diagnosed with myeloma among men and women in the USA is approximately 1 in 143, and estimates indicate that myeloma will account for more than 10,000 deaths in 2013 [60]. While survival is dependent on several factors including age, overall health, and stage at diagnosis, the overall 5-year survival rate for those diagnosed with myeloma is approximately 43% [60]. When multiple sites are affected at the time of diagnosis, the disease is referred to as multiple myeloma. This is the most common form of myeloma, it is incurable, and accounts for more than 90% of myeloma diagnoses [60].

Treatments for hematological malignancies include chemotherapy, radiation therapy, and bone marrow transplant (BMT), also known as hematopoietic stem cell transplant (HSCT). This form of treatment is generally used in conjunction

with high-dose chemotherapy and/or radiotherapy, which are two of the most common forms of treatment for lymphoma as well as several forms of leukemia. BMT/HSCT replaces stem cells that have been destroyed by the high-dose chemotherapy or radiation therapy. There are two main types of BMT/HSCT, autologous and allogeneic, depending on whether the stem cells were donated by another person (allogeneic) or they were removed from the patients themselves (autologous). Side effects associated with BMT/HSCT include graft versus host disease, infections, and the possibility of recurrence or secondary malignancy [198].

### **Psychosocial Impact**

The literature on hematopoietic malignancies suggests that several aspects of psychosocial functioning may be affected among individuals at many points throughout the cancer experience. For example, Carlson et al. [148] found HL, NHL, and leukemia to be among the cancer sites with patients endorsing the second-highest levels of distress. These results are similar to those reported by an earlier study which evaluated psychological distress with regard to cancer site [4]. For instance, among a sample of adult male survivors of HL, Cella and Tross [199] noted that up to 27% reported that the illness had negatively impacted their career, 57% reported physical stamina levels below premorbid levels, 27% indicated difficulty in concentration, and 27% reported sleep problems. Moreover, 85% of the sample reported a heightened preoccupation with their health and symptoms, and 67% reported somatic concerns.

Patients with myeloma have also demonstrated decrements in emotional well-being and quality of life [200]. In fact, a recent study reported that among a sample of longer-term survivors of multiple myeloma (greater than one year post diagnosis), 27.4% reported experiencing anxiety, and 25.2% reported signs of depression [201]. Furthermore, partners of these survivors were faced with similar psychosocial challenges and reported experiencing levels of psychological distress and unmet supportive care needs beyond those of the survivors themselves [201]. The authors indicated that levels of psychological distress seen among this sample were greater than those commonly seen in the general cancer literature.

Studies have shown that candidates for BMT/HSCT experience heightened levels of psychological distress as well, and among one sample, more than 30% of the patients being evaluated demonstrated elevated scores on measures of depression [202]. A study conducted by Sherman et al. [203] indicated that among their sample of patients being evaluated for BMT/HSCT for multiple myeloma, approximately one third endorsed heightened levels of distress, anxiety, and depression. Of this same sample, nearly 60% reported clinically significant levels of disrupted physical functioning, and 28% demonstrated symptoms of poor mental health functioning that also reached levels of clinical significance.

Among patients of hematological cancers who received aggressive treatment with BMT, studies have found that quality of life was most greatly impacted among those with multiple myeloma [204, 205]. Furthermore, among a sample of long-term



survivors (average 3.4 years post treatment) of BMT/HSCT, Rusiewicz et al. [206] found global psychological distress among 43% of their sample, with one quarter of their sample demonstrating clinically significant symptoms of depression and anxiety. While this study did not focus exclusively on leukemia or lymphoma survivors, individuals affected with these diseases made up approximately 80% of the sample. The authors reported no difference by cancer site, which suggests that these results may be a function of the form of treatment rather than being directly related to diagnosis. While not focused solely on hematopoietic malignancies, studies have also noted PTSD symptomatology among BMT/HSCT survivors at rates of 5–19% [206–209]. Taken together, these studies suggest impairment throughout the cancer continuum and speak to the importance of psychosocial interventions developed for this population.

### **Psychosocial Interventions**

Given the documented psychosocial burden of diagnosis and treatment for leukemia, lymphoma, and myeloma, there is a well-defined need for psychosocial interventions. However, the evidence base for targeted psychosocial interventions in this domain is limited. While it is likely that the evidence for psychosocial interventions developed specifically for individuals diagnosed with other malignancies would generalize to this patient population, there is a need for intervention research to test this assumption and possibly identify novel interventions that would address the specific, and sometimes unique, psychosocial issues faced by individuals diagnosed with leukemia, lymphoma, or myeloma. That being said, there are a few interventions that have been developed and demonstrated preliminary efficacy in their ability to help individuals with hematopoietic malignancies manage psychosocial sequelae.

Sherman et al. [210] developed a screening intervention designed to address preemptively the physical and psychosocial challenges faced by patients of hematopoietic cancers who undergo BMT/HSCT. Specifically, this preemptive intervention aimed to screen patients prior to transplant and provide coordinated, supportive care to those patients most at risk for further physical and psychosocial complications throughout treatment. The authors noted that among this sample, which was largely comprised of patients with multiple myeloma (85.3%), more than 50% of the participants reported decrements in their day-to-day physical functioning, more than 60% demonstrated nutritional deficiency, nearly 40% reported fatigue, and more than 30% reported pain, emotional distress, impairments in sexual functioning, and body image issues. In line with previously cited research [202, 203], results of this study suggest that patients treated with BMT/HSCT face psychosocial stressors at many points in their treatment, including the pre-transplant period. The investigators concluded that screening was a feasible intervention and facilitated identification of key psychosocial and physical concerns warranting treatment.

Among psychosocial interventions for those already treated with BMT/HSCT, Syrjala et al. [211] developed and evaluated an intervention addressing pain and

consisted of four conditions, including treatment as usual (TAU), psychotherapeutic therapist support, relaxation and imagery training, and training in CBT coping skills plus relaxation and imagery. The investigators found that the relaxation and imagery training condition and the CBT condition produced reports of less pain than the TAU or therapist support conditions. However, in line with their previous study [212], the authors found no difference between the CBT coping skills condition and the relaxation and imagery training conditions, suggesting that relaxation and imagery are important components of psychosocial interventions addressing pain among this population.

As previously discussed, symptomatology of PTSD and general psychosocial distress is often experienced by survivors of BMT/HSCT. With this in mind, Duhamel et al. [213] developed a telephone-administered cognitive-behavioral therapy (T-CBT) specifically targeting these symptoms. This intervention was 10–16 weeks in duration and consisted of ten telephone-administered sessions. Components of this psychosocial intervention included psychoeducation regarding the patient's illness, including PTSD symptoms and cognitive-behavioral approaches to address these issues, self-monitoring, and cognitive processing of experiences (e.g., altering maladaptive beliefs, guided exposure, communication skills training for enhancement of social support, and relaxation training). Results indicated that T-CBT was successful in reducing PTSD symptom scores, including illness-related intrusive thoughts and avoidance throughout all follow-up assessments. The authors noted, however, that the intervention was not effective with regard to numbing and hyperarousal, two additional components of PTSD.

## Summary

Hematologic malignancies are a heterogeneous group of cancers that affect the blood, lymphatic system, and bone marrow. The treatments include regional and systemic approaches that combine radiation and chemotherapy, but might also include BMT/HSCT in some cases. Data have indicated that individuals diagnosed with these cancers commonly experience some of the highest rates of psychological distress and that individuals that undergo BMT/HSCT may experience symptoms of PTSD. Despite the identified psychosocial burden of these malignancies and their treatment, there have been relatively less intervention development efforts targeting individuals with hematologic malignancy. Interventions developed to date have shown some promise in terms of managing both psychological distress and other symptoms.

## Conclusion

With advances in screening and improved treatment outcomes, there are many more cancer survivors than ever before [2, 3]. The increase in cancer survivorship has generated an appropriately increased focus on psychosocial well-being and quality

of life following cancer diagnosis and treatment. While not all individuals diagnosed with cancer will experience clinically relevant levels of distress and psychosocial morbidity following diagnosis, research shows that a substantial minority of individuals encounter emotional and psychosocial challenges that can be addressed with psychosocial interventions.

A solid foundation of evidence has emerged to inform EBP and contributed to the development of clinical practice guidelines. These psychosocial interventions include a combination of individual, couple, and group-based interventions that target a range of relevant psychosocial (e.g., distress, social support) and behavioral outcomes (e.g., tobacco cessation). While the literature is not without methodological weaknesses and has notable limitations, the preponderance of evidence suggests that psychosocial interventions have adequate utility and should be offered to individuals who experience clinically relevant levels of psychological distress. This point has been recognized by authoritative organizations, and the Institute of Medicine has targeted psychosocial cancer care as a component of quality cancer care.

The evidence supports the value of psychosocial cancer interventions, but there are still a number of important questions that remain to be answered as well as emerging questions and opportunities that could facilitate dissemination and implementation of evidence-based interventions. One of the first challenges is for clinical research to integrate more diverse samples to address concerns about data generalizability. In particular, efforts to extend interventions to underserved groups are particularly warranted, including racial and ethnic minorities, but also rural populations. Second, there are opportunities to target interventions more effectively to a broader range of malignancies and build a broader foundation of evidence for psychosocial care in cancers that are less common or have simply not been the focus of as much psychosocial research. Third, advances in technology have created opportunities to disseminate psychosocial interventions using a variety of platforms, including internet chat rooms for support groups, or smartphone-based interventions to treat tobacco dependence. Fourth, to date, much of the clinical psychosocial cancer research has focused on a deficit model of reducing psychological distress, but the last decade has demonstrated interest in approaches that promote positive adaptation to cancer or adopt a preventive approach to the development of psychosocial distress and morbidity following diagnosis. While these targets also have notable criticisms, there are open and testable hypotheses about the value of these approaches in psychosocial cancer care. Fifth, while maintaining methodological rigor remains important to establishing the foundation of evidence, practical and adaptive clinical trial designs also offer attractive options to building a stronger foundation of science and may lead to the development of interventions that have greater practical utility, including greater likelihood of dissemination and sustainability outside a clinical trial setting. Sixth, as in most emerging literatures, there is a need to understand the factors that modify treatment efficacy and effectiveness. Indeed, there is a need to work toward the ultimate understanding of psychosocial care by addressing the infamous question, “What specific treatment, by whom, is most effective for this individual with that specific problem, and under which set of circumstances.”

This chapter has focused on the evidence base for providing psychosocial care for adults with cancer who experience psychosocial distress. Additional intervention literature exists with regard to other domains within adult psychosocial oncology, including interventions targeting management of physical morbidity/symptoms, adoption of health behaviors (e.g., exercise), cognitive dysfunction, and mortality. Also, in the broader domain of psychosocial oncology, other literature addresses psychosocial care in pediatric oncology, interventions and care for long-term cancer survivors, psychosocial care for pre-vivors (i.e., individuals with elevated risk for cancer based on genetic testing), and caregivers or family members of cancer patients.

In conclusion, research has demonstrated that individuals diagnosed with cancer continue to experience a range of psychosocial sequelae following diagnosis, throughout treatment, and during survivorship. To address these psychosocial issues, a broad intervention literature has emerged and generally supports the utility of a number of individual, couples, and group interventions to reduce psychological distress and improve quality of life. Additional research is needed to address concerns about generalizability, but there is generally a reasonable foundation of support to guide EBP in behavioral and psychosocial oncology.

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# Chapter 24

## Physical Rehabilitation Programs

Erin E. Andrews and Timothy R. Elliott

### Introduction

Comprehensive rehabilitation for acquired disabilities such as amputation and spinal cord injury are increasingly important as the US population ages and as wounded military service members return home. Persons with disabilities constitute one of the largest minority groups in the USA. Approximately 49.7 million people in the USA live with some type of long-lasting health condition or disability [69]. In addition, an estimated 45% of persons in the USA live with a chronic health condition that has some disabling features [54]. Disability rates increase with age for both men and women, and more than 46% of people with a disability report having more than one disabling condition [69].

In rehabilitation settings, individuals with physical disabilities are typically treated by an interdisciplinary team of health care providers, including physiatrists (physicians specializing in rehabilitation medicine), occupational therapists, speech-language pathologists, physical therapists, nurses, audiologists, vocational counselors, recreational therapists, social workers, and psychologists, depending on the particular setting and the individual's needs. The team may also include other consulting physicians such as neurologists, orthopedists, psychiatrists, internists, and others [68]. Psychologists practice in a wide variety of inpatient and outpatient settings that serve individuals with disabilities and chronic illnesses. Common settings are public and private acute and postacute care hospitals, other postacute inpatient settings (i.e., skilled nursing facilities and intermediate care facilities), comprehensive outpatient rehabilitation facilities, specialty clinics (e.g., cardiac rehabilitation), and private practice, but also include schools, universities, nonprofit organizations, and state and federal agencies [63]. The Veterans Health

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673

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Administration is the single largest employer of psychologists who work with persons who incur SCIs. In hospitals and other institutional practice settings, psychologists almost always work within interdisciplinary teams in rehabilitation units.

In medical settings “physical medicine and rehabilitation” programs involve interdisciplinary team members who collaboratively set goals with patients for tasks related to functional independence, such as ambulation (with or without the use of adaptive equipment), transferring, dressing, and other activities of daily living (ADLs). The branch of professional psychology that specializes in rehabilitation—rehabilitation psychology—has been closely tied to this enterprise, beginning with its inception in the US Department of Veterans Affairs: After World Wars I and II (WWI and WWII), the specialty of rehabilitation psychology evolved in response to the needs of wounded veterans [27]. Rehabilitation psychology draws from several theoretical bases including biopsychosocial theory, behaviorism and learning theory, self-psychology, social psychology, neuropsychology, and cognitive-behavioral theory (CBT; [60]).

Psychologists contribute to the rehabilitation process in a number of ways. Services typically provided by psychologists in these settings can be divided into three broad categories [23]: assessment (e.g., psychological, neuropsychological, and psychosocial), intervention (e.g., counseling/psychotherapy, psychoeducation, behavioral management, family interventions, sexual counseling, cognitive remediation), and consultation (e.g., with interdisciplinary teams, primary caregivers, and/or outside parties and regulatory systems). Psychologists assess the mental health needs of rehabilitation patients. Rehabilitation psychologists possess a specific skill set to assess the differences between normal adjustment reactions in response to acquired disability and a more clinically significant mood or anxiety disorder. Other relevant psychological considerations are concomitant cognitive impairment, substance abuse issues, sexual concerns, pain problems, personality variables, vocational pursuits, and family system topics.

These psychologists also interface with other disciplines on the rehabilitation team and may co-treat or consult about specific issues. For example, a psychologist may be consulted by a psychiatrist who is frustrated that a vascular amputee patient refuses smoking cessation, or a psychologist may conduct a joint session with a physical therapist for a patient who has a phobia of movement related to pain. Furthermore, the psychologist in a rehabilitation setting should have knowledge of team and group dynamics in order to assist the team in functioning most effectively, especially in the management of patients with behavioral difficulties or noncompliant behaviors. Psychologists also provide education, support, and evidence-based therapeutic interventions for rehabilitation patients (and, as indicated, for their family members), particularly for those who experience clinically significant adjustment reactions and mental health problems. Elliott and Warren [28] also emphasize that psychologists in rehabilitation settings have unique skills in program development, outcome measurement, and evaluation that are of immense value in a rehabilitation setting.

In this chapter, we will focus on amputee and spinal cord injury rehabilitation settings to illustrate the role of psychology in physical rehabilitation.



## Amputation

Acquired amputation of one or more digits or extremities is an increasing health concern in the USA. The most common health concern leading to amputation is type II diabetes mellitus. Vascular-related problems are the leading cause of amputation. As such, prevention efforts and campaigns have become prevalent in medical settings. Planned surgical amputation provides an opportunity for presurgical involvement by an array of providers, including pain management specialists and psychologists who are not available in a traumatic amputation context. In terms of the psychological response to amputation, patients are faced with readjustments based on several factors, including life stages.

Amputation is a diverse disability; amputees vary considerably in the psychological responses observed and in the range of disability experienced [62]. It is important to understand that the majority of amputees make successful adjustments, measured not only on the absence of negative factors but also on the presence of positive factors. A significant subset of amputees, however, experiences significant emotional distress. Psychologists must differentiate a loss or adjustment reaction that is temporary and considered a normal part of the process from a clinically significant depression, which is estimated to occur in 21–35% of amputees [62].

Symptoms of depression and anxiety may appear resolved over the course of rehabilitation but reemerge after discharge [67]. Depression is associated with a variety of psychological factors, and it may be associated with chronic health problems that predate the amputation [73]. Anxiety problems have traditionally been studied less and may be less prevalent among amputees, and there is some evidence that anxiety problems may occur at a higher rate than depression among individuals who are within 5 years post amputation [3]. Traumatic amputation can contribute to the development of post-traumatic stress disorder (PTSD; [48]).

Overall, no significant differences in adjustment have been consistently found as a function of the cause of amputation. Yet it is believed that traumatic onset may increase emotional distress (e.g., polytrauma among wounded veterans). Interestingly, in vascular-related amputations, quality of life (QOL) may improve post amputation as a result of decreased pain and increased mobility. There is a common misconception that more physical impairment leads to poorer psychological adjustment, and that level, location, number, and site of amputations predict psychological adjustment. None of those factors has been empirically linked to adjustment. In one study [29], multiple limb loss was actually associated with higher QOL in veterans compared with single limb loss. Individuals with long-term prosthesis use are at risk for musculoskeletal problems and chronic pain over time [31, 32].

Research suggests that activity restriction related to personal values (activities essential to identity) may be a better predictor, which of course differs among individuals [62]. Time since amputation is not a significant predictor of adjustment in all studies although there is some evidence to suggest that adjustment occurs over time. QOL may improve due to meaning making, new perspectives, reprioritization, and/or increased coping skills, but this is not consistently supported across studies.

With nontraumatic acquired amputations, there may be a sense of initial relief coupled with a delayed-onset grief or loss reaction. In the literature, the initial prosthetic fitting is often discussed as a vulnerable time when unrealistic expectations may lead to disappointment.

## Spinal Cord Injury

Like amputation, spinal cord injury (SCI) is a diverse disability with a wide range of functional outcomes. Complete lesions to the spinal cord result in total sensory and motor functioning loss below the level of injury; incomplete lesions to the cord typically result in partial sensory or motor functioning loss below the level of injury. Tetraplegia is the result of SCI to the cervical spinal cord, affecting all four limbs; paraplegia results from injury to the thoracic spinal area or below, with greater involvement of the lower extremities in terms of sensory or motor functioning. There are also a number of SCIs that can be classified into specific syndromes (ventral cord syndrome, Brown–Sequard’s syndrome, central cord syndrome, etc.). More than 80% of individuals who incur a SCI are male; motor vehicle accidents (39.2%), falls (28.3%), and acts of violence (14.6%) are the leading causes of SCI [50].

Depressive symptoms are a relatively common secondary problem following SCI [22, 26]. Arango-Lasprilla et al. [1] found that major depressive disorder is a relatively common occurrence between 1 and 5 years following spinal cord injury, and that several demographic, physical, and psychosocial factors were associated with the incidence of depression. Females who were unemployed, individuals with indwelling catheters, and people with a high school education or less schooling were at the highest risk for depression. Other complicating conditions associated with SCI may be incurred at the time of the injury (e.g., concomitant head injury; neuropathic pain that becomes chronic), or may develop over time due to problems with adherence to therapeutic regimens, disparities in access to care or service provision, social factors, and activity restrictions (e.g., obesity, pressure sores), or as a consequence of the debilitating characteristics of the SCI (e.g., urinary tract infections, spasticity, and contractures; Warren et al. [70]).

## Models of Disability

There are several models of disability. The oldest and probably the least frequently (although still existent) used is the moral model. This model, heavily influenced by religious doctrine, postulates that disability is a result of a moral failing or sin on the part of the individual or his or her family members (e.g., parents; [53]). For example, individuals who perceive an acquired disability as punishment for past deeds are conceptualizing disability under the moral model. Following the WWI

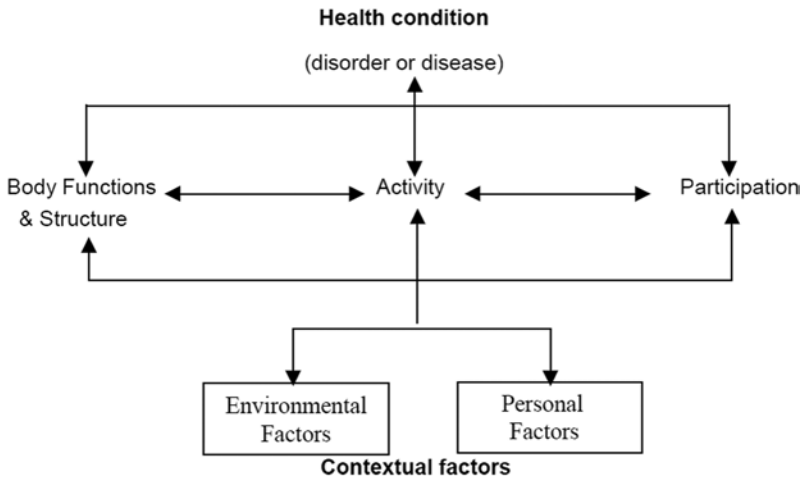


Fig. 24.1 The ICF model of functioning, disability, and health

and WWII, the medical model was developed in response to disability. The medical model stipulates that physical impairment is a problem in need of a remedy or cure [39]. As a derivative of this, the rehabilitation model assumes that physical impairment is a difficulty that requires rehabilitative efforts to compensate for or to ameliorate limitations.

The social and minority models of disability are more recent developments. These models shift the problem away from the individual and the impairments and focus on the attitudinal, structural, and general environmental barriers, which inhibit those with disabilities from full participation in society. Under these models, disability itself is not viewed as a problem, but rather a neutral characteristic and a natural form of human diversity. Like other demographic characteristics such as race and sexual orientation, disability may even be a valued or celebrated part of one's identity. However, the social model does not clearly distinguish who qualifies as a person with a disability or how disability is measured or determined [56].

A comprehensive biopsychosocial model integrating the strengths of many of these models of disability is that of the World Health Organization (WHO; the International Classification of Functioning, Disability, and Health, ICF; [74]), developed to address the limitations of the medical model and integrate elements of the social model of disability [56]. The WHO The International Classification of Impairments, Disabilities, and Handicaps (ICIDH) defines "impairment" as a difference in bodily function or structure, "disability" as a limitation in activity or participation restriction, and "handicap" as the interaction between a person with a disability and the environment with limited role fulfillment, which has incorporated the idea of disability as a social construct. As depicted in Fig. 24.1, the most recent ICF retains "impairment" as an alteration in bodily function or structure; importantly though, *impairments* are no longer defined as *problems* [56]. WHO ICF defines "activity limitations" as limitation in mobility or self-care. The term

“participation restriction” has replaced “handicap” in terms of life activities and roles such as attending school, gainful employment, or pursuing relationships. The old concept was that handicap resided in the person (“the person is handicapped”), but the new model emphasizes the role of the social and physical environments in restricting or enabling participation (“the person needs accommodations to get to work”). The WHO ICF has added “environmental factors,” which are the external elements which affect the experience of the individual, including technology, attitudes, and services. “Disability” refers to both activity limitations and participation restrictions.

The WHO ICF model applies to a wide range of different disabilities. Sometimes impairment does not result in any functional limitations. An injury may not necessarily lead to impairment. Activity limitations can change based on environmental factors. The dynamic nature of impairments and activity limitations are better reflected in this model than in other conceptualizations.

## Adjustment and Quality of Life

Adjustment is often thought of as a point at which an individual reaches and maintains psychosocial equilibrium, achieves a state of reintegration, positively strives to reach life goals, demonstrates positive self-concept, and experiences positive attitudes toward oneself, others, and the disability [46]. Increasingly, these concepts are discussed in rehabilitation psychology as not just the absence of negative factors but the presence of positive ones. However, persons with disabilities must constantly re-adapt to changing circumstances, including life changes, exacerbations of physical disabilities, aging, and interpersonal stressors. Clinically and theoretically, adjustment following acquired disability is best construed as a “...dynamic and fluid process in which characteristics of the person and the injury, their social and interpersonal world...and the historical and temporal context interact to influence physical and psychological health” (Elliott and Rivera [18] p. 423). A dynamic conceptualization of adjustment (and QOL) following SCI is warranted for several reasons. Individual differences, behavioral factors, and other psychological characteristics usually account for greater variance in the prediction of adjustment among persons with disability than does any condition-specific variable [60]. Stressors appear to vary as a function of psychological and social characteristics rather than being due to specific physical diagnostic conditions [56].

Additionally, it is important to view persons with acquired disabilities as active participants in the adjustment process and to avoid referring to these individuals as “victims” or “sufferers” of trauma or fate [15]. Failure to do so reinforces widely held beliefs that people with disabilities are dependent and incapable of making decisions for themselves, which in turn contributes to objectification [30]. A more appropriate focus may be on *disability acceptance*, a fluid and dynamic process by which a chronic condition or impairment becomes accepted as a nondevalued part of the individual’s self-concept (e.g., Wright [75]). In Olkin’s [53] description

of disability affirmative psychotherapy, based on the social/minority model of disability, the disability itself is not a problem, but rather the “problem” resides in the environmental and attitudinal barriers that impede people with disabilities. The recognition and integration of personal and environmental factors in adjustment is a fundamental tenet in rehabilitation psychology [27].

## Evidenced-Based Practice

Evidenced-based practice (EBP) in rehabilitation settings is based in a long history of clinical involvement, interdisciplinary collaborations, and innovative, flexible, yet broad skill sets. Expert practitioners possess competencies espoused by the American Board of Rehabilitation Psychology (a specialty of the American Board of Professional Psychology) depicted in Table 24.1 [34]. These competencies typify informed psychological practice in SCI rehabilitation and with persons with amputations.

These competencies require a keen awareness of the knowledge base fundamental to rehabilitation psychology; it also merits a familiarity with the issues associated with EBP in rehabilitation psychology, generally. The literature base for established competencies in the core practice areas—assessment, intervention, consultation—does not follow the linear pattern typically associated with EBP in more traditional areas of psychological practice. Rehabilitation is an interdisciplinary enterprise. Therefore, much of the extant literature concerning core competencies appeared in peer-reviewed outlets that featured studies of interest to an interdisciplinary audience (and thus out of the mainstream of psychological research; Shontz and Wright [66]). Assessment, for example, has always been a central focus of psychological practice in rehabilitation. Historically, important works about psychological assessment appeared in journals ranging from the *Archives of Physical Medicine and Rehabilitation* and *Artificial Limbs* to the *Journal of Clinical Psychology*. Rehabilitation psychologists are active in interdisciplinary associations germane to their practice, research, and policy interests (e.g., the American Congress of Rehabilitation Medicine).

Studies of psychological interventions also follow a circuitous route, shaped in part by the individualized nature of the rehabilitation process (in which treatments are tailored to the specific needs and assets of each individual as determined by a thorough, interdisciplinary assessment) and by the primary focus of the enterprise on the overall health and functioning of the person (rather than their “mental health”). Consequently, rehabilitation psychologists traditionally based their interventions on related areas of research (e.g., CBT for depression) rather than on evidence from randomized clinical trials of treatments for specific problems (depression) with a specific clinical population (persons with SCI; [26]).

Typically, rehabilitation psychologists do not subscribe to any single theory of behavioral change, although most have clear preference for a particular approach in therapy (cognitive-behavioral vs. psychodynamic, for example). As presented

**Table 24.1** Required and supplemental competencies by the American Board of Rehabilitation Psychology

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*Assessment*

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*Required*

Adjustment to disability: patient  
 Adjustment to disability: family  
 Assessment of extent and nature of disability and preserved abilities  
 Assessment as it relates to educational and/or vocational capacities  
 Personality and emotional assessment  
 Cognitive testing  
 Competency evaluation  
 Sexual functioning assessment  
 Pain assessment  
 Substance use/abuse  
 Social and behavioral functioning assessment

*Intervention*

*Required*

Individual therapeutic intervention as it relates to adjustment to disability  
 Family/couples therapeutic intervention as related to adjustment to disability  
 Behavioral management  
 Sexual counseling with disabled population(s)

*Supplemental*

Pain management  
 Cognitive retraining  
 Group therapeutic intervention as it relates to adjustment to disability

*Consultation*

*Required*

Behavioral functioning improvement  
 Cognitive functioning  
 Vocational and/or education considerations  
 Personality/emotional factors  
 Substance abuse identification and management  
 Sexual functioning and disability

*Supplemental*

Improvements in physical functioning  
 Integration of assistive technology for enhancement of cognitive, sensory, and physical functioning

*Competence in consumer protection*

*Required*

State laws of practice  
 Laws related to and including ADA  
 APA ethical principles  
 Awareness and sensitivity to multicultural and diversity factors  
 Issues related to patient confidentiality and privacy (e.g., HIPAA)

*Supplemental*

Advance directives/wish to die  
 Abuse/exploitation (sexual, financial, physical, psychological)  
 Prevention, e.g., advocacy of legislative policy changes, education  
 Establishment of standards of care/practice in rehabilitation

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**Table 24.1** (continued)

<i>Assessment</i>
<i>Professional development competence</i>
<i>Required</i>
Continuing education: must include documented CE credits in rehabilitation psychology areas within the previous 2 years
<i>Supplemental</i>
Professional presentation—local, state, national levels
Publications
Teaching
Involvement in advocacy groups
Gain expertise in related subspecialty areas (e.g., supervision, workshops)

earlier, there are several models of disability that guide the rehabilitation enterprise, and current practice is quickly embracing the ICF conceptualization. Although this model is not a “psychological” theory per se, it provides considerable opportunities for psychologists to provide meaningful, theory-driven assessments of function, impairment, and capacity, and for prescribing interventions and services to eliminate barriers and promote activity and QOL.

## Assessment

Psychological assessment in the rehabilitation setting relies on basic competency in conducting intelligence, cognitive, and personality assessments. It also requires an additional understanding of the unique issues an individual may face following SCI or amputation, and the personal assets, behavioral patterns, and social characteristics known to be associated with optimal adjustment. Usually there is no “standard” battery for use across rehabilitation settings. In inpatient SCI rehabilitation, for example, a routine assessment involves a brief evaluation of cognitive abilities and awareness (with particular attention to the occurrence of loss of consciousness at the time of the injury), distress (including symptoms of depression and anxiety), behavioral patterns (alcohol or other substance abuse; criminal activities), and social characteristics that concern rehabilitation and subsequent return to the community (such as social and family support). These evaluations are often conducted under fairly routine office conditions, but on occasion the psychologist may be compelled to assess a patient at bedside. Certain institutions may require additional measures that serve to monitor progress during rehabilitation and therapeutic outcomes following discharge. This may include specific yet established measures that are widely used (e.g., the PHQ-9; [44]).

Competent practice dictates that psychologists individualize assessments to address unique concerns of the patient. Older individuals with a complex medical history and chronic health problems may evidence cognitive problems following surgery that merit close scrutiny, and, in some cases, additional neuropsychological

evaluation. Similarly, individuals who incur SCI in high-impact accidents often acquire a severe brain injury that may override traditional SCI rehabilitation practice, and necessitate ongoing monitoring of neuropsychological functions. Persons with SCI and amputations are at a risk for neuropathic pain, so psychologists are alert to patients' reports of pain and displays of pain behavior (such as catastrophizing, sleep disturbance) that may signal a complicated adjustment and ancillary treatments.

Many psychologists may include domain-specific measures of characteristics that have theoretical and clinical importance. Individuals vary in their coping repertoire [62] and in their recognition and use of social problem-solving skills [24]. Research has found coping preferences [41, 42] and problem-solving abilities [16, 21] are predictive of psychological adjustment at discharge and following return to the community among persons with SCI. In a study of elderly amputee veterans in the UK, Desmond and McLachlan [11] investigated various coping strategies of problem solving, social support seeking, and avoidance in relation to general adjustment, social adjustment, and adjustment to limitations. Problem solving and social support seeking were negatively associated with depressive symptoms, while social support seeking was positively associated with social adaptation. Avoidance was associated with depression and anxiety, and poorer adjustment and social adaptation [11]. Other research attests that positive coping efforts [52] and positive appraisal mechanisms [57] are instrumental in optimal adjustment following amputation.

Comprehensive psychological evaluations—that include traditional measures of intellectual abilities and psychological profiles like the Minnesota Multiphasic Personality Inventory-2 (MMPI-2)—are time intensive and may lack immediate relevance to the rehabilitation enterprise. They are, however, recommended for clinical cases in which legal issues concerning liability and culpability are at stake (that can occur following a work-related injury). The traditional psychological assessment can help prepare a psychologist if subpoenaed to participate in the proceedings. In these situations, colleagues are expected to utilize appropriate norms, and to use and report any nonstandardized procedures in scoring or administration.

Rehabilitation psychologists conduct assessments with the intention to identify sources of personal strength and assets that may be integrated to facilitate rehabilitation and adjustment. Current research reveals that many individuals are quite resilient following the onset of SCI (54%), and resilience may be distinguished by high levels of positive affect throughout the inpatient program (Quale and Schanke [58]). In a study following individuals in the first 3 years post injury, resilient individuals endorsed fewer avoidant coping strategies, fewer perceptions of threat, and were more apt to sense a challenge in stress and display a “fighting spirit” than distressed individuals (Bonanno et al. [7]). Unfortunately, this conceptualization of resilience—based on Bonanno's influential model (Bonanno et al. [6])—has limited clinical utility for practitioners trying to identify resilient characteristics among individuals in an inpatient setting soon after incurring a disability. Alternative indicators of a trait-like resilient style appear promising. White et al. [72] studied a self-report measure of resilience among 42 individuals with SCI during inpatient rehabilitation, and found resilience was stable throughout the course of treatment



and it was significantly associated with life satisfaction and depressive symptoms. Examination of resilient traits derived from “Big Five” personality profiles of patients administered on admission to SCI rehabilitation found resilient persons had less depression at the beginning of the program and greater acceptance of disability and more effective problem-solving strategies at discharge than patients with rigid, inflexible, and overcontrolled personality styles [5].

In all assessment activities, the psychologist must be conscious of the use and availability of psychological data in rehabilitation. As discussed elsewhere in length (Elliott and Umlauf [19] pp. 327–328), a psychologist in a rehabilitation setting usually has multiple “clients” including the patient and the rehabilitation team. Other parties may also be invested in psychological data and vary in their immediate and eventual access to the data (including insurance companies and research teams). Disclosure of assessment data should always be in the best interest of the client. It is imperative that the client clearly understands these issues, and the psychologist should pursue due diligence in obtaining consent about sharing assessment data, and under what circumstances and to whom the information will be shared.

## Interventions

In rehabilitation psychology, blended and individually tailored approaches are often appropriate with a clientele who have more complex medical and psychological needs. Often an individual with a recent SCI or amputation does not perceive a personal “need” for a psychological intervention of any sort for any reason. Indeed, while psychological assessments are quite common (if not routine) in most inpatient rehabilitation settings, psychological interventions are not. Such interventions may be relegated to education or support sessions conducted for inpatients at an assigned time as a routine part of rehabilitation therapies. But psychologists are often in a position to provide individual and couples counseling to support those with recent injuries in the inpatient setting, and sometimes these sessions continue on an outpatient basis following discharge. In other scenarios, psychologists intervene with an individual who has a pronounced alcohol abuse problems, and may employ motivational interviewing techniques in the session. Rehabilitation psychologists also use a variety of techniques, including biofeedback and hypnosis, to help patients find relief from persistent pain sensations. Some interventions may require adaptation for disabilities, such as applied relaxation training for individuals with spinal cord injuries [36].

A few areas warrant particular attention as they address common and emerging areas for practice that often challenge psychologists who are unfamiliar with the field. These include interventions for emotional distress, to promote health and wellness, and for family members of individuals with severe disabilities.

*Interventions for depression, distress, and anxiety* We know that a significant minority of individuals with acquired disabilities will experience a clinical depression at any point in time. We also know that there are many well-established psychological interventions for depression in the extant literature and in routine practice.

Many of these can be utilized in treating persons with acquired disabilities. Many psychological interventions in the rehabilitation setting theoretically derive from behavioral and learning theories [60] and cognitive-behavioral approaches are often used by rehabilitation psychologists [25].

A recent meta-analysis found that CBT for depression exhibited large effect sizes (and similar effects were found on assertiveness, coping, self-efficacy, and elements of quality of life; Dorstyn et al. [13]). Similarly, another meta-analysis also concluded that there is sufficient evidence to support the use of CBT in treating depression and anxiety post SCI [49]. In both studies, there was ample evidence that CBT had effective short-term benefits, but there is no real evidence for long-term effects. Most of the studies reviewed utilized group formats to provide CBT to participants [14, 40, 43]. Self-management interventions that incorporate CBT principles are effective in promoting emotional adjustment of persons who have experienced limb loss [71].

An alternative model, congruent with a social construal of disability, is disability-affirmative therapy [53]. The framework for therapy centers on disability culture and affirmation of a positive disability identity. Olkin suggests taking this orientation in therapy with individuals with disabilities to provide a culturally sensitive environment that allows for the integration of disability cultural values. Some of the core values include the use of disability humor; acceptance of human diversity; a matter-of-fact acceptance of human vulnerability and interdependence as a natural part of life, skill in managing multiple problems, systems, technology, and assistants; and a flexible, adaptive, or nontraditional approach to tasks [33].

*Promoting health and wellness* Psychologists now participate in programs that emphasize secondary disease prevention and the promotion of health and wellness among individuals with disabilities. For example, women with disabilities (WWD) are at increased risk for preventable secondary conditions; these conditions can influence health status and QOL [9, 37, 51]. WWD are at risk for adverse health behaviors such as physical inactivity, smoking, poor nutrition, and alcohol overuse that are associated with numerous chronic health conditions (e.g., diabetes, obesity, hypertension, etc.), perhaps as a result of environmental barriers to preventative health care and treatment such as decreased physical and economic access and limited social and professional support [4, 38, 59].

Health promotion programs for this population are imperative to wellness [37, 55]. Programs that incorporate cognitive-behavioral principles have been used effectively to promote increased physical activity and increase self-efficacy and perceived control among participants with SCI [45]. Additional training in coping skills and planning can augment these interventions [2].

*Interventions for family members* A significant percentage of family members, including partners and caregivers, develop clinically significant problems with depression and anxiety [8, 12]. Family caregivers of persons with recent-onset SCI can benefit from brief cognitive-behavioral interventions that help them learn effective problem-solving skills [17]. In the most comprehensive demonstration to date, Schulz et al. [64] conducted a randomized controlled trial of two active intervention conditions and an information-only control group for caregivers of

older persons with SCI. The interventions that targeted both the caregiver and the care recipient resulted in significant decreases in caregiver depression and burden. Another single-site, randomized clinical trial that utilized long-distance technology to train family caregivers in problem-solving skills found significant reductions in caregiver depression over the course of a year, and persons with SCI, with family caregivers who received the intervention, experienced significant improvements in social functioning over the 12 months of treatment [20].

## Future Directions

The rate of acquired disabilities has increased in the recent years, placing considerable strains on our health care systems for rehabilitation and ongoing care. Combined with the increasing number of persons with chronic health conditions who have disabling features, the current influx of wounded veterans who return with an array of acquired disabilities (brain injuries, SCI, limb loss, chronic pain) and cooccurring PTSD tax practically all health care systems and institutions. To address the issues presented by wounded veterans, the US Department of Veterans Affairs—already the largest provider of SCI care and rehabilitation in the world [10]—has initiated advanced training programs in EBPs such as cognitive processing therapy and prolonged exposure for PTSD, acceptance and commitment therapy, CBT, and interpersonal therapy for depression, and CBT for insomnia. Ideally, these will increase the number of skilled psychologists to use these approaches with persons with acquired disabilities.

In addition, the Department of Veterans Affairs is moving toward patient-centered care in all VA Medical Centers, partnering with veterans to understand their values and preferences in order to optimize their health (U.S. Department of Veterans Affairs 2012). This type of patient–provider partnership is essential to promoting health and well-being over the lifespan among persons with acquired disabilities. It also requires psychologists to actively solicit input from individuals who live with disability about their needs and preferences, and to provide services that address the issues identified by these persons.

Given shifting medical reimbursement policies and fiscal challenges, the emphasis for rehabilitation is increasingly on outpatient services, with shorter inpatient rehabilitation stays. Health care services provided in the medical model paradigm are contingent on third-party reimbursement and the ability of specific programs and administrative systems to absorb financial losses not covered by third-party payers [27]. Financial costs associated with chronic and disabling conditions have strained health care delivery systems grounded in the medical model; cost-containment efforts have often involved cuts in disability services and insurance coverage [56]. Over the past 15 years, there has been a trend for rehabilitation resources to be reallocated from traditional acute and postacute inpatient settings to outpatient and home-based programs.

The degree to which these issues will be ameliorated by elements of the Affordable Care Act that are designed to benefit persons with disabilities (and their families) has yet to be realized. However, Elliott and Rath [27] observed that changes in rehabilitation psychology practice are already occurring in response to financial and reimbursement issues, and to the strategic allocation of scarce resources for inpatient rehabilitation. In summary, it appears that inpatient rehabilitation work will increasingly involve the use of psychologists who specialize in practices that are reliably and predictably reimbursed, such as neuropsychology. Psychologists may also develop specialty skills in the use of virtual reality technologies to help individuals in rehabilitation, including novel applications to cope with pain or to enhance their social mobility [35, 65].

Other psychologists, who have broader abilities including therapy, education, and developing community-based services, will likely gravitate to outpatient and even public health institutions in a manner consistent with the ICF model of disablement. Psychologists in these roles will be committed to increasing participation and engagement in desired activities and normative social and personal roles, and to reducing environmental barriers and facilitators of activity and participation for persons with disabilities in the community [47].

To effectively serve this large segment of society, psychologists in these roles may find ways to collaborate and utilize low-cost, nondoctoral-level service providers. This will undoubtedly involve a greater use of long-distance technologies to provide services to individuals in their homes and communities. In some clinical scenarios, supportive and psychoeducational interventions may be provided by psychologists (or staff under their supervision) to families in the home via videoconferencing ([20]). An innovative program now conducted by the Veterans Administration permits staff to perform annual evaluations with veterans in the community. The veterans are seen in a remote, community satellite clinic by a psychologist using videoconferencing technology at medical center. There is preliminary evidence that these technologies are effective [61]. These technologies offer considerable promise in reducing disparities individuals with disabilities currently encounter in access, service, and treatment.

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# Chapter 25

## Neurology and Neuropsychology

Dennis J. Zgaljardic and Lynn A. Schaefer

Clinical psychologists in medical settings are likely to interact with clinical neuropsychologists, particularly in departments of neurology, psychiatry, and physical medicine and rehabilitation. Clinical neuropsychologists have specialized training in brain–behavior relationships and therefore are uniquely suited to perform cognitive evaluations in addition to providing treatment.

In rehabilitation departments, clinical neuropsychologists often assess and treat patients who have acquired brain injury (including stroke). Similarly, in departments of neurology, clinical neuropsychologists are likely to work with patients with neurodegenerative disorders (including dementias and movement disorders), stroke, traumatic brain injury, and epilepsy. The clinical neuropsychologist thus plays a critical role as part of the multidisciplinary team and is directly involved in assessment and diagnosis, treatment of psychological and cognitive disorders, behavioral management, and education of patients and staff.

### Acquired Brain Injury

An acquired brain injury is any noncongenital, nondegenerative insult to the brain. Brain injury can be broadly classified into *nontraumatic brain injury* and *traumatic brain injury* (TBI).

Nontraumatic brain injuries are caused by *cerebrovascular accident* (CVA), brain tumor, infection, or *hypoxia* (lack of oxygen to the brain). A CVA (or “stroke”) is an interruption of blood flow caused by pathology in the vasculature of the brain

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and can be further distinguished by whether it is caused by a blockage of a blood vessel, or *ischemic*, or by rupture or leakage of blood vessels in or near the brain (*hemorrhagic*).

TBI, on the other hand, is caused by mechanical forces acting on the brain, such as by accidents, falls, penetrating head wounds, or blows to the head, and can be further divided into *open head injury* and *closed head injury*, depending upon whether or not the skull is breached. The following section will elaborate on the pathophysiological and clinical evidence of TBI, and closed head injuries specifically.

## ***Traumatic Brain Injury***

Risk factors for TBI include age (with children and the elderly at increased risk), male gender, use of drugs and/or alcohol, and involvement in risk-taking behavior and contact sports [1, 2].

Physiologically, TBI results in a primary injury, or injury at the time of impact, as well as secondary aftereffects. Types of primary injury include brain contusion, diffuse axonal injury, and hemorrhage or hematoma. The brain contusion directly beneath the mechanical force is known as the *coup*. However, the brain can also become damaged on the opposite side from the point of impact, known as the *countercoup*, and this can often be more severe than the coup itself. *Diffuse axonal injury* involves cortical white matter (myelinated axons). Here, axons may become sheared, compressed, or stretched. This type of injury may not be viewed on standard neuroimaging scans (e.g., magnetic resonance imaging [MRI], computed tomography). Possible *secondary aftereffects* include ischemia (or lack of blood flow), edema (swelling), bleeding, increased intracranial pressure, hypoxia, hydrocephalus, or seizures. Neurotransmitters are also disrupted, particularly serotonin, gamma-aminobutyric acid (GABA), acetylcholine, and glutamate. It is the acute influx of glutamate into cells immediately following a brain injury that may lead to indirect neuronal cell death at the time of impact [3].

Specific regions of the brain that are particularly vulnerable to TBI include the frontal lobe (e.g., orbitofrontal areas), anterior temporal lobe, corpus callosum, brain stem, and limbic structures such as the basal ganglia and hypothalamus [4]. Thus, cognitive deficits commonly observed are typically subserved by these regions. Specifically, arousal, attention, information processing, new learning, memory retrieval, fluency, and executive functioning (including organization and planning, sequencing, multitasking, judgment, and abstraction) are frequently disrupted. Decreased awareness is also common. Cognitive deficits following TBI typically vary with the nature of the trauma, location, and severity of injury, and extent of secondary aftereffects.

Symptoms of mild TBI may include headache, dizziness, nausea and vomiting, sensory problems (i.e., visual, vestibular), fatigue, changes in sleep patterns, and behavioral, mood, and cognitive changes such as those mentioned above. Moderate and severe TBI involve more exaggerated symptoms and may also include

**Table 25.1** Emotional and behavioral problems common in brain injury

Emotional problems	Behavioral problems
Depression	Agitation
Anxiety	Disinhibition
Post-traumatic stress disorder (PTSD)	Impulsivity
Adjustment disorder	Verbal/physical aggression
Denial	Abulia (lack of initiation)

weakness or numbness, speech deficits, seizures, and altered mental status (ranging from confusion, restlessness, and agitation to vegetative state and coma). TBI severity is measured by duration of loss of consciousness (LOC), and/or amnesia. For example, mild TBI is often defined by LOC less than or equal to 30 min and post-traumatic amnesia (PTA) of less than 1 h. Moderate TBI is measured by LOC over 30 min and PTA from 1 to 24 h; severe TBI involves PTA over 24 h [5]. The Glasgow Coma Scale (GCS) and Galveston Orientation and Amnesia Test (GOAT) are two tests that assess levels of consciousness and amnesia, respectively [6, 7].

### ***Psychological Comorbidities***

In addition to physical and cognitive dysfunction, acquired brain injuries frequently result in emotional and behavioral sequelae (see Table 25.1) that can have a profound effect on the patient's functioning and which are arguably the most distressing symptoms for the family/caregiver and the most challenging to treat.

These psychological comorbidities may result as a reaction to the injury itself and/or as a result of the experience of hospitalization, including loss of independence and separation from loved ones. Pain, common in this population, can also induce or exacerbate emotional symptoms. In addition, patients with brain injury must cope with cognitive as well as physical limitations, and the very real possibility that their lives may not return to pre-injury levels [8]. Emotional and behavioral sequelae can also be the direct result of underlying neurological impairment. For example, patients with left frontal lesions or those localized to subcortical areas of the brain may experience an "organic depression." [9] Alternatively, damage to specific frontal regions of the brain may also result in behavioral disturbances such as disinhibition, impulsivity, abulia, and emotional lability [10].

### **Neurodegenerative Disorders**

*Neurodegenerative disorders* include a broad spectrum of neurological conditions that stem from various etiologies (e.g., genetic, toxic exposure, or idiopathic). A common outcome for most neurodegenerative disorders is *dementia* that is typically associated with a decline in memory functioning, as well as other cognitive

**Table 25.2** Common neurodegenerative disorders differentiated by subtype

Subcortical	Cortical
Parkinson's disease	Alzheimer's disease
HIV/AIDS	Pick's disease
Huntington's disease	Creutzfeldt–Jakob disease
Parkinson-plus syndromes	Frontotemporal dementia
Multiple sclerosis	Lewy body disease

impairment (e.g., executive dysfunction). A complete delineation of all types of neurodegenerative disorders is beyond the scope of this chapter. Hence, this section provides a brief overview of the clinical evidence of two neurodegenerative disorder subtypes: (a) *subcortical* (e.g., Parkinson's disease, PD) and (b) *cortical* (e.g., Alzheimer's disease [AD]). See Table 25.2 for a list of common subcortical and cortical neurodegenerative diagnoses.

A *subcortical dementia process* involves pathology of the brain below the level of the neocortex (outer layer of brain consisting of gray matter). Cognitive and motor deficits associated with a subcortical process can be best characterized by executive dysfunction with extrapyramidal motor deficits (e.g., tremor) attributed to disruption of the circuitry connecting subcortical and frontal lobe regions [11, 12]. Memory and language deficits in patients with a subcortical dementia process are not uncommon, although they are typically attributed to executive dysfunction [13]. In contrast, a *cortical dementia process* involves pathology of the neocortex and is best characterized by gross deficits in memory (e.g., amnesia), praxis, and language (e.g., aphasia).

### ***Parkinson's Disease: Subcortical Dementia***

The hallmark of PD is a reduction (up to 90%) of neurons in the substantia nigra, accompanied by subcortical Lewy body inclusions [14, 15]. The substantia nigra is part of a larger group of subcortical structures, collectively known as the basal ganglia (which also include the striatum, globus pallidus, and subthalamic nucleus). The pigmented substantia nigra neurons produce the neurotransmitter *dopamine* and modulate cortical afferents in order to facilitate motor programs via direct and indirect striato-cortical pathways [16–18].

Dopamine therapy (e.g., levodopa) is the most effective pharmacological treatment to date in alleviating motor symptoms associated with PD (e.g., tremor, rigidity), although improvements can be complicated by side effects including, for example, dyskinesias, motor fluctuations, and visual/auditory hallucinations [19]. In addition, other neurotransmitter systems (i.e., serotonergic, noradrenergic, and cholinergic) are directly and/or indirectly compromised in PD, which may elicit the need for the development of additional types of neurochemical therapies [20].

Dementia occurs in approximately one third of patients with PD [21–23]. Factors shown to predict the onset of dementia in PD have been age at disease onset (>60 years), as well as substandard performance on neuropsychological (NP) measures

that assess visuospatial skills, response interference, and word-list generation [24, 25]. Cognitive and behavioral deficits associated with dementia in PD can include impaired learning, aphasia, and/or apraxia that may result from cortical pathology indicative of comorbid AD and/or Lewy body disease (LBD) [15]. PD patients with dementia predominantly exhibit impairments of declarative memory (with fairly preserved recognition), executive functions (e.g., set shifting), visuospatial skills, speech and language (e.g., sentence processing and motor speech output), and mood (e.g., depression and apathy) although these findings typically vary across studies due to the multiplicity of patient samples [11]. Cognitive deficits in patients with PD have been reported to be exacerbated by mood disorders associated with the disease process [26–29].

Depression and apathy are among the most common psychological sequelae of PD. Prevalence rates of depression are approximately 40%, with some studies reporting rates as low as 4% and some as high as 90% [14, 30, 31]. Apathy, on the other hand, is characterized as indifference to environmental, emotional, and/or physical states [32]. Reported prevalence estimates of apathy in PD currently range from 16.5 to 51% [29, 33–35]. Such epidemiological inconsistencies reported in the literature for both depression and apathy may be attributed, in part, to (a) differing levels of cognitive impairment across PD patients, (b) the manner with which a particular diagnostic inventory is constructed, validated, used, and/or interpreted, or (c) overlapping symptoms of various mood disorders (e.g., apathy and depression) [29].

### ***Alzheimer's Disease: Cortical Dementia***

AD is typically regarded as a “cortical” dementia, as brain pathology at autopsy is characterized by accumulation of amyloid- $\beta$  protein in plaques and vessels, neurofibrillary tangles, and synaptic and neuronal loss primarily within the neocortex. This loss results in gross atrophy of the affected regions, including degeneration in the temporal and parietal lobes, as well as parts of the frontal cortex and cingulate gyrus [36]. However, various etiologies for AD other than the amyloid hypothesis have been gaining support [36, 37]. Age at onset is generally more than 65 years and mean life expectancy following diagnosis is 7 years [38]. Current treatments for AD (e.g., cholinesterase inhibitors) usually offer a short-lasting cognitive benefit; however, there are no pharmacological treatments to date that have been shown to delay or halt disease progression. Routine exercise and a sensible diet, as well as alleviation of caregiver stress, are current recommendations for symptom management [39–41].

Patients with AD will present with cognitive and behavioral symptoms that are usually regarded as mediated by the neocortex (e.g., amnesia, aphasia, apraxia, and agnosia). In the early stage of AD, the most recognized symptom is memory decline [42], although attentional deficits have been found to occur concurrently or even to precede memory deficits [43–45]. Depression is common, at least in early AD,

and does not appear to hasten memory decline [46]. Mood symptoms appear to progress along with cognitive decline, at least until later stages. Depression in AD patients may manifest as irritability, and therefore may be used as an early indicator of depression [47]. Anxiety, on the other hand, is less commonly reported in AD patients [48].

With time, the individual with AD will experience a progressive worsening of dementia that may include symptoms of confusion, irritability and aggression, mood swings, aphasia, and changes in personality (e.g., withdrawal), eventually leading to death [49].

## Neuropsychological Evaluation

The comprehensive NP evaluation is typically regarded as the “gold standard” in assessing cognition in patients with various neurological etiologies. The NP evaluation involves a clinical interview, behavioral observations, and the administration of a wide variety of standardized tests (predominantly paper and pencil tests), which are done sitting at a table in an office or at bedside in a hospital. The evaluation can vary from less than 1 h to 6–8 h of face-to-face contact, depending on the information sought, as well as the patient’s stamina, effort, and/or motivation. Further, it can be performed at various stages of one’s disease process or recovery (e.g., while the patient is in an acute medical care facility, acute rehabilitation unit, residential post-acute rehabilitation facility, or as an outpatient). In general, more comprehensive NP evaluations are performed on an outpatient basis.

The NP evaluation is performed as a means to gauge an individual’s cognitive and emotional profile, establish a baseline, and aid in treatment planning, as well as determine the effectiveness of treatment and/or medication [50]. It can also aid in differential diagnosis, when brain-based impairment of cognitive function or behavior is suspected (i.e., memory complaints), or psychological factors are considered (i.e., dementia vs. depression). In the case of brain injury, NP evaluation may be requested for determination of disability, or to assist in recommendations with regard to driving ability or return to work. Hence, there is a great need for ecologically valid NP assessment measures [51].

The NP evaluation should be tailored to the needs of the individual patient. The neuropsychologist selects, administers, and interprets the particular test battery or individual tests that will yield the most comprehensive understanding of an individual’s cognitive strengths and weaknesses and/or best answer the referral question. Tests are administered in a standardized manner, and scores are compared to the patient’s normative group (typically controlled for age, education, etc.). Recommendations can then be made for continued treatment or for precautions due to specific limitations.

The clinical neuropsychologist is required to take certain factors into consideration before and during an evaluation. First, lengthy administration times may impact a given patient’s overall test performance due to factors such as low frustration

or pain tolerance, or heightened levels of agitation and/or fatigue [52]. These factors may be particularly pronounced for patients operating at low cognitive or functional levels. Second, sensory (e.g., poor visual acuity or visual field cut) and/or motor (e.g., ataxia) deficits need to be taken into consideration as several tests do require visual or manual manipulation of stimuli. Third, within the context of a residential setting, such as a brain injury rehabilitation unit, a given patient's length of stay may vary for numerous reasons (e.g., limits of external funding for services). As a result, a cognitive screening tool (e.g., Neuropsychological Assessment Battery—Screening Module [53]) may be an effective means to promptly gauge cognitive strengths and weaknesses in order to advise the treatment team and expedite the receipt of appropriate rehabilitation services until the time that a more comprehensive NP evaluation, if necessary, can be performed [52].

Relevant background information must be obtained via an exhaustive medical record review and clinical interview. Medical records will typically include nurse's and physician's notes, laboratory work, consultation notes, neuroradiological reports, and medication regimens, as well as reports from a prior NP evaluation or other assessment(s) of functioning (e.g., speech-language pathology). A clinical interview should involve a structured or semi-structured interview with the patient. In several cases, it is recommended that the clinical neuropsychologist conduct an interview with a family member or legal guardian as a means to confirm information disclosed by the patient and to provide additional pertinent information that the patient may not have shared. Of course, if the patient is his or her own legal guardian, one must seek their consent to include the family member as part of the clinical interview.

NP test batteries can be either *flexible* or *fixed*. Flexible test batteries are more commonly administered [50, 54]. This approach typically maintains a core set of tests with additional tests implemented, as needed, in order to address specific issues surrounding the patient's clinical presentation. Such a flexible battery approach may be particularly useful in dementia evaluations as a means to provide greater focus on the assessment of memory functions, which is essential for diagnosis. A clinical neuropsychologist may also decide to administer a test battery without a defined core of tests (i.e., *fully flexible approach*) [50].

A flexible battery approach permits the selection of tests on a case-by-case basis according to the patient's self-report, cognitive strengths and weaknesses (typically based on performance on a cognitive screening tool), and/or clinical observation [55]. For instance, focal injury of the dominant hemisphere can impede language which may prevent or limit administration of verbally mediated tests of cognitive ability. Sweet, Nelson, and Moberg [54] reported that a minority of clinical neuropsychologists surveyed utilize a *fixed battery approach* such as the Halstead–Reitan Battery [56] (HRB) or the Luria-Nebraska Neuropsychological Battery [57] (LNNB). Larrabee, Millis, and Myers [58] discovered that a flexible battery approach was just as sensitive as the HRB in discriminating patients with brain dysfunction from nonneurological medical control subjects.

The cognitive domains commonly assessed in an NP evaluation include intellectual functioning (premorbid estimate and current), memory and learning,

psychomotor function, processing speed, attention, language, and executive function. Given the risk for changes in mood and/or personality following brain dysfunction, as well as heightened levels of pain and fatigue, it is recommended that a comprehensive NP battery also include appropriate self-report mood and/or personality inventories with adequate reliability and validity in assessing these symptoms. In cases in which suboptimal effort or malingering is suspected secondary to, for example, external incentives or reduced motivation, tests of symptom validity should be considered to determine the probability of exaggeration or fabrication of cognitive dysfunction. Diagnostic criteria in classifying levels of malingering (possible, probable, or definite) using evidence from reports on external incentives, symptom validity testing performances, self-report, and overt behaviors are described elsewhere [59]. Lastly, it may be prudent for the neuropsychologist to perform a sensory and motor examination as a means to establish the presence of current neurological dysfunction (e.g., visual field cut), as this may be an influential factor on test performance. Here, sensory ability should be assessed within the visual, auditory, and tactile modalities. Table 25.3 provides a list of NP tests, categorized by cognitive domain, that are commonly used in the NP evaluation.

## **Rehabilitation/Treatment**

### ***Brain Injury Rehabilitation***

Brain injury rehabilitation is structured in a manner to facilitate the continuum of care for patients upon their discharge from an acute medical setting. Malec and Basford [109] provided a description, as follows, of the continuum of care for brain-injured patients. First, once a patient is deemed medically stable following a brain injury, they will typically be discharged to an *acute rehabilitation unit* either at their acute medical setting or at an acute rehabilitation hospital. At the acute level, the rehabilitation goals typically promote medical stability (e.g., improve respiratory function) and improve mobility (e.g., bed/toilet transfers) with an initiation of cognitive and behavioral management. Second, at the *subacute rehabilitation* level, coma management (for patients in a vegetative state), sensory stimulation (to accelerate arousal), and behavioral management (for those patients who may present with confusion or post-traumatic amnesia) are necessary and common interventions [109, 110]. Attempts are also made to help patients wean off of artificial nutritional and ventilation supports and restore autonomic independence. Third, *post-acute brain injury rehabilitation (PABIR)* is typically geared for patients who can tolerate and potentially benefit from more intensive therapies focused on improving physical, cognitive, and behavioral functions. A goal for PABIR programs is to foster community reentry. PABIR may include a *neurobehavioral program* that provides a more specific



**Table 25.3** Commonly used neuropsychological tests by domain

Cognitive/behavioral domain	Neuropsychological test(s)
General intellectual functioning	Wechsler Adult Intelligence Scale-IV [60]; Wechsler Abbreviated Scale of Intelligence-II [61]; North American Adult Reading Test (NAART) [62]
Mental status	Mini-Mental Status Examination (MMSE) [63]; Dementia Rating Scale—2 [64]
Memory and learning	Wechsler Memory Scale-IV [65]; California Verbal Learning Test-II [66]; Hopkins Verbal Learning Test-R [67]; Brief Visuospatial Memory Test-R [68]; Rey Auditory Verbal Learning Test [69, 70]; Benton Visual Retention Test [71]; Rey–Osterrieth Complex Figure Test [72]; Warrington Recognition Memory Test [73]
Psychomotor function	Finger Tapping [56, 74, 75]; Grooved Pegboard [76]; Purdue Pegboard [77]
Attention	Conner’s Continuous Performance Test [78]; Symbol Digit Modalities Test [79]; Paced Auditory Serial Attention Test [80]; Wechsler Adult Intelligence Scale-IV (Digit Span and Letter-Number Sequencing) [60]; Trail Making Test [81]; The Ruff 2&7 Selective Attention Test [82]; Selective Reminding Test [83]
Language	Multilingual Aphasia Examination [84]; Boston Diagnostic Aphasia Examination [85]; Peabody Picture Vocabulary Test—III [86]; Controlled Oral Word Association Test [75, 84]; Animal Naming [85]
Visuospatial skills	Visual Form Discrimination [87]; Judgment of Line Orientation [87, 88]; Hooper Visual Organization Test [89]; Wechsler Adult Intelligence Scale—IV (Block Design and Matrix Reasoning)[60]; Clock Drawing Test [75, 90]; Facial Recognition Test [87]
Executive function	Behavioral Assessment of the Dysexecutive Syndrome [91]; Frontal Systems Behavior Scale (FrSBs) [92]; Delis–Kaplan Executive Function System (D-KEFS) [93]; Category Test [56, 74]; Stroop Test [94]; Wisconsin Card Sorting Test [95, 96]
Mood/personality	Beck Depression Inventory—2 [97]; Beck Anxiety Inventory [98]; Geriatric Depression Scale [99, 100]; Symptoms Checklist 90-R [101]; Minnesota Multi-phasic Personality Inventory—2 [102]; Brief Pain Inventory [103]; Fatigue Severity Scale [104]
Sensory/motor examination	Visual acuity; visual, auditory, tactile, and olfactory discrimination; motor coordination; motor sequencing; finger localization; praxis; extinction to double simultaneous stimulation; graphesthesia
Symptom validity tests	Test of Memory Malingering (TOMM) [105]; Word Memory Test [106]; 21-Item Word List [107]; Portland Digit Recognition Test [108]

focus for patients with severe behavioral disturbances (e.g., verbal and/or physical aggression) or a *residential community reintegration program* that provides comprehensive inpatient cognitive, behavioral, physical, and vocational

rehabilitation services for those patients not yet suitable for *community reentry programs* on an outpatient basis.

### ***Comprehensive Holistic Day Treatment Program***

A *comprehensive holistic day treatment program (CHDTP)* offers a multitude of services including individual and group cognitive rehabilitation, psychotherapy, psycho-education, and family therapy on an outpatient basis [55, 111]. The members of the interdisciplinary treatment team can include clinical psychologists, occupational therapists, physical therapists, speech-language pathologists, and therapeutic recreational specialists typically under the direction of a clinical neuropsychologist. Such an interdisciplinary team is usually similar for both PABIR and CHDT programs.

The function of a CHDTP is to (a) develop coping skills, (b) provide strategies to help overcome cognitive and psychological challenges, (c) offer guidance and support upon eventual community reentry, and (d) provide an emphasis on improving one's awareness of their strengths and weaknesses following brain injury [112]. The latter is particularly essential as executive dysfunction (common following TBI) has been shown to be associated with declines in self-awareness and self-monitoring behaviors [113]. Treatment goals are more clearly defined at this level of care in order to assist the patient with successful community reentry. This may include, but is not limited to, issues related to return to work, return to school, maintaining sobriety (if a pre-morbid condition exists), pain management, anger management, social communication, and interpersonal relationships. Evidence-based data have suggested that the integration of cognitive and interpersonal interventions be considered a practice option in brain injury rehabilitation [114].

### ***Military Personnel and Brain Injury Rehabilitation***

With the advent of the wars in Iraq and Afghanistan, some of our military personnel are experiencing combat-related traumatic brain injuries secondary to blast forces or penetrating head wounds. In a similar vein, treatment and rehabilitation for our military personnel would in many ways mirror the standard approach for civilians. However, given the unique needs and circumstances of our military personnel, residential and day-treatment programs have specific aims in addressing "readjustment to civilian life, balancing military and family relationships, risk for posttraumatic stress disorder, and other factors." [111]

The draw in getting returning veterans to seek treatment is often a challenge. Many may not seek out military-specific programs. Military personnel are actually most likely to present to their primary care physicians for complaints such as sleep disturbance, pain, anxiety, and/or depression [115]. Primary care providers, in turn, might then refer the patient to a clinical psychologist or other behavioral health

provider for treatment of these symptoms, which would likely be related to their combat experiences. As needed, they may also refer military personnel to generic pain clinics or substance abuse programs. Clinical psychologists therefore should be aware of how returning soldiers might enter the medical or rehabilitation system, and be sensitive to their different needs.

### ***Common Psychological/Behavioral Interventions in Brain Injury Rehabilitation***

There is a growing need to incorporate interventions that address psychological sequelae resulting from brain injury (such as in a CHDTP) into comprehensive residential and outpatient rehabilitation programs. As mentioned previously, psychological disorders including anxiety, depression, irritability, aggression, and post-traumatic stress disorder are common following brain injury. For instance, Bowen et al. [116] reported that 38% of TBI survivors experienced mood disorders. More specifically, 3–27% of patients with TBI were discovered to present with symptoms related to post-traumatic stress disorder [117]. In a cohort of 75 patients with mild to moderate TBI, Bay and Bergman [118] reported that injury-related symptom frequency was significantly associated with heightened levels of anxiety, anger/hostility, and perceived global stress. Further, social isolation can be experienced immediately following brain injury and has been reported in upwards of 60% of patients [119]. In most cases, the limitations placed on a given patient's ability to re-enter pre-injury environments (e.g., home, workplace, recreational, and/or school) can result in an immediate reduction of routine social interactions including friends, colleagues, and loved ones.

While cognitive rehabilitation is instrumental in addressing cognitive deficits within a brain injury rehabilitation program, the combination of psychological and cognitive interventions is essential as psychological symptomatology can pose as an obstacle to improvements in cognitive processes, as well as overall rehabilitation goals [112, 118]. Bay and Bergman [118] have urged for the implementation of interventions that address the management of psychological stress in brain-injured patients, as chronic stress can result in further bodily tissue damage (including the brain) secondary to abnormal production of stress hormones (e.g., cortisol).

*Psychological Intervention.* Clinical psychologists can help the brain-injured patient (as well as the patient's family) understand their condition, manage emotions, and cope with stressors and pain. Management and treatment may include psychotherapeutics, stress management, medication, psycho-education and/or environmental modification, and cognitive remediation.

While the aforementioned approaches may assist in educating the brain-injured patient with regard to cognitive and behavioral sequelae, they may not particularly address psychodynamic and psychosocial etiologies of emotional and mood disorders in the traditional sense [112]. In an acute setting, individual psychotherapy is likely to be of short duration, supportive in nature, and more problem focused in

orientation. Cognitive-behavioral therapy (CBT) has been suggested for use in patients with brain injury as a means to alleviate symptoms related to depression, generalized anxiety, and post-traumatic stress disorder [118, 119]. CBT helps patients become more aware of maladaptive thinking and cognitive “distortions.” Psychotherapy with brain-injured patients may also involve a degree of awareness orientation. One intervention model, for instance, is based upon three types of awareness related to an individual’s ability to (1) understand a deficit, (2) recognize a problem while it is happening, and (3) plan ahead to avoid a problem [120]. Thus, education of patients may also include videotaping and/or in vivo exposure, with practice of compensatory strategies. The brain-injured patient’s ability to emotionally tolerate the impact of the deficit must also be considered [121]. Careful and titrated explanation of their injury and resulting deficits, and working through defensive denial when it exists, are often needed in a psychotherapeutic relationship [122]. Psychosocial or supportive groups benefit patients by allowing them to share common experiences, reduce isolation, and practice psychosocial skills (i.e., increase initiation, prevent interruptions, etc).

Cognitive remediation achieves functional change both by reinforcing, strengthening, or restoring previously learned patterns of behavior and by establishing new patterns of cognitive activity or compensatory mechanisms for impaired neurological systems. When performed by a rehabilitation therapist (i.e., clinical psychologist, psychological counselor, occupational therapist, or speech-language pathologist), under the direction of a clinical neuropsychologist, this is informed by theories of cognitive psychology, learning, and neuropsychology and is approached systematically in order to provide an empirical measure of change. With regard to compensation, a rehabilitation therapist should be able to make suggestions for structuring the environment and the patient’s support system to compensate for the brain injury. External prostheses (i.e., planners, calendars, recording devices, timers, pagers, etc.) as well as internal cueing strategies (i.e., developing mnemonics or an internal checklist) are also taught and their use reinforced.

*Pain Management.* Pain is common following brain injury. The relationship between prevalence of pain and TBI severity is an inverse one with 95% of patients with mild TBI and 22% of patients with moderate to severe TBI reporting significant amounts of pain [123]. Pain associated with headache is most frequently reported in brain injury, but is often accompanied by persistent postconcussive syndrome [124]. Various etiologies for pain in the patient with brain injury can stem from dysautonomia, neuropathy, spasticity (hypertonia), heterotopic ossification (abnormal bone formation in soft tissue), deep venous thrombosis, urinary retention, orthopedic trauma, and subluxation [125].

Since pain is a subjective phenomenon, it is difficult to assess objectively. Thus, when assessing pain the clinician needs to address several dimensions including pain intensity, pain unpleasantness, emotional state when experiencing pain, perceptions about subjective experience of pain, and behaviors related to pain experience in varying environments or situations [126]. Please refer to Martelli, Zasler, Bender, and Nicholson [127] for a review on the comprehensive pain evaluation.

Behavioral pain management is typically addressed in brain injury rehabilitation programs via individual or group therapy sessions. The appropriate route for pain management will depend on cognitive, behavioral, and emotional limitations that are independent from the experience of pain (e.g., aphasia, amnesia, low mental status, impulsivity). One of the most common forms of pain management intervention is progressive muscle relaxation (PMR) which involves a series of muscle tensing and relaxation exercises with diaphragmatic breathing. Other frequently utilized techniques include biofeedback, CBT, and imagery [127]. Pharmacological treatment for pain in the rehabilitation setting can include nonsteroidal anti-inflammatory drugs (NSAIDs), narcotics, anticonvulsants, botulinum toxin, or intrathecal baclofen therapy. The sedative effects of certain medications also need to be considered in a therapeutic setting as they can have an indirect and potentially negative impact on recovery.

*Substance Abuse Treatment.* The use of illicit substances tends to decline following brain injury and is most likely attributed to lifestyle choices, limits to availability and access, and functional status secondary to the injury. Not surprisingly, a positive relationship exists between functional status and substance abuse, as individuals with mild traumatic brain injuries are more likely to use illicit substances post injury due to increased functional status, mobility, and financial resources [128].

Cognitive (e.g., memory and executive), psychological, and behavioral dysfunction associated with brain injury can mitigate traditional treatment options and effectiveness [129]. The use of standard approaches in substance abuse treatment (e.g., motivational interviewing and 12-step programs) is not necessarily recommended in the treatment of patients with brain injury and may in fact be ineffective [130]. Kramer and Hoisington [131] suggested the implementation of “modified” Alcoholics Anonymous and Narcotics Anonymous programs, whereas others have recommended community-based treatment that incorporate skill-based interventions [128]. The latter approach is grounded in providing education about substance use with a focus on self-monitoring behaviors.

Research has shown that the duration of substance abuse treatment is one of the best predictors of outcome in the general population [132]. With that said, retention of patients with brain injury within outpatient substance abuse treatment programs is not optimal. Corrigan et al. [133] discovered that providing participants with brain injury either a financial incentive or a barrier reduction (i.e., providing accommodations or assistance prior to the appointment) improved appointment attendance and reduced the likelihood of patients terminating sessions prematurely.

Cigarette smoking is another maladaptive behavior that requires attention. Survivors from CVA are at an increased risk for future CVAs, with the greatest risk occurring immediately after the event followed by a 3-year period of decreased risk and an eventual rise in risk in the long term [134]. Thus, there is a great need for smoking cessation programs in the brain-injured population.

Guilmette, Motta, Shadel, Mukand, and Niaura [135] reported that of 233 stroke patients receiving inpatient acute rehabilitation, roughly 10% were cigarette

smokers prior to their admission. Of those who smoked cigarettes prior to admission, more than half of them reported being disinterested in participating in a smoking cessation program (if offered) despite their self-report of “high motivation” to quit. Ives, Heuschmann, Wolfe, and Redfern [136] utilized logistic regression analyses to predict patterns of smoking cessation up to 3 years post CVA in a sample of 363 patients. They discovered that those patients who were most likely to attempt smoking cessation during this period were from minority backgrounds (predominantly black) and were moderately to severely disabled secondary to their CVA. At 3 years post CVA, patients who were black and older (75 years and up) were most likely to have been successful in maintaining smoking cessation.

Guimette et al. [135, 137] stressed that clinicians need to continue to encourage the promotion of healthy choices to their patients during inpatient care as it may provide the best opportunity for a “teachable moment.” Given the time constraints imposed on lengths of inpatient hospitalization, Guilmette, Motta, Shadel, Mukand, and Niaura [137] provide suggestions for a truncated smoking cessation program. The program they propose focuses on (a) increasing perceived support, (b) identifying smoking habits and patterns, (c) providing education regarding adverse events related to cigarette smoking, (d) setting targets with coping strategies (e.g., reduce triggers, use alternatives instead of cigarettes, modify past smoking environments), (e) arranging for follow-up visits to discuss progress, and (f) providing education on potential for pharmacological intervention to promote cessation (e.g., transdermal nicotine patch or nicotine polacrilex gum). This model may also be used to promote and reinforce compliance to medical management of preexisting and injury-related medical conditions (e.g., diabetes, high blood pressure, high cholesterol, seizures, and nutrition).

### ***Behavioral Management and Direct Care Staff Attitudes in Brain Injury Rehabilitation***

Behavioral changes common to patients with brain injury may include, but are not limited to, impulsivity, disinhibition, poor motivation and initiative, sexual inappropriateness, reduced mental status, and/or verbal and physical aggression. It is not surprising that these behavioral changes can have a dramatic impact on a given patient’s progress in brain injury rehabilitation by limiting one’s participation or compliance with therapies. In addition, expression of these behaviors can pose a serious threat to the patients themselves or direct care staff at treatment facilities [138].

As mentioned in previous sections of this chapter, PABIR and/or comprehensive holistic rehabilitation programs are structured to address behavioral and emotional changes. Within such programs, the staff hail from different backgrounds, educational levels, and experiences with brain-injured patients and thus some staff members may not be formally trained in behavioral modification principles. Thus, providing cognitive-behavioral strategies to help manage behaviors in this patient population [139] via a structured classroom-like setting may be optimal in training direct care staff.

Several commercial crisis intervention training programs are in existence with a component that instructs staff on how to de-escalate the “acting-out” patient. These programs focus on assisting direct care staff members to identify the nature of verbally and/or physically aggressive outbursts and how to appropriately de-escalate the patient while keeping them and the patient safe. Despite the need for such programs across various medical and mental health settings, the literature on program efficacy is sparse. Temple, Zgaljardic, Yancy, and Jaffray [140] assessed staff attitudes toward various patient behaviors before and after completion of such a program. In addition, they assessed whether changes in attitude would be maintained over time (1 month) and how the training program would differentially impact licensed clinical staff as opposed to nonlicensed orderly staff. The training intervention consisted of approximately 12 h of classroom instruction and training in personal safety (e.g., escaping grabs and avoiding strikes) and safe restraint techniques. Staff attitudes were assessed using a validated self-report inventory designed to measure the level of difficulty that staff may experience with various situations common to the rehabilitation setting (Rehabilitation Situations Inventory, RSI [141]). The RSI was administered prior to training, immediately post training, and 1 month post training. Their findings revealed that staff attitudes as measured by self-report did not differ greatly between residential orderly staff and licensed clinical staff. As a whole, staff members did have significant decreases in discomfort with sexual inappropriateness, aggression, intra-staff interactions, motivation/adherence issues, and interactions with patient families immediately following the intervention. Declines in staff discomfort were maintained over time for issues related to sexual inappropriateness, aggression, and intra-staff interactions. These findings suggest that the implementation of such an intervention geared toward direct care staff (licensed or not) is effective in addressing staff attitudes toward maladaptive behaviors exhibited by patients with brain injury.

### ***Psychological Interventions in Neurodegenerative Disorders***

There is a mistaken belief that patients with dementia and other neurodegenerative disorders cannot benefit from treatment, given the progressive nature of their illness. However, interventions in this population can greatly decrease suffering and increase coping and quality of life. Clinical neuropsychologists are particularly well equipped to treat dementia patients, given their knowledge of cognitive functioning and brain–behavior relationships in addition to therapeutic techniques. Psychological interventions therefore include cognitive training and compensatory strategies as well as psychotherapy.

Cognitive training of patients with dementia is similar to that of patients with brain injury in that education is provided and techniques are taught to improve cognitive and functional skills. However, one difference is that while cognitive training in brain injury patients tends to rely on episodic memory, cognitive training with dementia patients does not, since episodic memory progressively declines in dementia (particularly in AD) [142]. Thus, techniques shown to be beneficial

with dementia patients include face–name associations using an errorless learning paradigm [143], spaced retrieval strategies [144], and computer-based memory training programs [145, 146]. Loewenstein and Acevedo [142] developed an integrated cognitive rehabilitation program for AD patients. This integrated program combined spaced retrieval techniques and errorless learning, and incorporated procedural and motor memory training for specific functional tasks (i.e., check-book balancing), memory notebook techniques, and co-training of a family member or friend. Patients with AD were shown to maintain an advantage over control subjects 6 months later.

Many of these training programs with patients experiencing progressive cognitive decline are performed on an individual basis. The advantages of a group setting for rehabilitation, however, include the support inherent in a group, the opportunity to practice new skills, and the cost advantage, especially compared to individual training. Thus, group cognitive training for dementia patients has also been studied, and has been shown to benefit both cognition and mood in these patients [147]. In their review, Belleville [148] provides evidence of the benefits of cognitive remediation with patients with mild cognitive impairment (MCI) and cites the need for well-controlled trials to access the effectiveness of this modality with this population.

Psychotherapy with dementia patients is less likely to be insight oriented, and more likely to be supportive and perhaps cognitive-behavioral or behavioral in approach. However, some work has shown benefit of psychodynamic therapy, at least in mildly demented patients [149]. Grief work is also common in this population. As in cognitive training, psychotherapy can take group form [150], although perhaps with accommodations for cognitive problems.

Life review, a form of reminiscence, is a therapeutic intervention shown to be effective in attenuating behavioral problems, depression, and attention deficits in elderly and demented populations [151, 152]. Life review interventions that use systematic and methodological approaches can facilitate grief work, enhance self-esteem, and assist the reviewer in developing a sense of control and competence [153, 154]. It can also be used as an intervention for caregivers, to facilitate giving and receiving, assist in providing forgiveness, and reducing issues of care as a burden [155, 156].

Behavioral issues common in patients with neurodegenerative disorders include agitation, sleep disturbance, and wandering, in addition to symptoms of anxiety and depression. Behavioral strategies in addressing depression [157] as well as agitation [158] in this patient population have been previously reported. Techniques for depression include encouraging enjoyable activities, distraction, and increased socialization. For agitation, behavioral management techniques such as softening noise and lighting, staying calm, and maintaining consistent routines help; these are similar to what is used in the brain-injured population, particularly at the acute level.

Thus, psychological interventions may be of great benefit to individuals with neurodegenerative conditions. Even with the use of pharmacological interventions, psychological interventions may still augment and be an important part of a comprehensive treatment approach.



## Caregiver Distress and Burden

### *Caregiver Distress and Burden in Brain Injury*

Caregivers of persons with brain injury typically face stressful changes in several facets of life. These changes are not simply attributable to the severity or type of a loved one's brain injury; we know families differ in their (a) personal and social resources, (b) perceived degree of distress imposed by an injury, (c) past medical and psychiatric histories, and (d) ability to cope with the changes they may encounter in everyday life. As for the patient, psychological, cognitive, and behavioral symptoms secondary to the injury can result in difficulty gauging, monitoring, and/or self-regulating their ability to cope with life stressors [159], which in turn may place a greater responsibility and burden on the caregiver.

Current health care practice expects family caregivers to assume the responsibility for patient adherence to complex self-care and medication regimens (e.g., medication management, activities of daily living, exercise, meeting appointments) in addition to the routine and rigors of family life (e.g., parenting, financial planning, meal preparation) and changes that may follow in the wake of a brain injury (e.g., change in family roles, loss of income) without adequate professional support and intervention [160–162]. It is not surprising then, that many caregivers feel overwhelmed and develop problems with their own medical and mental health [163]. Caregivers can exhibit difficulties with stress, depression, anxiety, psychosomatic disorders, increased consumption of prescription and nonprescription drugs, financial difficulties, role changes, and poor social adjustment, with increasing social isolation [164] that may require medical and mental health care services which they do not always receive.

Davis et al. [165] performed a correlational study to determine predictors of caregiver distress and perceived burden. They discovered that reports of medical and psychiatric illness in caregivers (predominantly female) preceding their loved one's injury were strong predictors for caregiver distress. Further, individuals who received treatment for psychiatric illness and/or used an escape-avoidance coping strategy (i.e., lack of a proactive approach to deal or cope with the situation posed by their loved one's brain injury) were predicted to be at greater risk for experiencing caregiver distress. Perceived caregiver burden was predicted to be greatest in caregivers with (a) brain-injured loved ones presenting with poor functional status, (b) diminished perceived social support, and (c) use of an escape-avoidance coping strategy.

In a similar vein, Rivera et al. [166] reported that in a sample of 60 caregivers (predominantly females) of loved ones with brain injury, those with increased self-report of physical symptoms and a negative problem-solving style were at greater risk for experiencing symptoms of depression independent of their time spent as a caregiver, caregiver age, or level of perceived burden. Interestingly, caregivers who were "at risk" for depression reported a negative problem-solving approach. However, those who exhibited a more positive problem-solving approach

were not significantly less “at risk” for having symptoms related to depression, suggesting that “the absence of negative tendencies was much more important (in reducing risk of depression) than the presence of positive skills.”

The findings from this line of work suggest the need for effective problem-solving training for caregivers of individuals with brain injury. In spite of the evidence suggesting the significant increases in actual caregiver distress and perceived caregiver burden, a substantial number of these individuals will most likely operate as the primary health care providers for their loved ones without the appropriate training, preparation, and support typically held by direct care staff in brain injury rehabilitation facilities.

Brain injury rehabilitation programs routinely develop post-discharge plans for the patient and the designated caregiver. However, the needs of the caregiver may not be adequately addressed in progress updates or discharge planning sessions provided during the inpatient or outpatient rehabilitation program or, in brief, infrequent outpatient visits with the patient’s care providers. While several brain injury rehabilitation programs will incorporate some aspect of family training or counseling, there are no coordinated “programs of care” for family caregivers of persons with brain injury upon community reentry following formal rehabilitation services. This situation exists in spite of the research evidence that caregivers who are distressed are more likely to develop severe problems with depression and ill health over the initial year of caregiving [164, 167]. The bulk of the evidence, to date, for caregiver interventions is limited to scenarios that involve relatively time-limited and age-related conditions (e.g., neurodegenerative disorders), and there is very limited systematic study of interventions to assist family caregivers of persons with brain injury. Even more disconcerting is the fact that some individuals with brain injuries may not have any access to brain injury rehabilitation services. As a consequence, some caregivers may receive little to no education, support, or counseling.

Prior work has demonstrated the feasibility and efficacy of extending psycho-education and training to caregivers through in-home, telephone, or web-based conferencing [166, 168–170]. Sander et al. [168] provided web-based videoconferencing sessions with 15 caregivers of patients with brain injury that resided in rural areas with reduced access to mental/medical health care. The sessions included a combination of psycho-education and problem-solving techniques to address cognitive and behavioral changes or limitations following brain injury. Outcome measures included satisfaction and perceived usefulness surveys immediately after completion of the intervention and at 18-month follow-up. Participants reported high levels of satisfaction with the intervention. In addition, at follow-up the participants reported continued utilization of the acquired techniques to help develop necessary coping skills.

Randomized controlled trials using in-home and telephone-based problem-solving training while implementing a predominant social problem-solving model [171] have been shown to be low cost and effective in decreasing caregiver depression. These effects have been observed among family caregivers of persons with stroke [172], spinal cord injury [173], and TBI [166]. The effects of

problem-solving training for caregivers have been superior to educational programs (i.e., control group), and the effects have been observed over 3 months to 1 year later among community-residing caregivers. In their study of caregivers of brain-injured patients, Rivera et al. [166] included a control group and a problem-solving training group. The control group received health-education materials that were sent to the participants in the mail and were later reviewed over the phone during structured telephone sessions. The experimental group received four in-home problem-solving training sessions over 1 year with eight additional structured telephone sessions over the same time period. Outcome measures included self-report measures of depression, health complaints, well-being, caregiver burden, and social problem-solving ability. Compared to participants in the control group, those individuals receiving problem-solving training reported significant declines in depression, health complaints, and dysfunctional problem-solving styles.

The research evidence demonstrates that the psychological sequelae of brain injury extends beyond the brain-injured patient and can have a great emotional impact on the caregiver, as well as on family dynamics. While local community brain injury support groups can be beneficial, there appears to be the need for a systematic approach to address the needs and well-being of caregivers.

### ***Caregiver Burden in Dementia***

As in brain injury, caregivers of patients with dementia also suffer changes and burdens. Caregivers themselves are often the child or spouse of the person with the neurodegenerative condition. However, unlike in sudden brain trauma, diagnosis of a neurodegenerative condition can be delayed many years, which can also further delay treatment and support. Stress is particularly high in cases of early-onset (or younger-onset) dementia [174] or instances of frontotemporal dementia, where personality and behavioral changes predominate. Education can go a long way in the latter case, as well as finding groups specific to frontotemporal dementia as opposed to AD. Lewis, et al. [175] discussed the efficacy of their Stress-Busting Program (SBP) for family caregivers of patients with dementia, which was delivered in a group-therapy format for 9 weeks. SBP incorporated stress management techniques, education, problem solving, and support. Results indicated improved physical and mental health among caregivers, as well as decreased stress and caregiver burden.

### **Conclusions**

The purpose of this chapter was to provide an insightful overview of the deficits and needs experienced by individuals with neurological impairment, particularly resulting from acquired brain injury or neurodegenerative disorder. Further, it may

function as an introduction for the nonneuropsychologist as to the practices of assessment, therapeutics, education, and research performed by clinical neuropsychologists in medical settings (e.g., neurology units and brain injury rehabilitation facilities).

Apart from their skills in assessment and diagnosis of cognitive dysfunction following insult or disease of the brain, the clinical neuropsychologist is required to have a well-rounded understanding of the impact neurological impairment can have on one's mood, cognition, personality, behavior, and functional status and how this may impede therapy and eventual progress. The severity of these influential factors can be related to the patient's premorbid level of functioning, nature of the insult, and perceived support. The clinical neuropsychologist is then able to direct therapy in a systematic fashion according to research evidence on best practice. Clinical neuropsychologists are also able to utilize effective behavioral health interventions for the prevention of risk factors and treatment of dysfunction comorbid with brain injury (i.e., pain and substance abuse).

There has been an ever-increasing need to consider the welfare of those who will serve as caregivers to individuals with chronic neurological disorders. Caregivers may become de facto health care providers to their loved ones without proper education or support. Research evidence has demonstrated that caregivers are at greater risk for experiencing declines in their own medical and psychiatric status.

The future of clinical neuropsychologists in medical settings such as neurology and rehabilitation departments is bright. Their training and specialized knowledge brings much to these multidisciplinary settings.

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# Chapter 26

## Preoperative Mental Health Evaluations

David B. Sarwer, Scott Ritter, Traci D’Almeida and Robert Weinrieb

### Introduction

Over the last several decades, there has been a growing appreciation that the successful outcome of a surgical procedure is the product of an interaction between medical technology and the patient’s ability to utilize that technology in the most appropriate manner. In this regard, a patient’s psychosocial status may influence medical decision making regarding the appropriateness of a patient for a given treatment. These same factors may play an important role in the ultimate outcome of a surgical intervention and a patient’s ability to follow postoperative treatment plans.

These observations are quite intuitive to mental health professionals. They also have long been of interest to surgeons with interests beyond the technical aspects of their procedures. Nevertheless, research on the relationship between psychosocial and behavioral factors and the outcome of surgery is relatively recent. Some areas, such as solid organ transplantation, are more fully developed. Other areas, such as bariatric surgery, have evolved more recently and in response to the evolution of the surgical procedures, recognition of the importance of multidisciplinary care, and standards of care dictated by professional organizations and third-party payers. Emerging areas of care, such as vascularized composite allograft (the procedures

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used in hand and face transplantation), are currently under development and our understanding of the psychological issues in these areas are clearly in their infancy. However, it is encouraging that many surgical teams have shown recognition of the importance of psychosocial factors early in their work in these areas.

Across surgical procedures, there are a number of common themes and similarities in the mental health evaluation process. At the same time, there are distinct differences and considerations for providers. In areas such as solid organ transplantation, predictions of compliance to the rigorous postoperative immunosuppressant regime and adaptation to a healthier lifestyle are central concerns. Postoperative compliance also plays a major role in the evaluation of bariatric surgery patients. In contrast, the evaluation of patients who present for cosmetic procedures focuses more on whether preoperative psychopathology may reduce the likelihood that the patient will realize the potential psychological benefits of the procedure.

The idea of surgery elicits a strong emotional response from many, if not most, individuals outside of the medical profession. Surgery introduces the potential risk of death, regardless of the severity of the underlying medical condition. The resulting fears and anxieties may compromise preoperative decision making by both the patient and family. Social support, or the lack of support, is considered to be one of the most important variables in most preoperative mental health evaluations. Yet, the focus remains on the patient and his or her ability to cope with the changes associated with surgical treatment.

### ***Preoperative Mental Health Evaluations: General Considerations***

Mental health professionals, including psychologists, psychiatrists, and social workers, are part of many surgical treatment teams. In some settings, mental health practitioners provide support and psychoeducation, often after surgery. Mental health professionals are increasingly asked to perform preoperative evaluations with the primary objective of identifying any preexisting psychopathology that may contraindicate surgery and/or detrimentally impact the patient's ability to appropriately engage in postoperative care.

In this regard, the evaluation is a prognostic assessment designed to evaluate risk. The evaluation is conducted before the surgeon makes the decision to operate, and is essentially a recommendation to the surgeon on whether to go ahead with the planned surgery, delay surgery until additional treatment is undertaken to help the patient be better prepared, or, in rare cases, a recommendation not to perform surgery. To a great extent, the evaluation and recommendations are more similar, rather than different, to preoperative evaluations conducted by cardiologists who are asked to evaluate a patient's cardiac health status prior to surgery: The cardiologist is asked to assess the status of the heart and provide a recommendation about whether or not the heart is healthy enough to undergo surgery. Regardless of the recommendation, the surgeon typically makes the final determination of "risk" and the decision on whether or not to proceed with surgery.

The preoperative mental health evaluation holds the potential to help the surgeon improve outcomes. It also can function to identify “problem patients” who may, regardless of their operative outcome, place excessive demands on the surgeon and the treatment team. It also may play a role in reducing the likelihood of medical malpractice litigation, by identifying patients with significant psychopathology that may contraindicate surgery or hint at the patient’s potential difficulty in adhering to postoperative treatment recommendations that may contribute to a malpractice case.

As a result, the mental health professional who functions in this role has significant responsibilities. The work requires knowledge of the surgical procedures in the specialty. It also demands that the mental health professional have an understanding of the comorbid medical conditions and how they may impact psychiatric status. Obviously, it requires the mental health professional to learn how to communicate mental health concepts to medical professionals, patients, and their families in a straightforward manner. Finally, it requires a detailed, up-to-date knowledge of the psychosocial risk factors associated with the surgical treatment as well as a willingness to incorporate new research findings into the evaluation process.

To this end, it is useful for the mental health professional to use a systematic process for these evaluations as much as possible. The evaluation should have a basic structure, which often will include a review of medical history and a clinical evaluation of the patient. This should be spelled out in some detail and the format should be followed most of the time and for most patients. Within this structure, there should be room to modify the evaluation as appropriate to the given case. For example, in the evaluation of patients with life-threatening illnesses such as end-organ failure, it is useful to ascertain the patient’s physical condition early in the interview. Patients may report that they are in significant discomfort due to worsening of their condition or because of a new symptom that may either make the interview impossible to complete or require that the patient be urgently evaluated by a physician. When no such emergency exists, the mental health professional must remember his responsibility to the patient. The recommendations regarding surgery should be shared with the patient and explained in detail. This last step may be especially difficult when the patient sees no other option for recovery or improvement.

### ***The Clinical Interview***

As noted above, the primary goal of the evaluation is to identify psychosocial “risk factors” that may contraindicate surgery or interfere with the patient’s ability to have the best possible result. Some of the information related to this goal can be obtained from the patient’s medical history and record. Much of it, however, will come from the clinical interview of the patient. In addition, obtaining collateral information from significant others and family members cannot be overemphasized. Often the two methods are used to help form the most complete understanding of a

given issue. Details describing these issues are expanded upon in the section below on the evaluation of the solid organ transplant patient.

Graduate-level mental health training teaches the professional how to obtain a history, build rapport, and convey empathy. Most of these skills, however, are taught in the context of evaluating a patient who will enter into psychotherapy. In the preoperative mental health evaluation, obtaining a comprehensive history is paramount. Rapport and empathy are somewhat less emphasized. Instead, the challenge comes from eliciting truthful information from a patient who may be acutely aware that evaluation may influence the surgeon's decision to operate. Thus, many patients engage in a fair amount of "impression management" or "damage control" during these evaluations, minimizing symptoms and experiences. Other patients may come to the evaluation misinformed about the purpose of the evaluation and arrive angry or anxious. Those with no history of mental health treatment may expect to be lying on a couch and talking about their family and personal history. Thus, they are surprised when they realize that the interview has a much more problem-focused approach.

There are several key elements to the interview. First, the evaluator must "normalize" the evaluation, informing the patient that it is a routine part of the preoperative process (although in some specialties and programs, an initial screen is conducted by a nurse or social worker with formal evaluation by a psychologist or psychiatrist being reserved for more complex cases). The professional also can use the onset of the evaluation to acknowledge reluctance to participate in the interview. This may present an opportunity to discuss the underlying medical condition, the resulting psychosocial impact, and the patient's expectations for surgery.

Once the nature of the evaluation has been communicated to the patient, and the experience has been normalized, the body of the evaluation contains a good degree of structure (which is often specific to the surgical condition, as detailed below). This allows the mental health professional to obtain all information critical to making the recommendation to the team, yet flexible enough to pursue issues specific to the patient. Another key aspect of the evaluation which is consistent across most procedures includes assessing the patient's motivations for surgery, as well as inquiring about historical factors that may impact the preoperative and postoperative processes. In addition, the patient's psychiatric status and history should be assessed in detail.

The patient's mental health history often provides important clues to an individual's appropriateness for a given surgical patient. Persons with a long history of noncompliance with medical recommendations and treatment plans are likely at risk to continue this pattern of behavior after surgery, even if the procedure is life-saving in nature, such as with solid organ transplantation. At the same time, patients with a long-standing history of severe psychopathology, particularly issues related to substance abuse, thought disorders, and profound mood disorders may, at the time of initial presentation to the surgeon, not be appropriately stable and ready for surgery. They may require additional mental health treatment prior to surgery.

A history of significant psychopathology may interfere with a patient's ability to cope with the physical and psychological stressor of surgery. For others, psychiatric



instability may threaten the patient's ability to comply with postoperative treatment protocols, which, in some cases, may require daily, lifelong engagement in order to optimize the outcome of surgery. In this regard, patients must truly see themselves as being part of the treatment team and being an active participant in their care.

As assessment of the patient's psychosocial status should include a consideration of personality issues (and disorders) that might impact postoperative recovery as well as interactions with the treatment team. The patient should be asked about his or her expectations for postoperative recovery and prognosis to ensure that these are realistically informed.

At present, there is a lack of consensus on the use of psychometric testing prior to surgical interventions. Some specialties (and professionals) augment their interviews with personality inventories such as the MMPI-2 or MBMD. Others do not use these instruments because of the lack of empirical evidence related to their predictive potential. Many professionals will use paper-and-pencil symptom inventories to further assess specific symptom areas. Others will make referrals for formal neuropsychological testing when relevant to a particular case, such as when there is concern about brain damage or limited intellectual functioning. However, this testing is often prohibitively expensive and time-consuming. As the field of presurgical psychosocial evaluation further develops, outcomes research may allow for the development of a consensus on the appropriate usage of psychometric testing.

## **Solid Organ Transplantation**

In 2010, a total of 28,662 organ transplants were performed in the USA [1]. Roughly 112,000 individuals are currently awaiting organ transplants [2]. Because of the scarcity of donor organs available for transplantation, individuals awaiting organ transplants are prioritized by severity of need and suitability. Psychological suitability is of particular importance because premorbid psychosocial conditions can influence solid organ transplantation morbidity and mortality [3, 4]. Thus, most solid organ transplant teams require psychosocial assessments from mental health professionals, such as social workers, psychologists, etc., psychiatrists, and psychiatric nurses [5]. These assessments include identifying problems, patient education, interventions, and follow-up care [6].

Mental health professionals responsible for the evaluation and treatment of the solid organ transplant candidate must have extensive knowledge of the complexities involved in their transplant patient's care. Furthermore, as suggested above, the professional is in the unique role of having to form an alliance with the patient in order to obtain sensitive personal information that could potentially delay or even eliminate the opportunity for their patient to be placed on the transplant waiting list. Thus, it can be a challenge to maintain the necessary balance between the needs of the patient and the requirements of the transplant team.

When a patient develops end-stage liver, lung, heart, or kidney failure, and has deteriorated to the point where their outpatient physician feels they must be

evaluated for an organ transplant, the patient will typically be referred to their local or regional transplant center. Alternatively, a much smaller proportion of patients will arrive at their hospital's Emergency Department in extremis without having developed a significant relationship with an outpatient specialist. Insurance companies sometimes dictate which transplant program a patient must go to based upon outcomes and survival statistics for that program. In most regions, organ procurement organizations (OPOs) serve only specifically designated geographic areas, but patients may be evaluated and listed in multiple regions if they wish. This is, however, perceived by many to be an unfair advantage because it favors patients who are financially and physically able to travel in order to increase their likelihood of receiving a transplant sooner.

Solid organ transplant psychological assessments often occur as part of a larger pretransplant workup that often includes specialty evaluations from cardiology, pulmonary, gastroenterology, and nutrition. Information collected during psychological assessments is shared with these specialists to identify and minimize risk factors that could affect a successful outcome. Thus, it is important that patients understand that the psychological evaluation is a collaborative process and that the information they provide in their psychological evaluation can influence their suitability for transplantation [6].

*The Pretransplant Psychiatric Interview* The goal of the preoperative psychiatric or psychological evaluation is to gauge a patient's psychological suitability for the transplant. The psychological evaluation for solid organ transplant patients has four components: (1) a medical records review, (2) a patient interview, (3) quantitative testing, and (4) collateral information.

*Records Review* Medical records should be reviewed prior to meeting the patient, as they may contain important information for the psychological evaluation. Past and current medical treatment, psychiatric treatment, and medication records can be useful in assessing psychosocial functioning and compliance.

*Patient Interview and Collateral Information* Face-to-face patient interviews between the transplant candidate and the mental health professional strive to provide the transplant team with information on psychological, cognitive, and social functioning. Behavioral health issues such as a history of addictions, chronic pain, etc., depression, anxiety, and psychosis need to be evaluated because the presence of these psychiatric conditions can limit the success of solid organ transplants by interfering with the patient's ability to be compliant with medication management and follow-up visits [7]. Issues with cognition may include delirium or encephalopathy that can impair a patient's ability to follow medical instructions or care for themselves [6]. Issues of social functioning, particularly the patient's history of complying with medication, exercise, or lifestyle prescriptions, as well as the patient's ability to keep medical appointments, must also be assessed. Also relevant are issues pertaining to coping, stress, education, occupational history, social support, and relationships with authority figures [8]. In particular, a patient's relationships with medical professionals and their ability to work with the transplant team are of key importance for achieving transplant success.

When patients themselves cannot be interviewed, information must be gathered from other sources, including family members and other medical providers. Friends and family members can verify information provided during the patient interview, and can report any psychological, cognitive, or social changes that may have gone unnoticed or were unobtainable via the patient interview. Friends and family members can also provide information on how much social support they or others can provide to the organ transplant candidates before or following, etc.

*Quantitative Testing* Quantitative testing provides the transplant team with additional data to gauge the suitability of patients for transplantation. Short instruments, like the Folstein Mini-Mental State instrument and the Neurobehavioral Cognitive Status Exam, provide information on cognitive functioning and can identify major problems, like delirium or dementia [9, 10]. Other instruments, like the Repeatable Battery for the Assessment of Neuropsychological Status, provide further detailed assessment of cognitive functioning [11]. The Psychosocial Assessment of Candidates for Transplantation (PACT), the Transplant Evaluation Rating Scale (TERS), and the Structured Interview for Renal Transplantation (SIRT) have been specifically tailored for the pretransplant psychosocial evaluation process [12–14]. The PACT consists of eight items on a 5-point scale plus a final rating by the interviewer; higher scores predict better posttransplant outcomes. The TERS is a ten-item scale and each item is rated from 1 to 3 (a lower score is better). Although both scales were originally designed for assessment of solid organ transplant candidates, a head-to-head study comparing the PACT to the TERS in 40 consecutive bone marrow transplant candidates found that inter-rater reliability was very similar [15]. Both measures have been translated into a number of foreign languages and are widely used by some programs. A new tool has been developed and studied by Maldonado et al. [16] to evaluate potential candidates for solid organ transplant eligibility and to describe domains of a patient's strengths and limitations based upon their psychosocial functioning. It is called the Stanford Integrated Psychosocial Assessment for Transplant (SIPAT) and can be administered by a Social Worker, Psychologist or Psychiatrist in a structured interview format. It takes from 30–40 minutes to complete and asks about 18 risk factors in 4 domains that were gleaned from the literature and the authors' experience. The 4 domains are patients' readiness, social support, psychological stability and substance abuse. In this study, the instrument was applied retrospectively by 5 blinded examiners to 102 randomly selected liver, heart and lung transplant recipients. The authors reported "excellent inter-rater reliability (Pearson's correlation coefficient = .853)", and "high predictability of psychosocial outcomes;  $p = <0.001$ ". While the aforementioned inter-rater reliability was assessed in all study patients, only liver transplant recipients were assessed for psychosocial predictability ( $n = 23$  "positive" compared with  $n = 29$  "negative" outcomes. The authors did not specify the duration of follow up in their liver patients but do acknowledge the limitations of the study, especially the retrospective design. An administration manual and the Long Form of the interview may be accessed at <http://psychiatry.stanford.edu/Psychosomatic>. Most experts agree that the clinical interview is currently the most widely used method for the assessment of psycho-

social stability and perhaps the most sophisticated tool available to the consulting professional.

*Informed Consent for Transplantation* One of the most important components of the pretransplant assessment is the evaluation of a patient's capacity to comprehend at least the basics of the transplant process (informed consent). The level of education, the presence of language and cultural barriers, possessing preconceived erroneous notions of who does and does not get listed, and fears of surgery and organ rejection may need to be addressed in the interview. Evaluating whether patients have adequate and accurate information and freedom from coercion that may have affected their decision-making process should be assessed.

*Substance Abuse* The importance of understanding a patient's coping style and skill set as well as the record of adherence to medical treatment cannot be overstated. Patients who adopt a passive approach to quitting smoking or stopping the use of illicit drugs and alcohol by simply "going cold turkey" without the benefit of professional addictions treatment or even self-help groups should be a red flag to transplant teams that signals an increased risk of returning to these maladaptive behaviors. Adherence to addictions and psychiatric treatment in addition to drug, alcohol, and nicotine abstinence must be emphasized at each transplant team visit. In our clinical experience, denial of having had a serious alcohol or drug problem in an alcohol-dependent or drug-dependent patient who has only recently quit using is common, and when severe, may manifest itself as disregard for other modifiable risk factors and medical noncompliance. Nearly all transplant programs require such patients to attend formal drug and alcohol treatment programs in order to be eligible for being placed on the transplant waiting list. Patients' adherence to these recommendations must be assiduously monitored.

*Psychiatric Disorders* The presence of formal psychopathology, specifically major depressive disorder, bipolar disorder, anxiety disorders, and psychotic disorders must be evaluated in detail and decisions regarding transplant eligibility related to the presence of those conditions must be made on a case-by-case basis. Because there are no conclusive data regarding the feasibility and safety of organ transplantation in patients suffering from these disorders, it is important to thoroughly screen for their presence and recognize that there are ways to mitigate the possible harm that may come to these individuals from the surgery or from medications such as steroids and immunosuppressants. Methods used to ameliorate psychiatric distress typically include antidepressants for anxiety or depression, antipsychotics for delirium or insomnia, and the provision of supportive and expressive psychotherapy.

*Social Support* Adequate social support is perhaps the most significant factor associated with posttransplant health-related quality of life improvement and adherence to appropriate medical management [17]. While "social support" has no consistent definition, most programs are interested in whether a patient has able, reliable, and available people in their lives to assist them whenever assistance is needed. This can range from requiring debilitated patients with no family support and limited social supports to live in a skilled nursing facility, to requiring patients who are being

physically abused by their spouses or partners to find alternative living arrangements in order to be considered for placement on the transplant waiting list.

In summary, with the goal of solid organ transplantation to improve both length and quality of life, mental health professionals need to be involved in all phases of the transplant patient's care, including the indefinite duration of the postoperative period. This is particularly important when issues found in the initial evaluation are predictive of posttransplant distress [18]. As many have described, transplant surgery offers not a cure, but rather an exchange of one set of medical problems for another [19]. Helping patients understand that posttransplant life will not be without problems is essential, and the best route to maintaining their newfound health will involve their commitment to partnering with their transplant team members and their supportive partners.

## Bariatric Surgery

At present, slightly more than one-third of American adults are obese, defined as a body mass index (BMI) of at least 30 kg/m<sup>2</sup>. Roughly 5% of the American population suffers from extreme obesity (BMI ≥ 40 kg/m<sup>2</sup>). Obesity, and extreme obesity in particular, is associated with major health complications including coronary heart disease, hypertension, non-insulin-dependent diabetes mellitus, and osteoarthritis [20–22].

There are a number of interventions for weight loss. Lifestyle modification in all of its forms (self-directed diets, commercial weight-loss program, dietary counseling, etc.) is the cornerstone of most weight loss treatments [23]. These treatments typically produce a 5–10% weight loss over a 6–12-month period and that is associated with improvements in weight-related health problems [24, 25]. Unfortunately, most individuals regain the weight that they lose following these treatments within 3–5 years [26, 27].

Bariatric surgery presently is the most effective treatment for obesity. Bariatric surgery is currently recommended for individuals 18 years and older with a BMI ≥ 40 kg/m<sup>2</sup> (or a BMI ≥ 35 kg/m<sup>2</sup> in the presence of significant comorbidities) [28, 29]. The American Society of Metabolic and Bariatric Surgery (ASMBS) estimates that approximately 200,000 procedures are performed annually in the USA at present [30]. The most common surgical procedures include laparoscopic adjustable gastric banding (LAGB) and Roux-en-Y gastric bypass (RYGB). In both procedures, food intake is restricted by the creation of a gastric pouch (approximately 30 ml in size) at the base of the esophagus. RYGB also is thought to induce weight loss through selective malabsorption and favorable effects on gut peptides [31, 32]. Within the past several years, the sleeve gastrectomy has grown in popularity and combines the restrictive elements of the other procedures with a presumed impact on gut peptides. With all three procedures, patients typically lose 25–35% of initial body weight within 12–18 months postoperatively [21, 22, 33–38]. These weight losses are associated with significant improvements in obesity-related comorbidities.

ties and with decreased mortality, as compared to individuals who have not undergone surgery [21, 22, 33–47].

Despite these impressive outcomes, 20–30% of patients are believed to experience suboptimal outcomes, defined as either a less-than-expected initial weight loss or regain of substantial amounts of weight within the first postoperative decade. These outcomes are often attributed to preoperative psychological and behavioral characteristics [48]. As a result, most patients who present for bariatric surgery are required to undergo a psychological evaluation prior to surgery [44]. Such evaluations have been recommended for approximately 20 years, before bariatric surgery became as popular as it is today. Despite the widespread use of these evaluations, there is no uniform consensus of the structure of them.

Mental health professionals who conduct these evaluations typically rely on a clinical interview of the surgery candidate [47]. Many augment the interview with paper-and-pencil symptom inventories or personality assessments. The focus of these evaluations is often on screening for psychopathology. Ideally, the evaluation ideally includes an assessment of the behavioral factors that may have contributed to the development of extreme obesity, as well as the potential impact of these factors on the patient's ability to make the necessary dietary and behavioral changes to experience an optimal postoperative outcome [49]. Most mental health professionals agree that active substance abuse, active psychosis, bulimia nervosa, as well as severe, uncontrolled depression contraindicate surgery without adjunctive treatment [46, 50].

In evaluations at the University of Pennsylvania, we organize our information into four factors: biological, environmental, social/psychological, and timing [49]. We use this framework to communicate our impressions and recommendations about the appropriateness for bariatric surgery to the patient as well as the bariatric surgeon. The resulting written report is also forwarded onto the patient's insurance company.

### ***Biological Factors***

This part of the evaluation typically confirms that the patient meets the BMI criteria for surgery and provides a summary of any obesity-related comorbidities. While both patients and referring surgeons typically have this information already, patients often find it useful to hear, from another professional, that they are physically appropriate for surgery (and perhaps not a more conservative weight loss treatment).

### ***Environmental Factors***

Environmental factors and eating behaviors also are assessed. Patients' previous weight loss efforts are reviewed. Most patients are "dieting veterans" who have tried numerous weight loss programs in advance of surgery [51]. Patients' eating

habits—when and where they eat, who shops and cooks in the home, etc.—also are discussed. Portion sizes, snacking, as well as beverage intake are evaluated. The registered dietitian in the bariatric surgery program also assesses much of this; however, it is useful to be reviewed by the mental health professional as well.

The eating behavior and dietary intake of patients prior to surgery often range greatly. Patients typically report consuming approximately 2,400 kcal/d or approximately 400+ kcal/d more than recommended by the US Department of Agriculture and other government agencies [43, 52]. Some patients will report eating almost twice that amount, with many meals a week consisting of food from fast food or takeout restaurants and including sweetened beverages. In contrast, some candidates for bariatric surgery, often those working diligently to control their type 2 diabetes, will report quite healthy eating habits. Nevertheless, many patients who present for bariatric surgery report difficulties controlling their ability to limit their eating behavior in response to emotional or social cues [47]. Physical activity also is assessed, although most patients are quite sedentary as a result of their weight or comorbid health issues.

The presence of formal eating disorders is assessed. Binge eating disorder (BED) receives the greatest attention. Early reports suggested that up to 50% of candidates for surgery had some form of BED. More recent reports, however, suggest that BED occurs in approximately 5–10% of patients [53, 54]. Bulimia nervosa is quite rare, seen in approximately 1% of patients.

### ***Psychological Factors***

Most of the evaluation focuses on the patient's psychiatric status and history. This includes an assessment of patients' psychiatric status and history. Particular attention is paid to the presence of the disorders that contraindicate surgery, as noted above. Mood and anxiety are assessed, as is the presence of thought disorders such as schizophrenia and dissociative identity disorder, both of which occur, albeit rarely.

In the past several years, several comprehensive reviews of the literature on the psychosocial and behavioral aspects of bariatric surgery have been published [28–34]. Collectively, these reviews have found a high rate of psychopathology among candidates for bariatric surgery. Between 20 and 60% of patients have been characterized as suffering from an Axis I psychiatric disorder, the most common of which were mood and anxiety disorders [35, 36]. Smaller percentages have been diagnosed with substance-abuse problems and personality disorders, both of which may impact preoperative management and postoperative outcomes. Candidates for bariatric surgery typically report significant impairments in both health- and weight-related quality of life, body image, and other impairments in psychosocial status and functioning.

Up to 40% of patients who present for bariatric surgery are engaged in some form of mental health treatment and approximately 50% report a history of mental health treatment [55, 56]. In many cases, these medications or other forms of treatment are

appropriately controlling the mood symptoms. The treating or prescribing professional should be contacted to confirm that patients are stable and appropriate for surgery.

### ***Timing Factors***

The final part of the assessment focuses on the timing of surgery. Ideally, patients elect to undergo surgery at a time that is relatively free of major stressors. Thus, the presence of these stressors is assessed. Patients are also asked about their knowledge of the dietary and behavioral changes required of surgery and their readiness to change their previous maladaptive behaviors to increase their likelihood of a successful outcome.

Candidates for bariatric surgery often believe that the preoperative mental health evaluation is designed to “rule out” patients for surgery. Studies have suggested that between 70 and 90% of patients are unconditionally recommended for surgery by the mental health professional [47, 55–58]. The remaining patients are typically asked to enter into some additional mental health and/or dietary treatment for a period of time to help them better prepare for surgery. These patients are typically reevaluated after a period of time (often 3–6 months); the majority who follow the recommendations of the mental health professional and return for further assessment are typically recommended for surgery.

In summary, bariatric surgery is presently the most powerful tool to treat obesity. For the majority of patients, the surgical procedures produce sizable weight losses that are well maintained and are associated with significant improvements in mortality as well as physical and psychological comorbidities. Unfortunately, these impressive outcomes are not experienced by a sizable minority of patients. These suboptimal outcomes are most often attributed to behavioral and psychological reasons rather than surgical ones, underscoring the important role that mental health professionals play in the preoperative evaluation process.

### **Cosmetic Surgery**

According to the American Society of Plastic Surgeons, approximately 14 million Americans undergo a cosmetic surgical or minimally invasive treatment annually [59]. As cosmetic surgery has grown in popularity over the past two decades, so has interest in the psychological aspects of these procedures. At present, there is a rather well-developed literature that both describes the typical characteristics seen in patients as well as the psychosocial changes that occur postoperatively. There also is some consensus that certain psychiatric conditions, primarily body dysmorphic disorder (BDD), serve as contraindications to surgery (as detailed below).

Physicians who offer cosmetic treatments are encouraged to obtain a psychiatric history and status on their new patients, as are all medical professionals. Like these



other professionals, many probably do not inquire about this information. Others likely omit or skim over these questions. Given the psychological issues associated with cosmetic surgery, obtaining this information is of greater importance [60]. This history, along with observations from the patient's demeanor and presentation in the initial consultation, may suggest the presence of psychopathology that would warrant additional assessment and or treatment from a mental health professional.

The vast majority of patients interested in cosmetic surgical and nonsurgical procedures are thought to be psychologically appropriate for such treatments [61–64]. Most patients typically have specific appearance concerns, internal motivations, and realistic postoperative expectations. Thus, most do not need or are required to undergo a psychological evaluation prior to undergoing a cosmetic treatment. However, many cosmetic surgeons will ask a mental health professional to consult on a patient if they have identified potential mental health concerns. This most often occurs in the case of a patient who has displayed signs of distress prior to their initial procedure. In other situations, the patient may be struggling with psychological issues postoperatively.

The psychological assessment and screening of patients interested in cosmetic surgery are critical for at least two reasons [61–66]. First, such screening can help determine if patients' preoperative motivations and postoperative expectations are realistic. Second, the screening is vital to identify patients who have psychiatric conditions that may contraindicate treatment. A comprehensive assessment of prospective patients can help identify patients, who, at a minimum, may become a clinical management problem. In the worst-case scenario, these may be the patients who threaten or follow through with threats of legal action or violence following surgery.

All of the major psychiatric diagnoses can likely be found within the population of individuals who seek cosmetic surgery [61–64]. Conditions such as untreated major depression, uncontrolled schizophrenia, and active substance abuse are relatively easy to identify and contraindicate treatment, just as they contraindicate many medical treatments. The relationship between less severe psychopathology, such as mild depression or anxiety, and postoperative outcomes is less clear. In the absence of definitive prospective studies of this relationship, patients who have these conditions should be evaluated on a case-by-case basis, conditions such as BDD and eating disorders, may be overrepresented among these patient populations. As a result, they warrant additional attention.

The cognitive-behavioral assessment of the cosmetic surgery patient focuses on the patients' thoughts, behaviors, and experiences that have contributed to their dissatisfaction with their appearance as well as the decision to seek treatment [60]. The evaluation should determine if the patients' thoughts and behaviors are maladaptive to the point that they reflect some form of psychopathology that would contraindicate cosmetic treatment. In addition to utilizing the basic principles of cognitive-behavioral assessment, the assessment by the mental health professional, like that of the treating physician, should focus on the patients' motivations for and expectations about cosmetic surgery, their appearance and body image concerns, as well as their psychiatric history and status.

## ***Motivations and Expectations***

The mental health professional should inquire about patients' motivations and expectations for cosmetic surgery. In assessing patients' motivations for surgery, the mental health professional may want to begin by asking, "When did you first think about changing your appearance?" Similarly, it may be instructive to ask, "What other things have you done to improve your appearance?" In addition to providing important clinical information, these questions also may reveal the presence of some obsessive or delusional thinking, as well as compulsive or bizarre behaviors, related to physical appearance. It is not uncommon for cosmetic surgery patients to report that they have tried several "do-it-yourself" treatments, such as treatments widely available on the Internet, in an attempt to improve their appearance. Many of these were likely not helpful and some may have been potentially dangerous.

The role of patients' social relationships in the decision to seek surgery should be assessed. Patients should be asked how romantic partners, family members, and close friends feel about the decision to change a physical feature. Patients who seek treatment specifically to please a current partner, or attract a new one, are thought to be less likely to be satisfied with their postoperative outcomes [67].

## ***Physical Appearance and Body Image***

Prospective patients should be able to articulate specific concerns about their appearance. Patients who are markedly distressed about slight defects that are not readily visible may be suffering from BDD. The nature of the appearance defect may be difficult for mental health professionals to assess for at least two reasons. First, appropriate ethical care would prohibit mental health professionals from asking patients to remove article of clothing to observe the defect. Second, the judgment of an appearance defect as "slight or imagined" is highly subjective. What a mental health professional judges to be a slight defect well within the range of normal may be a defect that a cosmetic surgeon judges to be observable and easily correctable. As a result, the degree of emotional distress and impairment, rather than the specific nature of the defect, may be more accurate indicators of BDD in these patients [61–66, 68].

Nevertheless, some heightened body image dissatisfaction is considered "normal" for persons interested in cosmetic surgery, as found in numerous studies [69–74]. Some of the thoughts and behaviors that contribute to both the development and maintenance of this dissatisfaction are likely maladaptive. Many patients believe that others take notice of their appearance defects; others report increased anxiety or avoidance of specific social situations because of self-consciousness about their appearance. Thus, the degree and psychosocial consequences of dissatisfaction should be assessed. Asking about the amount of time spent thinking about a feature or the activities missed or avoided, may indicate the degree of distress and impairment a person is experiencing and may help determine the presence of BDD.

## ***Psychiatric History and Status***

The assessment of the patients' psychiatric history and current status is a central part of the evaluation. Particular attention should be paid to disorders with a body image component, such as eating disorders and somatoform disorders, as well as mood and anxiety disorders. The presence of these disorders, however, may not be an absolute contraindication for cosmetic surgery. In the absence of sound data on the relationship between psychopathology and surgical outcome, appropriateness for surgery should be made on a case-by-case basis and include careful collaboration between the mental health professional and the referring surgeon.

Studies conducted throughout the world have suggested that 5–15% of individuals who present for cosmetic surgery have some form of BDD [75, 76]. These patients are often convinced that a cosmetic procedure is the only thing that will help to eliminate their preoccupation with their appearance and the majority end up seeking some form of cosmetic surgery during their illness. Unfortunately, studies have suggested that greater than 90% of persons with BDD who undergo a cosmetic treatment report either no improvement or a worsening of their BDD symptoms after these treatments [77]. There also is concern that these patients may be more likely to bring legal action or threaten, if not commit acts of violence directed at the surgeon. Thus, it is critically important that plastic surgeons screen for the disorder and refer patients to mental health professionals for further assessment prior to surgery.

Mood and eating disorders also may be overrepresented among patients who seek cosmetic surgery and related treatments [64, 78]. Over the last decade, seven epidemiological studies have found that women who have cosmetic breast implants are two to three times more likely to commit suicide than other women [79]. While several potential explanations of this relationship have been offered, most authorities believe that these women were likely suffering from some preexisting psychopathology that contributed to their subsequent suicide [79]. Thus women with a history of mental health treatment (particularly for depression) as well as those suspected by the surgeon of experiencing symptoms of depression likely should undergo a mental health evaluation prior to breast augmentation [79]. Eating disorders such as anorexia or bulimia also may occur with greater frequency among women who seek procedures such as liposuction or breast augmentation.

Approximately 20% of patients who seek cosmetic medical treatment report using a psychiatric medication [80]. As mental health professionals frequently observe, patients who receive these medications from primary care physicians often do not experience complete relief from their symptoms. Thus, a psychopharmacologic evaluation should be considered if symptoms do not appear to be well controlled. If patients are in treatment with another mental health professional, the consultant should contact this professional and discuss patients' appropriateness for cosmetic treatment.

At the conclusion of the evaluation, the mental health professional should share his or her clinical impressions with the patient, as well as their ultimate recom-

mentation to the referring physician about the appropriateness for surgery. The results of the evaluation can be communicated to the referring physician with a letter summarizing the assessment and recommendations. Obviously, referring physicians will make the ultimate decision about the decision to go forward with surgery. Nevertheless, it is good practice to share the results of the consultation with the patient.

In summary, the psychological assessment of patients interested in cosmetic surgery is a critical part of the patient selection process. Failure to identify patients who are psychologically inappropriate for treatment can create significant problems for the treating physician and his or her staff, as well as for the patient. As part of the initial consultation, patients should be asked about their motivations and expectations for treatment. Their appearance and body image concerns should be assessed carefully and the potential presence of BDD and mood and eating disorders should be determined. In addition, a psychiatric history should be obtained on all patients.

## Conclusion

As the specialty of health psychology has grown, there has been an increasing appreciation of the role of the mental health professional in the assessment of the surgical patient. In many surgical subspecialties, such as solid organ transplant and spine surgery, mental health professionals have long been part of the multidisciplinary treatment team. In rapidly growing areas, such as bariatric surgery, mental health professionals have been fortunate to be “invited to the table” early in the development of the field. Mental health consultations are less common in cosmetic surgery. However, the psychological issues are profound and the growth of cosmetic medicine may provide more opportunities for the involvement of mental health professionals in the future.

The specific role of the mental health professional on the surgical treatment team, and the specific nature of the preoperative mental health evaluation, varies as a function of the surgical specialty. At the same time, there are many commonalities. The mental health professional’s primary role is to assess for the presence of psychopathology and determine the potential impact of any pathology on preoperative or postoperative outcomes. The consultant also plays an important role in providing patients with information and education regarding their condition as well as the behavioral and lifestyle changes they are likely to encounter postoperatively. While patients often assume that the primary role of the mental health professional is one of “gatekeeper” designed to rule out patients from surgery, most professionals work with patients and the rest of the treatment team to prepare patients for optimal postoperative outcomes and only in a minority of cases recommend that a patient not undergo surgery.

Future medical and surgical advances, coupled with the growing appreciation of the role of mental health issues in surgical outcomes, will likely provide more opportunities for mental health professionals to routinely collaborate with surgical specialties.

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# Chapter 27

## Behavioral Dentistry

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### Introduction to Behavioral Dentistry

Behavioral dentistry involves the application of knowledge from the behavioral sciences for the assessment and treatment of dental disorders [1]. The most common setting for behavioral dentistry work by psychologists is in academic health centers that include schools of medicine and dentistry. Over the past 50 years, the number of psychologists who work at medical and dental schools has increased dramatically. The number of psychologists employed by American medical schools grew from about 250 in the 1950s to 3,500 in the 1990s [2]. Similarly, the average number of psychologists employed by each medical school grew from 2 to 28 during this same time frame.

The primary focus of this chapter is on the application of behavioral dentistry by psychologists working in medical and dental settings. Because the most common dental conditions addressed by psychologists are temporomandibular disorders (TMDs) and dental anxiety, this chapter particularly focuses on these conditions and includes a review of their epidemiology and etiology. It also provides a review of evidence-based assessment and treatment approaches and incorporates practical suggestions for the translation of research evidence into clinical practice.

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## **Temporomandibular Disorders**

The TMDs are a group of medical and dental conditions affecting the temporomandibular joints (TMJs), the muscles of mastication, and contiguous tissue components [3, 4].

### ***Function of the TMJs and Causes of TMJ Pain***

The TMJ is the most complex joint in the human body [5]. The bilateral TMJs articulate the lower jaw or mandible with the glenoid fossa in the temporal bones of the cranium. A cartilaginous articular disc lies between the mandibular condyle and the glenoid fossa that cushions the joint and permits a wide range of movement in all directions. The disc divides the joint into an upper and a lower compartment, each containing synovial fluids that lubricate the joints. The term internal derangement refers to various abnormalities of disc position and function relative to other joint components. The articular disc has no nervous innervation and is insensitive to pain; however, the disc may become dislocated, allowing sensitive and thinner portions of the fibrous attachments of the disc to be compressed, and in severe cases, permitting bone-to-bone contact. Such disc displacements comprise one of the most common TMDs. A common symptom is a clicking or popping sound upon opening or closing the jaw. Jaw mobility also may be limited. Other causes of TMD include direct trauma as well as degenerative and inflammatory diseases, such as arthritis.

The masticatory muscles also can be a source of facial pain. The two main chewing muscles are the temporalis and the masseter, although smaller muscles also can be involved. Overuse of these muscles, as occurs with chronic jaw clenching, may lead to painful fatigue, inflammation, and joint compression and irritation. Pain originating in the muscles and their connective tissues is referred to as myofascial pain. Another term often used to describe this subgroup of TMDs is temporomandibular joint dysfunction syndrome. The majority of patients referred for behavioral treatment will have myofascial TMD; however, behavioral techniques for managing chronic pain may be useful with other types of TMD as well. This is particularly beneficial considering that individuals can suffer from more than one form of the disorder concurrently.

### ***Diagnosis of TMD***

The diagnosis of TMD is based on both signs and symptoms. Symptoms are abnormalities described by the patient to the dentist, whereas signs are clinical changes observed by the examining dentist. Both are important. Symptoms of TMD include, but are not limited to, pain in the face, head, neck, or ear; limitation of jaw motion; clicking or popping sounds from the TMJ; and locking of the TMJ. The diagnostic

workup includes a social, medical, and dental history, a physical examination, and possibly imaging techniques. Computed tomography (CT) scans are helpful for looking at the maxillofacial skeleton, while a magnetic resonance imaging (MRI) scan can be particularly useful in looking at soft tissues in and around the temporomandibular joint [6]. Typically, the dentist will perform the clinical examination by manually palpating the muscles and joints, listening for joint sounds, and measuring the mandibular range of motions [7]. Pain originating from the teeth, ears, sinuses, and facial neuralgias can mimic TMD pain, so a good differential diagnosis is important before initiating behavioral therapy. Furthermore, it is important to make sure that facial pain is not just a manifestation of other pain disorders such as fibromyalgia syndrome or trigeminal neuralgia.

### ***Epidemiology of TMD***

Mild TMD is a common problem, affecting up to 33% of individuals within their lifetime [4]. As with other common headache disorders, many sufferers simply ignore the problem or use home remedies, rest, or over-the-counter analgesics. Mild TMD also tends to follow a cyclical course, so symptomatic treatment and watchful waiting up to 6 months can be an appropriate response. Progression of mild symptoms to severe pain and dysfunction is rare [8]. However, in a minority of cases the pain becomes chronic and/or severe. The lack of standardized, objective diagnostic criteria and our ignorance of where to draw the line on severity have hampered studies on TMD epidemiology. The US National Health Interview Survey estimates the overall self-reported prevalence of TMD pain at 4.6%, and at 6.3% for women compared to 2.8% for men [9]. Another cross-sectional study physically examined a large random sample of women and applied the Research Diagnostic Criteria for TMD (RDC/TMD) [10]. The overall prevalence of myofascial TMD was 10.5% (95% CI=8.5–13.0%). The prevalence also was somewhat elevated for younger women, those with lower socio-economic status, and for Black and non-Hispanic women. The annual incidence of TMD among adolescents is about 2.9%, as assessed by a questionnaire (4.5% for girls and 1.3% for boys [11] and about 4% among dental students assessed by RDC/TMD criteria) [12]. The finding of higher prevalence in women compared to men is common, and the reason for this is unknown. The hypothesis that female sex hormones may be responsible is controversial [13–15]. The possibility that men and women report pain conditions differently and may have different thresholds for seeking care also should be considered.

### ***Etiology of TMD***

The etiology of TMD is not well understood, and it usually is idiopathic [16]. Factors that have been linked to etiology include trauma, oral parafunctional habits, nocturnal and diurnal bruxism, muscular tension, internal derangements, changes in

dental occlusion including orthodontic treatment, psychological stress, and systemic and developmental conditions. Unfortunately, most of the evidence supporting these conditions comes from weak, cross-sectional studies that link self-reported TMD to self-reported risk factors. Such studies carry a high potential for bias. Recent systematic reviews find that few conclusions can be drawn [16–18]. A few of the risk factors for TMD deserve individual notice.

Once the predominant theory of TMD etiology, the idea that occlusal interferences are TMD's primary cause has fallen into disfavor. This theory contends that occlusal interferences cause muscular imbalances and proprioceptive feedback that can trigger spasm and pain. However, research evidence does not support a relationship between any particular type of malocclusion and TMD [19]. Even gross alterations of the occlusion—such as surgically repositioning the jaws and orthodontic therapy—neither cause nor cure TMD [20–22].

More attention has been given to bruxism than any other oral parafunction. For many years, nocturnal bruxism was hypothesized to be a significant causal factor related to TMD [23]. Studies of patients with TMD have indicated that nocturnal bruxism occurs in 70–80% of TMD patients [18]. However, subsequent research has indicated that the relationship of nocturnal bruxism with TMD is less clear, whereas stronger associations have been found between daytime bruxism and oral parafunctional habits and the symptoms of TMD [24, 25]. Studies that rely on a self-report diagnosis of nocturnal bruxism often show a significant correlation to TMD. However, these studies have high risk of bias; in fact, many TMD patients are told by a dentist that bruxism is responsible for their pain. As more objective means of diagnosing bruxism are required, particularly through the use of polysomnography, electromyography, and tooth wear patterns, the evidence grows inconclusive [24]. One noteworthy longitudinal study [26] found that self-reported bruxism and other parafunctions recorded at ages 7–15 years predict TMD at age 30 years.

Oral parafunctional habits are oral motor behaviors that are not related to typical oral functions such as eating and speaking. Common oral parafunctions include daytime tooth contact or clenching; lip and cheek biting; nail biting; tooth grinding; thumb sucking; tongue thrusting; gum chewing; resting the chin on the palm; and sleeping on one side. Parafunctional tooth contact during waking hours is one parafunctional habit with strong associations with TMD. Two studies paged individuals using ecological momentary assessment to assess the presence or absence of tooth contact during daytime hours [27, 28]. The results indicated that individuals with TMD reported significantly higher levels of tooth contact, intensity of contact, tension in the jaw, face, and head, emotional distress, stress, and pain compared to matched groups of individuals without TMD. The simplest model linking parafunctional habits to TMD contends that these habits lead to muscle overuse and fatigue. A psychophysiological model links parafunctional habits to psychological stress [29]. More complex models invoke a self-perpetuating vicious cycle variously involving occlusal disharmonies, parafunction-related occlusal changes, muscle contraction, increased pain sensitivity, and degenerative joint changes [18, 30]

Recently, stronger evidence has emerged from prospective studies that followed subjects having a putative risk factor for TMD and measured the progression or

incidence of new TMD cases over time. One such study found a modest association between the presence of oral parafunctions and the progression of TMD pain or jaw dysfunction symptoms within 1 year following conservative treatment [31]. Another study found no association between self-reported teeth grinding and the 2-year incidence of chronic orofacial pain [32].

Psychological stress is another factor that should be mentioned in the context of TMD etiology. Stress and other psychosocial factors, probably not true etiological (i.e., causative) factors, may play a predisposing, initiating, or aggravating role. Stohler noted that in cases where there is the inability to resolve muscular TMD by adjusting the dental occlusion, "...psychological reasons are typically used to explain the failure" [33, p. 77]. A significant proportion of TMD patients report that their symptoms worsen during periods of psychological stress [34]. The reason for this is often assumed to be that psychological stress is accompanied by masticatory muscle hyperactivity, which in turn causes muscle fatigue, increased pain sensitivity, raised intra-articular pressure, abnormal joint biomechanics, and microtrauma to the joint capsule [35]. Psychological stress also has been claimed to increase daytime and sleep bruxism and other oral parafunctions, but the evidence for this is inconclusive [36, 37]. Several investigators have used electromyography to identify muscle hyperactivity in patients with TMD or other muscular pain conditions, yielding inconclusive results [38]. Electromyography cannot distinguish the TMD patient from a healthy person, and therefore muscle hyperactivity cannot unequivocally explain the link between reported psychological stress and pain. Psychologically based therapies, including stress management, relaxation, and biofeedback, may be effective in relieving some types of TMD pain; however, therapeutic usefulness does not strongly support psychological stress or muscle hyperactivity as diagnostic or etiological constructs.

### ***Assessment of TMD***

The primary complaint of patients with TMD is facial pain [6]. Oftentimes, patients with TMDs will also present with limitations in TMJ movement and sounds associated with TMJ movement (such as popping, clicking, or grinding sounds) [6]. Since dental practitioners are often the first to see patients for TMD, they typically provide basic screening for both physical and psychosocial components of the disorder. It is recommended that all patients who indicate the presence of psychosocial factors influencing mandibular functioning and pain be referred to a psychologist for further psychosocial evaluation. Dental and psychological professionals must take a collaborative approach to treating patients with psychosocial problems associated with TMD in order to provide a comprehensive evaluation and treatment plan and to improve chances of a positive treatment outcome.

There is no widely accepted diagnostic test, nor are there any accepted objective clinical criteria for TMD. However, the RDC/TMD provide a helpful starting point for the evaluation of a patient with TMD [39]. Though the RDC/TMD were

developed primarily to standardize the diagnosis and classification of TMDs for clinical research purposes, and they are currently undergoing revisions [40], accumulated research on the RDC/TMD suggests its usefulness in a clinical setting [41]. The RDC/TMD includes both a physical component (Axis I) and a psychosocial component (Axis II), as to provide a full, biopsychosocial conceptualization of the disorder. Axis I provides a standardized framework for gathering a clinical history and conducting the clinical examination, using techniques such as palpitation and observation of mandibular motion (RDC from University of Washington).

Axis II was created to serve as a screener for biopsychosocial factors impacting and developing from TMD-related pain [42]. Axis II includes the Graded Chronic Pain Scale (GCPS), which provides an overall rating of pain-related disability [42]. Characteristic pain intensity measure (the average scores for current pain, worst pain during the last 6 months, and average pain during the last 6 months) is derived from responses of the GCPS [42]. The Axis II questionnaire also includes a screening for depression and nonspecific physical symptoms from the Symptom Checklist-90, as well as a measurement of limitations in jaw functioning [42]. The next version of the RDC/TMD may include assessments for other related psychological problems, such as anxiety and sleep disorders [41].

Patients who are experiencing TMD-related psychosocial problems will require more thorough evaluation from a psychologist or other mental health professional. Turner and Dworkin [43] recommend some additional screening measures that can be used by dentists to determine when TMD patients may experience psychosocial complications and would benefit from referral to a psychologist. The psychologist should carefully evaluate the patient for any behavioral, cognitive, emotional, and social factors associated with the onset of TMD, maintenance of TMD, or caused by TMD [44]. Several measures are commonly used to assess these components of TMD.

The West Haven-Yale Multidimensional Pain Inventory [45] (MPI) is commonly used in patients with various types of chronic pain and can be used to assess facial pain in patients with TMD. The assessment is designed to resonate with a cognitive-behavioral conceptualization of chronic pain. It therefore assesses several dimensions of the subjective experience of pain, including the cognitive, emotional, and behavioral dimensions of pain and pain-related dysfunction [45, 46]. The MPI includes 52 self-report items divided into three sections. Part I examines several dimensions of the pain experience, including pain interference, support from significant others, severity of pain, self control, and negative mood [45]. Part II assesses for the type of response received from the significant other regarding expression of pain (i.e., punishing, solicitous, or distracting responses), and Part III examines functionality by determining level of engagement in various activities (i.e., household chores, outdoor work, activities away from home, and social activities [45]). The internal consistency of the subscales range from satisfactory to excellent ( $\alpha=0.70-0.90$ ), and test-retest reliability analysis indicated that the scales were fairly stable over time [45]. Analyses also suggested good discriminate validity of each subscale and good convergent validity with other related measures [45]. Andreau and colleagues [46] demonstrated that the MPI has good psychometric

properties when used with TMD patients, though they recommended some modifications of the scale, including elimination of certain items, for this population.

The Oral Behaviors Checklist [47] (OBC) is a self-report measure that assesses the frequency of oral parafunctional behaviors, such as clenching, pressing the tongue against the teeth, and holding the teeth together [47, 48]. This measure may be particularly useful for assessing progress in behavioral treatments such as habit reversal [49] that are targeting change in parafunctional oral behaviors. The measure might also be more generally useful for determining the extent to which parafunctional oral behaviors may be related to the patient's profile of TMD symptoms. When individuals with and without TMD were asked to perform the behaviors listed on the checklist, electromyographic (EMG) measures indicated that all participants performed the same behavior, confirming the criterion validity of the OBC [50]. Previous research has also demonstrated that the OBC has good test-retest reliability [47].

The Jaw Functional Limitation Scale (JFLS) was designed to measure functioning related specifically to the masticatory system [51]. The 20-item JFLS yields a global functioning score, as well as three subscale scores pertaining to mastication, vertical jaw mobility, and emotional and verbal expression [51]. Patients rate the degree to which they were limited in performing various activities (e.g., "chew tough food," "open wide enough to bite into a sandwich," and "sing") during the past month due to pain or difficulty [51]. A shortened, eight-item version of the JFLS that yields a global masticatory functioning score has also been developed, and it has demonstrated good validity and reliability in TMD patients [48, 51].

The Coping Strategies Questionnaire (CSQ), which is the most widely used assessment of pain coping strategies, measures both cognitive and behavioral methods of coping [52, 53]. The cognitive strategies measured by the subscales of the CSQ include diverting attention, reinterpreting pain sensations, coping self-statements, ignoring pain sensations, praying or hoping, and catastrophizing [53]. Behavioral strategies include increasing activity level and increasing pain behavior (i.e., behaviors aimed at reducing pain) [53]. Finally, two items measure perceived ability to control and decrease pain level [53]. Each of these rationally derived subscales has good internal consistency, with the exception of the increasing pain behavior subscale [53]. However, studies seem to have conflicting findings regarding empirically derived factors of the CSQ [52–54]. The CSQ seems to be predictive of adjustment to chronic pain even after controlling for other important factors, such as tendency to somatize, disability status, number of surgeries, and duration of continuous pain [53]. Research with TMD patients specifically has demonstrated scores on the CSQ are associated with a patient's level of pain-related interference [55]. Scores on the Catastrophizing subscale specifically are also associated with one's level of pain-related interference, nonmasticatory limitations in jaw functioning, and depression [55]. Furthermore, scores on the Catastrophizing subscale improve during TMD treatment for patients evidencing high levels of psychological distress [56].

The Survey of Pain Attitudes (SOPA) was originally developed by Jensen and colleagues [57] to assess the attitudes of chronic pain patients toward their pain and

to survey their understanding of their pain in context of the medical and legal environments in which it is embedded. The SOPA is in a 57-item, self-report format in which a patient rates the extent to which each item is true for himself or herself [58]. The seven attitudes assessed by the scales within the SOPA include the beliefs that (1) one can control one's own pain (Control scale); (2) the patient's family should respond solicitously to a patient in pain (Solicitude scale); (3) medications are the best treatment for pain (Medication scale); (4) pain interferes with functioning and causes disability (Disability scale); (5) pain is related to emotions (Emotion scale); (6) a medical cure exists for pain (Medical Cure scale); and (7) exercise and activity should be restricted because pain signifies harm (Harm scale) [58]. Studies with chronic pain patients suggest that the SOPA is related to both physical and psychosocial functioning [58, 59]. A study examining the roles of control, disability, and harm-related beliefs in cognitive behavioral therapy for TMD found that all three of these SOPA scales mediated treatment outcome [60]. Each of the subscales of the SOPA has somewhat low test-retest reliability (0.63–0.68) but acceptable internal consistency ( $\alpha=0.71-0.81$ ) [58]. Though the 57-item SOPA is the most reliable version of the scale [61], research also supports the validity of abbreviated 30- and 35-item versions of the SOPA [61, 62].

Additional psychological factors related to chronic pain conditions, such as sleep quality, stress level, depression, and anxiety, may also be important to include in a comprehensive assessment of patients with TMD. Potential easy-to-use, self-report assessments for these domains include the Pittsburgh Sleep Quality Index [63], the Perceived Stress Scale [42, 64], the Beck Depression Inventory-II [65, 66], the Center for Epidemiologic Studies-Depression Scale [66, 67], the Patient Health Questionnaire-9 for depression [42, 68], the Beck Anxiety Inventory [69], and the State-Trait Anxiety Inventory [70].

## ***Treatment of TMD***

Numerous treatment approaches, stemming from both psychological and biological methodologies, have been evaluated in the research literature with varying degrees of success. The specific profile of TMD symptoms expressed seems to have a bearing on treatment response. For example, TMD patients who have major concomitant psychological symptoms due to TMD-related pain benefit most from a multidisciplinary approach that addresses these symptoms with techniques such as cognitive behavioral therapy [71]. However, patients without these symptoms receive comparable benefit from a more simple treatment approach [71].

Though many TMD treatments have a 75–95% success rate, no single treatment has emerged as clearly superior to another [72]. This suggests both the complexity of the wide-ranging etiological possibilities of TMD in any given patient and the vast limitations in our current knowledge about TMD. Despite absence of definitive knowledge, treatment providers must continue to try to help their patients, though they must take a conservative approach. The general consensus is that because TMD



is associated with such a wide variety of physical and psychological etiologies, it is most effectively managed with a multidisciplinary approach using a team with a variety of specialists, such as dentists and psychologists or psychiatrists [3, 44]. Though mental health specialists will most likely provide only the psychological assessment and intervention for TMD patients, maintaining a working knowledge of the multidisciplinary approaches to the assessment and treatment for TMD is essential for safely and effectively treating such a complex disorder [44].

**Minimal Treatment.** Many simple steps are often recommended in the initial treatment approach for TMD patients. For example, a universal recommendation is that patients are educated about TMD so that they can receive reassurance that the condition has been well studied by health care professionals [6, 73]. Patients should also receive basic instruction on the relationship of parafunctional activities (e.g., grinding and clenching) and stress in increasing TMD-related pain [6]. Allowing the jaw to rest by avoiding certain activities (e.g., eating chewy or crunchy foods, singing, yawning widely, and clenching the jaw) and working on stress management can be helpful strategies for pain reduction [73]. Sometimes, applying heat or ice packs to the TMJ area and practicing massaging and stretching exercises also helps to relieve muscle tension [6, 73, 74]. Patients are typically given an education in these simple techniques for managing TMD-related pain when they are first diagnosed; however, patients with chronic TMD usually receive additional treatments such as those described below.

**Dental Occlusal Splints.** Dental occlusal splints are often considered by dentists to be the first-line treatment for TMD. In a survey of 10,000 American Dental Association members, 68% responded that they used splints to treat myofascial pain dysfunction [75]. Dental occlusal splints, sometimes called stabilization appliances or orthopedic interocclusal appliances, are removable, hard acrylic resin or resilient plastic devices fabricated to fit snugly over the maxillary or mandibular teeth and against which the teeth in the opposing arch fit evenly. Splints are hypothesized to help TMD patients to reduce clenching and bruxing behavior, and some types of splints are designed to readjust occlusion or jaw positioning. Although occlusal splints can prevent tooth damage during episodes of daytime and nighttime bruxing, there is limited evidence that splints actually reduce the clenching or grinding that are thought to be the primary cause of myofascial pain.

Research overall suggests that splints modestly improve TMD-related pain in comparison with placebo treatments and that splints are generally not superior to other therapeutic approaches [76, 77]. A scientifically rigorous review of the research surrounding splints reveals that the quality of the research is weak, due in part to inconsistencies in the diagnosis and classification of TMD patients, and only equivocal evidence suggests that improvement in pain with splint treatment stems from the proposed mechanism of splint therapy [77]. Preliminary research findings suggest that behavioral therapy may be more effective in the long term for patients with concomitant psychosocial problems [76]. In order for splints to work effectively, the appropriate type of splint must be selected, and it must be adjusted correctly [76]. Using splints incorrectly or excessively can lead to several complications,

such as gingival inflammation, speech problems, mouth odor, and permanent, possibly damaging occlusal alterations [76]. Generally speaking, the widespread acceptance and use of splint therapy as the primary treatment for TMD has outpaced its research support.

**Occlusal Adjustment.** The most common strategy for occlusal adjustment is grinding down the surfaces of teeth to create a more harmonious occlusion; however, it can also be achieved with the use of appliances such as readjustment splints and dentures. The treatment of TMD with occlusal adjustment stems from the original hypothesis that TMD is primarily caused by occlusal maladjustment, and that readjustment of occlusion will relieve jaw pain and dysfunction [78]. In contrast to this theory, experimentally introduced occlusal interferences seem to be more strongly linked with tooth pain and mobility problems, as opposed to chronic jaw dysfunction [79]. A thorough review of research on occlusal adjustment for TMD reveals that there is not sufficient evidence to suggest that occlusal adjustment outperforms placebo (such as mock adjustment) or noninvasive therapies in the treatment of TMD [3, 79, 80].

**Surgery.** The primary types of surgery used to treat TMD are arthrocentesis and lavage, arthroscopy, and open joint surgery (also called arthrotomy) [73]. Arthrocentesis and lavage involve injecting a needle into the space between the disc and the fossae, then eliminating possible vacuums in the synovial fluid between these two structures by adding and draining fluid. Arthrocentesis and lavage are particularly helpful in cases of a persistent lock of the TMJ [81]. Arthroscopy is also minimally invasive, only requiring small incisions into which a camera and operating instruments can be inserted. Open joint surgery, on the other hand, requires a larger incision so that the surgeon can operate on the joint while directly observing it [74]. Generally speaking, surgical interventions for TMD should be approached with caution since studies of the efficacy of surgical treatments for TMD have produced mixed results [22, 82]. Surgical interventions should furthermore only be used when internal derangement of the condyle resulting in open or closed locking can be established as the primary cause for the TMD, and when other less-invasive interventions have failed. However, it is important to note that accurate diagnosis, rather than failure of nonsurgical interventions, should be the primary prerequisite of surgical intervention, because nearly 20% of TMD patients receiving nonsurgical interventions have been misdiagnosed or incompletely diagnosed [83].

**Pharmacotherapy.** Pharmacotherapeutic agents are commonly used in the treatment of pain associated with TMD [84]. Analgesics are used for simple pain relief, and nonsteroidal anti-inflammatory agents and corticosteroids are used to reduce inflammation [85]. Occasionally, benzodiazepines are used to relieve stress and muscle tension when TMD is thought to be related to emotional stress [73]. Low doses of tricyclic antidepressants are also sometimes used because they are thought to reduce muscle tension in bruxers [73]. Though pharmacotherapy for TMD is typically only associated with mild side effects [85], practitioners must be wary of the potential for patients to overuse or become addicted to particular medications

such as opiates [73]. Research has not revealed a drug that is effective for all cases of TMD [73]. A thorough review of previous randomized controlled trials testing the effectiveness of pharmacological interventions does not provide clear support for their effectiveness in treating TMD-related pain [85]. However, studies of sufficient methodological strength and statistical power are lacking [85].

**Massed Practice.** Massed practice is a behavioral treatment in which the patient deliberately performs a teeth-clenching exercise for a specified period of time (e.g., 30 min) interspersed with brief periods of rest (e.g., 4 min exercise, 1 min rest). The goal of massed practice is to consciously perform a behavior that is usually automatic to increase awareness of the behavior and eventually reduce its occurrence [86]. Research on massed practice has yielded mixed results, with some studies finding that it reduced self-destructive oral habits [87, 88], while other studies have found that massed practice is either ineffective in reducing bruxism [89] or that it slightly increases the frequency and duration of nocturnal bruxism episodes [90]. Massed practice, furthermore, is associated with risks such as increased severity of TMD symptoms and broken teeth [86]. Due to both its lack of support and associated risks, massed practice is not recommended for treatment of TMD.

**Habit Reversal Treatment.** Habit reversal is the only behavioral treatment to specifically target the detection and reduction of parafunctional oral habits that are thought to be a primary cause of TMD. It is a comprehensive behavior modification or behavior therapy treatment that has been demonstrated to be effective for the treatment of a variety of tic and habit disorders [91, 92]. The primary components of habit reversal treatment include awareness training, self-monitoring, competing responses training, relaxation training, and contingency management [93]. Habit reversal treatment begins by teaching awareness and self-monitoring of when and under what circumstances the undesired habit occurs. After the patient becomes aware of the habit and its triggers, he or she learns to replace the habit with a competing response [92]. A competing response is a behavior that is opposite to or incompatible with the undesirable habit, capable of being maintained for 1–3 min at a time, and socially inconspicuous. The competing response is practiced during and outside the session whenever the habit has occurred or seems likely to occur. The habit reversal competing response for TMD involves separating the teeth slightly, about the width of the tip of the tongue; relaxation of the jaw and other facial muscles; and relaxed breathing. For example, a patient may be instructed to perform a competing response for about 1 min whenever he or she engages in a parafunctional habit, such as teeth clenching, and even when the teeth touch together lightly [49]. Habit reversal treatment for TMD can be conducted in as few as two-to-three 30-min treatment sessions.

Research support for habit reversal for parafunctional behaviors is limited, primarily due to sample sizes that have been between 3 and 20 participants. However, the available studies provide strong preliminary evidence that habit reversal reduces myofascial pain, pain-related interference, and maladaptive parafunctional habits linked to TMD [49, 94–97]. Results of one study [97] suggest that habit reversal is a more cost-effective method of achieving pain reduction that is comparable to splint

therapy. However, additional research is necessary before definitive conclusions can be drawn about the effectiveness of habit reversal for TMD in comparison with both control group and other front-line treatments for TMD.

**Biofeedback.** EMG biofeedback is a behavioral treatment that targets the reduction of head and facial muscle tension to reduce the pain associated with TMD [98, 99]. Surface electrodes attached over patients' masseter, temporalis, and/or frontalis muscular sites record muscle activity, which is then reported back to patients in the form of auditory or visual feedback [99]. Patients are instructed to use this biofeedback to learn to relax their muscles. Support for the use of biofeedback and other relaxation strategies comes from research findings that lifestyle stress leads to muscular hyperactivity or parafunctional habits like clenching and bruxing, which then leads to muscular pain [100–102]. These lifestyle stresses can induce a variety of oral habits, including lip biting, cheek biting, clenching, grinding, and nail biting. When these behaviors are prolonged, they can lead to pain. One study experimentally manipulated clenching behavior in normal subjects and found that those who engaged in clenching behavior (20 min a day for 5 days) reported significantly higher levels of pain in comparison with subjects who decreased clenching behavior [103]. Two out of seven participants in the clenching group even met criteria for myofascial pain diagnosis by the end of the study [103].

A review of randomized controlled trials suggests that treating TMD pain with biofeedback training can result in long-term improvements in domains such as pain severity, pain-related dysfunction, affective distress, stress-related muscle reactivity, use of adaptive coping strategies, and mandibular functioning [104–107]. Research suggests that biofeedback is superior to conservative medical interventions for TMD such as occlusal splints [107, 108]. Though biofeedback seems to be superior to cognitive behavioral therapy alone [107], the combination of biofeedback and cognitive behavioral therapy seems to result in the most comprehensive, long-term improvement [104, 109]. There are a number of hypotheses for how biofeedback works. Biofeedback may work by reducing overall muscular tension as measured by EMG activity, it may teach patients better coping strategies or help them to believe that they have some control over their TMD symptoms, or it may work by increasing self-awareness of muscle tension [110].

**Nocturnal Biofeedback.** The approach to biofeedback training described above is helpful for patients who experience problems while they are awake [99]. However, stress-induced muscular hyperactivity such as nocturnal bruxing can also occur at night. Nocturnal bruxing is defined as nonfunctional clenching, grinding, or gnashing of the teeth during sleep [111]. Bruxing alarms operate on the premise that sleep bruxism may be controllable by using a biofeedback device that detects episodes of sleep bruxism and awakens or disturbs the patient enough to interrupt bruxing behavior. Though nocturnal alarm biofeedback devices can reduce the duration of nocturnal bruxing episodes, it does not reduce the frequency of the episodes of nocturnal bruxing. Studies suggest that once nocturnal biofeedback is withdrawn, bruxing returns to pretreatment levels [90]. Furthermore, the deleterious consequences of sleep disruption, such as daytime sleepiness and increased sensitivity to pain,

are a major drawback to this treatment approach [112, 113]. Nocturnal biofeedback therefore is not a well-supported or widely used treatment for TMD [112].

**Cognitive Behavioral Therapy.** Cognitive behavioral therapy (CBT) for TMD trains patients in skills adapted from cognitive behavioral treatments for chronic pain and/or depression [104, 114]. CBT for TMD-related pain may include relaxation training such as progressive muscle relaxation and diaphragmatic breathing; stress management skills like problem solving; and techniques to reduce the impact of pain on functioning, such as distraction and pleasant activity scheduling [104, 106, 107, 114]. Evidence suggests that TMD-related cognitions, and especially beliefs about whether or not pain is debilitating, are strongly associated with both physical and psychological functioning in TMD patients [55]. Therefore, cognitive restructuring, which involves identifying, challenging, and replacing maladaptive cognitions, may be a particularly important component of CBT for TMD-related pain [106].

Research suggests that CBT for TMD-related pain improves pain, jaw functioning, and depression in comparison with a control group [114], and it can be delivered successfully in a cost-effective, group format [115]. However, other research has demonstrated that biofeedback produces better results than CBT in domains such as pain, interference, and distress [107]. Combined CBT and biofeedback treatment (CBT-BF) has been demonstrated to be superior to either treatment alone [104, 106]. The combination of a dental occlusal splint, CBT, and BF may result in even better outcomes, suggesting a trend of “more is better” in treatments for TMD [109]. However, a primary limitation of this combined treatment is that it requires collaboration with a dentist to fabricate the occlusal splint, more highly trained CBT therapists, and 10–20 treatment sessions. In addition to being significantly more costly, replication of these findings is necessary before these treatment combinations could be provided as a definitive treatment recommendation and whether they result in better long-term outcome than a simple and brief treatment such as habit reversal.

## Dental Anxiety

### *Definition and Diagnosis*

Although dental anxiety is a common condition seen by dentists, a formal definition is lacking, and there are no established diagnostic criteria. Terms used more or less interchangeably in the literature include dental anxiety, dental phobia, dental fear, and odontophobia. Some patients meet DSM-IV diagnostic criteria for specific phobia, but most do not. A few authors have attempted to distinguish between anxiety and fear [116, 117], but this distinction is rarely applied and has not yet been proven useful. In the research setting, eligibility for participation often depends on exceeding a certain criterion score on a self-report dental anxiety scale, but the

sheer number of these scales is indicative of the ongoing problem of settling on a definition. Furthermore, most dental anxiety scales lack a good theoretical foundation, so there is the danger of using the same scale to both define and measure the phenomenon [116]. Throughout this chapter, we make no distinctions among the various names used to describe the disorder. We distinguish among assessment methods only when necessary to make a specific point.

### ***Epidemiology of Dental Anxiety***

The prevalence of dental anxiety among adults is variable, depending on the population, definition, and research methods used. However, an average point prevalence of about 5% has been given for strong dental anxiety and about 20–30% for moderate dental anxiety. This rate is relatively constant across many countries of the world and appears not to have changed by much over the past few decades despite advances made in dental care [118, 119].

Dental anxiety is associated with poorer oral health, as patients with dental anxiety have more decayed teeth, missing teeth, and calculus than those without dental anxiety [118, 120]. Moreover, individuals with dental anxiety are likely to delay or avoid dental treatment, and they may not maintain adequate preventive care. Consequently, more extensive, invasive dental treatments may be required, thereby exacerbating dental anxiety [121]. In addition to its ramifications for oral health, dental anxiety has negative implications for quality of life and other aspects of psychological functioning. Patients suffering from dental anxiety report lower oral health-related quality of life relative to both the general population and TMD patients [122]. They also experience low self-esteem and morale [123], as well as diminished psychological well-being, vitality, and social functioning [124].

### ***Etiology of Dental Anxiety***

Dental anxiety often is assumed to be closely linked to the expectation of pain or injury; however, it is more complex than that. Patients also express aversions related to choking, fainting, gagging, vomiting, suffocating, contamination, loss of control, distrust of the dentist, and the cost of dental treatment [125]. All these situations can involve anxiety and other emotions to various degrees. Traumatic dental experiences, as well as dental-related cognitions and perceptions, may provide insight as to whether individuals experience dental anxiety, and to what degree this anxiety manifests. Cognitive perceptions of uncontrollability, unpredictability, dangerousness, and disgustingness are significantly associated with dental anxiety and fear as measured by the Index of Dental Anxiety and Fear (IDAF-4C) scores, accounting for 46.3% of the variance in dental anxiety and fear beyond demographic variables and negative experiences [125].

Negative dental experiences, including pain, gagging, fainting, or experiencing a personal problem with a dentist, are also significantly associated with dental anxiety and fear. However, these negative experiences appear to be less predictive of dental anxiety than dental-related cognitive perceptions, accounting for only 0.9% of the variance in dental anxiety and fear beyond that accounted for by age, gender, and cognitive perceptions [125]. In light of this, communication and interaction patterns on the part of the dentist appear to be important aspects of aiding patients in regulating dental anxiety [126]. Positive examples include giving the patient a sense of control, as well as efforts to keep patients apprised of what sensations they may experience and what the dentist is currently doing.

In considering dental anxiety, it should be noted that many patients experience some level of anxiety or unpleasant associations involving dental care. While certain patients experience low levels of anxiety that do not interfere with dental treatment, or are able to effectively regulate their anxiety, others may not be able to sufficiently modulate their anxiety so as to be able to participate in dental treatment. Attachment style may be related to this, as patients with secure attachment patterns were found to be more effectively able to modulate their dental anxiety than patients with insecure attachment patterns [127]. Patients with generalized anxiety disorder, posttraumatic stress disorder, obsessive compulsive disorder, or panic disorder might experience difficulties at the dentist's office, but not necessarily more so than in other situations that involve similar close social contact, submission to authority figures, loss of control, or risk of social embarrassment.

It is also too commonly assumed that when people avoid dental care, the reason is dental anxiety. A general classification system applied to a large population-based survey identified 49.6% of dentally anxious individuals as suffering from simple phobia, 7.8% as fearing catastrophe, 19.4% as having generalized anxiety, and 9.9% as having distrust of the dentist, with the remaining 13.3% falling outside these categories [128]. In a survey of specific anxiety-eliciting stimuli, dental anxiety patients identified pain- and injury-related items at a high rate, but they also identified such things as being pushed about, having things at the back of their mouth, uncertainty, lack of control, and being enclosed in the dental chair [129]. Whatever definition is used, dental anxiety constitutes a serious problem for the dentist and is a barrier to patient care. Therefore, recognizing and helping patients overcome dental anxiety is an important aspect of dental patient management. Psychologists and other behavioral health specialists have important consultation and clinical roles to play in the assessment, treatment, and management of dental anxiety.

### ***Assessment of Dental Anxiety***

The most commonly used measure for assessing dental anxiety is the Dental Anxiety Scale (DAS) [130, 131]. This measure has been revised to include the addition of an item about anxiety over a local anesthetic injection, and options for all

responses have been standardized, resulting in the Modified Dental Anxiety Scale (MDAS) [132]. These measures have adequate reliability, validity, sensitivity, and specificity [121], but they have low value for predicting attendance at regular dental appointments [133].

The Index of Dental Anxiety and Fear (IDAF-4C+) measures dental phobia and feared dental stimuli, as well as cognitive, emotional, behavioral, and physiological components of dental anxiety and fear included within the IDAF-4C module. This scale demonstrated good test-retest reliability at a 4-month interval ( $r=0.82$ ), as well as good internal consistency (Cronbach's  $\alpha=0.94$ ). In addition, the IDAF-4C exhibited strong convergent validity, as it correlated positively with the DAS [130, 131]. The scale predicts future dental visiting patterns, dental avoidance, diagnosis of dental phobia, and perception of dental visits. Thus, the IDAF-4C+ may be a reliable and valid means of assessing dental anxiety and fear [125].

In addition to the aforementioned measures, instruments have been developed for assessing dental anxiety in pediatric populations. The Children's Fear Survey Schedule Dental Subscale (CFSS-DS) [134] was designed for use with children up to 14 years of age and includes a patient self-report version as well as a parental version. Fifteen five-point Likert items are included in the measure. This measure is widely used and preferred by many compared to other measures due to availability of normative data, psychometric properties, more precise measurement of dental fear, and more thorough coverage of aspects of dental anxiety [134]. However, Klingberg and Broberg [134] point out weaknesses of this measure, including unsatisfactory validation of cutoffs and lack of investigated level of congruence between child and parental versions.

The Modified Child Dental Anxiety Scale (MCDAS) [135] consists of eight items covering dental-related experiences and procedures, including having a filling and being sedated for a treatment. Patients indicate how they would feel about each experience or procedure on a five-point scale, with 1 corresponding to "relaxed/not worried" and 5 signifying "very worried."

The Smiley Faces Program-Revised is a five-item, computer-based tool for assessing dental anxiety in children. Patients are asked to rate how they would feel in the following situations: they had to have dental treatment the following day; they were sitting in the dentist's waiting room; they were about to have a tooth drilled; they were about to have an injection in the gum to make it go numb; the dentist is about to take a tooth out. Patients are given seven options of faces, with the middle face neutral, and the faces getting progressively sad and happy on the extremes. They are instructed to click on the face that signifies their emotion for that item. Messages within the computer program supply instructions if needed, and in Buchanan's study [136] evaluating the measure, a research assistant read items and provided necessary instructions for younger children. All children were able to complete the measure. The SFP-R exhibited good test-retest reliability over a 2-week interval ( $r=0.8$ ) and acceptable internal consistency (Cronbach's  $\alpha=0.7$ ). Additionally, the SFP-R demonstrated good convergent validity with the MCDAS ( $r=0.6$ ) [136].



While instruments are available for assessing dental anxiety, it should be noted that many of the existing measures have psychometric limitations and lack theoretical basis. Moreover, existing measures may not adequately account for the multidimensional nature of dental anxiety and fear, which is comprised of cognitive, emotional, behavioral, social, and physiological components [125]. Additionally, existing measures tend to be comprised of item content that is restricted to dental stimuli and procedures; moreover, they do not adequately address guilt, embarrassment, helplessness, financial concerns, fear of loss of control, and feelings of inadequacy involved in dental anxiety [121].

### ***Treatment of Dental Anxiety***

**Behavioral Interventions.** Exposure therapy aims to reduce dental anxiety through processes called “extinction” or “habituation.” In exposure therapy, a neutral stimulus that has come to be associated with an anxiety-inducing stimulus by classical conditioning is presented without the stimulus that induces fear, thereby weakening the associations between the stimuli. Exposure therapy also combats avoidance of fear-inducing stimuli. In the case of dental anxiety, patients may avoid dental appointments or tools used in dentistry. While this avoidance reduces anxiety in the short term, avoidant patients are unable to break the associations between the neutral and anxiety-inducing stimuli, which contribute to the persistence of the anxiety.

Exposure therapy may involve *imaginal* or *in vivo* exposure. In *imaginal* exposure, patients are asked to imagine themselves in scenarios that induce anxiety, such as sitting in the waiting room prior to a dental appointment, undergoing a dental cleaning, or receiving a filling. *In vivo* exposure involves real-life exposure to anxiety-inducing stimuli based upon a hierarchy of such stimuli developed by the patient and dentist or psychologist [137, 138]. Examples of stimuli and events that could be included in such a hierarchy include sitting in an exam chair, holding an injection needle, and listening to the sound of a dental drill. Exposure may be implemented gradually through a process known as systematic desensitization, which involves progressively exposing patients to increasingly anxiety-inducing stimuli. Conversely, patients may be initially exposed to a maximally anxiety-inducing stimulus for an extended period of time via a technique called flooding. Through the process of exposure, the learned associations between neutral and anxiety-inducing stimuli are weakened, thereby reducing the anxiety response to dental stimuli [121, 137, 138].

A meta-analysis conducted by Kvale et al. [139] suggests that behavioral interventions such as relaxation, biofeedback, behavioral therapy, systematic desensitization, participant modeling, and stress inoculation training are effective in reducing dental anxiety and in facilitating attendance at dental appointments. However, heterogeneity among the interventions utilized made it difficult to compare the relative effectiveness of the various modalities of behavioral interventions. A behavioral approach combining systematic desensitization, progressive muscle relaxation, and biofeedback training was found to be superior to general anesthesia in

reducing dental anxiety, as well as dental avoidance as measured by cancellation of appointments [140].

Music therapy has been studied as a possible treatment for dental fear and anxiety. A meta-analysis of studies related to music therapy and dental fear and anxiety found that music therapy significantly reduced both anxiety and pain related to dental procedures. When combined with other treatment modalities, such as relaxation exercises, the reduction in anxiety was greater than that resulting from treatment with music therapy alone. Further, there was no significant difference in pooled effect estimates between active music therapy, which involves interacting with a music therapist, and passive music therapy, in which the patient simply listens to background music. Thus, playing music for dental patients may be a relatively inexpensive, feasible, and effective intervention for reducing dental anxiety [141].

**Hypnosis and Relaxation.** Hypnosis may also reduce dental anxiety and pain for some patients. Hypnosis involves the induction of a trance state and may include guided imagery and suggestions for relaxation and reduced dental anxiety. Progressive muscle relaxation, in which patients tense and then relax various muscles and portions of their body, moving progressively down their bodies, is commonly utilized in conjunction with hypnosis. Both hypnotic relaxation and progressive muscle relaxation have been shown to significantly reduce physiological anxiety in the dental context [142]. There is some evidence that hypnosis may be superior to controls involving no treatment in managing disruptive behavior of children undergoing dental procedures with local anesthetics [143, 144]. Further, a review by the Cochrane Collaboration found hypnosis to be more promising than cognitive-behavioral therapy and distraction-based interventions in reducing distress associated with needle-related procedures [145].

Previous research has compared the effectiveness of music distraction and a brief relaxation intervention involving a series of movements of the neck, shoulders, back, and chest in reducing dental anxiety [146]. Both interventions reduced anxiety significantly with moderate effect sizes, with the patients in the brief relaxation intervention group experiencing a significantly greater reduction in anxiety than those in the music distraction group. Among those receiving the brief relaxation intervention, the greatest reduction in anxiety was found in the most highly anxious participants. Corah et al. [147] also found greater reduction in dental anxiety from relaxation than from distraction-oriented techniques. In comparison with cognitively oriented therapy, relaxation has been shown to more significantly reduce dental anxiety, although a higher percentage of patients completed the cognitively oriented therapy than the relaxation intervention [148].

Hypnosis may be underutilized in general clinical practice, due in part to misconceptions that some practitioners may have about this modality of treatment [149]. In addition, patients may be more likely to terminate prematurely from a hypnosis intervention than from other treatment modalities [150].

**Cognitive-Behavioral Therapy.** Cognitive-behavioral therapy (CBT) may also be effective in treating dental anxiety, as maladaptive cognitions and irrational beliefs likely contribute to and maintain dental anxiety and avoidance for many patients.

Patients reported reduced dental anxiety, as well as decreased avoidance of dental treatment, after undergoing a brief, one-session CBT intervention targeting dental anxiety [151]. Those who received a five-session CBT intervention showed reduction in dental anxiety and avoidance of dental treatment comparable to that exhibited by those who received the one-session CBT intervention, and both the one- and five-session CBT interventions were found to be superior to a wait-list control in reducing anxiety and avoidance [151].

## Sedation Dentistry and Pharmacotherapy

Sedation dentistry has gained significant popularity in recent years. Sedation, which includes intravenous sedation, inhalation sedation, as well as general and local anesthesia, may be utilized for managing anxiety and pain for dental patients [152]. However, a meta-analysis of studies on sedation for children with dental anxiety could not conclude whether a particular medication regimen was more effective than others in reducing dental anxiety [153]. Triazolam, a benzodiazepine, is widely used in sedation dentistry [154–157]. The short half-life of triazolam allows for fairly quick recovery and safe return to home or work, following dental procedures. Sublingual administration allows for rapid absorption and a level of systemic availability that is 27% greater than that achieved through oral administration. Other short half-life benzodiazepines, including midazolam and alprazolam, are also widely utilized for sedation dentistry [158, 159].

Sedation dentistry aims to reduce physiological anxiety in order to help patients with overall anxiety management so that they can proceed with dental procedures. This in turn helps counter patients' avoidance of dental procedures and associated detriments to health and quality of life. To sustain sedation for lengthier procedures, "upward titration" or administration of subsequent doses may be utilized [155].

While medications are effective in reducing dental anxiety for many patients, they may produce a less significant reduction in anxiety than can be achieved with behaviorally oriented interventions [150]. Further, short-term benefits from medications do not necessarily translate to long-term reduction in dental anxiety, as anxiety may increase after the medication is no longer being administered. One study compared a one-session cognitive-behavioral intervention including imaginal exposure and progressive muscle relaxation to treatment with midazolam and a no-treatment control group [160]. The results indicated that both the one-session cognitive-behavioral intervention and midazolam reduced dental anxiety relative to the control group. However, at one-day, one-week, and two-month follow-ups, the patients who had received the one-session cognitive-behavioral intervention exhibited lower dental anxiety than those who had been treated with midazolam, as those treated with midazolam returned to pretreatment levels of anxiety. This suggests that pharmacotherapy may result in relapse of dental anxiety, while psychological intervention may allow for maintenance of reductions in anxiety. Treatment with medications may mask anxiety symptoms, and they may enable highly anxious

patients to participate in dental treatment, but they may not treat underlying anxiety as can be achieved by behavioral interventions [121].

Another study also found that patients treated with behavior therapy (systematic desensitization and biofeedback) or with premedication with a benzodiazepine had greater reductions in dental anxiety than those who were treated with general anesthesia [161]. At a 10-year follow-up, those who had been treated with the behavioral intervention had the highest proportion of regular attendance at dental appointments relative to those who had been treated with premedication and general anesthesia. Moreover, Lu et al. [162] posit that combined treatment with sedation and hypnotherapy may be superior to sedation alone in reducing dental anxiety and pain.

## **Practical Considerations for the Dental Environment**

Attending to certain factors related to the dental environment may enable dentists to address patients' dental anxiety in practical, feasible ways. Self-report questionnaires completed by anxious dental patients suggest that certain attributes of dental environments are preferred by anxious patients. Respondents indicated preference for decorated walls (89%) and slightly cool temperature (61%). Among respondents endorsing dental anxiety, 89% perceived music playing in the background as helpful, 75% found having magazines and books available to be helpful, and 48% indicated that having access to a television with headphones was helpful [163]. Concerning interventions that dentists could utilize to alleviate patients' anxiety, guided imagery (i.e., imaging oneself in a pleasant place; 40%), taking a relaxation drug (33%), nitrous oxide (15%), and hypnosis (7%) were perceived as helpful by anxious respondents [163]. Further research is needed to replicate and establish the generalizability of these results. However, asking anxious patients about their preferences concerning the dental environment and anxiety-related interventions may be useful in alleviating dental anxiety.

## **Conclusion**

As evidenced by the research reviewed in this chapter, psychologists and other practitioners of behavioral medicine have an important role to play in comprehensive dental care, particularly in the treatment of TMD and dental anxiety. Though several universities and research settings have begun incorporating behavioral dentistry, many places have not yet caught up to the research, so incorporation of behavioral medicine practitioners into dental care is not as widespread as the evidence seems to suggest would be helpful. However, organizations such as the National Institute of Dental and Craniofacial Research (NIDCR) within the National Institutes of Health are greatly contributing to the integration of behavioral practice into dentistry by recognizing and promoting the importance of the application of the behavioral and social sciences to dentistry [164].

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## Chapter 28

# Conclusion: Final Thoughts from the Editors

Christine M. Hunter, Christopher L. Hunter and Rodger Kessler

Much has changed since the first edition of the *Handbook of Clinical Psychology in Medical Settings* was published more than 20 years ago. Radical changes in telehealth and health information technology have resulted in electronic, medical, and patient health records that facilitate collaborative health care among the patient and their health care team. Social media, smartphone applications, video conferencing, and webinars not only make it easier for patients to gain important health care information and support but also allow more efficient and effective dissemination of evidence-based care. These advances can also support enhanced access to specialist care for patients and consultation roles with other professionals. However, despite these advances and the potential for greater reach, significant health disparities remain with too many Americans not receiving adequate care and not reaching important disease management milestones.

The importance of training a new clinical psychology workforce for today's health care settings is receiving increasing attention as reflected in recent publications on training and core competencies (e.g., [1, 2]). Having the clinical administrative and operational skills to work in these settings will be expected by other health professionals and consumers as these training and competency benchmarks become the

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new standard. This increased emphasis on evidence-based psychological care in the medical setting represents an exciting time for psychology professionals.

As the number of clinical psychologists in medical settings increases, there will likely be an expanding expectation for not only expertise in a given specialty condition (e.g., chronic pain) but also the requisite skills to assess and intervene with comorbid physical and mental health presentations with diverse populations. Being able to provide evidence-based assessment and intervention, while at the same time developing a research base to understand how to make those work in real-world settings and populations, is an important step toward providing patient-centered care.

Although progress is being made on reimbursement of clinical psychology services in medical settings, there is still great room for improvement. Variations in state laws and interpretations of those laws by payers can make reimbursement for services a challenge. Continuation of lobbying efforts at the local, state, and national level and an understanding of how to work within your current system's rules of engagement is important to ensure that clinical psychology services are a valued and standard part of future medical care.

We hope the chapters in this book can serve as a foundation to expand and improve your skills and enhance your ability for optimal functioning in any medical setting. We offer our sincere thanks to these tremendous set of authors that contributed the high-quality chapters in this book.

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# Index

## A

- Academic health centers (AHCs), 65
- Acculturation, 223, 228, 229
- Acquired brain injury, 691, 709
- Actigraphy, 567, 568, 569, 582
- Adherence, 172, 242, 248, 250, 251, 255, 348, 354, 371, 383, 395, 423, 427, 428, 430, 440, 517, 528, 530, 532, 533, 535, 536, 538, 540–543, 545–547, 549–555, 576, 578, 579, 580
- assessment of, 541
  - barriers to, 254, 533, 535, 550
  - cognitive aspects of, 530
  - effect of nausea on, 391
  - electronic monitoring in, 541
  - evidence-based assessment of, 536
  - in COPD patients, 540, 544
  - in IBD patients, 476, 477
  - in research, 533
  - interventions on, 251
  - maintainance of, 253
  - measure of, 534
  - medication, 176, 177, 182, 184, 186
  - promotion of, 576
  - role of environment factors, 253
  - role of lifestyle regimes on, 335
  - to behavior changes, 513
  - to medical regimes, 165
  - to treatment, 186, 328, 329, 332, 530
- Adherence monitoring capabilities, 581
- Adherence monitoring capabilities\t see also Adherence, 581
- Adjustment, 114, 261, 264, 272, 278, 284, 333, 334, 374, 383, 389, 423, 674, 675, 678, 679, 681, 682, 684
- challenges in, 352
  - disorders, 169, 225, 229, 430
  - emotional, 370
  - factors affecting, 253
  - in children, 256
  - in illnesses, 398
  - in women, 336, 349
  - of dosage, 268, 279
  - problems, 172
  - problems associated with, 278
  - psychological, 390
  - psychosocial challenges in, 536, 555
  - treatment of, 254
- Aging, 170, 265, 268, 270, 278, 283, 328, 330, 349
- Alcohol, 11–14, 177, 294, 388, 568
- excessive consumption of, 4, 11
  - treatment programs on, 13
- Alcohol-related problems, 14
- Alcohol Use Disorder Identification Test (AUDIT), 179
- American Board of Professional Psychology (ABPP), 33
- Amputation, 392, 404, 405, 673, 675, 679, 681–683
- Assessment, 3, 23, 46, 61, 62, 82, 102, 151, 319, 329, 333, 345, 348, 350, 353, 371, 379, 380, 381, 391, 392, 394, 435, 501, 545, 555
- approaches to, 8, 178, 393
  - aspects of, 43
  - behavioral, 444, 446–448, 501
  - risk factors for, 501
  - clinical health psychology, 32
  - competencies in, 91, 93
  - differential, 398
  - expertise related to, 31
  - factors affecting in, 555
  - front-line, 309
  - guidelines for, 509
  - in behavioral health, 317, 319
  - in health care setting, 6
  - in medical care, 341

- in obesity treatment, 446
  - in patients, 382
  - interventions on, 80
  - in women, 335
  - in women healthcare, 328
  - measures on, 41, 82, 318, 530
  - methods of, 317, 542
  - of clinical psychology, 399
  - of health behaviors, 515
  - of hospitals, 378
  - of IBS symptoms, 465
  - of meal time behaviors, 552
  - of mental capacity, 395
  - of motivation, 186
  - of physical functioning, 515
  - of substance use and abuse, 502
  - of systems, 377, 382
  - opportunities in, 48
  - patient- and system-focused, 393
  - procedures involved in, 379
  - programs of, 13
  - psychological, 209
  - psychosocial, 344, 395
  - role of behavior on, 86
  - service delivery model of, 63
  - services on, 34, 35
  - sexual risk, 389
  - systematic psychological, 26
  - tools used for, 13, 89, 356, 540
  - training on, 58
  - training opportunities in, 33
  - Association of Postdoctoral and Internship Centers (APPIC), 65
  - Asthma, 22, 83, 183, 246, 254, 385, 386, 527–530, 532–537, 541, 555
- B**
- Bariatric surgery, 139, 140, 142, 203, 440, 442, 446, 448, 719, 720, 727–730, 734
  - Behavioral Activation (BA), 383
  - Behavioral dentistry, 739, 758
  - Behavioral Family Systems Therapy (BFST), 429
  - Behavioral health risks, 6
  - Behavioral medicine, 27, 28, 46, 47, 57, 58, 116, 175, 199, 201, 204, 206, 208, 209, 291, 376, 381, 547
  - Behavioral Medicine and Clinical Health Psychology, 29
  - Behavioral oncology, 34, 43, 633
  - Billing, 71, 110–112, 204–208, 321, 381, 448
  - Biofeedback, 25, 26, 28, 29, 35, 255, 342, 346, 348, 384, 385, 391, 544, 571, 743, 750, 751, 755, 758
  - Biopsychosocial, 30, 32, 83, 86, 93, 164, 175, 211, 212, 271, 370, 380, 496, 513, 519
    - aspects of, 81
    - Engel's model, 27
    - factors associated with, 35
    - role in diabetes management, 86, 88
  - Blood pressure, 25, 26, 29, 285, 428, 443, 500, 501, 503, 509, 515, 516, 518
    - role of alcohol in, 502
  - Bone marrow transplantation, 92, 657
  - Brain injury rehabilitation, 697, 698, 700, 701, 703, 704, 708, 710
  - Breast cancer (BrCa), 637, 638, 639, 641, 655
- C**
- Cancer
    - breast cancer, 350
    - colorectal cancer, 461
    - genitourinary cancers, 332
  - Cardiac rehabilitation, 34, 46, 81, 375, 509, 513, 514, 520
  - Cardiovascular disease, 10, 54, 276, 277, 320, 444, 460, 495, 502–504, 506–509, 513–519
    - consequences of, 495
    - effect of diet and activity on, 501
    - forms of, 505
    - health behaviors associated with, 509
    - impact of psychosocial factors on, 503
    - in rural population, 294
    - management of, 496
    - psychosocial risk factors for, 502
    - risk assessment for, 498
    - risk factors of, 505
    - role of alcohol in, 502
    - role of obesity in, 436
    - studies on, 501, 506
    - treatment of, 498, 501
  - Caregivers, 203, 204, 254, 271, 283, 284, 330, 516, 519, 530, 533, 535, 552, 706–710
  - Caregiving, 283, 330
  - Care management, 187, 313–315, 317, 321, 322
  - Carve outs, 203
    - impacts of, 201
  - Catastrophizing, 390, 465, 468, 470, 598, 599
  - Chemotherapy, 107, 164, 385, 391, 628, 637–639, 641, 642, 645, 648, 649, 657, 660
  - Chronic illness, 35, 171, 175, 240, 242, 246, 248, 251–255, 292, 295, 298, 302, 371, 389, 392, 535, 543



- Chronic Obstructive Pulmonary Disease (COPD), 527, 538
- Chronic pain, 35, 82, 83, 93, 95, 302, 315, 320, 345, 383–385, 390, 448, 463, 589–604, 606–609
- Clinical health psychology, 19, 29, 30–35
- Clinical interventions, 3, 5
- Clinical notes, 101, 113
- Code of Conduct, 100–102
- Cognitive behavioral therapy, 12, 59, 425, 426, 428, 442, 445, 469, 476, 534, 543
- Cognitive decline, 266, 269, 276, 279, 285
- Collaborative consultation, 370
- Co-located care, 313
- Colorectal cancer (CRC), 641, 643
- Combined behavioral intervention (CBI), 12
- Combined Pharmacotherapies and Behavioral Interventions (COMBINE) Study, 12
- Competencies, 32, 33, 45, 46, 47, 48, 56, 63, 70, 71, 77–81, 83, 84, 87, 89–91, 93, 94, 97, 105, 107, 116, 120, 322, 355, 429, 767
- Confidentiality, 14, 47, 51, 99, 101, 106, 108, 109, 112–116, 118, 120, 162, 163, 296  
issues of, 378
- Consultation and liaison services, 417
- Consumers, 100, 105, 152–154
- Coordinated care, 46, 65, 162, 313, 314, 322
- Coping skills training, 429
- Cosmetic surgery, 730–734
- Cost benefit, 188  
analysis, 170
- Cost offset, 172–174, 177, 187, 188, 376
- Cost savings, 187  
approaches for, 172  
for collaborative care, 177, 178
- Council of Clinical Health Psychology Training Programs (CCHPTP), 33
- CPAP, 576, 578–582
- Cultural competence, 220, 232, 233, 331
- Current Procedural Terminology (CPT), 321
- Cystic fibrosis (CF), 241, 246, 251, 256, 384, 527, 547, 554
- D**
- Dementia, 70, 228, 266, 271, 273, 274, 278, 284, 387, 392, 395, 399, 432, 691, 694, 695–697, 705, 706, 709
- Dental anxiety, 477, 739, 751–758
- Depression, 169, 171, 172, 175, 176, 179, 181, 184, 187, 227, 266, 267, 274–276, 279, 320, 331, 332, 334, 344, 350, 352, 353, 385, 387, 391, 392, 394, 425, 427, 428–430, 435, 436, 465, 476, 503, 513, 540, 542, 545  
antenatal, 333  
assessment tools used for, 181  
assessment of, 164, 508, 516  
cognitive model of, 53  
collaborative care for, 182, 185, 186, 314  
collaborative care model of, 176  
comorbid psychological factors for, 89  
differential assessment for, 398  
effect of caregiving on, 330  
factors responsible for, 171  
healthcare cost in, 176  
history of, 336  
in COPD patients, 544  
in LGBT youth, 226  
in rural communities, 294  
in women, 230, 335  
models of, 316  
postnatal, 333  
predominant approaches to, 177  
reports on, 133  
research on, 27, 178, 253, 536  
risk factors in, 507  
role in brain abnormalities in, 272  
role of mental health problems in, 86  
role of urinary infection in, 347  
screening tools for, 431  
studies on, 504  
symptoms of, 503  
treatment of, 54, 264, 504
- Developmental stage, 79, 239, 240
- Diabetes  
Type 1 diabetes, 418, 420, 421, 422, 429  
Type 2 diabetes, 85, 210, 262, 417–422, 425–428, 433, 434, 440
- Diabetes self-management education (DSME), 423, 424
- Diet, 10, 11, 181, 276, 430, 443, 465, 496, 501, 508, 514, 515
- Directors of Clinical Training (DCTs), 58
- Disability, 30, 83, 170, 171, 174, 179, 187, 225, 241, 264, 275, 283, 284, 345, 389, 448, 497, 549, 591, 592, 594–596, 599, 600–602, 605, 673–678, 681, 682, 684, 685
- Disease management, 4, 5, 254, 301, 423, 429, 476  
definition of, 5  
programs on, 170

Distress screening, 432, 630, 631, 632  
 Diversity, 41, 48, 70, 72, 78, 105, 219, 220,  
 282, 292, 554

**E**

Efficiency, 55, 92, 95, 99, 105, 114, 134, 178,  
 181, 185, 187, 188, 570  
 Esophageal disorders, 467, 468, 469  
 Ethical principles, 99–103, 108, 109, 112  
 Ethical Principles of Psychology, 100, 101,  
 102  
 Ethnic identity, 222  
 Ethnicity, 5, 115, 220, 222, 227, 228, 419, 421  
 Evidence-based care, 176, 328, 509, 554, 767  
 Evidence-based cognitive-behavioral  
 interventions, 3  
 Evidence-based practice (EBP), 30, 95,  
 125–128, 142, 301, 399, 448, 509  
 definition of, 128  
 Evidence-supported treatment (EST), 125,  
 280, 331, 341

**F**

Family systems  
 interventions of, 241  
 Financially sustainable, 199, 205  
 Functional  
 dysphagia, 468, 469  
 gastrointestinal disorders, 459, 477  
 heartburn, 459, 468, 469, 471

**G**

Gastroesophageal reflux disease (GERD),  
 467–469, 477–479, 483  
 Gender, 12, 128, 220, 221, 226, 230, 283, 341,  
 394, 479  
 Gender variants, 221  
 Geriatrics, 70, 160, 272  
 Globus, 459, 468, 469, 471, 478  
 Guidelines, 32, 33, 100–104, 133, 134, 158,  
 181, 184, 211, 233, 286, 311, 345,  
 355, 378, 383, 433, 434, 440, 509,  
 547, 548  
 by GINA, 529  
 definition of, 102  
 dosage, 177  
 for CF care, 552, 553  
 for children and adolescents, 442  
 for IBS, 467  
 for medical management of COPD, 538  
 for NHLBI, 441  
 Gynecologic cancer, 647, 648–651  
 Gynecology, 43

**H**

Habit reversal, 745, 749–751  
 Health  
 and behavior codes, 213, 214, 321, 435  
 care access, 109, 291, 292, 302  
 disparities, 73, 291, 294, 298, 302, 767  
 information, 301  
 information technology, 767  
 Healthcare costs, 169, 170, 174, 176, 182,  
 185, 277  
 Health Insurance Portability and  
 Accountability Act of 1996  
 (HIPAA), 99, 101, 108, 109  
 HIPAA\ See Health Insurance Portability  
 and Accountability Act of 1996  
 (HIPAA), 182  
 Holistic care, 261  
 Hospital-based psychology, 370

**I**

Independent consultation, 370  
 Indirect consultation, 370  
 Infertility, 329, 331, 332, 352–355  
 Inflammatory Bowel Diseases (IBD), 459, 473  
 Information technology, 4, 291, 297, 298  
 Integrated care, 42–48, 51, 54, 56–59, 62, 65,  
 67, 71, 72, 162, 204, 300, 312–316,  
 321, 328  
 concept of, 43  
 models on, 59, 65  
 research in, 47  
 settings, 41, 44  
 training models of, 47  
 training programs on, 56  
 Integrated primary care, 78, 86  
 Interdisciplinary, 24, 25, 27, 28, 35, 45, 47, 48,  
 58, 70, 71, 78, 80, 85, 90, 93, 95,  
 161, 163, 200, 345, 435, 581  
 biobehavioral, 28  
 collaboration, 32, 161  
 Internship, 21, 23, 33, 44, 47, 48, 54, 56, 58,  
 65, 66, 70, 72, 78, 79, 92  
 Interprofessional, 42, 43, 44, 57, 58, 72, 84,  
 85, 87  
 training, 43, 67  
 Interprofessionalism, 84, 97  
 Interprofessionalism, 84  
 Irritable Bowel Syndrome (IBS), 344, 459,  
 460, 483

**L**

Legal, 47, 91, 93, 94, 100, 101, 105, 107, 108,  
 111, 121, 331, 382, 395

- Long-term care, 310, 448, 449  
 Long-term care facilities (LTC), 278  
 Lung cancer, 5, 644, 645, 647
- M**  
 Marketing, 83, 93, 94, 120, 151–159, 165–167  
 Mental status, 380, 395, 399  
 Movement disorders, 691  
 Multicultural psychology, 219, 220  
 Multiple medical conditions, 11, 92, 385, 496  
 Multiple relationships, 291, 295, 297  
 Musculoskeletal disorders, 10  
 pain, 589, 591, 596, 598, 599, 601, 602  
 Mutuality, 331
- N**  
 Neurodegenerative disorders, 691, 693, 705, 706, 708  
 Neuropsychology, 160, 203, 702  
 Non-cardiac chest pain (NCCP), 468, 471  
 Nonerosive reflux disease (NERD), 478
- O**  
 Obesity, 4, 6, 12, 29, 35, 83, 89, 139, 206, 240, 266, 417, 419, 434, 436, 437, 439, 440, 442, 444, 446–450, 507, 518  
 behavioral interventions for, 443  
 Biodyne model of, 183  
 Cochrane review on, 139  
 determinants of, 26  
 extended care model for, 444  
 in children, 6  
 prevalence of, 9, 444  
 role in chronic diseases, 10  
 treatment of, 204, 442, 443  
 use of behavioral therapy in, 25  
 Obstetrics, 43  
 Obstructive sleep apnea (OSA), 566, 567, 575, 578, 582  
 Older adults, 100, 225, 263–272, 274, 276, 277, 279, 280, 282–285, 571  
 Outcomes management systems, 179
- P**  
 Pain quality, 595, 597  
 measures of, 597  
 Parental involvement, 443  
 Pathophysiology, 29, 340, 345, 369, 437, 461, 478, 496, 527  
 Patient-Centered Medical Home (PCMH), 42, 169, 170, 299, 310, 449  
 Payer models, 200  
 Pediatrics, 43, 162, 248  
 Polysomnography (PSG), 565, 567, 575, 582  
 Population health, 5, 7, 10  
 approaches to, 4  
 definition of, 4, 5  
 interventions of, 3, 4, 8, 10  
 management of, 3, 5–7, 14  
 pioneers of, 4  
 Post-doctoral, 46, 65, 71  
 fellowship, 92  
 training, 32, 33  
 Pre-doctoral, 58, 63, 92  
 training programs, 59  
 Pregnancy, 329, 332–336, 339, 342, 350, 352, 353, 476  
 Preoperative evaluation, 720, 730  
 Preoperative treatment, 446  
 Presurgical evaluation, 723  
 Presurgical psychological evaluations, 203, 207  
 Prevention, 6, 11, 24, 25, 27, 28, 35, 46, 73, 104, 183, 185, 220, 270, 295, 310, 333, 349, 421, 425, 437, 439, 441, 442, 443, 502, 513, 538
- Primary  
 insomnia, 565, 566, 569, 571, 573  
 prevention, 5, 6  
 Primary care, 34, 35, 42, 46, 47, 51, 54, 70, 309–314, 316, 319, 322, 589, 590, 593, 594, 600–604, 608  
 clinical psychology in, 34  
 clinical skills, 58  
 ethical and legal standards of, 47  
 focus of, 34  
 goals of, 315  
 health clinics, 62  
 interventions for, 8  
 mental health, 70  
 perspectives of, 44  
 role of behavioral health in, 315, 316, 322  
 services, 312  
 settings, 8, 41, 44, 51, 65, 67  
 Primary care clinics, 4, 6, 58, 65, 310  
 Primary Care Training Task Force (PCTTF), 57  
 Privileges, 108, 161  
 Problem solving therapy, 429, 449  
 Professional services, 151, 155, 157, 158, 166  
 Prostate Cancer (PrCa), 301, 651  
 Psychological Services Center, 63  
 Psychology training, 41, 57  
 Psychopharmacology consultation, 291, 297

- Psychophysiology, 25, 28
- Psychosocial  
  functioning, 344, 507, 529, 534, 539, 540,  
  541, 542, 549, 551, 553  
  risk, 498, 502, 507, 508, 518
- Psychosomatic medicine, 22, 23, 28, 370
- R**
- Race, 220, 222, 283, 336
- Radiation, 628, 641, 642, 645, 648, 660
- Referral, 20, 42, 46, 55, 83, 96, 154–158, 163,  
  164, 328, 372, 374, 376, 379, 380,  
  385, 388, 391–394, 399, 400  
  algorithms, 89  
  benefits of, 93  
  certifications, 110  
  factors affecting, 376  
  for care, 4  
  for psychiatric consultation, 55  
  for self-change programs, 8  
  Level III, 63  
  marketing challenges for, 153  
  market segmentation in, 157  
  medication, 329  
  nature of, 162  
  resources, 51  
  role of behavioral observation in, 380  
  role of primary care in, 310  
  to Fibromyalgia (FMS) patients, 94
- Rehabilitation psychology, 160, 674
- Reimbursement, 57, 71, 73, 200–206, 208,  
  209, 449
- Relational context, 330, 331, 345
- Responsibilities, 85, 87, 90, 106, 117, 118,  
  158, 210, 329, 330, 550
- Rural populations, 14, 291, 292, 294, 297, 302
- S**
- Screening, 4, 13, 89, 170, 179, 181, 188, 211,  
  254, 277, 311, 317, 318, 387, 421
- Screening and brief intervention (SBI), 13
- Secondary prevention, 6
- Sexual  
  health, 332, 338, 339  
  identity, 220–222
- Sleep diary, 568, 569, 571
- Society of Behavioral Medicine, 28
- Socioeconomic status, 5, 128, 220, 229, 280,  
  282, 349, 506, 533
- Solid organ transplantation, 719, 720, 722,  
  723, 727
- Spinal cord injury (SCI), 203, 344, 673, 674,  
  676
- Spirituality, 220, 225, 338
- Standards, 21, 28, 33, 47, 78, 79, 84, 100–105,  
  108, 112, 117, 122, 143, 158, 204,  
  205, 211, 509, 577
- Stress management training, 426
- Stroke, 43, 269, 283, 350, 384, 395, 420, 422,  
  433, 575, 691, 703, 708
- Substance abuse, 12, 42, 55, 70, 165, 172,  
  173, 177, 187, 199, 201, 211, 226,  
  295, 311, 344, 374, 379, 384, 388,  
  389, 513
- Systemic  
  interventions, 391  
  symptoms, 477
- T**
- Target markets, 153
- Technology, 9, 165, 299
- Telehealth, 4, 119, 291, 298–301, 578, 580
- Temporomandibular disorders (TMDs), 385,  
  739, 740
- Tertiary prevention, 6
- Tobacco, 4–9, 11, 12
- Training, 19, 20, 32–35, 41, 44–48, 58, 59, 61,  
  63–67, 71, 72, 105, 160, 166, 312,  
  316, 320, 322, 329, 508  
  approaches to, 29  
  clinical, 21  
  in integrated care, 44  
  in primary care, 41, 67  
  in professional psychology, 32  
  in the biopsychosocial model, 30  
  models, 42, 44  
  programs, 24, 56  
  sites, 23  
  types of, 28
- Translation, 47, 211, 263, 341, 448, 449
- Traumatic Brain Injury (TBI), 395, 691, 692,  
  701, 708
- U**
- University of Louisville Graduate Psychology  
  Education (GPE), 63
- W**
- Weight management, 5, 6, 10–12, 34, 81, 89
- Women's health, 327, 330, 332, 355, 356
- Women's healthcare settings, 328, 329, 331,  
  355
- Workforce, 43, 44, 47, 72, 170, 313
- Work Limitations Questionnaire (WLQ), 179