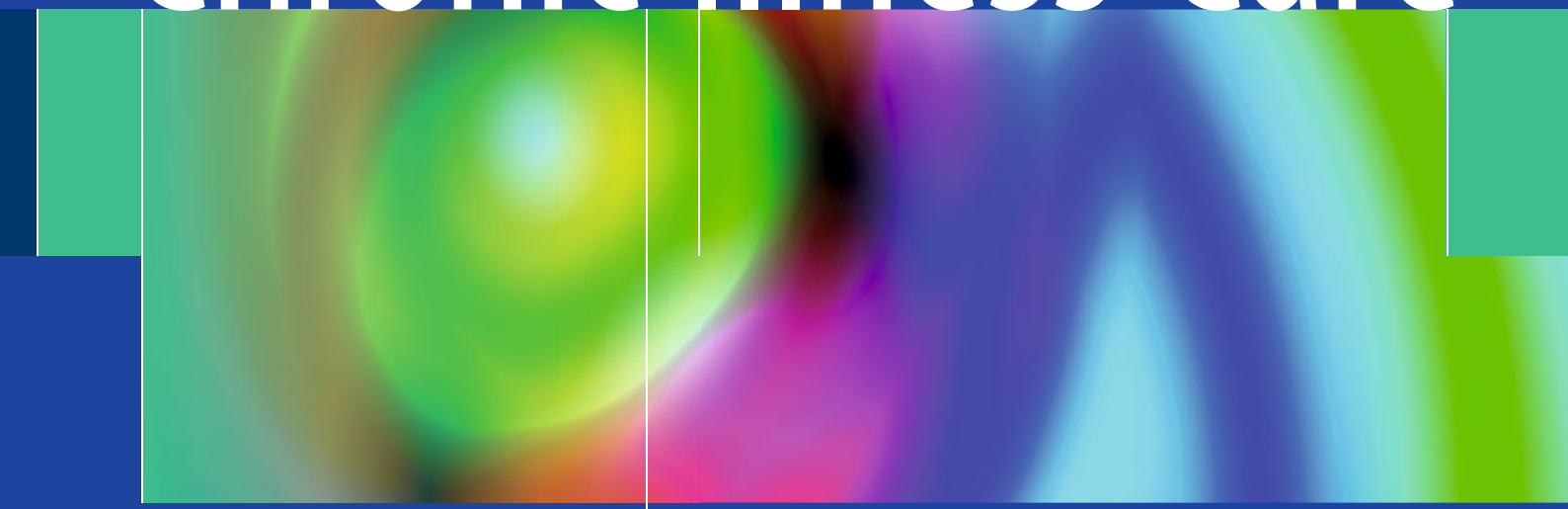
Timothy P. Daaleman
Margaret R. Helton
Editors

Chronic Illness Care



Principles and Practice

Springer

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Editors
Timothy P. Daaleman
Department of Family Medicine
University of North Carolina at Chapel Hill
Chapel Hill, NC, USA

Margaret R. Helton
Department of Family Medicine
University of North Carolina at Chapel Hill
Chapel Hill, NC, USA

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To our spouses, Ann and Terry,
and our children, Peter, Claire, Brian, Hannah, and Paul,
for their love and support.

To our patients, who remind us of the power of healing,
the vitality of the human spirit,
and the privilege of serving as a physician.

Dat dit boek er nu ligt,
danken wij aan het arbeidsethos en het doorzettingsvermogen
die onze Nederlandse roots ons hebben gebracht.

Timothy P. Daaleman
Margaret R. Helton
Chapel Hill, North Carolina

Preface: Introduction to Chronic Illness Care

Over a hundred years ago, acute communicable diseases – tuberculosis, diphtheria, and influenza – were the leading causes of morbidity and mortality in the United States, greatly contributing to death rates in children and young adults. In 1900, for example, the average life expectancy at birth was 46 years for men and 48 years for women [1]. Today, the estimated life expectancy is 76 years for men and 81 years for women, and the advent of antimicrobial therapy and public health initiatives, such as vaccinations, has dramatically reduced mortality in the younger years of life, transforming the manifestations of acute and chronic diseases and, concomitantly, the experience of illness and healthcare. Most notably, chronic diseases, such as heart disease, stroke, cancer, mental and behavioral disorders, and diabetes, have displaced acute infectious diseases as the major causes of morbidity and mortality.

About half of all US adults – 117 million people – reported one or more chronic health conditions in 2012, with one in four adults acknowledging two or more chronic health conditions [2]. Much of the current healthcare system, unfortunately, is primarily oriented and structured to respond to acute, short-term biomedical problems. From the way medical learners and other healthcare providers are trained, to the design features of acute hospitals and medical settings, to the reimbursement practices and policies that are indexed to episodes of care, there is an underlying assumption that illness and other medical problems are acute, curable, and narrow in their scope of healthcare services. This is no longer the lived experience of patients and caregivers in the United States – and across much of the developed world – where chronic disease has supplanted acute disease as the predominant form of illness.

Chronic disease is generally defined as a condition that lasts for more than 3 months, is not prevented by vaccines or cured by medication, does not spontaneously resolve, and has long-lasting and significant effects on an individual's quality of life [3]. In contrast to acute illness, chronic disease can cause a person to lose function over years, in either a stepwise or a gradual pattern, until death occurs [4]. The human toll associated with chronic conditions – physical, emotional, and social – is also tied to the staggering financial costs needed to provide healthcare for these patients. For example, 86% of all healthcare spending in 2010 was for people with one or more chronic medical conditions [5], and increased spending on chronic diseases is a major driver in the overall growth of Medicare [6]. With such growth, it is predicted that the Medicare Hospital Insurance Trust Fund will be depleted in 2030 and that only the advent of more efficient care approaches, new payment models, and less rapid growth of reimbursement rates will salvage the program [7].

Improving the health status and promoting the quality of life for individuals with chronic conditions necessitate culture change on many levels, as well as a paradigm shift regarding care approaches to chronic disease [8]. This book contributes to that paradigm change by providing a comprehensive and organized body of information regarding the principles and practices of chronic illness care, which is the coordinated, comprehensive, and sustained response to these diseases and conditions – from initial diagnosis to the end of life – by a wide range of healthcare professionals, formal and informal caregivers, and healthcare and community-based systems [9].

The book is organized using a social-ecological framework, which is derived from systems theory and looks at the interdependent influences between individuals and their larger

environment [10]. This framework considers multiple domains across several levels of influence and provides a grounding to the book (Fig. 1). Different sections of the book aggregate individual chapters, presenting key principles and concepts, as well as evidence and examples that illustrate and support these ideas. The book starts with eight chapters that focus on individual factors that influence chronic disease. Individual-level characteristics include factors that may be considered fixed (e.g., genetics), those that are more socially constructed (e.g., race and ethnicity), and key areas of behavior change (e.g., tobacco use, physical activity, nutrition, alcohol and other drug use) that intersect with chronic disease. This section also includes a chapter on chronic disease self-management, as well as one that covers approaches to determining quality-of-life and patient-centered outcomes in this population.

Part II addresses the role of others in an individual's experience of chronic disease and acknowledges formal and informal social networks and support systems, including family,

Fig. 1 Social-ecological framework (Adapted from the Centers for Disease Control and Prevention (CDC), The Social Ecological Model: A Framework for Prevention, http://www.cdc.gov/violenceprevention/overview/social-ecologicalmodel.html (Retrieved October 19, 2016))

friends, and peers [10]. Chapters will cover areas from the usually supportive role of family and other caregivers to the negative influence of domestic violence, abuse, and neglect. In addition, this section recognizes the role of community support from patient navigators, peers, and agencies and organizations as emerging players in the management of chronic disease.

The section on principles and practices that are foundational to providing chronic care constitutes the largest part and occupies a central place in the book. Part III does not focus on the medical diagnosis and treatment of specific chronic diseases, due to the rapid pace of research and scholarship that informs and changes practice and the ready dissemination of clinical information via information technology and other electronic sources. Rather, chapters in this section cover key principles that form the base of care provision, in addition to approaches that are organized around the healthcare settings where chronic care is provided. These settings include the outpatient and inpatient setting, the emergency department, nursing homes, rehabilitation centers, and community-based care. There are information and skill needs that are common for chronic care providers across these settings, and this section includes chapters on secondary prevention, medication management, patient-provider communication, and end-of-life care. Finally, there are chapters which provide approaches to caring for chronically ill patients who have unique needs and challenges, such as children and adolescents, older adults, adults with disabilities, and vulnerable populations.

As the paradigm for chronic illness care changes, the organizational structures for delivering healthcare services are also undergoing transformation. The Chronic Care Model, which identifies key healthcare system elements that promote quality chronic illness care, helps to frame Part IV [11]. Chapters in this section address novel and emerging care models that are located in increasingly functional outpatient settings and include integrated behavioral healthcare, care management, transitions of care, team-based care, quality improvement, and the use of health information technology. Although the patient-centered medical home is becoming the predominant organizational structure, varieties of practice designs are discussed, including direct-care practices and concierge care.

Part V recognizes that social and environmental factors affect chronic illness, whether through a cumulative exposure to unclean air or water or through health behaviors that are mediated by social interactions. This section closes with a chapter on the life course as an orientation in approaching how historical and social determinants influence the health of an individual and sets up the final section that focuses on health policy. Local, state, and national regulations and laws, including policies regarding the allocation of resources and access to healthcare services, are components of the policy environment in which chronically ill patients live and receive their healthcare [10]. These are critical issues that require ongoing examination and improvement if a viable and sustainable healthcare system is to meet the needs of chronically ill patients. Chapters in this section include the major federal programs influencing chronic care delivery (Medicare and Medicaid) and the emergence of new payment models focused on value-based care. Providing quality chronic illness care to the people who need it will require an understanding of population health and a retooled healthcare work force, and this book provides a grounding in both areas. The section closes with an international perspective since other developed countries are facing comparable challenges and have care models and policy lessons that can inform the way forward in the United States.

The book closes with a perspective on future directions in chronic illness care, which will continue to evolve in the foreseeable future. As noted earlier, this book hopes to be a part of the paradigm shift in ways of thinking about chronic disease care by being a useful resource to the physicians, nurses, social workers, pharmacists, policy-makers, educators, and others who are committed to the care of people with chronic illness.

Chapel Hill, NC, USA

Timothy P. Daaleman
Margaret R. Helton

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Contents

Contributors

Nailah Safiya Adams Broward Community and Family Health Centers, Inc

Rayhaan Adams Department of Family Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

Ramine Alexander Department of Nutrition, UNC Center for Health Promotion and Disease Prevention Department, Chapel Hill, NC, USA

Alice S. Ammerman Center for Health Promotion and Disease Prevention, Department of Nutrition, Gillings School of Global Public Health and School of Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

Evan Arthur Ashkin University of North Carolina at Chapel Hill, Department of Family Medicine, Chapel Hill, NC, USA

Amir H. Barzin Department of Family Medicine, University of North Carolina School of Medicine, Chapel Hill, NC, USA

Jim Bellows Kaiser Permanente, Care Management Institute, Oakland, CA, USA

James O. Breen Moses H. Cone Memorial Hospital, Department of Family Medicine, University of North Carolina at Chapel Hill, Greensboro, NC, USA

Jada L. Brooks School of Nursing, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

Mallory McClester Brown UNC Dept of Family Medicine, University of North Carolina, Chapel Hill, NC, USA

Sylvia Willie Burgess One Step at a Time Consulting, Greensboro, NC, USA

Lori Carter-Edwards Gillings School of Global Public Health and The North Carolina Translational and Clinical Sciences Institute, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

Leah Elizabeth Chapman Department of Nutrition, The University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

Maggy Muchieh Coufal Peers for Progress, Department of Health Behavior, Gillings School of Global Public Health, University of North Carolina-Chapel Hill, Chapel Hill, NC, USA

Asian Center for Health Education**,** Plano**,** TX**,** USA

Timothy P. Daaleman Department of Family Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

Maureen C. Dale Division of Geriatric Medicine, Department of Medicine, University of North Carolina, Chapel Hill, NC, USA

Amy C. Denham Department of Family Medicine, University of North Carolina School of Medicine, Chapel Hill, NC, USA

Darren A. DeWalt Division of General Medicine and Epidemiology, University of North Carolina-Chapel Hill School of Medicine, Chapel Hill, NC, USA

Michael Dulin UNC Charlotte, Public Health Sciences, Charlotte, NC, USA

Henry M. Dunnenberger Center for Personalized Medicine, NorthShore University HealthSystem, Evanston, IL, USA

Margaret A. Drickamer University of North Carolina at Chapel Hill, University of North Carolina Hospitals, Department of Medicine, Division of Geriatrics, Chapel Hill, NC, USA

Robert L. Ferrer Department of Family and Community Medicine, UT Health San Antonio, San Antonio, TX, USA

Edwin B. Fisher Peers for Progress, Department of Health Behavior, Gillings School of Global Public Health, University of North Carolina-Chapel Hill, Chapel Hill, NC, USA

Erin Fraher Department of Family Medicine School of Medicine, Program on Health and Workforce Research and Policy, Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

Bruce J. Fried Health Policy & Management, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

Megan Gately Departments of Occupational Therapy and Community Health, Tufts University, Medford, MA, USA

VA Medical Center, Geriatric Research and Clinical Center, Bedford, MA, USA

Jacqueline MacDonald Gibson Department of Environmental Sciences and Engineering, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

Adam O. Goldstein UNC Tobacco Intervention Programs, UNC School of Medicine, Department of Family Medicine, Chapel Hill, NC, USA

Margaret L. Gourlay Department of Family Medicine, University of North Carolina, Chapel Hill, NC, USA

Mark D. Gwynne UNC Chapel Hill School of Medicine, Department of Family Medicine, Chapel Hill, NC, USA

Karen D. Halpert Department of Family Medicine, University of North Carolina, Chapel Hill, NC, USA

Emily M. Hawes Department of Family Medicine, University of North Carolina School of Medicine, Chapel Hill, NC, USA

UNC Eshelman School of Pharmacy, Chapel Hill, NC, USA

Sherry S. Hay UNC of Family Medicine, Community Health Initiatives, Chapel Hill, NC, USA

Margaret R. Helton Department of Family Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

Weiping Jia Shanghai Diabetes Institute, Shanghai Jiao Tong University Affiliated Sixth People's Hospital, Shanghai, China

Department of Endocrinology & Metabolism, Shanghai Clinical Center for Diabetes, Shanghai Jiaotong University Affiliated Sixth People's Hospital, Shanghai, China

Alexander Kaysin Department of Family Medicine, University of North Carolina, Chapel Hill, NC, USA

J. Kevin Hicks H. Lee Moffitt Cancer Center and Research Institute, Department of Individualized Cancer Management, DeBartolo Family Personalized Medicine Institute, Tampa, FL, USA

Thomas C. Keyserling Division of General Medicine and Clinical Epidemiology, Department of Medicine, UNC Hospitals, Chapel Hill, NC, USA

Christine E. Kistler UNC School of Medicine, Department of Family Medicine, Chapel Hill, NC, USA

University of North Carolina at Chapel Hill, University of North Carolina Hospitals, Department of Medicine, Division of Geriatrics, Chapel Hill, NC, USA

Keren Ladin Departments of Occupational Therapy and Community Health, Tufts University, Medford, MA, USA

Research on Ethics, Aging, and Community Health (REACH Lab), Medford, MA, USA

Yee Lam University of North Carolina Hospitals, Department of Family Medicine, Chapel Hill, NC, USA

Yuexing Liu Shanghai Diabetes Institute, Shanghai Jiao Tong University Affiliated Sixth People's Hospital, Shanghai, China

Jennifer Martini Department of Family Medicine, University of North Carolina, Chapel Hill, NC, USA

Ann Scheck McAlearney Department of Family Medicine, The Ohio State University, Columbus, OH, USA

Morgan A. McEachern Department of Family Medicine, University of North Carolina School of Medicine, Chapel Hill, NC, USA

Terri Menser Center for Outcomes Research, Houston Methodist Research Institute, Houston, TX, USA

Carlton R. Moore Department of Medicine, Division of Hospital Medicine, UNC Hospitals, University of North Carolina School of Medicine, Chapel Hill, NC, USA

Mary R. Mulcare NewYork-Presbyterian Hospital/Weill Cornell Medicine, Division of Emergency Medicine, New York, NY, USA

Linda Myerholtz University of North Carolina, Chapel Hill, Department of Family Medicine, Chapel Hill, NC, USA

Dana M. Neutze Department of Family Medicine, University of North Carolina, Chapel Hill, NC, USA

Warren P. Newton Department of Family Medicine, University of North Carolina at Chapel Hill School of Medicine, Chapel Hill, NC, USA

Jonathan Oberlander Department of Social Medicine, School of Medicine, and Department of Health Policy & Management, Gillings School of Global Public Health, University of North Carolina-Chapel Hill, Chapel Hill, NC, USA

Cristen Page Department of Family Medicine, University of North Carolina School of Medicine, Chapel Hill, NC, USA

Marcus Plescia UNC Gillings School of Global Public Health, Chapel Hill, NC, USA

Lauren Porras University of North Carolina Chapel Hill, Department of Family Medicine, Chapel Hill, NC, USA

University of North Carolina Chapel Hill, Department of Orthopaedics**,** Chapel Hill, NC, USA

Deborah S. Porterfield Department of Family Medicine, UNC School of Medicine, Chapel Hill, NC, USA

RTI International, RTP, NC, USA

John S. Preisser Department of Biostatistics, UNC Gillings School of Global Public Health, Chapel Hill, NC, USA

Amy N. Prentice Department of Family Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

Shana P. Ratner Division of General Medicine and Epidemiology, University of North Carolina-Chapel Hill School of Medicine, Chapel Hill, NC, USA

Carol E. Ripley-Moffitt UNC Nicotine Dependence Program, UNC School of Medicine, Department of Family Medicine, Chapel Hill, NC, USA

Jamie Ryan Pardee RAND Graduate School, Santa Monica, CA, USA

Richard Saitz Department of Community Health Sciences (CHS), Department of Medicine, Boston University Schools of Public Health and Medicine, Boston Medical Center, Boston, MA, USA

Dana Sarnak The Commonwealth Fund, New York, NY, USA

Samantha Schilling University of North Carolina, Department of Pediatrics, Chapel Hill, NC, USA

Arnav Shah The Commonwealth Fund, Policy and Research, New York, NY, USA

Nicholas P. Shungu Department of Family Medicine, Medical University of South Carolina, Charleston, SC, United States

Harry Stafford UNC Hospitals, Department of Family Medicine, Chapel Hill, NC, USA

Lindsay Stortz Practice Quality and Innovation, UNC Health Care System, Chapel Hill, NC, USA

Patrick Y. Tang Peers for Progress, Department of Health Behavior, Gillings School of Global Public Health, University of North Carolina-Chapel Hill, Chapel Hill, NC, USA

Hazel Tapp Carolinas Healthcare System, Department of Family Medicine, Charlotte, NC, USA

Forrest Toms One Step at a Time Consulting, Greensboro, NC, USA

Jenny T. van der Steen Leiden University Medical Center, Public Health and Primary Care, Leiden, The Netherlands

Sarah E. Wakeman Department of Medicine, Massachusetts General Hospital, Boston, MA, USA

Margaret C. Wang Kaiser Permanente, Care Management Institute, Oakland, CA, USA

Gregg A. Warshaw Department of Family Medicine and Internal Medicine, Geriatrics Division, School of Medicine, University of North Carolina, Chapel Hill, NC, USA

Adam J. Zolotor University of North Carolina School of Medicine, Department of Family Medicine,, Chapel Hill, NC, USA

Part I

Individual Influences on Chronic Disease

Genetic Contributions and Personalized Medicine

1

J. Kevin Hicks and Henry M. Dunnenberger

Role of Genetics in Chronic Disease

There are multiple factors that contribute to the development of chronic disease including lifestyle, environmental exposures, socioeconomic status, and in certain instances genetics. Genomic alterations may increase the risk of having a chronic disorder, and genetic susceptibility can be potentiated by lifestyle choices or environment. Mutations in the lipid homeostasis genes *LDLR*, *APOB*, or *PCSK9* can result in familial hypercholesterolemia, thus enhancing the probability of premature cardiovascular disease, though individuals may remain asymptomatic [1, 2]. Harboring mutations in these lipid homeostasis genes concomitantly with tobacco use or obesity exacerbates the risk for cardiovascular disease [3]. For certain chronic conditions, as exemplified by cystic fibrosis, genetic polymorphisms alone can directly result in disease. An autosomal recessive genetic disorder, cystic fibrosis is caused by mutations in the cystic fibrosis transmembrane conductance regulator (*CFTR*) gene [4]. Because of advances in management and treatment over the past few decades, cystic fibrosis has transitioned from a disease associated with infant mortality to a chronic condition with a life expectancy of over 40 years [4]. Other examples of inherited genomic variations that can enhance the risk for chronic disease include familial cardiomyopathy (e.g., mutations in heart muscle genes such as *TNNI3*, *TNNT2*, *MYH7*), inherited neuropathies (e.g., mutations in genes associated with myelination such as *PMP22*, *EGR2*), Alzheimer's disease (e.g., mutations in genes associated with amyloid plaque development such as *APOE ε4*), and cancer (e.g., mutations in genomic stability genes such as *BRCA1*, *BRCA2*, *MSH6*) [5–8].

Along with contributing to the development of chronic disorders, genomic polymorphisms influence the response to disease treatment. Patients diagnosed with a single chronic disease are likely to take at least one maintenance medication, whereas those with multiple chronic conditions may be treated with ten or more drugs [9, 10]. Within a population diagnosed with the same chronic disease and prescribed similar medications, the response to a particular drug or occurrence of an adverse drug reaction may vary greatly among individuals. Interindividual differences in pharmacotherapy response have been attributed to genomic alterations encoding proteins affecting the pharmacokinetics (i.e., metabolism or transport) or pharmacodynamics (i.e., target) of a drug [11–13]. The *CFTR* gene, which encodes for a chloride channel that is a vital regulator of ion and fluid transport, is an example of how polymorphisms influence drug response [4]. Over 1900 *CFTR* mutations have been observed that can have deleterious effects such as disruption of biosynthesis or folding and trafficking of the CFTR protein, along with mutations that cause the ion gate to be in a mostly closed position [14]. Ivacaftor is a drug that increases the likelihood of the ion gate being in an open configuration. Thus, within a population of cystic fibrosis patients, only those harboring mutations (e.g., *CFTR G551D*) that affect ion channel gating would likely benefit from taking ivacaftor [14]. Dependent on the drug and associated polymorphism, approximately 20–95% of observed variability in drug response can be attributed to inheritance [11, 12].

Adverse drug reactions and nonresponse to pharmacotherapy are major causes of morbidity and mortality. Serious or fatal adverse drug reactions are estimated to affect millions

J.K. Hicks (✉)
H. Lee Moffitt Cancer Center and Research Institute, Department of Individualized Cancer Management, DeBartolo Family Personalized Medicine Institute, Tampa, FL, USA
e-mail: james.hicks@moffitt.org

H.M. Dunnenberger
Center for Personalized Medicine, NorthShore University HealthSystem, Evanston, IL, USA
e-mail: mdunnenberger@northshore.org

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of patients each year and are thought to be a leading cause of death in the United States [15, 16]. For individuals diagnosed with a chronic disorder requiring numerous maintenance medications, it may be inferred that there is a greater probability for those patients to experience an adverse drug event. Understanding associations between genomic variation and drug effectiveness and identifying polymorphisms predictive of adverse drug risk have the potential to decrease morbidity and mortality caused by gene-drug interactions [17]. Pharmacogenomics is the study of how genetic variants influence drug response and was first described in the 1950s regarding observed interindividual differences in drug metabolism [18–20]. Single-nucleotide polymorphisms (SNPs) are the most commonly observed genomic variants that affect drug response. SNPs can cause loss of protein function or if located in the promoter region can influence gene expression [21–23]. Over 40 million SNPs were identified in the initial sequencing of the human genome, and it is estimated that one SNP occurs in every 600 DNA base pairs [24, 25]. Other genomic variants that influence drug response include DNA base pair insertions or deletions (indels), short DNA sequence repeats, and copy number variation (i.e., gain or loss of a gene) [26, 27]. The term allele is used to describe the SNPs or other genomic variants harbored within a gene. Dependent on how genomic variants affect protein function and an individual's diplotype (i.e., summary of the inherited maternal and paternal allele), a phenotype can be assigned. In the context of drug-metabolizing enzymes, a predicted phenotype may be ultrarapid, rapid, normal, intermediate, or poor metabolizer [28]. In most instances, phenotypes at the extremes of the drug metabolic continuum have the greatest potential to affect pharmacotherapy outcomes.

For many chronic conditions, there are numerous medications that are available for treatment. Therapeutic options to treat major depressive disorder include tricyclic antidepressants, selective serotonin reuptake inhibitors, and serotonin norepinephrine reuptake inhibitors. Even when adhering to current guidelines and best practices, multiple treatment strategies exist [29, 30]. Each drug has its own unique side-effect profile, and dependent on an individual's genetic profile, the risk for an adverse event may be greater for some drugs than others. Utilizing pharmacogenomic results in a similar manner as kidney or liver function tests; rational drug-prescribing strategies can be established to allow for the selection of a drug with lower potential for an adverse event among the many drugs that would be a suitable treatment option. For certain gene-drug pairs, the evidence demonstrating an association between polymorphisms and drug response is sufficiently strong to warrant clinical implementation [31–33]. Thus, genetic variants can have a role in patient care across the continuum of chronic disease including screening, prevention strategies in genetically susceptible populations and treatment strategies (Fig. 1.1).

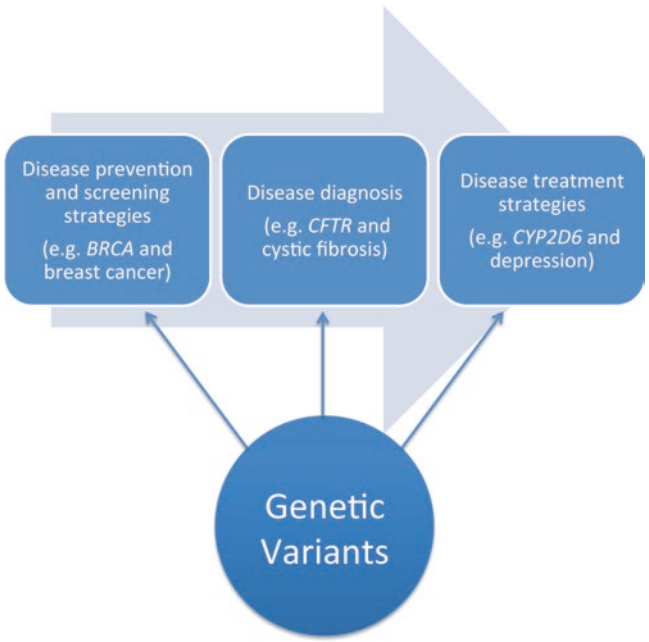

Fig. 1.1 Genomic medicine has applicability across the continuum of chronic disease including prevention, diagnosis, and treatment

Gene-Drug Considerations for Chronic Disease

Numerous studies have been published demonstrating a correlation between genetic variation and chronic disease or associations between genetic polymorphisms and drug response, far too many to discuss in detail. Therefore a comprehensive list of all gene-drug interactions will not be provided, but rather gene-drug pairs that are currently utilized in clinic or have the potential for clinical implementation over the coming years that are applicable to chronic diseases will be highlighted.

Autoimmune Disorders

There are multiple chronic autoimmune diseases including rheumatoid arthritis, lupus, and inflammatory bowel diseases that can be pharmacologically managed with the thiopurine drug class. Azathioprine and mercaptopurine are relatively inexpensive drugs and are often prescribed before initiation of the more expensive tumor necrosis factor-α inhibitors. Thiopurine methyltransferase (TPMT) degrades azathioprine and mercaptopurine to compounds with less pharmacological activity [34, 35]. In the absence of TPMT activity, thiopurines are converted at a greater rate than expected to thioguanine nucleotides which at high concentrations can cause bone marrow toxicity. Those who inherit one nonfunctional *TPMT* allele (intermediate metabolizers) are at an

increased risk of myelosuppression, whereas those who inherit two nonfunctional *TPMT* alleles (poor metabolizers) are at very high risk of myelosuppression if prescribed standard doses of thiopurines. It is recommended to decrease the dose of azathioprine or mercaptopurine by 30–60% and titrate to response for intermediate metabolizers [36]. Consideration should be given to avoiding azathioprine or mercaptopurine for TPMT poor metabolizers or reducing the dose by 90% and administering three times per week instead of daily [36].

Cancer

Cancer susceptibility and drug response can be influenced by both germline variations and somatic mutations. Germline polymorphisms are inherited from maternal and paternal alleles, whereas somatic mutations are not inherited but rather acquired after conception. Inheritance of *BRCA1* or *BRCA2* variations increase the risk for certain types of cancer; however those with *BRCA1*/*BRCA2* variations are more likely to respond to the poly(ADP-ribose) polymerase inhibitor olaparib [37]. Likewise, inheritance of *MSH6* polymorphisms increases the risk of Lynch syndrome (also known as hereditary nonpolyposis colorectal cancer) where immunotherapy may be a treatment option [38]. Treatment regimens for hematologic malignancies such as acute lymphocytic leukemia include mercaptopurine. Dosing strategies for TPMT intermediate and poor metabolizers are the same as the dosing strategies described for autoimmune diseases [36]. Dihydropyrimidine dehydrogenase, encoded by the *DPYD* gene, is responsible for the elimination of the chemotherapeutic drug 5-fluorouracil [39]. In rare instances, an individual may inherit two nonfunctional *DPYD* alleles and if exposed to 5-fluorouracil can experience severe or even fatal toxicities [40]. DPYD poor metabolizers should avoid 5-fluorouracil, whereas a 50% dose reduction should be considered for intermediate metabolizers [40].

Interrogating tumor biopsies for somatic mutations is becoming increasingly common, and for some cancers (e.g., lung cancer), somatic testing is considered standard of practice. As an example, epidermal growth factor receptor (*EGFR*) mutations influence the selection of EGFR-tyrosine kinase inhibitors (TKI) that are used to treat lung cancer patients [41, 42]. *EGFR* exon 19 deletions can be targeted by the first-generation EGFR-TKI erlotinib, whereas *EGFR T790M* mutated cancers are resistant to first-generation TKIs but susceptible to the third-generation EGFR-TKI osimertinib. Precision oncology medicine is revolutionizing the treatment of cancer patients as many of the targeted therapies can be taken orally, may have less severe side effects than the older DNA damaging chemotherapeutic agents, and may be more effective. Numerous targeted chemotherapeutic agents that have specific mutations listed in the Indications and Usage section of the package label are now entering the drug market (Table 1.1). As clinical trials begin to enroll patients based on the presence of specific somatic mutations and independent of tumor histology, the number of approved chemotherapeutic agents targeting specific somatic mutations is predicted to grow [43].

Table 1.1 Examples of chemotherapeutic agents that target specific somatic mutations

Drug	Genomic variant
Ado-trastuzumab	*ERBB2* gene amplification
Afatinib	*EGFR* exon 19 deletion
	$EGFR^{L858R}$
Alectinib	*ALK* fusion
Bosutinib	*BCR-ABL1* fusion
Ceritinib	*ALK* fusion
Cetuximab	*EGFR* gene amplification
Cobimetinib	$BRAF^{V600E}$
	$BRAF^{V600K}$
Crizotinib	*ALK* fusion
Dabrafenib	$BRAF^{V600E}$
Erlotinib	*EGFR* exon 19 deletion
	$EGFR^{L858R}$
Gefitinib	*EGFR* exon 19 deletion
	$EGFR^{L858R}$
Imatinib	*BCR-ABL1* fusion
Lapatinib	*ERBB2* gene amplification
Nilotinib	*BCR-ABL1* fusion
Olaparib	*BRCA1* deleterious mutations
	BRCA2 deleterious mutations
Osimertinib	$EGFR^{T790M}$
Pertuzumab	*ERBB2* gene amplification
Trametinib	$BRAF^{V600E}$
	$BRAF^{V600K}$
Trastuzumab	*ERBB2* gene amplification
Vemurafenib	$BRAF^{V600E}$

Infectious Diseases

Although there is currently no cure for the human immunodeficiency virus (HIV), antiretroviral therapy has drastically increased survival with studies suggesting that the life expectancy of HIV-infected individuals now being similar to the general population [44–46]. Early initiation of antiretroviral therapy along with medication compliance is essential for viral load control and improved outcomes. Antiviral agents, though, can induce serious and sometimes life-threatening side effects that disrupt therapy or influence compliance. Abacavir is a nucleoside analog reverse-transcriptase inhibitor with potent antiviral activity and is a component of numerous combination therapies. Approximately 6% of indi-

viduals exposed to abacavir will experience a hypersensitivity reaction that in rare instances can be fatal [47, 48]. Human leukocyte antigen B (HLA-B*)* is a member of the major histocompatibility complex and has a role in immune response including drug-induced immune reactions. Though the mechanism of action is poorly understood, it is hypothesized that HLAs recognize drugs as foreign (non-self) and present drug-peptide complexes to the immune system inducing a hypersensitivity reaction [49]. The *HLA-B*57:01* allele has been demonstrated to be predictive of abacavir-induced hypersensitivity reactions [50–52]. A prospective, randomized, double-blind study investigating the use of genomics to guide abacavir prescribing found that preemptive *HLA-B*57:01* screening significantly reduced the incidence of hypersensitivity reactions (3.4% genotyping group versus 7.8% control group, $p < 0.001$) [53]. The Food and Drug Administration (FDA) placed a warning in the drug package insert stating that patients should be screened for *HLA-B*57:01* before prescribing abacavir. Atazanavir is a protease inhibitor that is concomitantly prescribed with other antiretrovirals as part of a first-line treatment for HIV [54, 55]. A side effect of atazanavir is hyperbilirubinemia due to inhibition of uridine diphosphate glucuronosyltransferase (UGT) 1A1. UGT1A1 converts bilirubin into a water-soluble conjugated form that can be eliminated from the body. DNA sequence repeats in the *UGT1A1* promoter region, such as *UGT1A1*28* defined by an extra TA, cause a reduction in protein expression resulting in Gilbert's syndrome [23, 56]. Carriers of *UGT1A1*28* who are prescribed atazanavir have a higher treatment discontinuation rate due to hyperbilirubinemia that can cause discoloration of the skin and eyes [57, 58]. Incorporating preemptive genotyping of *HLA-B*57:01* and *UGT1A1* into HIV antiretroviral treatment algorithms could assist with identifying those at increased risk of hypersensitivity reactions or premature discontinuation and further guide drug-prescribing strategies [48, 53, 59, 60].

Chronic hepatitis C viral infection is a major cause of liver disease including cirrhosis and hepatocellular carcinoma [61, 62]. Pegylated interferon-α concomitantly with ribavirin is an effective treatment as measured by sustained virological response (defined as absence of viremia 24 weeks after treatment) and is associated with decreased morbidity and mortality [63]. Approximately 30–45% of patients, though, will not achieve a sustained virological response when treated with pegylated interferon-α/ribavirin [63–66]. Because therapy lasts up to 48 weeks and causes multiple adverse effects that can be severe, identifying those less likely to respond could assist with clinical decision making. A genome-wide association study in 1137 hepatitis C patients discovered that a SNP in *IFNL3* (also known as *IL28B*) is predictive of an unfavorable response to interferon-α-based therapy [66]. Those with an unfavorable genotype have an approximately 30% chance for a sustained virological response with attainment of response doubling to 60% if a protease inhibitor is added to the pegylated interferon-α/ribavirin regimen [67]. Individuals with a favorable genotype are eligible for shortened therapy (24–28 weeks versus 48 weeks) [67]. *IFNL3* genotyping has been integrated into clinical practice, though newer more effective antiviral therapeutic regimens (e.g., ledipasvir/sofosbuvir) are lessening the clinical use of *IFNL3* for guiding hepatitis C treatment decisions.

Invasive fungal infections are more commonly observed among chronic diseases that affect immune defense mechanisms such as HIV and cystic fibrosis [68]. Furthermore, medications used to treat autoimmune disorders or cancer can weaken the immune system thus necessitating antifungal prophylaxis. Voriconazole is an antifungal agent that is considered a first-line treatment for aspergillosis [69]. Voriconazole has a narrow therapeutic range (1–6 mcg/ml) with sub-therapeutic plasma concentrations associated with progressive fungal infections and poor outcomes [70, 71]. CYP2C19 metabolizes voriconazole to compounds with less antifungal activity. Approximately 25% of the population carries a SNP (c.−806C>T) in the *CYP2C19* gene promoter region, referred to as *CYP2C19*17*, that causes upregulation of gene expression and increased metabolic capacity [22, 72]. *CYP2C19*17* carriers metabolize voriconazole to a greater extent than normal metabolizers resulting in lower drug plasma concentrations and increased risk of progressive fungal infections [70, 73, 74]. *CYP2C19* genotyping in populations at risk of a fungal infection has the potential to identify those requiring higher initial voriconazole doses or those who may benefit from selection of an antifungal agent not metabolized by CYP2C19.

Psychiatry and Neurological Disorders

Major depressive disorder is a leading cause of disease burden and over the next 20 years may emerge as the most prevalent disease among high-income countries [75, 76]. Depression may be considered a chronic disorder itself or arise as a comorbidity due to diagnosis of another chronic disease such as cancer, chronic obstructive pulmonary disease, or congestive heart failure [77]. Approximately 30–50% of patients fail initial therapy due to intolerance or ineffectiveness, and it is estimated that in the United States, antidepressant-induced adverse events result in over 25,000 emergency department visits per year [78–80]. The majority of antidepressants are metabolized by polymorphic cytochrome P450 enzymes including CYP2D6 and CYP2C19. There is a substantial body of evidence demonstrating an association between *CYP2D6* or *CYP2C19* polymorphisms and pharmacokinetic parameters along with treatment outcomes for the selective serotonin reuptake inhibitors (SSRIs)

and tricyclic antidepressants (TCAs) [81, 82]. Initial clinical implementation studies showed that using pharmacogenomic testing to guide drug prescribing in depressed patients resulted in better antidepressant response rates and was cost-effective when compared to those who were not genotyped, though further studies are needed to support these findings [83–85]. Due to high initial pharmacotherapy failure rates and no single drug clearly being a more effective treatment, pharmacogenomic testing has the potential to become part of routine care for those with depression to assist with drug-prescribing strategies [86, 87].

CYP2D6 and *CYP2C19* gene-based dosing guidelines are available for the SSRIs and TCAs [81, 82]. CYP2D6 ultrarapid metabolizers are at risk of therapeutic failure due to low drug plasma concentrations, and it is recommended to prescribe an SSRI or TCA that is not metabolized by the CYP2D6 enzyme for those patients. CYP2D6 poor metabolizers have an increased risk of adverse drug effects due to elevated drug plasma concentrations, and an initial 50% dose reduction of SSRIs and TCAs is recommended with titration to response. For the SSRI and TCA drugs metabolized by CYP2C19, similar recommendations exist for CYP2C19 ultrarapid or poor metabolizers [81, 82]. There are currently limited gene-based guidelines for other antidepressants that are metabolized by CYP2D6 or CYP2C19, though such guidelines are likely to evolve over time [88]. In addition to drug-metabolizing enzymes, there is a growing body of literature suggesting that polymorphisms in serotonin receptors and transporters may influence antidepressant response [89, 90].

Drugs metabolized by CYP2C19 and CYP2D6 that may be used to treat chronic neurologic diseases include clobazam, cholinesterase inhibitors, and tetrabenazine. Clobazam is used to treat Lennox-Gastaut syndrome, which requires lifelong therapeutic management of seizures. CYP2C19 poor metabolizers have a three to five times higher exposer to the metabolite n-desmethylclobazam which is thought to be associated with an elevated risk of side effects [91]. Although the clinical utility of *CYP2C19* genotyping to dose clobazam is evolving, the drug manufacture suggests that for adult CYP2C19 poor metabolizers, the initial dose should be reduced by 50% and titrated carefully based on clinical response. Cholinesterase inhibitors (e.g., donepezil and galantamine) are used to treat Alzheimer's disease. Both donepezil and galantamine are metabolized by CYP2D6, but currently there are no strong correlations between *CYP2D6* genotype and drug response [92]. CYP2D6 poor metabolizers may have a greater exposure to galantamine than normal metabolizers per the drug package insert, and care should be taken during dose titration. Chorea associated with Huntington's disease can be treated with tetrabenazine. Limited evidence suggests that those who are CYP2D6 poor metabolizers may be more likely to experience tetrabenazine-induce side effects such as suicidality, particularly at higher doses [93]. The drug manufacturer recommends *CYP2D6* genotyping before titrating to higher doses and for those who are CYP2D6 poor metabolizers limiting the maximum single dose to 25 mg and maximum daily dose to 50 mg.

Carbamazepine can be utilized for the management of many chronic conditions including seizures, nerve pain such as trigeminal neuralgia or diabetic neuropathy, migraine prophylaxis, and other neurological disorders. Serve side effects such as Stevens-Johnson syndrome and toxic epidermal necrolysis can be caused by carbamazepine and are fatal in up to 30% of individuals diagnosed with these cutaneous adverse events. A small study consisting of 44 patients with pathology-proven Stevens-Johnson syndrome found that all patients were positive for the *HLA-B*15:02* allele [94]. Subsequent studies confirmed this finding and suggested that those who carry the *HLA-B*15:02* allele are approximately 100-fold more likely to develop carbamazepine-induced Stevens-Johnson syndrome/toxic epidermal necrolysis, though the occurrence of this side effect is low with a positive predictive value of about 8% [95]. A prospective study consisting of 4335 individuals found that *HLA-B*15:02* preemptive genotyping completely prevented Stevens-Johnson syndrome/toxic epidermal necrolysis in the study population by prescribing alternative medications to those positive for the *HLA-B*15:02* allele [96]. The FDA placed a warning in the drug package insert stating that particular patient populations should be screened for *HLA-B*15:02* before prescribing carbamazepine.

Chronic Pain

Considering only the US population, one in three individuals is thought to suffer from chronic pain [97]. Genomic alterations in genes encoding proteins involved in pain perception (e.g., *COMT*) along with the metabolism (e.g., *CYP2D6*), transport *(*e.g., *ABCB1*), and targets (e.g., *OPRM1*) of pain treatment drugs can affect treatment response [98]. One investigation suggested that as high as two-thirds of observed interindividual variability to morphine response may be due to genetic variation [99]. Catechol-O-methyltransferase (COMT) is an important regulator of dopamine, epinephrine, and norepinephrine in the pain perception pathway [100]. Four SNPs in *COMT* have been proposed to influence pain perception, and dependent on how many SNPs an individual harbors, the sensitivity to pain can be predicted as low, average, or high [101–103].

Chronic pain treatment will vary based on the type of pain an individual has (e.g., neuropathic pain, nociceptive pain) and severity. Tricyclic antidepressants, typically at low doses, can be used to treat neuropathic pain. CYP2D6 ultrarapid metabolizers have an increased risk of a drug such as

amitriptyline not being effective due to faster than expected metabolism that can lead to low or undetectable drug plasma concentrations [82]. Dose adjustments may not be needed for CYP2D6 poor metabolizers, as the typically lower amitriptyline doses may not place a patient at risk of side effects due to high drug concentrations. If higher doses of tricyclics are used for neuropathic pain treatment, then gene-based dosing strategies used for depression treatment can be considered. Nonsteroidal anti-inflammatory drugs (NSAIDs) may be used for chronic pain conditions such as arthritis. The NSAID celecoxib is metabolized by the polymorphic P450 drug-metabolizing enzyme CYP2C9. Two *CYP2C9* variants that cause decreased enzyme function, *CYP2C9*2* and *CYP2C9*3*, are associated with a longer elimination half-life of celecoxib [104]. The FDA package insert for celecoxib suggests a 50% dose reduction for known CYP2C9 poor metabolizers.

Opioids such as codeine are commonly prescribed to those with chronic pain. Codeine is a prodrug that is converted to the more active compound morphine by CYP2D6. Multiple deaths have been reported in children who were prescribed normal doses of codeine [105]. It was later recognized that these children were CYP2D6 ultrarapid metabolizers and converted codeine to morphine to a greater extent than normal metabolizers likely resulting in a morphine overdose. Other pain medications metabolized by CYP2D6 include tramadol, hydrocodone, and oxycodone. For CYP2D6 ultrarapid metabolizers, a pain medication not metabolized by CYP2D6 should be considered [106]. Because CYP2D6 converts these medications to more active compounds, those who are CYP2D6 poor metabolizers are less likely to benefit from tramadol, codeine, hydrocodone, and oxycodone [106]. Opioids target the μ-opioid receptor, OPRM1. Polymorphisms in *OPRM1*, such as *OPRM1 A118G*, have been associated with the need for higher opioid doses [107, 108]. Research is ongoing to determine the potential for utilizing *OPRM1* genetic variants to predict opioid doses that may better treat pain.

Cardiovascular Disease

Cardiovascular disease is a leading cause of morbidity and mortality in the United States and accounts for approximately one in three deaths [109]. Hypertension is a major risk factor for cardiovascular disease, with genetic polymorphisms influencing the response to antihypertensive agents. Results from the Veterans Affairs Cooperative Studies revealed that patients with Northern European ancestry responded better to angiotensin-converting enzyme (ACE) inhibitors and β-blockers, while patients with West African ancestry responded better to calcium-channel blockers and diuretics [110–112]. This observed difference is thought to be due to polymorphisms in genes affecting plasma renin activity along with genetic variants influencing the response to antihypertensives [113]. For example, polymorphisms in *NEDD4L* are associated with a greater response to thiazide diuretics [114–116], whereas *ADRB1* variants (rs1801252 and rs1801253) are associated with a decrease response to β-blockers [114–119]. However, there are limited examples of hypertension pharmacogenomics with enough validity to be implemented into clinical practice at this time. This may be due to the relatively low effect size of each individual variant, with combinatorial gene studies needed to create a large enough effect size to achieve genetically guided antihypertension treatments.

Dyslipidemia is a modifiable risk factor for cardiovascular disease. Familial hypercholesterolemia is an inherited dyslipidemia disorder characterized by high low-density lipoprotein (LDL) concentrations [120]. Familial hypercholesterolemia is autosomal dominant, with variants in *LDLR* accounting for 79% of familial hypercholesterolemia cases followed by variants in *APOB, PCSK9,* and *LDLRAP1* [3]. About 15% of cases are either polygenic or have an unknown genetic cause. Like other forms of dyslipidemia, statins are a mainstay of treatment. OATP1B1 (encoded by the *SLCO1B1* gene) is hepatic transporter that facilitates the uptake of statins. The *SLCO1B1* variant rs4149056 is thought to reduce transport activity resulting in greater exposure to statins such as simvastatin thus increasing the risk for myopathies [121]. There are dosing guidelines for simvastatin and *SLCO1B1*, where carriers of rs4149056 are recommended to receive lower doses to prevent myopathies [122].

Antiplatelet therapy with aspirin, clopidogrel, prasugrel, or ticagrelor is indicated to prevent ischemic events following acute coronary syndrome (ACS) and percutaneous coronary intervention. Clopidogrel is metabolized in the liver by several cytochrome P450 enzymes including CYP2C19 to its active form which irreversibly inhibits platelet activation and aggregation. CYP2C19 poor metabolizers are at an increased risk of therapeutic failure due to non-activation of clopidogrel. A meta-analysis found patients who carry *CYP2C19*2* (a decreased function allele) are at an increased risk of major adverse cardiovascular events and stent thrombosis compared to wild-type patients, hazard ratio 1.55 and 2.67 for heterozygotes and 1.76 and 3.97 for homozygotes respectfully. This effect is strongest in high-risk ACS patients. Dosing guidelines are available for clopidogrel and *CYP2C19*, where alternative antiplatelet therapy (e.g., ticagrelor) is recommended in CYP2C19 intermediate or poor metabolizers [123]. A large randomized controlled trial is currently underway to evaluate the clinical outcomes of *CYP2C19* genotype-guided antiplatelet therapy, TAILOR-PCI. Currently, prasugrel and ticagrelor have no genetic links to response.

Anticoagulation therapy is a hallmark of atrial fibrillation treatment for which warfarin is the traditional drug of choice. It is metabolized mainly by CYP2C9. The decreased function *CYP2C9*2* and *CYP2C9*3* alleles are associated with lower warfarin dose requirements and an increased risk of bleeding in Caucasians [124, 125]. These variants along with *CYP2C9*5*, *CYP2C9*6*, *CYP2C9*8*, and *CYP2C9*11* influence warfarin dose requirements in African Americans [126]. VKORC1 is the target of warfarin and is the rate-limiting enzyme for the conversion of vitamin K-epoxide to vitamin K, which is important for blood clotting. The −1639G>A variant in the promoter region of *VKORC1* results in lower protein expression thus resulting in decreased warfarin dosing requirements [127]. The FDA package labeling contains dosing recommendations for warfarin using a combination of *CYP2C9* and *VKORC1*. Two randomized controlled trials evaluated the clinical benefit of genetically guided warfarin dosing, EU-PACT and COAG trials [128]. These trials had conflicting results. The EU-PACT trial, which had a greater than 90% Caucasian population, found genotype-guided warfarin dosing was associated with better outcomes. The COAG trial, which had a population with more than 20% African Americans, found no difference between a clinical dosing algorithm and genetic-guided warfarin dosing. It should be noted that neither trial genotype patients for *CYP2C9*5*, *CYP2C9*6*, *CYP2C9*8*, and *CYP2C9*11* which may improve dosing prediction particularly in African Americans [123]. There are two more trials underway which may resolve these discrepant results, GIFT NCT01006733 and WARFARIN NCT01305148. For the newer oral anticoagulants, there is much less known about their pharmacogenomic profile.

Diabetes

Diabetes is a major health problem across the world. There are two major subgroups of diabetes: type-1 (autoimmune) and type-2 (non-autoimmune). Diabetes occurs when genetic predisposition collides with environmental and lifestyle factors [129]. It is an area of intense research; however few findings, especially related to treatment, have progressed to clinical practice.

Type-1 diabetes is estimate to have 80% heritability [130]. Variants in multiple genes have been linked to autoimmune diabetes: *HLA, INS, CTLA4, PTPN22, PTPN2, IL2RA, IFIH1, CAPSLIL7R,* and *CLEC16A* [131]. Type-2 diabetes is estimated to have 26–73% heritability [132]. More than 100 loci are associated with non-autoimmune diabetes [101, 133, 134].

No genetic variants have been found to be associated with treatment response to insulin. Metformin, the first-line agent to treat type-2 diabetes, has been thoroughly studied for genetic links to response. The pharmacokinetics of metformin is affected by variants in *SLC22A1* and *SLC47A1*; however no consistent effect on clinical outcomes has been found [135–138]. Sulfonylureas are inactivated by CYP2C9. Patients with *CYP2C9* reduced function alleles (**2* and **3*) are consistently observed to have greater glycemic response than those who do not carry these variants [138]. Two forms of type-2 diabetes are caused by variations in single genes and are highly sensitive to sulfonylureas: maturity-onset diabetes of the young (*HNF1A)* and neonatal diabetes mellitus (*KCNJ11* or *ABCC8*) [139, 140].

Implementation of Personalized Medicine

Identifying those with genomic susceptibility to chronic conditions can allow for preventative actions including education about lifestyle changes and individualized plans for disease screening [141, 142]. For those diagnosed with a chronic disorder, integrating pharmacogenomics into clinical practice can help guide medication prescribing strategies by identifying gene-drug interactions predictive of poor response. Although it has been recognized for decades that genomic variants are associated with chronic disease development and pharmacotherapy outcomes, genomic medicine is only now in the early stages of robust routine clinical implementation. Changes in health-care delivery are one of the factors contributing to the growing interest in genomic medicine implementation. Reimbursement for medical services is transitioning away from a volume incentive model to a value-based model that takes into account both costs and outcomes [143]. Within a value-based health-care model, utilizing genomic testing to identify patient populations at risk of poor outcomes and taking preventative measures may translate into cost savings. Furthermore, advances in technology have led to decreasing genotyping costs that make genomic medicine financially feasible. The adoption of electronic health records, incentivized by the 2009 American Recovery and Reinvestment Act, theoretically enables the curation of genomic information and dissemination of clinical decision support at the point of computerized drug order entry [144]. Besides family health history which is used as a tool to detect familial syndromes, pharmacogenomics has been integrated into routine clinical practice to a greater extent than other areas of genomic medicine. Lessons learned from pharmacogenomic implementation can be extrapolated to other areas of genomic medicine.

Implementation Barriers

Pharmacogenomic results can have clinical utility for years and potentially the entire life span of a patient. It is not feasible for clinicians to remember what genomic variants

were interrogated years ago, the associated phenotype, and all pertinent gene-based dosing recommendations for each individual patient. Electronic health records (EHRs) can be utilized to discretely curate important genomic information and clinical decision support employed to remind end users (e.g., physicians, pharmacists, nurses) of important results and gene-drug interactions [145, 146]. Most EHR software, though, are not optimized to store and present genomic data to clinicians. In many instances, genetic test results are scanned into the EHR as a PDF or entered as unstructured data and organized in a time-dependent manner. Finding a particular genetic result would require remembering the exact date the information was entered into the medical record. Ideally, genetic test results should be discretely summarized in an easily accessed section of the EHR and organized in a time-independent manner so results from years earlier can be readily displayed.

Perhaps the biggest barrier for integrating genomic results into the EHR is the lack of machine readable codes to discretely convey information. Logical Observation Identifiers Names and Codes (LOINC) or Systematized Nomenclature of Medicine (SNOMED) terminology allows for discrete transmission of results between a reference laboratory and EHR software. There are currently few standardized LOINC or SNOMED genomic terms that enable discrete transmission of results [28]. Without discrete entry of results, datamining the EHR for pharmacogenomic data is difficult and prevents the deployment of clinical decision support tools [147]. There are multiple national groups that are working on optimization efforts and development of best practices for integrating genomics into the EHR including the Electronic Medical Records and Genomics (eMERGE) Network, Implementing Genomics in Practice (IGNITE) Network, and the Displaying and Integrating Genetic Information Through the EHR Action Collaborative (DIGITizE-AC) [148–150]. Other potential barriers for implementation include paucity of third-party reimbursement for genomic testing or clinical services, knowledge deficiency regarding what to do clinically with test results, and integration of genetic testing and distribution of pharmacogenomic knowledge in a manner that complements existing clinical workflows.

Pharmacogenomic Implementation Tools

The Clinical Pharmacogenetics Implementation Consortium (CPIC), a collaboration between the Pharmacogenomics Knowledgebase and the Pharmacogenomics Research Network, publishes peer-reviewed gene-based dosing guidelines that can be found at www.cpicpgx.org [31]. Guidelines for over 30 gene-drugs pairs have been published, with the number of unique gene-drug pair dosing guidelines growing every year (Table 1.2). These guidelines do not inform clinicians if a test should be performed but rather how to apply the results to patient care. Every CPIC guideline has an available comprehensive pharmacogenomic translation table that links all possible diplotypes to a phenotype, priority notation (i.e., actionable or non-actionable result), and interpretation language [146]. Over 100 drugs have pharmacogenomic information in the FDA package insert, and for certain drugs, specific gene-based prescribing recommendations are provided. Other resources for gene-based dosing recommendations include the Dutch Pharmacogenetics Working Group (DPWG) [151].

Table 1.2 Published CPIC guidelines

Specialty	Gene	Drug
Cardiology	CYP2C19	Clopidogrel
	SLCO1B1	Simvastatin
	CYP2C9/ VKORC1	Warfarin
Infectious disease	CYP2C19	Voriconazole
	IFNL3	Peginterferon
	UGT1A1	Atazanavir
	HLA-B	Abacavir
Oncology	G6PD	Rasburicase
	DPYD	Capecitabine, fluorouracil, tegafur
Psychiatry	HLA-B	Carbamazepine
	CYP2C19/ CYP2D6	Amitriptyline, clomipramine, doxepin, imipramine, trimipramine
	CYP2C19	Citalopram, escitalopram, sertraline,
	CYP2D6	Desipramine, fluvoxamine, nortriptyline, paroxetine
Other	CYP2D6	Codeine
	CFTR	Ivacaftor
	CYP2C9/ HLA-B	Phenytoin
	CYP3A5	Tacrolimus
	TPMT	Azathioprine, mercaptopurine, thioguanine
	HLA-B	Allopurinol

Although commercial gene-drug interaction software are becoming more readily available, most early pharmacogenomic adopters have created local solutions for EHR clinical decision support. The CPIC Informatics Working Group provides examples of EHR agnostic clinical decision support tools that complement each CPIC guideline [152]. The eMERGE and IGNITE networks recently created the Clinical Decision Support Knowledgebase (CDS_KB, www.cdskb.org) that provides tools for developing and disseminating genomic decision support. These decision support resources provide examples of clinical workflows, considerations for when interruptive alerts should fire, and recommendations on preventing alert fatigue. As the number of clinically important gene-drug interactions increases, the utilization of interruptive alerts to notify clinicians of important information will likely

become overwhelming. Indeed, many health-care systems have significantly reduced the number of drug interaction and drug duplication pop-up notifications because of alert fatigue. Long-term, other solutions besides interruptive alerts will be needed for presenting genomic information to clinicians, for example, passively displaying pharmacogenomic data during computerized drug order entry [145]. Additional implementation tools includes the IGNITE network (www.ignite-genomics.org) toolbox that contains resources for clinicians and educators along with the Pharmacogenomics Knowledgebase (www.pharmgkb.org).

Implementation Strategies

Strategies for implementing personalized medicine will depend on the needs and goals of each individual health-care system. For those earlier adopters of pharmacogenomics, common themes have emerged that likely will apply to most health-care settings [33, 145, 153]. There are multiple strategic partners that should be engaged early in the implementation process including executive leadership, pathology, health informatics, financial services, patients, and the end users such as physicians and pharmacists. It may be difficult to initially recognize all strategic partners, but lack of support from any of these groups has the potential to derail the formation of a personalized medicine service. Another common theme is utilization of preexisting committees to help guide the integration of personalized medicine into patient care. For example, most health-care systems have a Pharmacy and Therapeutics committee that reviews and approves practices pertaining to drug utilization. A Pharmacy and Therapeutics committee could potentially approve decision support language for gene-drug interactions and approve alternative drugs or doses. Creating implementation cost models in cooperation with financial services that utilizes institution-specific data could help formulate meaningful business plans [72]. Furthermore, certain genotype tests (e.g., *HLA-B*57:01*, *HLA-B*15:02*, *TPMT*, *CYP2C19*) are reimbursed by third parties, dependent on the clinical scenario and necessity. An initial implementation strategy may include focusing on those gene-drug pairs where the testing is reimbursed [145].

Certain genomic variants are more likely to be observed among particular ancestries and ethnicities. The allele frequency for *HLA-B*15:02* is 0–0.02% for those of West African or Northern European descent, whereas the allele frequency among some Asian ethnicities is as high as 10–12% [154]. Patient populations should be taken into consideration when selecting gene-drug pairs for systematic implementation. Taking the approach of *HLA-B*15:02* genotyping for every patient prescribed carbamazepine would be of limited cost-effectiveness for health systems with more homogeneous populations consisting of those with West African and Northern European ancestry. A better implementation approach may be clinical decision support reminding providers to assess ancestry and order an *HLA-B*15:02* genotype when appropriate. Implementation strategies may also consist of selecting a reference laboratory or testing platform. A genotype test should include variants representative of the patient population. CYP2C9 metabolizes warfarin, with *CYP2C9* polymorphisms predictive of warfarin dose [155]. *CYP2C9* genotype tests may only interrogate a limited number of variants such as *CYP2C9*2* and *CYP2C9*3*. However, variants such as *CYP2C9*8* may be an important predictor of warfarin dose for those of West African ancestry; therefore if implementing a warfarin pharmacogenomic clinic that will serve patients of African descent, then a *CYP2C9* test that encompasses all important variants should be selected [156].

Future of Personalized Medicine

The immediate future of personalized medicine will focus on creating the guidelines and best practices for integrating those gene-drug pairs with strong evidence for clinical applicability into patient care. As the number of patients who are genotyped continues to increase, additional gene-chronic disease and gene-drug associations will be discovered. A challenge of personalized medicine going forward will be translating the ever-growing clinically significant genomic information into patient care. Of particular difficulty will be the genomic variants that alone have mild to moderate penetrance but in combination predict severe phenotypes. Enduring, large-scale adoption and sustainment will likely depend on outcome studies. Conducting personalized medicine cost-effectiveness and other types of outcome studies is challenging but necessary to demonstrate clinical utility. Other future considerations will include ethical, legal, and social implications of widely available genomic information. Genomics is the first step in personalized medicine, as additional data from proteomics, epigenomics, metabolomics, and other omics will need to be integrated into personalized medicine in the future.

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Websites of Importance

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Race, Ethnicity, and Cultural Influences

2

Lori Carter-Edwards, Jada L. Brooks, Sylvia Willie Burgess, and Forrest Toms

Introduction

The current transformation of racial demographics in the US population will have a significant, social, economic, and political impact on the future access, delivery, and utilization of health care, particularly in the context of health disparities. This demographic shift known as the "browning of America" [1] reveals the complexities in the exponential growth of non-White populations and the simultaneous reduction in growth of White populations. These patterns will also radically affect the ways in which the nation has historically addressed racial discrimination and inequality over the last 60 years through provisions of equal access policies [2]. Most immigrants today are of color – African, Asian, and Latin American [3] – and the Urban Institute projects that by 2070 over half of the US population will be of color.

At a societal level, this transformation will call into question the fundamental values and principles of equality, democracy, and the rights of individuals. It will require a different level of social and political engagement for years to come, especially within health care. For example, efforts to repeal and replace the Affordable Care Act reflect the polarizing and uncertain nature of this racial demographic shift, as well as the marked gaps in care that perpetuate disparate health outcomes. Nevertheless, there is an inherent need and responsibility of health-care professionals to ensure there is an equitable standard of care for all, regardless of race or ethnicity, or political underpinnings in an ever-changing health-care landscape.

Race, ethnicity, and culture are socially derived constructs that are critical in addressing and remediating health disparities between distinct populations. Arguably, race deeply penetrates the surface, with its conception historically rooted in inequality [4]. Ethnicity and culture, closely related to race, are multifaceted concepts that transcend time, place, space, and person, and their application to chronic illness care requires an in-depth understanding of their meaning, as well as how they reflect the lives of individuals. Chronic illness is often experienced differently along the life course for Americans who are racially and ethnically different than White Americans. Non-White populations, for example, face a greater burden of chronic illness, injury, disability, morbidity, and mortality compared to White populations [4]. Despite advances in health-care quality, as well as the demographic shift described above, racial and ethnic disparities persist, and in some instances, they have widened [5].

Unequal burdens of social adversities and environmental health threats, layered with individual, provider, and health-care system complexities, contribute to disproportionate rates of morbidity and mortality among non-White populations. These disparities often represent a limited understanding of the social and cultural context and the unique strengths of these populations. Such disparities can contribute to missed opportunities in health-care decision-making and negatively impact the capacity to prevent or treat chronic disease and develop self-management plans [6]. Policies and practices that do not address cultural context can subtly perpetuate injustices and inequities that diminish these vulnerable populations' quality of life [7], placing a tremendous economic burden on an already complex and fragile health-care system. Eliminating health disparities and improving overall health for all US citizens, regardless of racial and/or ethnic background, requires that health-care professionals fully understand and address the

L. Carter-Edwards (✉)
Gillings School of Global Public Health and The North Carolina Translational and Clinical Sciences Institute, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA
e-mail: lori_carter-edwards@unc.edu

J.L. Brooks
School of Nursing, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

S.W. Burgess • F. Toms
One Step at a Time Consulting, Greensboro, NC, USA

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underlying dynamics that perpetuate chronic illness at the individual level.

This chapter examines how race, ethnicity, and culture impact the occurrence, detection, treatment, and outcomes of chronic illness in diverse populations. The first section defines and views race, ethnicity, and culture as a complex dynamic and discusses their interrelatedness in the context of health equity, health inequities, and health disparities. The second section includes an overview of chronic illness in racially and ethnically diverse populations. The importance of culture in the provision of care in diverse racial and ethnic populations will be highlighted, including the role of provider empathy in understanding patients' beliefs, attitudes toward treatment, and outcomes. The next section elucidates the intersection of ethnicity and cultural influences at multiple levels and its implications in chronic illness self-management, provider provision of care, and system approaches. The chapter concludes with future directions in chronic illness care that account for racial, ethnic, and cultural factors at the individual provider, system, and policy levels.

Understanding Race, Ethnicity, Culture, and Health Disparities

An individual's racial and ethnic composition and cultural background is complex and can influence the experience of chronic disease and the health care that accompanies it. These constructs, often described interchangeably, have distinct meanings and dynamic relationships with each other. The persistent chronic disease burden among populations typically defined by these concepts is often associated with other interrelated constructs, such as health equality, health equity, and health disparities. The definitions for such constructs are constantly evolving and can vary in operationalization based on the stakeholder. While these variations exist, there are elements within these constructs that are important to consider for those providing chronic disease care and management. Furthermore, from a population health perspective, specifically in terms of a patient-centered outcomes approach, a basic understanding of these constructs in the context of community and stakeholder engagement is critical in building the necessary capacity in the transformation to more effective models of care.

Concepts of Race, Ethnicity, and Culture

Race, while often used interchangeably with ethnicity, describes groups of people by their phenotype. A historically controversial, politically charged, and politically derived construct, race emerged as a term in North America during the sixteenth and seventeenth centuries [8]. During post-colonialism, the term race was used with increased frequency as economic and colonial powers grew. It distinguished people, not only by physical traits but also by intellectual and moral characteristics [8]. Further distinction of race during this period was justified through religion, denoting lineage, or ancestry, and purity of blood [8, 9]. As slavery increased along with increased economic power of White Americans, so did the increased segregation and discrimination of people through religion as well as other culturally driven classifications, legalizing the marginalization of those of non-European descent.

By the nineteenth century, the biological concept of race surfaced, and attempts were made to use science to indicate a hereditary link to race, further marginalizing non-European groups, in particular African Americans [10–12]. At the same time and into the twentieth century, *manifest destiny*, or the belief that it was the "God-given destiny" of White Americans to control and dominate the continent [9, 13], emerged, continuing the separation of races and widening the power differential. These beliefs had significant influence on race and land ownership, where the US government seized sacred land of American Indians [8] and invaded Mexico leading to the signing of the Treaty of Guadalupe Hidalgo that ultimately resulted in Mexican's loss of land in several Western states [14]. Today, the use of race as a construct to classify distinctions among groups of people is still rooted in these historical contexts. However, with the increased diversity within and between races, race is linked now, more than ever, to ethnicity and culture.

Ethnicity is an ever-changing social construct and refers to the classification of people based on shared experiences, whether through ancestry, culture, language, nationality, cuisine, art, religion, or even physical appearance [15]. While race and ethnicity both refer to one's heritage, ethnicity often refers to learned cultural behaviors. These behaviors represent ways groups establish their identity, whether it is a set of beliefs that distinguishes them from other groups, markers they use to emphasize their differences, or ways to establish boundaries when developing relationships with outsiders. Ephraim Squier stated, in describing the US, "nowhere else can we find brought in so close proximity, the representatives of races and families of men, of origins and physical and mental constitutions so diverse" [16]. Thus, in describing the dynamic nature of ethnicity in this nation, people often shift between ethnic groups and reshape their identity.

Culture, which is interrelated with ethnicity and race [17, 18], is "a set of learned values, beliefs, customs, and behaviors that is shared by a common social group and is passed down through generations of family" [19]. Culture reflects and influences beliefs and values, communication styles, health beliefs, and practices [20, 21]. Through overt socialization, culture is a set of shared ideas that guide members of a group

in their interactions as they perform the tasks of everyday life. Through tacit socialization, culture includes observations, experiences, and family/group rituals, such as food preference and practices, views of well-being, health practices, and spiritual beliefs [21–24]. Multidimensional and dynamic [25], culture can penetrate social boundaries to influence several life domains including personal identity, thoughts, actions, expressions, interactions, and beliefs [26].

Culture shapes people's understanding and perceptions of the world around them by influencing how they perceive, act, and react to people, places, and objects in similar and different environments. The tendency is to confuse the individual and the group (i.e., ecologic fallacy), which can lead to mistaken assumptions and stereotyping that culture is automatically a discussion about all individuals within the culture [27]. Thus, understanding the meaning of culture presents a challenge, as it closely relates to the constructs of race and ethnicity [17, 18].

Health Disparities

Race, ethnicity, and culture are historically associated with social determinants of health, and the systematic, disproportionate differences in social determinants that negatively impact less advantaged groups are referred to as *health disparities* [28]. The World Health Organization and the Centers for Disease Control and Prevention define *social determinants of health* as "the conditions in which people are born, grow, work, live, and age" [29, 30] and the "wider set of forces and systems shaping the conditions of daily life" [29]. These circumstances, shaped by the distribution of money, power, and resources at global, national, and local levels, contribute to health inequities or the unfair, unjust, and avoidable difference in health status between groups and populations [29].

Historically, health disparities for minority populations date back to more than 300 years. These disparities are associated with the imposed distinctions between the races as described previously, from "savages" in the seventeenth and eighteenth centuries to "culturally disadvantaged," "culturally deprived," and "lower class" in the nineteenth century; African Americans were systematically viewed and treated as weak and inferior in terms of survival [31]. Racial inferiority permeated virtually every field of science, including education, psychology, sociology, biological sciences, health, and medicine [10]. These disparities continue to be a serious problem for racially diverse groups, particularly as the non-European immigrant population increases. Few inroads exist that indicate change or progress in this arena. The World Health Organization states that "The context of people's lives determines their health, and so blaming individuals for having poor health or crediting them for good health is inappropriate. Individuals are unlikely to be able to directly control many of the determinants of health" [29]. The nation's first National Prevention Strategy further asserted that "preventing disease before it starts is critical to helping people live longer, healthier lives and keeping health care costs down". Poor diet, physical inactivity, tobacco use, and alcohol misuse are just some of the challenges. Housing, transportation, education, workplaces, and environments are major elements that impact the physical and mental health of Americans [32]. Therefore, although current policy and existing solutions attempt to minimize or eliminate this racial divide, addressing ethnic and racial disparities in health care requires new approaches that maximize equity through effective engagement and better understanding and valuing of diverse cultures.

Health Equity

Achieving health equity is a challenge despite the recognition of health disparities over the past decades, as well as policies to dismantle or eliminate them [33]. *Health equity* is the equal opportunity for people to attain their full health potential, regardless of the position or circumstance determined by society. It is associated with social justice, fairness, and equitable distribution of resources [34]. Unlike *health equality*, where fairness is only the equal distribution of available health resources to different groups and populations, health equity is an approach that represents the absence of systematic disparities in both health and the determinants that can reflect disadvantage between populations. Since health disparities start early along the life course, as evidenced by infant mortality rates being twice as high for some race groups than others because of inherent disadvantages [5], achieving health equity has increasingly involved the health-care community adopting new strategies to measure disparities early and developing guidelines for reducing inconsistencies in health care [35].

Despite such efforts, as well as interventions, to address access to and the quality of care [36–38], health outcomes have marginally improved [39], and persistent disparities remain in chronic diseases, such as cardiovascular disease and cancer [39, 40]. These challenges toward achieving health equity exist due to health disparities and conditions external to clinical care settings [35, 41] as well as a complex, ever-changing health-care system [42]. Equity in health care in the current social, economic, and political climate requires transformative dialogue that is broad, inclusive, and crosscutting, relying on shared frames of thought and subsequent action that involves a diverse set of stakeholders [41]. Progress in addressing health inequities requires complementary policies to reduce inequities in other sectors, such as education, employment, housing, transportation, and public

safety. The decision-makers with the greatest power to influence health inequities work on school boards or in municipal government, legislative bodies, housing authorities, transit agencies, or the business sector [41]. Thus, in the context of social determinants, stakeholders increasingly influence health care through a much broader lens than even a decade ago. While there is modestly growing evidence of opportunities for achieving equity that reduces the burden of chronic illnesses [43], the challenge remains in the representative engagement of sectors, particularly among the most vulnerable populations [43, 44].

Cultural Competence and Community Engagement

Creating opportunities to achieve health equity through cross-cultural engagement and collaborative efforts is complex and challenging. Different and sometimes opposing cultural beliefs, power dynamics, and values about health can generate high levels of dissonance that ultimately result in inadequate or failed policies for the most vulnerable populations who have less optimal or no care. These issues, and the need for solutions, are especially critical for individuals with multiple chronic conditions, not only at the patient-provider level but also at local, state, and national levels. To engage in sector-specific discussions for meaningful dialogue with subsequent, sustainable actions, an understanding of intercultural competence is necessary [45].

Cultural competence is the ability to have knowledge of a population's cultural differences and typical behaviors or belief, which is based on the context of norms, beliefs, and practices within an organization or community [46]. Using this meaning-centered approach can reveal how community conditions are determined by social, economic, and political forces rather than simply by individual choices [46–48]. The emergence of contemporary cultural competence trainings and standards, such as the National Standards for Culturally and Linguistically Appropriate Services [49], has a goal to provide health-care providers with skills to diagnose and treat patients of color while avoiding stereotypes that generalize an individual with a culture. However, these trainings are insufficient without skills to assess one's own nonconscious or implicit biases that result in differential diagnosis and treatment and subsequently cause groups of people to become nonadherent or decline seeking care [50, 51].

To effectively address bias in health care, training in cultural competence should incorporate research on the psychology of nonconscious stereotyping and prejudice [51]. A study that examined intentions to help and report biases of medical students, based on patient race and perceived patient responsibility for their health, substantiates this point [50]. The study found biases toward African American patients, where increased perceived responsibility of the patient led to increased provider anger and decreased intentions to help the patient (e.g., extra effort to help a patient) [50]. Alternatively, a lower level of perceived responsibility of the patient led to increased provider empathy and intentions to help the patient.

Empathy, which is the ability to meet the patient where the patient is at in their self-management of their care, involves being aware of, or sensitive to, the thoughts, feelings, and experiences of another [52]. Often in these situations, providers can focus on building empathic relationship with patients to understand the larger context of their life. By doing so, treatment adherence and better health outcomes can increase. This approach to care, especially to those in vulnerable populations, cannot occur in isolation, particularly as the health-care system evolves. In recent years, community engagement has become a powerful tool for addressing health disparities and inequities [53].

Community engagement is the process of working collaboratively with groups of people that are affiliated by geographic proximity, special interest, or other affinities, to address issues affecting the well-being of the population [54]. Historically, minority communities have often used engagement in the context of community organizing to bring focus to issues requiring social change. Since the 1950s, strategies and tactics of community organizations increasingly have been applied to achieve broader social change objectives (i.e., civil rights, women's rights, gay rights, and disability rights movements). From the mid-1990s forward, groups across the political spectrum have built online communities, organizing support on a mass scale [55].

Community engagement today focuses on consensus building rather than conflict and is a multifaceted process that includes both an organizational and a community framework [56]. The organizational framework takes an "inside-out" approach focusing on processes, plans, and strategies needed to continually assess, examine, and revise the structures, practices, and policies of organizations to ensure a readiness and preparedness of service providers to render culturally competent service delivery while engaging diverse consumers. The community framework also takes an "outside-in" approach, noting that communities and leaders must be prepared to participate and engage in planning and development, committee work, and decision-making, policy development, and implementation of community programs that address disparities in health, education, and economic development.

Chronic Illness in Racially and Ethnically Diverse Populations

A disproportionate and persistent burden of chronic illnesses, most with at least one modifiable risk factor, is associated with racially and ethnically diverse populations. For example, cardiovascular disease (CVD), including heart disease and stroke, is the leading cause of death that impacts

nearly 86 million Americans with an estimated annual cost in expenditures and productivity of $320 billion [57]. Morbidity and mortality rates are nearly twice as high for African Americans than White Americans. Modifiable risk factors are also higher among African Americans, Mexican Americans, and American Indians or Alaska Natives compared to White Americans [57].

Cancer, the second leading cause of death, impacts approximately 14.5 million Americans with an estimated direct total cost of nearly $90 billion [58]. Disparities often associated with race and ethnicity, socioeconomic status, gender, and geographic location are disproportionately present for African Americans and especially women [58]. Diabetes, the seventh leading cause of death, affects an estimated 29 million Americans and is approximately $245 billion for direct medical costs and productivity [59]. Mental health is a growing problem, where racial and ethnic minorities are inefficiently addressed yet disproportionately represented and at risk for mental health disorders [60]. Mental health impacts roughly 44 million adults in the US, with 8.4 million diagnosed with a mental health and substance abuse disorder [61]. Approximately 25% of homeless adults have a serious mental illness [61]. African Americans, Hispanics, and Asian Americans are 33–50% less likely to use mental health services than White Americans [61] and more often undiagnosed, underdiagnosed, or misdiagnosed for historical, linguistic, or cultural reasons [60].

There is an emerging problem of adult comorbidities. One in four Americans has multiple chronic conditions, and these comorbidities affect three-quarters of the elderly 65 years of age and older [62]. Obesity, diabetes, and chronic kidney disease prevalence have dramatically increased in the past few decades, even after the series of studies of the metabolic syndrome. Based on analyses of data from the National Health Interview Survey, American Indians and African Americans have significantly elevated rates of comorbidities compared to White Americans and Asian Americans [63]. Although controlling for individual and environmental factors resulted in no excess risk for African Americans, comorbidities remain a major health problem.

There is also an alarming rise in chronic disease risk factors in children, specifically diabetes. Approximately 200,000 children in the USA have type 2 diabetes [63]. For example, children with type 2 diabetes are more likely to experience complications as teens and as young adults compared to children with type 1 diabetes [64]. African American children had the highest mortality rate compared to White American and Hispanic children. These deaths are considered preventable through earlier treatment, education, and diabetes management [65].

While disparities extend to other racial and ethnic populations for these and other chronic illnesses [66–70], disparate trends also exist for immigrant populations. In addition to barriers in access to care [71], Westernized acculturation contributes to excess risk of chronic disease. For instance, acculturation is associated with insulin resistance [72] and poorer dietary habits [73] among Chinese immigrant women; colorectal cancer, diabetes, and heart disease among Middle Eastern populations [74]; and patterns of overweight among Asian American and Mexican American female youth [75]. Although lifestyle factors, such as transitions in dietary habits, serve as major contributors to increased risk among various racial and ethnic populations, the complexities of different social and environmental factors (e.g., family support, healthcare access, etc.) may protect, or exacerbate, trends in health outcomes. Local, state, and national policy efforts exist to help mitigate these health disparities, but the burden remains due to the social determinants and cultural divisions that limit access to care. Race, ethnicity, and culture are part of the set of complex factors that broadly influence both health systems' and individual providers' delivery and quality of care [76].

Providing Care to Diverse Racial and Ethnic Populations

Research on race, ethnicity, and cultural influences on chronic illnesses indicates that comprehensive solutions are needed to address barriers at the patient, provider, and system levels [77]. The Chronic Care Model provides a framework for approaches to multidisciplinary, multi-level patient-centered care, recognizing the importance of self-management, the health system and delivery system design, decision support, clinical information systems, and the community [78–80]. Applying feedback from health-care systems, the modified version of the model [81] accounts for emerging trends in chronic care through the addition of five themes, including cultural competency and care coordination, both in delivery system design, and community policies in community resources and policies. These additions imply a level of commitment by providers and health-care systems in eliminating health disparities by gaining a greater understanding of cultural and community context in chronic care.

To provide effective, coordinated care for diverse racial and ethnic populations, providers need to understand the integrated burden of chronic diseases [82] at several levels: (1) provider level, (2) dyadic/communication level, and (3) organizational/health-care system level. This approach underscores an understanding of equity in access and delivery of quality care as a composition of contextual, interrelated factors rather than isolated constructs [83].

Provider Level

Ideally, health-care providers should routinely incorporate patient-centered approaches during clinical encounters and consultations, which in turn can optimize high-quality care. In terms of facilitating equity to reduce racial and ethnic disparities, the quality of these approaches is influenced by the providers' ability to provide and recommend services that respect varying cultural norms. Patient-centered approaches to care have increased in the past two decades. In a review of such interventions for providers [84], most approaches revealed a positive effect on consultations, where empathy, along with communicating treatment options, represented provider attentiveness to the patients and their concerns [84]. However, the impact of these approaches on patient satisfaction, health behaviors, and health outcomes is more mixed [84]. A survey of physicians revealed self-reports of providing good service to diverse populations. Unfortunately, this finding does not translate to adopting best practices in cultural competence when communicating with patients, since there is variability in the capacity of physicians to tailor discussions to individual patients in a way to culturally reach them [85].

Some studies indicate that provider empathy has a positive impact on client satisfaction and patient health outcomes and reduces the likelihood of malpractice [86, 87]. One study of patients with chronic pain and depression revealed that, when patients experience empathy, they also feel understood, believed, and taken seriously and that their needs were met [88]. On the other hand, lack of provider empathy can have a negative impact on their own job satisfaction [89].

Empathic provider skills are necessary to counteract or reduce implicit bias when caring for patients from diverse racial, ethnic, and cultural backgrounds. Empathy, which historically was introduced by aestheticians in the mid-nineteenth century and was expanded in the late nineteenth century as a concept meaning "feeling one's way into the experience of another" [90], can be innate for some providers and cognitively developed in others. Self-empathy is an area where training may be required, which can provide insight of seeing situations from another's perspective plus more technically based skills [90]. Greater precision in tools that can measure empathy is also needed [91, 92], as they offer ways to help providers improve their communication skills with patients who may have varying racial, ethnic, and cultural backgrounds from their own.

Variations in the quality of care may also point to other provider level factors that impact the awareness and consistency in care. Although there is more attention on the quality of care provided to racially and ethnically diverse populations, there is a growing body of literature on variations in providers' decision-making and recommendations for care. Research, for example, reveals racial and ethnic differences in providers' diagnosis of chronic disease [93], counseling and medication recommendations [94], and nonadherence despite access to care, all of which may be due to patients' lack of knowledge, fear, or varying family support received [95]. There is also evidence that some providers may still negatively stereotype patients, attributing patients' medical conditions solely to their individual behaviors, and not to the health-care system or environmental factors [96, 97]. Therefore, to improve understanding and increase awareness of the needs of diverse populations, effective communication will be a key strategy.

Dyadic/Communication Level

Effective communication is critical to establishing sustainable patient-provider relationships. This may be even more important for racially, ethnically, and socioeconomically diverse patients with chronic illnesses. Given that addressing chronic illnesses involves components of self-management, the quality of patient-provider relationships also influences patient self-efficacy [98]. Research indicates a strong relationship between patient-provider communication and patient outcomes, where better communication is associated with improved patient-reported, chronic disease-related outcomes [99]. Effective patient-provider communication is also associated with better self-management [100]. However, poorer provider communication is associated with patient perceived discrimination, lack of trust, and lack of knowledge of the patient's perspective by the provider [101].

Poor patient communication can result from reluctance to discuss self-management behaviors due to shame, guilt, or fear of judgment and is a barrier to addressing patients' chronic care needs [102]. In some instances, the barriers may be patients "not wanting to be bothersome" in their encounter with their provider [103]. Although patients and providers may endorse open and honest communication, providers may not have effective communication skills and strategies available to assist patients with the challenges of self-management [102]. For racially and ethnically diverse patients in particular, this may be a result of the cultural contexts of daily living and in negotiating a complex health-care environment. Effective, meaningful patient-provider communication during clinical encounters may be dwarfed by larger barriers to chronic care, such as lack of insurance, education materials, and provider cultural competence training [104].

The evidence based on patient-centered approaches to health care reveals that patients want to be informed and involved in the decision-making about their own care [105, 106]. The nature and context of the patient-provider relationship during encounters with providers is important [106]. To increase patient knowledge and self-efficacy,

communication strategies should address patient needs regardless of literacy or economic level. Measures such as the Ask, Understand, and Remember Assessment (AURA) serve as useful, validated tools to empower patients and can help them improve their communication, knowledge, and self-efficacy in self-management of chronic illnesses, including patients with low literacy levels [107]. The Consultation and Relational Empathy (CARE) scale is another validated tool, and it assesses patients' perceived empathy of the provider and their satisfaction with their consultative encounter [92].

For health-care providers, the Four Habits Model can assist in training providers to improve the effectiveness of their patient-provider relationships [106, 108, 109]. The model, developed at Kaiser Permanente, describes a series of four behaviors, or habits, across the clinical experience. These include the following: (1) invest in the beginning (i.e., creating quick rapport and planning the content of the visit); (2) elicit the patient's perspective by gauging the patient's understanding of the problem, understanding the patient's goal for the visit, and determining the problem's impact on the patient's life; (3) demonstrate empathy in ways that include encouraging, accepting, and responding to the patient's emotional expressions; and (4) invest in the end by focusing on effective decision-making and information sharing [108]. These habits collectively represent a contextual experience for shared decision-making, where providers can be trained to establish effective communication and relationship with the patient [106].

Organizational/Health-Care System Level

Sustainable improvement in health outcomes among patients with chronic illnesses must be a coordinated care approach at the provider and the organization or health-care system level [110]. The ability to provide integrated services that can reach vulnerable and racially and ethnically diverse populations is critical in effectively addressing health disparities. The processes for delivering such care in conjunction with health-care systems are complex, dynamic, and challenging. However, coordinated care efforts that use clinical care managers, pharmacists, allied health professionals, and community health workers, along with community outreach, patient education, technology, and medication assistance programs, can be effective at both the health organization and the community levels [42].

At the health-care system level, a cultural shift toward a socioecological framework may be necessary for comprehensively improving the quality of care [111], particularly among racially and ethnically diverse populations. The socioecological framework, used to guide public health interventions [112], posits that the greatest impact on health outcomes occurs when a pyramid of services are addressed: counseling and education, clinical interventions, long-lasting protective interventions, changing the context to make individuals' default decisions healthy, and socioeconomic factors [112]. The factors having the most robust impact are changing the context (so that the decisions patients make can be healthy) and socioeconomic factors (or social determinants of health). From a population health perspective, achieving health equity is tied to securing a range of services that are available and coordinated within communities (e.g., affordable transportation). In addition, these services reflect the cultural norms of the respective community in order to maximize healthy behaviors and actions.

Sustained preventive and clinical care services are promoted through counseling and education, strategies that are key in individuals with chronic illness and can be maximized through family support [113]. Families, whether defined as traditional, nontraditional, or extended, often provide culturally familiar support and encouragement in health care, a resource that may particularly important for patients with comorbid conditions [82]. However, to be effectively adopted at a health-care system level, such support must be viewed as aligned with value-based goals at the organization [114].

The rise in Accountable Care Organizations (ACOs), which are designed to transform health-care system delivery to value-based care, may also indirectly reduce disparities, by being responsive to resource-constrained environments [115]. In this way of thinking, improving the quality of care within health-care systems would direct attention to cultural factors that influence care in vulnerable populations. Care coordination is a core part of the ACO and recognizes that the effective delivery of care is not only based on improving the health-care structure and its incentives but also the quality of care by building skills of providers and staff in collaboration, communication, and teamwork [115]. The necessary cultural shift in the organizational/health-care system workforce requires strategies to develop skills in care coordination and approaches to include not only patient feedback but also peer feedback into the measure of performance [115].

Emerging strategies must also extend to coordinated care team members in communities, individuals who are primed to reach racially and ethnically diverse patient populations with chronic illnesses. For instance, community health workers have been a part of coordinated care for decades [116], and their cost benefit has been well established [117]. Community health workers are advocates for vulnerable populations, individuals who provide health education and outreach that can address health disparities, improve quality of services, and reduce low value care [116, 118]. These workers have the potential to improve ACO efficiencies by identifying community health issues, serving as liaisons to health-care providers and the community, and tailoring

interventions for patients with complex health and social issues [116]. However, organizational and fiscal models to integrate community health workers into ACOs remain.

Health-care strategies and models to eliminate health disparities and achieve health equity are a large, complex challenge that requires an integration of care delivery at multiple levels. Transformative strategies must (1) identify innovative opportunities to develop standards for measuring effectiveness among racially and ethnically diverse patient populations, (2) expand the workforce to be responsive to the growing needs of coordinated care, (3) implement the most effective evidence-based interventions, and (4) include patients in the decision-making of their care [42]. Efforts must involve an inclusive approach within and outside of the health-care system to optimize quality and reach in the most vulnerable populations.

Future Directions

The influence of race, ethnicity, and culture on chronic illness is complex, representing a constellation of factors that are dynamic and diverse, based often on the interface between social determinants and culture. Patients, providers, and systems can no longer operate in isolation of each other when seeking to improve health outcomes of an individual or population. New paradigms will be necessary to provide optimal care that is more responsive to the needs of populations as well as individuals. Cultural competence will be a critical area of importance for clinical and public health education in the twenty-first century [119].

One area of future emphasis will be a greater understanding and application of social determinants of health at the point of care. These factors are the fundamental drivers of health disparities and must be part of conceptualizing the clinical conditions of patients. In addition to existing populations, there will also be a growing need to understand the social determinants for more diverse immigrant populations that will be accessing health care in the future. While there are efforts to include greater awareness about these factors in clinical care, health-care systems will need to develop ways to promote partnerships with community-based organizations that can help augment needed services. Partnerships may include an expansion of coordinated care initiatives and the development of new models that more effectively link services to ensure the availability of care, even in remote locations. Health information technology applications will play a role in this expansion but must account for education and literacy levels, as well as cultural competency in end users.

Another future direction will be approaches to address and mitigate implicit bias among health-care providers across the workforce spectrum. The development and utilization of interventions to increase provider skills in recognizing and addressing these biases will be especially important. Given the evidence that building trust can positively impact health behaviors and outcomes and that quality communication is associated with patient satisfaction, providing capacity to build and subsequently demonstrate skills that address personal biases and vulnerabilities in perceptions of others may further optimize patient-provider relationships. The use of service learning models to develop these skills for working with vulnerable populations will be key [120]. However, addressing these biases should not just be limited to patient-provider relationships but also inclusive of peer-to-peer provider relationships.

A third future direction will be a concerted focus on implementing evidence-based prevention strategies. There is increased pressure to build and implement care models that address health and lifestyle behaviors that intersect with chronic illness, such as physical activity, nutrition, and smoking cessation. However, the emergence of dissemination and implementation science is in its relative infancy. While comparative effectiveness research seeks to identify the best strategies to promote health outcomes, clinical and pragmatic trials that include racially and ethnically diverse populations are often not designed to determine the nuanced differential effects of race, ethnicity, and culture in these populations. For health policy to be truly evidence-based, a greater number of interventions should be tested in these populations and take into account community and other stakeholder inputs to promote effectiveness, implementation, and dissemination.

Lastly, a new set of workforce skills will be needed to better address chronic illness in diverse populations. Training programs designed to improve communication and increase provider interpersonal skills should include educational opportunities for care teams, including nontraditional team members like community health workers. The adoption of policies for shared learning, whether through ACOs or other organizations and health-care systems, is a necessary step to shift the work culture toward optimal care that is more inclusive of social determinants and cultural contexts.

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Chronic Disease Self-Management

3

Hazel Tapp, Michael Dulin, and Marcus Plescia

Introduction

Chronic conditions, such as heart failure, chronic obstructive pulmonary disease (COPD), stroke, diabetes, and arthritis, are among the most common, costly, and preventable of health problems. About half of all adults in the USA (117 million people) live with one or more chronic health conditions, and one-quarter of adults have two or more chronic diseases [1]. Patients with chronic health problems consume over 85% of healthcare costs. Enhancing patient engagement with self-management, shared decision-making, and peer support improves medical care and quality of life. Redesigning and implementing healthcare delivery systems in a way that supports self-management improve outcomes and reduce costs. These principles have been proven effective in several chronic diseases.

Patient-Centered Care

Providers are challenged by the realities of dealing with chronic diseases for which daily care is in the hands of the patient. Despite attempts to encourage, cajole, and persuade patients to perform self-care tasks, clinicians are often frustrated and discouraged when patients are unwilling or unable to follow advice and achieve desired outcomes [2]. To manage chronic diseases successfully, patients must set goals and make frequent daily decisions that are both effective and fit their values and lifestyles while taking into account multiple physiological and personal psychosocial factors. Intervention strategies that enable patients to make decisions about goals and therapeutic options are effective in helping patients care for themselves. In the past, most health profession training was based on a medical model designed to treat acute healthcare problems. Newer approaches recognize that patients are in control of and responsible for the management of their chronic conditions, and effective treatments must include strategies that fit patients' goals, priorities, and lifestyle [3].

Empowerment

Many models have been developed for patients with diabetes, and these concepts are generalizable to the majority of chronic diseases. Empowerment is a patient-centered, collaborative approach tailored to the realities of diabetes care [3]. Empowerment is not a technique or strategy but rather a vision that guides each medical encounter and requires that both professionals and patients adopt new roles. The role of patients is to be well-informed active partners in their own care. The role of the health professional is to help patients make informed decisions to achieve their goals and overcome barriers through education, appropriate care recommendations, expert advice, and support. Providers give up feeling responsible for their patients and become responsible to them. People with chronic illness have shifting perspectives due to the waxing and waning of the disease as well as psychological factors that affect treatment [4]. Self-management empowers and prepares patients to care for their health, keeping wellness as a focus. This is done by concentrating on three tasks—medical management, role management, and emotional management [2, 5]. The first task is the medical management of the condition such as taking medication, adhering to a special diet, or using an inhaler. The second task involves creating, changing, and maintaining meaningful behaviors or life roles. For example, people with back pain may need to change the way they garden or participate in favorite sports. The third task addresses emotions such as anger, fear, frustration, and

H. Tapp (✉)
Carolinas Healthcare System, Department of Family Medicine, Charlotte, NC, USA
e-mail: Hazel.Tapp@carolinashealthcare.org

M. Dulin
UNC Charlotte, Public Health Sciences, Charlotte, NC, USA

M. Plescia
UNC Gillings School of Global Public Health, Chapel Hill, NC, USA

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depression, which are commonly experienced by people with chronic diseases. Acknowledging these emotions is part of the work required to manage the condition. Self-management is key to chronic disease management and requires setting goals, collecting and interpreting information, and making decisions, action, and self-efficacy [6]. Successful self-management depends not only on education but also on the development of self-efficacy and resilience [7]. Perceived self-efficacy refers to the patient's belief in his or her capability to organize and execute the courses of actions required to attain a goal [7, 8]. Self-efficacy implies a level of confidence that the patient can achieve certain behaviors or physiological states. Both baseline self-efficacy and changes in self-efficacy are associated with future health status. Enhanced self-efficacy by learning self-management improves health status.

The Chronic Care Model

There are three facets to integrating self-management interventions into the healthcare system: (a) preparation of the system, (b) preparation of patients, and (c) payment mechanisms. A well-known description of chronic disease management is Wagner's Chronic Care Model [9] which is a comprehensive approach that includes self-management and system integration [10]. The model is population-based and creates practical, supportive, evidence-based interactions between an informed, activated patient and a prepared, proactive practice team. The elements are the community, health systems, self-management support, delivery system design, decision support, and clinical information systems (Fig. 3.1). Evidence-based change concepts foster productive interactions between informed patients who take an active part in their care and providers with resources and expertise.

Shared Decision-Making

Shared decision-making is the ideal model of interaction between patients and providers [11]. The shared decision-making approach engages patients and their healthcare providers as equal partners in making decisions about medical tests and treatments under consideration. Providers contribute knowledge and expertise about the medical condition and treatment options, while patients bring perspective on their own personal values, lifestyles, and beliefs. Shared decision-making approaches that teach self-management show improved outcomes and reduced costs [12–14]. Shared decision-making uses a framework upon which information is shared and a patient's preference is supported by a deliberative process based on *choice*, *option*, and *decision talk* [15]. Introducing choice, describing options, and helping patients explore preferences and "what matters most" lead to decisions. The Agency for Healthcare Research and Quality (AHRQ) promotes a five-step process that explores and compares the benefits, harms, and risks of each treatment option through meaningful dialogue about what matters most to the patient [16]. Known as the SHARE approach, the process instructs providers to *s*eek your patient's participation, *h*elp your patient explore and compare treatment options, *a*ssess your patient's values and preferences, *r*each a decision with your patient, and *e*valuate your patient's decision.

Peer Support

Peer support is practical, social, and emotional support from a person who has knowledge from his or her own experience with a chronic disease or health problem (Fig. 3.2) [17, 18]. In order to integrate this approach into policy, it must be grounded within a theoretical framework that promotes

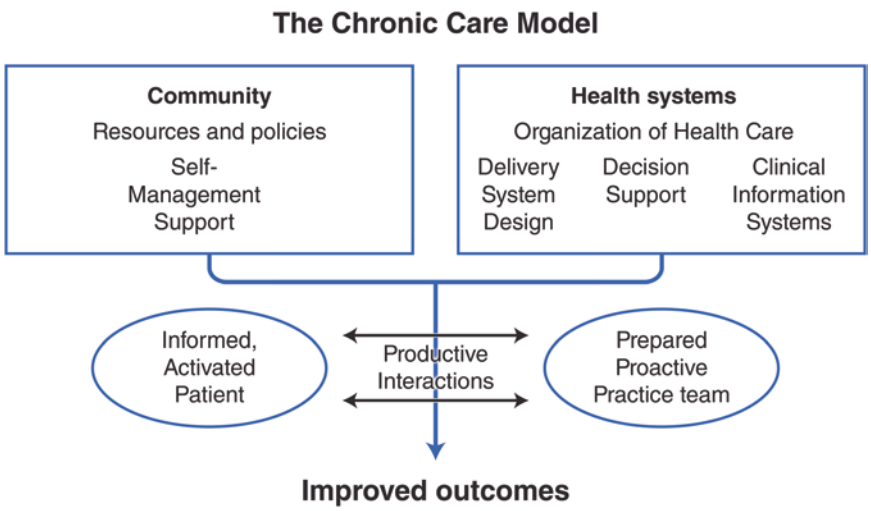

Fig. 3.1 The chronic care model identifies the essential elements that encourage high-quality chronic disease care. The model can be applied to a variety of chronic illnesses, healthcare settings, and target populations

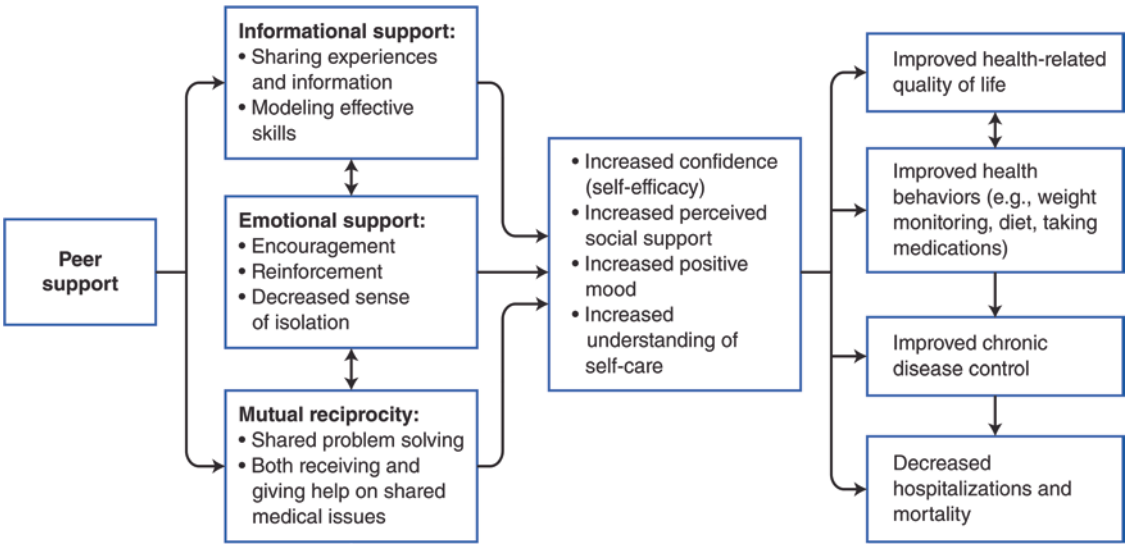

Fig. 3.2 Peer support can improve chronic disease outcomes [17]

advocacy. The Institute of Medicine provides a framework that addresses the individual, family, home environment, community, and primary care provider within the broader context of the healthcare system [19]. Peers can provide the ongoing support needed for sustained self-management, which can otherwise be short-lived. Peer support is a powerful and affordable tool for facilitating the kind of knowledge, skills, encouragement, and linkages to resources that people need to adopt to maintain healthy behaviors (http://peersforprogress.org/learn-about-peer-support/). Peers understand the challenges facing their community, thus allowing them to function as "barrier busters" to help community members access and utilize healthcare services. Peer support improves chronic disease outcomes by strengthening community connections between the medical practice and the home environment and supporting patient-centered care such as shared decision-making [20, 21]. Diabetes care is a good example of a chronic disease where most of the management is carried out by patients away from the medical office. Many patients face difficulties carrying out this self-management task and often do not have effective support from family members and friends. Peer support programs provide social and emotional support, assist patients in daily management, and promote linkages to clinical care [22, 23].

Deploying Self-Management into Practice

Providers are challenged to provide care and recommendations regarding chronic disease within the constraints of a busy office setting. The current healthcare system is designed to deliver acute symptom-driven care and is poorly configured to support effective treatment of chronic diseases, which requires the development of a collaborative self-management plan. Evidence on best practices in terms of changing delivery systems is still developing, but effective concepts include strategy development, rapid cycle process improvement, and implementation of the chronic care model.

There are two dimensions to the process of patient empowerment: an interpersonal dimension and an intrapersonal dimension [24]. As a result, empowerment may be apprehended from the provider-patient interaction, from the patient alone, or from both, as in shared decision-making. Primary care/family medicine is a suitable setting for promoting patient empowerment, given its provision of continuous, comprehensive, and coordinated care. Tools such as electronic health records, interactive tools for health coaching, decision aids, and decision support for both health professionals and patients are developing rapidly [25, 26]. Practices can also help patients access community and online resources. All this teaching culminates in the ability of the patient to take action that may include a short-term response to a medical issue or a long-term behavior change. Patient self-efficacy is key to behavior change. Patients with high self-efficacy expectancies—the belief that one can achieve what one sets out to do—are healthier, more effective, and generally more successful than those with low self-efficacy expectancies. Practices and providers can support efficacy through appropriate training [2, 7].

Current guidelines from the American Diabetes Association, the American Association of Diabetes Educators, and the Academy of Nutrition and Dietetics state that it is important for healthcare providers and their practice settings to have the resources and a systematic referral process to ensure that patients with type 2 diabetes receive both diabetes self-management education and support in a consistent manner [27].

The initial diabetes self-management education is typically provided by a health professional, whereas ongoing support can be provided by personnel within a practice and a variety of community-based resources. Diabetes self-management education and support programs are designed to address the patient's health beliefs, cultural needs, current knowledge, physical limitations, emotional concerns, family support, financial status, medical history, health literacy, numeracy, and other factors that influence each person's ability to meet the challenges of self-management.

Rapid Cycle Process Improvement

The Agency for Healthcare Research and Quality (AHRQ) and the Institute for Healthcare Improvement (IHI) recommend rapid cycle process improvement to implement practice change. New ideas start with pilot projects that use the framework of a PDSA cycle where an intervention is *p*lanned, implemented on a small scale (*d*o), and evaluated to determine impact and opportunities to improve with a *s*tudy step, with resultant information that allows the group to *a*ct (Fig. 3.3). This approach can help healthcare teams adopt new practices that help meet goals as well as train staff and providers on ways to support self-management.

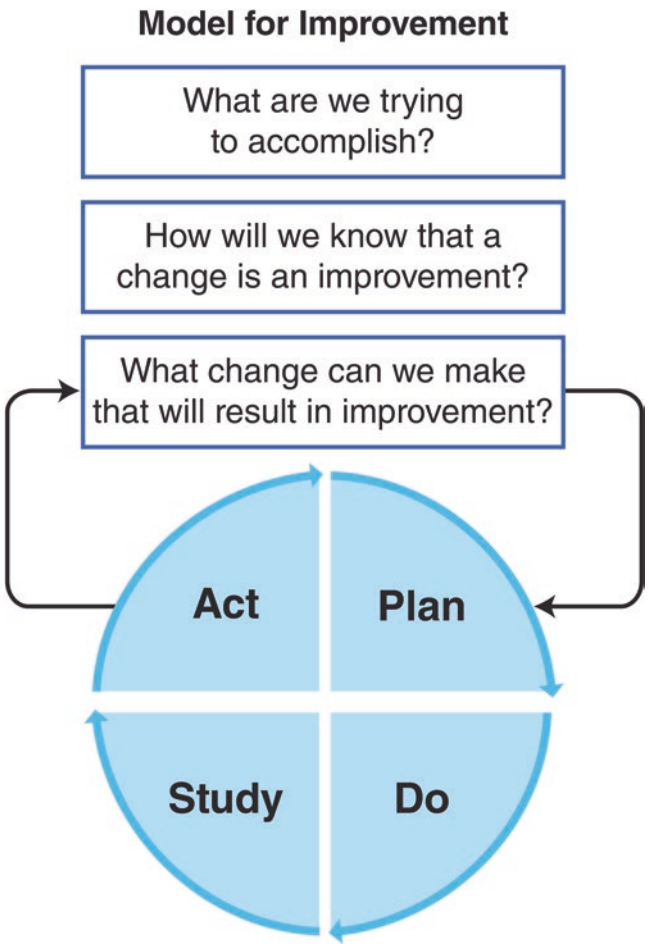

Fig. 3.3 The PDSA framework for changing practices

Setting Practice Goals

Changing practice to accommodate new models of care in managing patients with chronic diseases requires a strategy that drives the changes. This starts with the collection and review of data describing providers' baseline clinical performance, comparison of performance with benchmarks from similar organizations, and creation of goals. The clinical data is collected from electronic medical record systems and/or claims reports for patients with one of more chronic diseases. Standard metrics are then used to establish best practice goals. The metrics are available from the Healthcare Effectiveness Data and Information Set (HEDIS) from the National Committee for Quality Assurance (NCQA). Using this data, providers can work with their healthcare system to improve their performance and meet agreed-upon goals. These goals include *process measures*, such as completion of a foot exam in a patient with diabetes, and *outcome measures*, such as hemoglobin A1C levels in patients with diabetes. Process measures support the goal of perfect care delivery, while outcome measures reflect the number of patients meeting preset criteria. Large healthcare systems may combine the measures from all providers to create composite metrics that reflect aggregate clinical performance for a large number of diverse clinical practices. Many systems incentivize improvement by linking payment to providers and practices based on their attainment of the clinical goals. Performance data is transparent, and individual providers generally want to improve their numbers. Improvement depends on both individual effort and teamwork. Since outcome measures also depend on the patient doing his or her part to manage the chronic disease, practices find ways to engage patients and support self-management and shared decision-making.

Practical Approaches to Self-Management

Self-Management at Home

Self-management increases self-sufficiency, reduces costs, and is best accomplished by shifting healthcare to home and community settings. Self-efficacy aims to have patients solve their own problems though the provider or other members of the healthcare team are available as partners. Information technology provides the opportunity for virtual partnerships that supplement physical visits to the clinic, allowing the management of the patient's chronic illness to be readily

integrated into one's life [28]. Consumer health informatics is an emerging field where applications such as remote monitoring systems, personal health records, decision support systems, and online health communities support patients' efforts to self-manage. Diabetes health informatics tools show moderate but inconsistent effects on a variety of psychological and clinical outcomes including optimizing blood sugar management and controlling weight. Although some positive outcomes have been seen, they have not yet proven to be clinically significant [29]. Some of the most successful uses of mobile technology involve text messaging. Mobile phone alert interventions can increase desired health behaviors such as adherence to medications or other health-related activities [30]. For example, patients with asthma are often not compliant with their medications, and targeted text messages increase adherence to asthma maintenance inhalers [31]. Other effective text-messaging interventions are those addressing diabetes self-management [32, 33], weight loss [34], physical activity [35], smoking cessation [33], and medication adherence [36] [37]. However, there is limited evidence to inform recommended intervention characteristics. Although strong evidence supports the value of integrating text messaging into public health practice, additional research is needed to establish longer-term intervention effects, identify recommended intervention characteristics, and explore cost-effectiveness [38].

The telephone and the Internet are additional tools for self-management support at home. Tobacco cessation telephone quitlines offer convenient self-management support to smokers. Participating in three or more quitline counseling sessions increases the odds of quitting compared to receiving self-help materials, brief advice, or pharmacotherapy [39–41].

Encouraging Self-Management

One way to offer self-management in the clinical setting is by implementing models developed around self-management such as the Prochaska-DiClemente stages of change transtheoretical model [42] which offers a framework for designing patient-centered self-management programs. In one example, a clinical site used the stages of change concepts and created communication and self-management tools for each stage of change. For patients in the precontemplation stage, posters with messages and a project logo were developed and placed around the clinic. For those in the contemplation stage, clinics had a "Wall of Fame" with pictures and testimonials from local people who had adopted self-management behaviors. A self-assessment form for those in the preparation stage indicated patients' stage of readiness to adopt a behavior change. For patients in the action stage, the project staff created informational and action-planning booklets around each message. Patients in the maintenance stage were given a "passport" booklet to monitor their progress. Patients in the action and maintenance stages were also referred to support groups, group exercise classes, and the Stanford Chronic Disease Self-Management Program (CDSMP), which was offered at the health centers. The CDSMP is a workshop for people with different chronic diseases. It teaches the skills needed in the day-to-day management of treatment and to maintain and/or increase life's activities [43, 44]. This program supports patients with chronic disease and their need to make decisions in response to changes in their condition [7]. It also requires the knowledge necessary to meet those common changes, such as recognizing a proper amount of exercise or when a symptom is medically serious. Practices can help patients form partnerships with their healthcare providers who play the role of teacher, partner, and professional supervisor.

Health Literacy

Inadequate functional health literacy impacts self-management in chronic disease. Clinicians and practices need a useful roadmap for implementing strategies that support care for people with limited health literacy. Practices need tools that are concise and actionable and are not perceived as being resource intensive such as those contained in the Health Literacy Universal Precautions (HLUP) Toolkit [45]. One health literacy tool is the teach-back method, where patients are asked to repeat back instructions given by the provider. Another health literacy tool is Ask Me Three, an educational program that encourages patients and families to ask three specific questions of their providers to better understand their health conditions and what they need to do to stay healthy. The questions include "What is my main problem?" "What do I need to do?" and "Why is it important for me to do this?" Designed by health literacy experts, Ask Me Three is intended to help patients become more active members of their healthcare team and provides a platform to improve communications between patients, families, and healthcare professionals. Typically health literacy tools are organized into four categories: improving spoken communication, improving written communication, improving self-management and empowerment, and improving supportive systems.

Group Visits

Many self-management interventions can be delivered with group visits, which can reduce costs and provide peer support. Individual interventions are often justified on the basis that the intervention can be tailored to individuals' needs, and they might also be easier to integrate into clinical practice. Evidence on the effectiveness of group versus individual delivery is

scarce because comparisons are confounded by many other differences. One study involving patients with diabetes [46] compared group and individual care and reported that the group-based intervention resulted in greater improvements in blood glucose at 6-month follow-up; however, no differences were recorded for any other outcomes [47].

Case Management

Under the current fee-for-service payment system, finding the resources to develop and implement new models of care can be difficult. Moreover, to improve clinical outcomes, new resources need to be devoted to facilitate care outside the office. Case managers are the ideal members of the healthcare team to extend care from the office to the community. Case managers are trained in methods of self-management such as motivational interviewing, finding resources, addressing social issues, and providing encouragement. Community Care of North Carolina (CCNC) is a successful model involving active case management in a partnership between a large funder of healthcare (Medicaid) and primary care physicians. This program demonstrated improvements in quality of care while reducing resource utilization and costs in the management of care for Medicaid recipients across North Carolina [48].

Motivational Interviewing

Skill mastery requires the active involvement of patients in behavior change. Motivational interviewing is a counseling approach that helps patients resolve ambivalence about health behavior change by exploring actual and ideal behaviors [49, 50]. In motivational interviewing, providers express empathy, develop discrepancy, avoid argumentation, roll with resistance, and support self-efficacy. Motivational interviewing supports the self-management concepts of internal over external motivation, collaboration, and being respected for one's perspective. A component of motivational interviewing is assessing a patient's confidence in his or her ability to make a recommended change, often by using a scoring scale between 1 and 10. If the answer is less than seven, the plan can be adapted or changed. Physicians can be trained in motivational interviewing and successfully assist patients in choosing behavior-specific self-management goals (e.g., walking 1/2 h every other day) using techniques such as open-ended questions, affirmation, reflection, and summarizing (Fig. 3.4) [49, 51]. There is considerable evidence for the effectiveness of motivational interviewing (MI) in the treatment of chronic diseases [52].

Examples of Self-Management in Chronic Disease

Asthma

Asthma is a chronic lung disease that affects both children and adults and has significant morbidity and mortality. More than 23 million people in the USA are affected with asthma, including approximately seven million children [53, 54]. Asthma in the USA annually accounts for 14 million physician office visits, 2 million emergency department visits, 504,000 hospitalizations, and over 4200 deaths while costing $15 billion for direct medical management [55–57].

Despite advances in medical knowledge, poor outcomes and disparities for patients with asthma persist. Self-management is a strategy developed to improve asthma outcomes. Shared decision-making in outpatient clinical settings improves asthma outcomes and satisfaction with care [58–62]. Patients and their healthcare providers make joint decisions about medical tests and treatment with the patient sharing his or her personal values, lifestyle, and beliefs, while the provider contributes knowledge and expertise. It is important that providers include patients and/or parents when determining treatment goals [63]. Shared decision-making approaches that teach self-management improves outcomes and reduces costs [64–67]. A randomized controlled study by Kaiser Permanente (the BOAT study) showed that use of the asthma shared decision-making toolkit that involved patients in the negotiation process about treatment decisions significantly improved both clinical outcomes and patients' adherence to asthma control medication [8]. During an asthma visit, non-physician providers such as pharmacists, nurses, or patient educators functioned as health coaches and assessed patients' perception of asthma control, provided basic asthma education, and elicited patients' goals for treatment [60, 65, 66]. Providers helped each patient determine relative priorities for medication options regarding symptom control, regimen convenience, avoidance of side effects, and medication cost. Each patient's actual level of severity or control was reviewed, which was often found to be worse than the patient originally thought. The provider and patient/parent then negotiated a treatment regimen that accommodated the patient's goals and preferences. The patient/parent was shown a list of age-appropriate treatment options for all levels of asthma severity and control, based on national asthma guidelines [68]. The treatment options varied regarding the number and type of medications, their dosing schedule, and the method of delivery. Using a simple worksheet, the patient and clinician compared the pros and cons of the options, taking into account the patient's attitudes and beliefs regarding medications. The option of continuing with the patient's current treatment, even if inadequate such

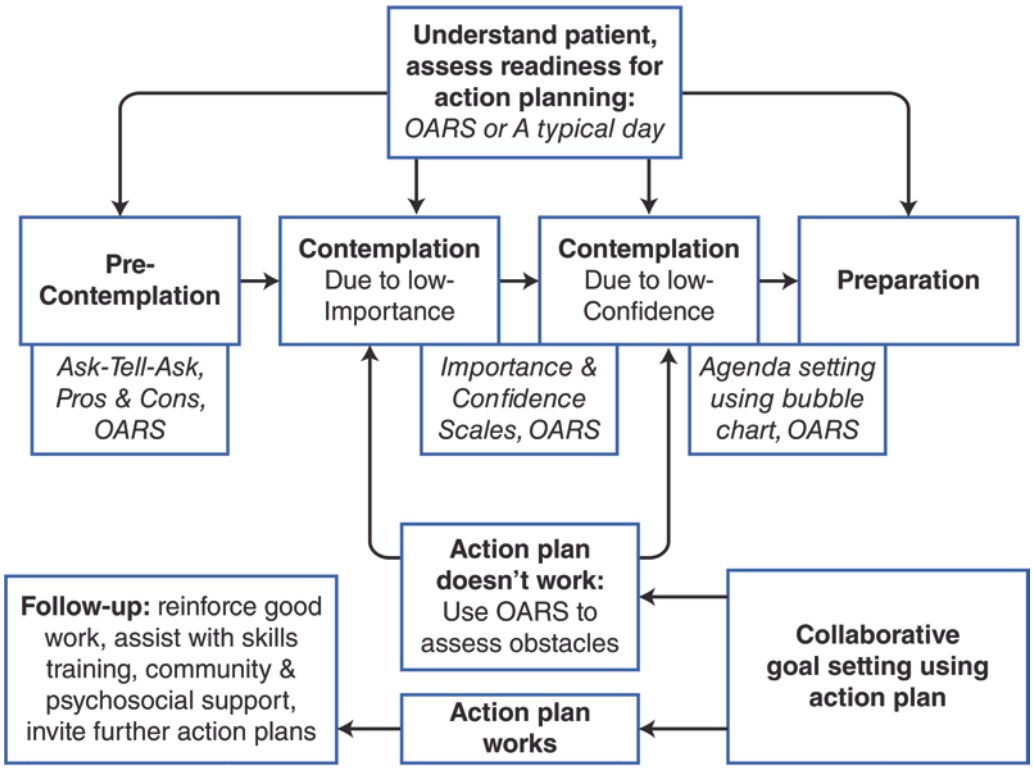

Fig. 3.4 Self-management support linked to brief motivational interviewing tools (italicized) and stages of change [51]. Abbreviations: *OARS* open-ended question, affirmation, reflection, summarizing

as only a rescue inhaler, was always included. After then also considering the added factors of which medications were available and covered by the patient's formulary, a treatment plan was selected [69]. Figure 3.5 outlines this shared decision-making intervention for asthma.

Diabetes

Stanford University's Chronic Disease Self-Management Program (CDSMP) is a successful model of care for patients with diabetes [70]. CDSMP was developed and evaluated in the early 1990s, recognizing that physician care is only part of the disease management process and that persons with chronic conditions must be good self-managers [71–73]. Workshops take place in community settings once each week for 6 weeks and provide tools and support for becoming positive self-managers. The CDSMP is based on years of research addressing patient self-efficacy and is built on several underlying assumptions, including [1] people can learn skills needed to better manage their diseases; [2] people with chronic conditions have similar challenges, regardless of the type of condition; [3] people with chronic conditions deal not only with their disease(s) but also the impact it has on their lives; [4] laypeople with chronic conditions can, when given a detailed leader's manual, teach the CDSMP as and perhaps more effectively than can health professionals; and [5] the way in which the CDSMP is taught is as important as the subject matter being conveyed. The CDSMP is effective across socioeconomic and education levels, settings, populations, and chronic conditions and results in statistically significant and measurable improvements in physical and emotional outcomes and in self-rated overall health and health-related quality of life. Peer leaders who facilitate each workshop have chronic conditions and act as "models," because participants tend to have a greater sense of trust when workshops are led by people facing similar challenges and problems. Topics covered include techniques to deal with frustration, fatigue, pain, and isolation; appropriate exercise for maintaining and improving strength, flexibility, and endurance; appropriate use of medications; communicating effectively with family, friends, and health professionals; nutrition; and how to evaluate new treatments.

In one national study involving participants over at least 1 year who used both Web-based and face-to-face workshops, the CDSMP was associated with clinically significant benefits including better sugar control, less depression, better medication adherence, and improved exercise. The majority of the participants had meaningful improvements in at least one of these areas. This study demonstrates that a peer-facilitated program, offered outside of the traditional healthcare system, can help patients improve their diabetes

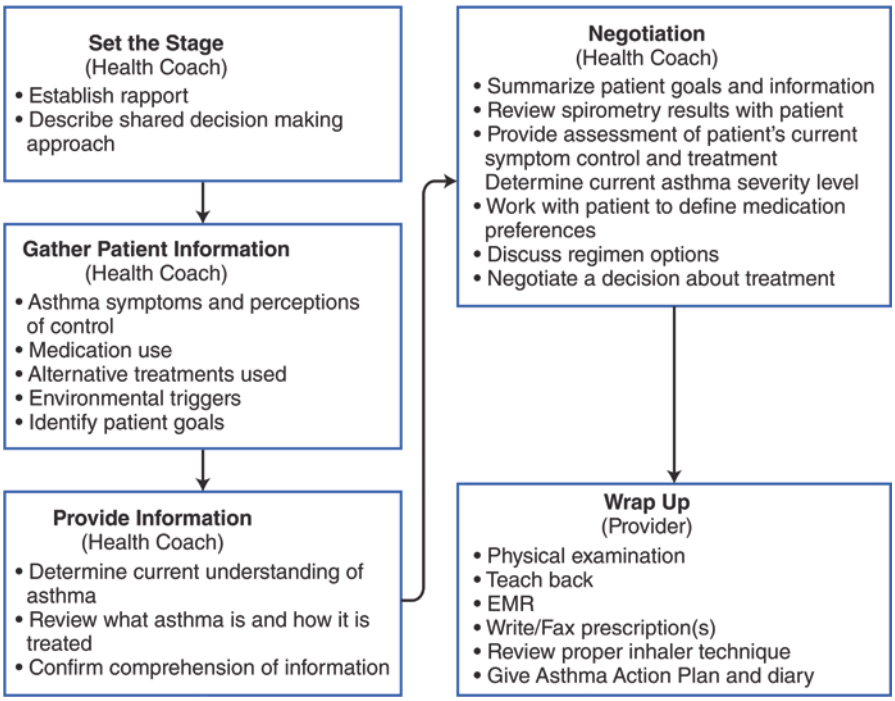

Fig. 3.5 Shared decision-making intervention for asthma [15, 60]

management, with benefits persisting for at least 1 year [70]. An evidence-based self-management curriculum called Living Healthy in NC (North Carolina), based on the CDSMP, uses peer-to-peer learning to improve the ability of persons to manage their diseases, including diabetes and other chronic conditions [74]. This program was implemented through partnerships within and between multiple systems and was adopted by the state's Division of Public Health as part of an effort to improve chronic disease self-management. Living Healthy with Diabetes is a similar program that targets individuals with type 2 diabetes. These programs are the leading providers of chronic disease self-management services in North Carolina and have involved thousands of patients since 2005 [74].

Medication Management

Anticoagulation with warfarin improves outcomes for patients with several conditions such as atrial fibrillation and recurrent deep vein thrombosis. However, management of warfarin is complex and requires frequent blood testing with subsequent dose adjustment based on the result. Advances in testing technology now allow for the blood to be tested using a finger-stick sample drawn by the patient at home. Patients taught self-management techniques are able to collect the blood sample, review the result, and then use a personalized treatment guideline to adjust their medication. This is a safe and effective management option for patients when provided with guidelines and medical support. Patients must successfully complete a structured training course and must be willing to accept the responsibility for self-management. The ability to learn how to perform self-management is not associated with a defined age group; however, both age and comorbidity correlate with outcomes [75].

Cost-Effectiveness Associated with Self-Management

There is increasing need for chronic disease self-management interventions to not only provide health benefits but also reduce healthcare costs. Diabetes is expected to take an increasingly large financial toll in the future. It is projected that one in three individuals will have type 2 diabetes by 2050 leading to unsustainable associated cost, given that the cost of diabetes in the USA in 2012 was already $245 billion [76, 77]. The US healthcare system will be unable to afford the costs of care unless incidence rates and diabetes-related complications are reduced. Generalized programs for self-management offer great potential for cost savings [27].

For example, the CDSMP has been shown to help participants improve their health behaviors and health outcomes and reduce healthcare utilization. The program for diabetes reduced visits to the emergency room (5%) and hospitalizations (3%) among CDSMP participants. This equates to a potential net savings of $364 per participant and a national savings of $3.3 billion if 5% of adults with one or more chronic conditions were enrolled [78]. Other diabetes self-management education and support programs have been

shown to be cost-effective by reducing hospital admissions and readmissions [79–81], as well as reducing lifetime healthcare costs due to fewer medical complications [82]. Self-management programs for asthma have shown similar reductions in readmissions and associated cost savings [25, 83, 84]. A heart disease management program utilizing a self-regulation process tailored to older women showed 46% fewer inpatient days and 49% lower inpatient costs [85]. One aspect of self-management is improved medication adherence, the cost of which is more than offset by lowering other healthcare costs. One study looked at medical costs in patients with one of four chronic conditions that are major drivers of spending (diabetes, hypertension, hypercholesterolemia, and heart failure). For patients with diabetes, hypercholesterolemia, or hypertension, a high level of medication adherence was associated with lower disease-related medical costs. For all four conditions, hospitalization rates were significantly lower for patients with high medication adherence [86].

Future Trends in Self-Management

Developing effective self-management will improve clinical outcomes and patient satisfaction and lower healthcare spending. Mobile technologies including text messaging, patient data self-reporting, and telemedicine are likely to play an increasing role in the provision of individual support to patients with chronic disease. Regardless of the specific self-management strategy, patient and healthcare provider adoptions are crucial [87]. The effectiveness, efficiency, and patient-centeredness of the various tools remain to be determined. Health informatics show promise, but the actual use of such applications is often suboptimal, particularly over time [88]. Although there is evidence suggesting benefit, high-quality trials of optimized interventions are required to evaluate effects on objective outcomes [30]. For example, in the field of text messaging, there is a need to assess the relative effectiveness of specific text messaging delivery characteristics, such as frequency of messaging, timing of delivery, duration of interventions, interactivity of text messaging interventions, and impact of complementary interventions and communication modalities [38].

Electronic patient diaries have the potential to enable patients to collect health data autonomously, increasing self-reliance and reducing strain on health professionals [87]. Diaries can be used for recording disease symptoms, medication adherence, exercise, and food intake. By deploying patient diaries on mobile platforms, health data can be collected and entered at any time and place, which is convenient for patients with chronic disease who may need to enter health data frequently. Mobile units can provide immediate feedback with clinical decision support software. New frameworks will integrate informatics into daily routines with consideration given to activity and context [89]. These programs will be adapted to the patient's work environment and will accommodate differences in culture and socioeconomic status. Insight from social science and human behavior will enhance the development of these applications.

Telecommunications technology (telemedicine) that connects providers and patients who are geographically separated or require a more cost-effective or convenient approach to care has significant potential in the management of chronic disease [90, 91]. Using electronic games to improve self-management is a trend with promise, especially for people in the younger demographic. Gamification is defined as the implementation of common and enjoyable mechanics of video games into non-video game contexts [92]. Gamification mechanics are found in several mobile health applications and may improve self-management. Currently only a few applications are available in the context of healthcare and as a strategy for self-management [92].

Social media such as Facebook, online support groups, discussion forums, chat rooms, and meet-up groups offer an ever-increasing capacity to improve self-management in chronic disease. These media can provide social support, information, insight, and a sense of meaning in the opportunity to share with others. Users may choose to be active or passive (mainly absorbing, rather than actively participating). Social media use can empower patients [93].

Technology interventions have the potential to improve health outcomes if they promote patient engagement that is tailored to the individual [94]. This will play a significant role in the future of self-management of chronic disease.

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Tobacco Use and Dependence

4

Carol E. Ripley-Moffitt and Adam O. Goldstein

Introduction

In the USA, prevalence of cigarette smoking among adults fell to 15% (36 million people) in 2015 [1], the lowest since a peak of 42% in 1965 [2]. However, disparities exist by region, state, race and ethnicity, socioeconomic status, occupation, and in vulnerable populations, such as the LGBTQ community. In medical practice, smoking by people with one or more chronic diseases, including mental health and substance use, remains significantly higher than those with no comorbidities [3].

Despite progress, tobacco use and dependence remain the number one preventable cause of disease and death in the USA. Globally, tobacco use causes 6 million deaths each year and is projected to be responsible for 8 million deaths annually by 2030. Deaths caused by tobacco use include 30% of cancer deaths, including lung, bladder, cervical, colorectal, liver, pancreatic, stomach, esophageal, laryngeal, and oropharyngeal and myeloid leukemia, and one out of three cardiovascular deaths [4, 5]. In addition, for every person who dies from tobacco-related disease, 30 more people suffer debilitating chronic illnesses, including diabetes, decreased immune function, rheumatoid arthritis, hip fractures, vascular disease, chronic obstructive pulmonary disease, blindness, cataracts, strokes, and pneumonia [5]. Exposure to secondhand smoke increases risk of premature death and disease for people who have never smoked and negatively impacts fetal development as well as the health of infants and children [6, 7]. In the USA, illness related to tobacco use costs more than $300 billion annually, which includes direct medical care for adults and lost productivity [5, 8].

C.E. Ripley-Moffitt (✉)
UNC Nicotine Dependence Program, UNC School of Medicine, Department of Family Medicine, Chapel Hill, NC, USA
e-mail: carol_ripley-moffitt@med.unc.edu

A.O. Goldstein
UNC Tobacco Intervention Programs, UNC School of Medicine, Department of Family Medicine, Chapel Hill, NC, USA

Since the 1964 US Surgeon General's report on smoking and health, a comprehensive tobacco control strategy has sought to decrease the initiation and prevalence of smoking through public health policy initiatives such as clean air statutes, media campaigns, taxes on cigarettes, and comprehensive state programs, including Quitlines, to provide effective treatment for those who use tobacco. Despite advocacy for health-care system change that supports treatment, evidence-based interventions remain underprescribed or underemployed by providers and underutilized by patients [9, 10].

Tobacco Use and Chronic Disease

Tobacco Use as a Chronic Disease

The US Public Health Service's 2008 update on Treating Tobacco Use and Dependence includes 10 key recommendations, with the first stating:

> Tobacco dependence is a chronic disease that often requires repeated intervention and multiple attempts to quit. Effective treatments exist, however, that can significantly increase rates of long-term abstinence. [11]

Only a small minority of people who use tobacco are able to achieve long-term abstinence in an initial attempt. The experience of most involves multiple attempts, many unassisted, with periods of abstinence followed by periods of relapse, hence the ongoing, chronic nature of tobacco use. Like managing blood pressure or diabetes, providers who approach tobacco use as a chronic disease will be more likely to include at least brief interventions in every patient encounter, give patients more realistic expectations about achieving success, view relapse with less judgment and greater support, and take less personally a patient's inability to follow through on advice or recommendations. As in treatment for hypertension, adjusting doses and trying different medications may be needed before patients see success. Identifying sources of support for changing routines, rituals, and patterns

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of life that have become associated with tobacco use will be necessary to sustain progress while using medications.

Viewing tobacco dependence as a chronic illness is also related to the changes in brain chemistry from use of tobacco and the effects of nicotine and other chemicals involved in the upregulation of nicotine receptors and brain function. Many chronic medical conditions related to substance use are marked by biological changes. When people stop using tobacco, physiologic changes in the brain result in withdrawal symptoms. Whether the site of disease is in the lungs (asthma), the adipose tissue (diabetes), or the nucleus accumbens (tobacco dependence), it deserves the same attention for treatment [12].

The unintended consequences of de-normalizing tobacco use in society include negative stigma with an increased sense of isolation and judgment felt by people who continue to smoke. This stigma can be felt in medical practices as well. Patients state that they are more likely to report smoking fewer cigarettes or not smoking at all if they anticipate a lecture from their providers. They prefer a show of understanding about the difficulty of stopping tobacco use and support and resources that set them up for success [13].

Impact on Other Chronic Diseases

In addition to seeing tobacco use as a chronic condition, it has significant impact on other chronic conditions. Tobacco use, and specifically smoking, damages nearly every part of the body [5] (Fig. 4.1). Although prevalence of smoking in the general US population has declined, smoking by people with one or more chronic conditions has declined little if at all. From 2005 to 2013, adults with asthma, diabetes, heart disease, hypertension, and substance abuse did not reduce their rate of smoking compared to adults without chronic conditions, and those with substance use disorder or mental health problems smoke at significantly higher rates [3]. While evidence for stopping smoking supports better outcomes regardless of comorbidity, the stress of living with and managing chronic disease while trying to stop a highly addictive behavior and cope with withdrawal symptoms can feel overwhelming to patients and their families. People who smoke may be hesitant to give up the one thing that they believe helps them deal with stress, even when they know about the harmful effects of smoking. In addition, those with obesity, diabetes, or cardiovascular disease may not want to

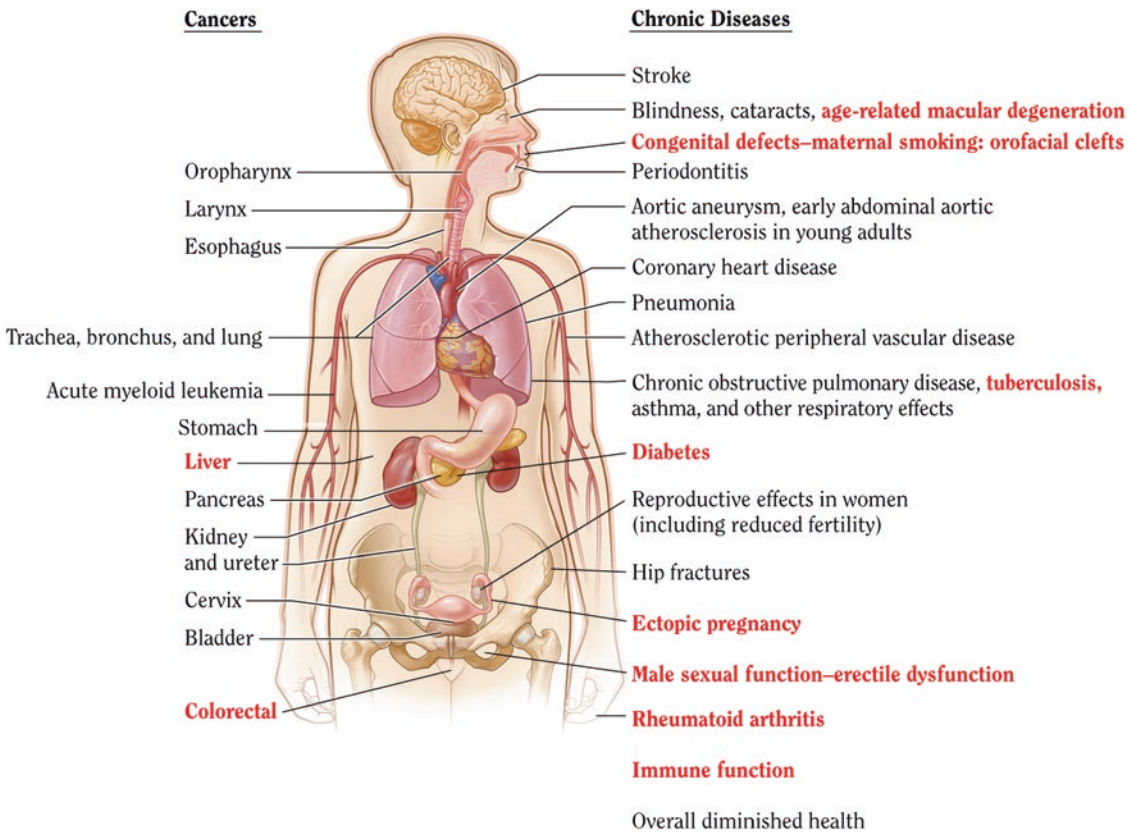

Fig. 4.1 The health consequences causally linked to smoking. Notations in red are newly added in the 2014 Surgeon General's Report (Reprinted from public domain: http://www.cdc.gov/tobacco/data_statistics/fact_sheets/health_effects/effects_cig_smoking/)

risk weight gain associated with stopping smoking. Yet most people are open to the support and resources that providers can offer. Treating chronic illness without addressing tobacco use decreases treatment effectiveness and leads to increased adverse outcomes, while stopping tobacco use can decrease health risks and increase quality of life and treatment effectiveness [14, 15]. Positive effects of stopping smoking for specific chronic diseases will be discussed below.

Definition of Tobacco Use Disorder

Tobacco use disorder involves tobacco use on a regular basis for which abstinence produces withdrawal symptoms, meeting criteria for addiction (Table 4.1). Tobacco products, defined and regulated by the US Food and Drug Administration (FDA), include smoked, smokeless, and heated/vaporized.

Types of Tobacco Products

Smoked (Combustibles)

Combustible tobacco includes cigarettes, cigarillos, little cigars, cigars, pipes, and hookah. Cigarettes contain tobacco wrapped in a paper, usually with a filter to reduce the harshness of the inhaled smoke. Cigarettes are sold in packs of 20 or cartons of 10 packs. Sales of single cigarettes, sometimes known as "loosies," are illegal, but readily available. Previous attempts by tobacco companies to brand cigarettes as safer included "light" and "low-tar" designations. These misleading labels are now prohibited but still identifiable by color labels, e.g., light products are now identified as "gold." Cigarettes are a highly effective and efficient drug delivery system, delivering a bolus of nicotine to the brain within 10 s of inhalation. The only flavor allowed in US cigarettes after FDA regulation in 2009 is menthol. Menthol masks the harsh taste and feel of inhaled smoke and allows for deeper inhalation, with the ability to deliver higher levels of nicotine in fewer cigarettes. In 2014, 30% of all cigarettes sold in the USA were mentholated [18]. Use of menthol makes it easier to start smoking and more difficult to stop [19]. Young people smoke menthol cigarettes at higher rates than adults, and almost three fourths of African-Americans prefer menthol cigarettes [20].

Cigarillos, little cigars, and cigars use tobacco leaf as the wrapper and range in size from just over the 4 oz. limit that defines a cigarette to large cigars. They have greater density of nicotine than cigarettes and may be inhaled less deeply, depending on size. For example, someone who smokes 20 cigarettes a day (one pack) who switches to "Black and Mild" little cigars will use about 3 little cigars per day, lighting then relighting them throughout the day to maintain nicotine levels. Until recently, cigars were taxed at lower rates. Cigarillos, little cigars, and cigars have no prohibitions on flavors in the USA, so marketing "Swisher Sweets" and other cigarillo products with cherry and grape flavors, along with lower prices, have given tobacco companies greater access to the youth market. The FDA has announced intentions to potentially ban cigarillo, little cigar, and cigar flavors.

Pipe smoking involves use of different blends of tobacco stuffed into the pipe bowl, lit, and inhaled through the pipe stem. With the lowest prevalence among combustible tobacco products, it also delivers nicotine through the lungs.

Hookah, originally from the Middle East, has become more popular in the USA, often smoked in a group setting. Burned tobacco passes through a water pipe which filters out some chemicals, but the inhaled smoke still contains high levels of toxic chemicals that come from the burning of the charcoal, tobacco, and flavorings.

Smokeless (Noncombustibles)

Smokeless tobacco is placed in the mouth cavity where nicotine and other chemicals are absorbed through the oral mucosa. Included in this category of tobacco products are chew, dip, snuff, and snus, as well as newer products like orbs and strips. Chew and dip usually require expectorant of the liquid that pools in the lower jaw, hence the name spit tobacco. Snuff may be sniffed up the nose. Snus contain tobacco in a small pouch that does not require spitting. Dissolvable products include nicotine pellets, called orbs, sticks the size of toothpicks, and thin film strips. These are newer products from tobacco companies that have not yet gained significant market share.

Heated/Vaporized (Electronic Nicotine Delivery Systems)

E-cigarettes and vape pens deliver nicotine by heating, rather than burning tobacco. All are relatively new, with e-cigarettes introduced in the USA in 2007. These products use a battery

Table 4.1 Tobacco use disorder definitions [16, 17]

Tobacco use disorder definitions	
Tobacco use disorder	A problematic pattern of tobacco use leading to clinically significant impairment or distress
Abstinence	A period of being tobacco-free
Withdrawal symptoms	Signs or symptoms experienced within 24 h of tobacco cessation, including the following: 1. Irritability, frustration, or anger 2. Anxiety 3. Difficulty concentrating 4. Increased appetite 5. Restlessness 6. Depressed mood 7. Insomnia
Addiction	Continued use of a substance despite negative consequences

to heat nicotine in a cartridge or tank, which is inhaled or vaped, and produces a cloud that simulates smoking. Newer heat products have been tested by the tobacco industry in Japan and may soon be available in the USA. A tobacco cigarette is placed in a box where it is heated rather than burned, and a hit is inhaled through the mouthpiece. While people who vape are not exposed to the carbon monoxide, tars, or carcinogens of smoked tobacco, the safety of these products is still being studied, and as of this writing, the FDA has just begun the process of regulating.

Secondhand and Thirdhand Smoke Exposure

While those who use combustible tobacco products receive the most concentrated exposure to the smoke, drugs, and chemicals carried in it, the effects of smoke can be experienced by anyone who is in the presence of smoke or who may be exposed to the smoke that remains embedded in porous surfaces long after active smoking. Secondhand smoke (SHS) is a combination of smoke that comes directly from burning cigarettes, cigars, or pipes, called "sidestream smoke" and smoke that is exhaled by the person smoking or "mainstream" smoke. Sidestream smoke comprises 85% of SHS. SHS can remain in the air for hours after an individual has finished a cigarette, which increases the time others are made vulnerable [6]. People who do not smoke increase their risk of developing heart disease by 25–30% when exposed to secondhand smoke at home or at work, yet providers rarely ask about exposure [5].

Thirdhand smoke (THS) is a more recently recognized carcinogen that involves residual nicotine and other chemicals found in tobacco smoke adhering to surfaces long after a cigarette has been finished [21]. These lingering toxins are found in hair, skin, clothes, carpets, furniture, walls, insulation, and vehicles. The molecules react with oxidants in the air and other compounds in the environment to generate secondary contaminants that can be even more toxic to humans than the original contaminants [22].

Individuals exposed to SHS and THS can suffer the same adverse health effects as those who smoke voluntarily [6]. Adults who are exposed to tobacco smoke in the environment have increased adverse effects on their cardiovascular system and can develop lung cancer. In the USA, SHS annually causes about 3400 lung cancer deaths and 42,000 heart disease deaths in people who do not smoke. Children who are exposed to smoke have elevated risk for sudden infant death syndrome (SIDS), acute respiratory infections, ear infections, and asthma [6]. In the USA, this translates to between 150,000 and 300,000 lower respiratory tract infections in children younger than 18 months. Approximately 30% of US children live in a household with at least one person who smokes, which increases their vulnerability to tobacco smoke and the resulting consequences [23].

Disparities in exposure of non-smoking Americans to SHS include not only children but also African-Americans, those below the poverty level, and those who rent their homes. Especially vulnerable are people living in multiunit housing like apartments and condominiums. Even if they adopt smoke-free policies for their own living units, they can be exposed to smoke from nearby units and shared areas. Tobacco-free policies in workplaces and public places, including public housing, have contributed to reducing exposure to SHS and THS [24].

Children are at the greatest risk for exposure to thirdhand smoke, as they more frequently come in contact with surfaces on which the toxic particles reside both through hand-to-mouth and dermal exposure. They also can be exposed over long periods of time, from in utero until leaving home as young adults. Exposure to nicotine and tobacco-specific nitrosamines is of particular concern [25]. Thirdhand smoke is not easily removed and can take months to years to dissipate [26]. Although the risks of exposure are not fully known, human and in vitro animal studies link THS to DNA damage, altered fibroblast migration involved in wound healing, and impaired respiratory development [27, 28].

The Chronic Care Model and Treatment for Tobacco Dependence

The goal of chronic care management is for patients to understand their condition and have access to the most effective evidence-based treatment. The chronic care model (CCM), developed to improve health outcomes through system changes that support patient-centered and evidence-based care, includes effective team care, planned interventions, self-management support, use of community resources, integrated decision support, patient registries, and other supportive information technology [29].

A core strategy of effective system delivery of *self-management support* for chronic diseases follows a *planned intervention* such as the 5As model, which was first studied for tobacco use: ask, advise, assess, assist, and arrange (sometimes agree is included) [30]. Various studies have demonstrated the effectiveness of *team-based care* for ensuring that the 5As are addressed at each visit. Effective use of information technology includes integrating the 5As into electronic health records (EHR). Most EHRs now include tobacco use status (ask) in vital signs. Many use prompts or best practice advisories to remind providers to advise, assess, assist, and arrange. Providing *decision support* for pharmacotherapy and behavioral treatment referrals addresses the assist and arrange components, which can include access to *community resources*. Using information technology to develop registries creates opportunities for population level interventions such as reminders and targeted messaging.

EHR prompts may also help providers code for appropriate services to be billed.

Implications for Each Area of the Ecological Framework

Individual

When individuals view tobacco use from a chronic disease perspective, they may feel less sense of failure and be able to moderate the expectation that, if strong enough, they should be able to quit by willpower alone. Understanding the relapsing nature of the addiction, while knowing that support and effective treatment exist, can increase self-efficacy.

Family

Family members who understand tobacco use as similar to hypertension or diabetes may put less pressure on persons to "just quit" and may be more supportive. In addition, if others in the family smoke, the patient will be changing the status quo for his or her family. Identifying those who can give support, emphasizing that becoming tobacco-free can improve the health of the whole family, and pointing out that the cost of tobacco use comes at the expense of other family purchasing priorities, may be strategies to promote quitting.

Provider

Providers working from the chronic disease model will address tobacco use with a long-term mindset and offer effective treatment and follow-up. Providers may not have time to offer intensive behavioral support, but they can give accurate information about medication use, what to expect, and provide follow-up or referral to specialized or community resources. Patient-centered care makes use of shared decision-making and considers patient experience, resources, and motivation, particularly around medications. It will address concerns such as failure, boredom, and addiction, as well as fears such as weight gain and loss of a social circle. It also requires understanding barriers to the use of medications, such as cost, availability, or misinformation.

Community

Awareness of the way advertising and policy influence individual behavior may decrease judgment while maintaining a social norm of clean air. In the USA alone, the tobacco industry spends billions of dollars to advertise products, or nearly $25 million per day. In addition to direct advertising, these marketing dollars are spent on price discounts paid to retailers or wholesalers to reduce the price of cigarettes and promotions such as two-for-one pricing. In addition, advertising is targeted to younger populations, women, racial and ethnic communities, and the LGBTQ community.

System Level

Tobacco use should be addressed throughout the health-care system including protocols for treatment and ensuring adequate reimbursement for treatment. The significant cost to society for health care and lost productivity in the workplace concerns public health as well as economic viability of the health-care system. Policies that address price of cigarettes, limits on marketing, and tobacco-free policies have the greatest impact on reducing prevalence of tobacco use.

Characteristics of Effective Treatment of the Individual

A comprehensive tobacco control program includes effective clean air policies, high taxes on tobacco products, media campaigns, and access to treatment services. Individual treatment will not move the needle on overall prevalence the way the other three strategies will. At the same time, it is a necessary component for improving lives of individuals, families, and communities.

Patient Centered

Patient-centered care sees a person in unique context as opposed to disease diagnosis. Recognizing the biopsychosocial-spiritual nature of tobacco use can help providers tailor evidence-based care to patients. Offering patient-centered care includes listening to patients to learn what works, how they want to be treated, and what might increase interest in treatment. Identified barriers can be addressed mutually and identified strengths affirmed.

Provider and Patient Informed

Patients trust providers, and providers will want to have the most up-to-date and effective treatment information. Even brief interventions improve outcomes, especially when offered frequently.

Several common misperceptions held by patients and providers can be barriers to successful management of this chronic condition. The first misperception is that the

responsibility for change rests entirely on the individual who uses tobacco, viewing tobacco use as "just a bad habit" or "just a mind thing." This view reinforces judgment and shame. While there are certainly aspects of habit involved in tobacco use, the highly addictive nature of cigarettes, coupled with the frequency of use requried to prevent withdrawal symptoms, makes smoking an automatic, ingrained behavior. Effective abstinence requires continued practice to relearn new behaviors while dealing with the difficult symptoms of withdrawal. Willpower alone rarely succeeds, especially with patients who deal with multiple chronic diseases, financial insecurity, or other life stress.

A second misperception is the association of smoking with stress relief. Nicotine triggers the release of dopamine, leading to a temporary feeling of well-being and enhanced cognitive performance. However, as the Cleveland Clinic aptly describes it, this is a "cruel illusion" [31]. While the immediate hit of nicotine causes feelings of well-being, it also puts stress on the heart by increasing heart rate and blood pressure and, after a few hours, adds the stress of withdrawal that can only be relieved by smoking again. It is important that both patient and provider understand this phenomenon if they are to find effective strategies to improve health.

Team and System Support

While providers may be in the best position to relate smoking to health outcomes, having all clinic staff involved will increase delivery of effective treatment. Not only does team-based care demonstrate the importance of addressing tobacco use, it also increases efficiency and quality by allowing team members to work at the top of their skill levels, reducing the time needed by providers to address tobacco use in short clinic visits. As described earlier in the chapter, the health-care system should prioritize insurance coverage for evidence-based interventions that treat the chronic disease of tobacco use, including dosing of pharmacotherapy and behavioral health counseling that can be individualized to patient need. One patient described stopping smoking as divorcing the Marlboro Man and taking back the control he had over her. We would hardly expect that someone trying to get out of an abusive relationship can only receive four counseling sessions to do so. With enactment of the Mental Health Parity Act in 1996, limits to number of sessions eligible for reimbursement are determined by individual need and progress, consistent with medical and surgical benefits. While some who smoke are able to stop, others are so addicted that they see abstinence as impossible. Low self-esteem and feelings of failure discourage them from contemplating new efforts to stop. When coupled with other life stressors, such as financial concerns, family problems, mental illness and substance use, and need for shelter, many people need longer-term therapy to address the tobacco addiction, and this should be supported by our health-care system. Engaging case or care managers as members of the clinic team can facilitate coordination of services and ensure that patients are linked to appropriate resources.

A Patient-Centered, Team-Based Approach to the 5As

The following 5A approach to counseling was developed based on patient focus group reports and other patient-centered literature and the chronic care model [13, 30, 32, 33] (Fig. 4.2).

Ask

Team-based care starts when a nurse or medical assistant about tobacco use while taking vital signs. Patients may be especially sensitive about how they are asked about their tobacco use, and this can determine receptivity to discussing with the provider. A straightforward "Have you ever smoked?" with a positive response followed by "Do you currently smoke or use other tobacco products?" has a very different feel than the accusatory tone of "Are you (still) a smoker?" or "You don't smoke, do you?" Patients also express reluctance to be truthful with providers because they are embarrassed that they smoke. The term "smoker" reinforces judgment and stigmatization, labeling a person by the disease or addiction. In shifting perspective by labeling the behavior instead of the person, clinicians can see patients who smoke as people first, who are caught in a cycle of addiction that has both individual and societal determinants. It does not take a lot of effort to change "smoker" to "a person who smokes," and the very act of doing so can influence the

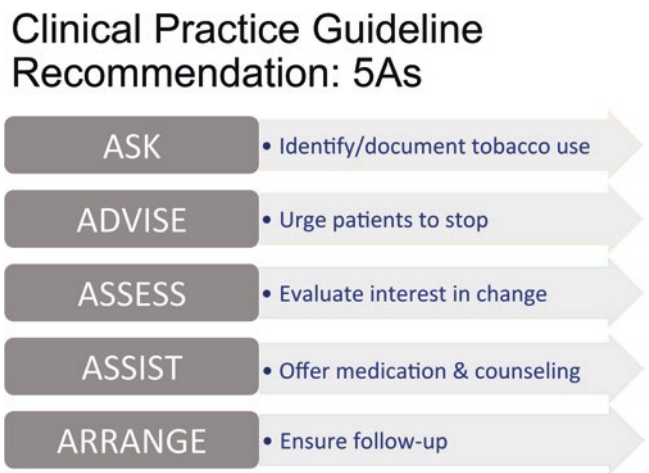

Fig. 4.2 The Five As for treating tobacco use (Reprinted from public domain)

way patients are seen and treated. The difficulty many providers have in making this seemingly simple change can increase empathy when seen in context of patients who are being asked to change whole daily routines that revolve around smoking while fighting off cravings and irritability.

Advise

Many patients report that their doctor told them to quit smoking but did not offer any help or information about how to quit. They do not like being preached to or having fingers wagged or hearing about all the bad things that will happen if they continue to smoke. Instead, they appreciate having providers give specific information related to individual circumstance such as "Stopping all tobacco use is one of the best things you can do for your health. You will notice significant reductions in your asthma symptoms, without having to rely on higher doses of medications. I understand how difficult this change can be. We have effective medications and resources for supporting you in becoming tobacco free." In this brief message, the provider has voiced belief in positive outcomes of stopping tobacco use, demonstrated empathy, and offered resources to support the patient. Giving patients positive messages or "gain-framed" statements may be a positive moderator of treatment [34].

Assess

Assessment has typically been framed as a yes/no question such as "Are you ready to quit?" with an affirmative answer required for further assistance. Seventy percent of people who smoke say they want to stop but may not say they are ready to quit because of perceived stress, lack of success in previous efforts, or not knowing how. An open-ended prompt, such as "I'd like to hear your thoughts about cutting down or stopping smoking" or "Tell me about your smoking and your interest in making any changes," will allow patients to state their concerns and give providers clues about how to best approach efforts to become tobacco-free. The provider can listen for patient fears and perceived difficulties, then address those with empathy, education, and resources. Assessment may also include "What do you enjoy about smoking?" "What do you not like about dipping?" "What has helped/not helped you when you've tried to change your tobacco use?" or "What would your life be like without tobacco?"

People can stop smoking, regardless of readiness. For example, when offered treatment, patients in a Danish study who were not ready to quit actually had higher rates of 6 month abstinence than those stating their readiness to quit in the next 30 days [35, 36].

Providers will want to assess both strengths and challenges that the patient brings to any attempt to change tobacco use. Strengths can be found even in statements that first appear as weakness such as, "I've tried a hundred times and failed," which can be reflected positively by the provider saying, "You've had a lot of practice and it sounds like you can be quite persistent." The patient may refer to a trigger, cue, or situations that prevented abstinence such as, "I quit for a few months but then my husband lost his job," to which the provider might reply "You were able to quit and a very stressful situation set you back." Naming strengths can be useful in finding strategies to deal with the challenge of changing tobacco use behaviors.

Assist

Evidence-based treatment includes a combination of pharmacotherapy and behavioral counseling. The strength of the addiction to nicotine and other substances means that changing behavior "cold turkey" will be extremely difficult for most people. While medications can double quit rates, they do not guarantee sustained abstinence. Used without behavioral support, they fail to address the routines and the psychological factors that reinforce tobacco use. Given the increase in amount of nicotine delivered per cigarette in the past few decades, one reason for treatment failure is undertreatment, especially with nicotine replacement therapy. The advent of e-cigarettes has made this abundantly clear, as patients can self-dose without restrictions.

The two most effective pharmacotherapies are varenicline (Chantix) or combination nicotine replacement therapy (NRT) such as a long-acting patch plus short-acting gum, lozenge, inhaler, or nasal spray. Varenicline is a nicotine agonist and is proven safe, even in populations with mental health diagnoses [37]. Combination NRT allows for self-dosing of nicotine to minimize withdrawal symptoms, which is the most common cause for relapse or inability to stop use. When withdrawal symptoms are managed with these medications, more energy can be devoted to working on behavior changes that will sustain abstinence in the long term. Other FDA-approved medications include sustained-release bupropion, which can be combined with NRT, and single-use NRT. Behavior change can be supported through coaching on strategies for dealing with triggers and cues, through cognitive therapies that help reframe notions of weakness or lack of willpower and by nutritional and physical activity coaching to manage weight gain.

Arrange

As with any chronic illness, long-term follow-up ensures the best outcomes for patients. Immediate follow-up to support quit attempt or changes in tobacco use behavior helps patients to increase adherence to medication. Without

follow-up they may experience side effects and discontinue or cut down but think that because they have not quit completely, they should stop medications. Short-term follow-up may include referral to a Quitline or a tobacco treatment specialist or other behavioral health provider. Long-term follow-up focuses on relapse prevention, which reinforces the positives of a tobacco-free life and anticipates challenges or cause for return to tobacco use. Asking about and congratulating patients for progress on goals take only a few seconds at follow-up visits. Connecting patients with the community resources that offer support will extend provider care and may include community classes, not only for tobacco use but for developing healthy lifestyles, or referral to mental health resources. Telephone quitlines provide evidence-based telephone and online support and are a recommended resource in the Public Health Guideline [11]. Any state quitline can be accessed at 1-800-QUIT-NOW. Fax referrals to quitlines that initiate calls to patients can also be integrated into EHRs.

Outcomes of Effective Treatment for Tobacco Use and Dependence

Asymptomatic Patients and Disease Prevention

People who stop using tobacco decrease the risk for cancer, lung disease, cardiovascular disease, and add years to life expectancy [38] (Fig. 4.3). They report increased sense of taste and smell, overall well-being and sense of accomplishment, a newfound freedom, and increased self-efficacy for making other behavior changes.

Patients with Chronic Disease

The effects of stopping tobacco use on individual chronic conditions are discussed below and based on several review articles [14, 15].

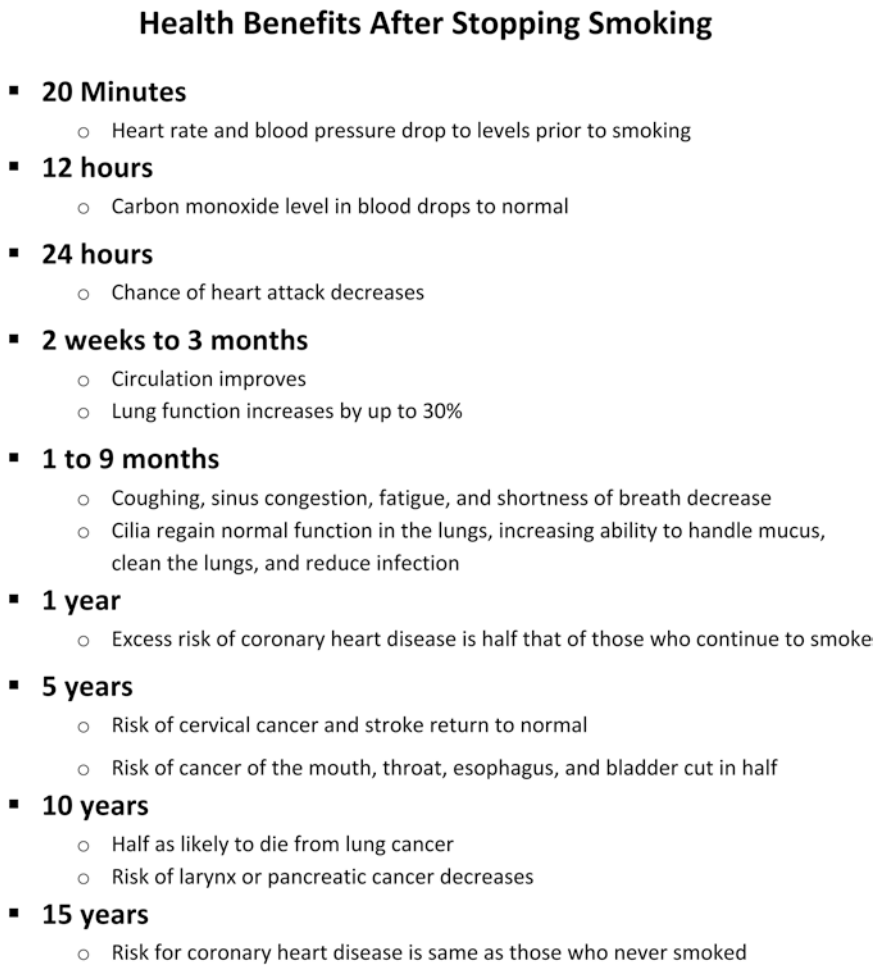

Fig. 4.3 Positive outcomes from stopping tobacco use (Modified from public domain: https://www.cdc.gov/tobacco/quit_smoking/how_to_quit/benefits/ Accessed January 12, 2017)

Cardiovascular Disease

For patients at risk for or with current cardiovascular disease (CVD), stopping smoking can be the single best intervention for improving cardiovascular health and has greater cost effectiveness than interventions for hypertension and hyperlipidemia [39]. Benefits begin immediately, including decrease in sudden cardiac death, and within a few years for acute myocardial infarction [40] (Fig. 4.3). Cessation also decreases the risk of stroke [41]. All FDA-approved tobacco use treatment medications can be effectively used with patients who have CVD. While misconceptions about use of nicotine replacement therapy persist, no clinical evidence links NRT and CVD, even if patients smoke while using NRT [42]. Intensive behavioral therapy can significantly increase quit rates in patients with CVD [43].

Diabetes

Long-term effects of stopping smoking for people with diabetes include improved blood lipid levels and rates of inhaled insulin absorption that approaches those of people who do not smoke [44, 45]. Varenicline is well-tolerated in people with diabetes and can help achieve continuous abstinence rates of 18%, which is double that of placebo, with an average weight gain in those who stopped smoking similar to study participants who did not have diabetes (around 2 kg) [46].

Chronic Obstructive Pulmonary Disease

In early-stage chronic obstructive pulmonary disease (COPD), people who stop smoking can dramatically reduce disease progression [47]. In more advanced COPD, decreased lung function can be slowed, and risk of death decreases compared to continued smoking, though mortality risk from COPD remains higher than from heart disease and lung cancer in those who have stopped smoking [48, 49]. Interventions that include pharmacotherapy, educational materials, and behavioral strategies demonstrate significant 6 month abstinence rates when compared with usual care and showed effectiveness in patients regardless of perceived readiness or motivation [50].

Asthma

Smoking cessation improves asthma control, with significant reductions in chest tightness and nighttime symptoms, improved lung function, and decreased sputum neutrophil count [51–53]. Since smoking can reduce the effectiveness of inhaled corticosteroids (ICSs), stopping smoking can potentially result in reduced ICS use and increased efficacy [54]. Persons with asthma may be able to quit at similar rates, but they may experience slower declines in nicotine withdrawal symptoms and cravings compared to people without asthma [55]. Promising approaches include peer interventions with adolescents, mobile applications and online education, and consideration of specific individual needs of asthma patients who smoke [56].

Cancer

With increasing survival following cancer diagnosis, the need for addressing continued tobacco use has become even more important. Surgery, radiation, and chemotherapy treatments are more effective when patients stop using tobacco and patients who are tobacco-free have a lower rate of cancer recurrence [5]. They also report higher quality of life measures [57]. Interventions that include both pharmacotherapy and behavioral strategies demonstrate effectiveness in achieving tobacco abstinence for cancer patients [58].

HIV/AIDS

Effective human immunodeficiency virus (HIV) treatments have extended life expectancy and decreased the risk of many AIDS-related diseases. However, among patients who adhere to HIV treatment, those who smoke decrease life expectancy by twice as much as HIV itself [59]. People with HIV smoke at higher rates (42%) and are less likely to quit than the general population [60]. Those who stop smoking in the course of HIV treatment can gain up to 5.7 years of life by decreasing risks of pneumonia, thrush, and hairy leukoplakia as well as cancer, cardiovascular disease, and respiratory disease [59]. Barriers to treatment include the belief by people with HIV that they will not live long enough to experience the negative consequences of smoking, as well as lack of access to telephones, transportation, or stable housing [61, 62]. Pilot studies on treatment that include adherence-focused interventions, such as peer counseling, prepaid cellphones, or texting, have demonstrated potential effectiveness for increasing quit rates for people with HIV [63–65].

Mental Health and Substance Use

People with a mental health or substance use problem have higher rates of tobacco use compared to the general population [66]. They are often in environments that normalize smoking and may have less access to tobacco use treatment resources [67]. Over the past few decades, this disparity in

both treatment and health outcomes related to tobacco use has begun to be addressed. People with mental health disorders who stop smoking experience decreased depression, anxiety, and stress, with improved mood and quality of life, when compared to those who continue to smoke [68]. Studies also show increased abstinence from illicit drug and alcohol use in those who stop smoking [67, 69]. Effective treatment includes pharmacotherapy and behavioral interventions that often require greater intensity over longer periods of time. Peer counseling and integrated treatment models have also shown effectiveness.

Family and Society

When effective treatment is offered and patients are able to become tobacco-free, the positive impact extends beyond individual health. Persons living in the same household experience reduced exposure to SHS and THS. Children see positive role models and will be less likely to initiate use. Families have more income for purchasing healthy food, paying bills, or taking a vacation together, and feel decreased stress related to finances and dealing with health issues. In the larger society, effective treatment reduces health-care costs, hospital admissions, cigarette butt and package litter, and improves the cleanliness of air for everyone.

Integrating Tobacco-Free Initiatives into the Health-Care System

Tobacco use is so detrimental to the health of individuals that efforts to promote abstinence should be prominent in the health-care system. Delivery of tobacco use treatment services should be streamlined into patient visits, including integration of protocols into electronic health records (EHR). Tobacco use can be used as one of the behavioral conditions addressed for receiving the patient-centered medical home (PCMH) recognition. This can include creation of a registry for tobacco use or ensuring that tobacco use is documented in other chronic disease registries [70, 71].

Impact of Affordable Care Act

The Affordable Care Act requires coverage for all preventative services that receive grade A or B, including tobacco use counseling and medication. Treatment is covered up to four treatment sessions twice a year with 12 weeks of pharmacotherapy coverage. This is a start but does not recognize the long-term nature of behavioral change, especially in people who are trying to address mental health or other substance use at same time, or for whom smoking has become the primary coping strategy for grief, stress, discomfort, and loneliness.

Future Directions

eHealth Initiatives and Social Media

Texting interventions are effective in supporting other activities needed to manage chronic disease such as physical activity, HIV medication adherence, and management of asthma and diabetes [72]. This suggests that efforts to stop using tobacco can also be supported in this manner and text-message-based interventions have demonstrated improved quit rates [73]. Facebook interventions have the potential to be useful with adolescents, who are a difficult population to engage in treatment. Several recent studies show use rates are not affected and continue to climb even with Facebook interventions, as some choose to use e-cigarettes instead of NRT [74, 75]. Online and text-based interventions are becoming more common. While recruitment can be a problem, peer recruiting through social media has showed some promise, with one online social network (Share2Quit) quadrupling recruitment [76].

Pharmacotherapies

A 2016 review of novel pharmacotherapies studied several products that are undergoing clinical trials [77]. Cytisine, new to the US, but used widely in Europe, may be safe, effective, and affordable. Nicotine vaccines and galenic formulations of varenicline may be effective in producing antibody levels that reduce side effects. Lorcaserin may moderate the weight gain that some people experience when they stop smoking. Although electronic cigarettes have grown in popularity and are touted by some as an approach to treatment, long-term safety and efficacy have not been established. While new treatments may be helpful, for now greater effort should be spent on well-established therapies and addressing misperceptions about evidence-based medications, especially comparing the low risk of these agents to the significant health risks of continued smoking.

Behavioral Therapies

Mindfulness, as both primary and adjunct therapy for becoming tobacco-free, may reduce craving and manage stress, leading to improved abstinence and relapse prevention [78–80]. This approach can be especially helpful when combined with other established treatments.

Genetics

Research on the human genome has opened a new dimension for understanding tobacco use and dependence. An association between the nicotinic receptor alpha 5 (CHRNA5) and

increased risk of addiction-associated phenotypes may explain why some people smoke more heavily than others. The potential for using genetic data includes individualized treatment as well as the ability to target prevention efforts [81–83].

Effective Adolescent and Prenatal Treatments

Pharmacotherapy options for adolescents and pregnant women are limited as there is little research in these special populations. A better understanding of the effects of nicotine on the developing brains of fetuses and adolescents will be necessary to recommend use of NRT or other agents as treatment.

Medical Education in All Health-Care Fields

Team-based care is a growing concept in US health-care systems. All health-care providers in practice or training, including physicians, nurses, physician assistants, and nurse practionioners, as well as those in the allied health fields such as dentists, physical, speech, and occupational therapists, should be well versed in the harms of tobacco use and taught the skills to address this leading cause of preventable disease and death.

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Promoting Physical Activity

5

Lauren Porras, Harry Stafford, and Nailah Safiya Adams

Relationship of Reduced Physical Activity and Chronic Disease

During the early 1900s, infectious disease accounted for the vast majority of deaths in our population. However, by the middle of the twenty-first century, chronic disease became the leading cause of death in the United States [1]. One of the major factors associated with this epidemic of chronic disease is physical inactivity. Muscle wasting and premature fatigue due to intrinsic changes in peripheral skeletal muscle observed in chronic diseases, such as chronic obstructive pulmonary disease (COPD) and chronic kidney disease, are compounded by disuse from physical inactivity [2]. Overall, physical inactivity is the fourth leading risk factor contributing to deaths and the burden of disease, globally ranking ahead of being overweight or obese [3]. If physical activity was eradicated, life expectancy of the world's population would likely increase by 0.68 years, making inactivity comparable to the risk factors of smoking and obesity [4]. Unfortunately, 24% of US adults partake in no leisure-time physical activity [5]. Persons over the age of 65 are the most sedentary age group, spending 8–10 h of their day sitting [6]. As life expectancy continues to rise, the portion of society aged 60 years and above has become the fastest growing population in developed nations [7, 8]. Quality of life in older age, which may be dampened by the presence of chronic disease and physical inactivity, is increasingly important.

Frailty

Frailty is a clinically defined condition of age-related increased vulnerability due to neurally modulated multisystem decline in physiologic reserve and function [9]. Measures of frailty including low grip strength, slow gait speed, inability to rise from a chair five consecutive times without using the arms, unintentional weight loss, and poor energy have been associated with disability, falls, hospital admissions, institutionalization, and premature death among community-dwelling older persons [10, 11]. In addition to an intuitive conclusion, evidence has shown that frailty is associated with a lower quality of life [12]. Low-grade inflammation is a hallmark of aging and appears as a common determinant for chronic diseases, sarcopenia, and frailty [13]. Adequate aerobic and resistance trainings have been shown to not only prevent but reduce frailty through increased muscle mass, strength, and endurance, improving physical function.

Aging and Exercise

Physical performance comprises neuromuscular endurance, strength, capacity, and power [8]. Aging is associated with a significant decline in these entities in persons 60 years and older. Sarcopenia is the gradual loss of muscle mass associated with aging and is the result of reduced regenerative capacity and perfusion with increased oxidative stress, mitochondrial dysfunction, and chronic inflammation [13]. The changes leading to sarcopenia position it as a mediator between various chronic diseases and frailty [14, 15]. A low ratio of appendicular lean mass to body mass index (ALM_{BMI}) is associated with a 50% increased risk of mortality [16].

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L. Porras (✉)
University of North Carolina Chapel Hill, Department of Family Medicine, Chapel Hill, NC, USA

University of North Carolina Chapel Hill, Department of Orthopaedics, Chapel Hill, NC, USA
e-mail: lauren_porras@med.unc.edu

H. Stafford
UNC Hospitals, Department of Family Medicine, Chapel Hill, NC, USA

N.S. Adams
Broward Community and Family Health Centers, Inc

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Fortunately, there is a wealth of evidence establishing the reversal effects of exercise on sarcopenia and age-related declines in function and cognition. Aerobic endurance training improves aerobic capacity (VO_{2max}) and, thus, reduces frailty in older adults [13]. Aerobic exercise also improves muscle insulin sensitivity in older individuals and prevents declines in mitochondrial respiratory capacity, leading to increased muscle endurance [13, 17]. Resistance exercise induces remarkable gains in strength and power in older adults, showing increases in muscle mass by 16–23% in healthy older subjects in response to 4 months of resistance training [13, 17]. Thus, exercise should be encouraged at all ages for its health benefits and improvements in quality of life.

Defining Physical Activity and Exercise

Physical activity is defined as "bodily movement that is produced by the contraction of skeletal muscle and that substantially increases energy expenditure." Exercise is defined as "a type of physical activity that is defined as planned, structured, and repetitive bodily movement done to improve or maintain one or more components of physical fitness [18]." Exercise occurs outside the expected or unexpected activities of a patient's day.

Exercise is divided into four domains:

1. Aerobic exercise, defined as any activity that uses large muscle groups, can be maintained continuously and is rhythmic in nature [19].
2. Resistance training improves muscular fitness by exercising muscles against external resistance. Adults should train each major muscle group 2–3 days each week using a variety of exercises and equipment. Light intensity is best for older persons or previously sedentary adults. These exercises improve strength and power in adults, usually two to four sets of 10–20 repetitions per set [20].
3. Flexibility training involves stretching or repeated movement through a joint's complete range of motion that works to increase joint range or prevent loss of motion [21]. Types of flexibility exercises include ballistic stretching ("bouncing") that use momentum to produce the stretch, dynamic stretching which involves gradual transitioning from one position to another, static stretching which involves holding the muscle in a stretched position utilizing an agonist muscle, and proprioceptive neuromuscular facilitation which involves the isometric contraction of one muscle group to induce static stretching of the agonist group [19].
4. Neuromotor exercise, or functional fitness training, incorporates motor skills such as coordination, balance, gait, agility, and proprioceptive training. These modalities are incorporated in Tai Chi and yoga and may be beneficial as part of an exercise program for the older adults to improve balance and reduce risk of falls [19].

The intensity of exercise is usually characterized by the absolute energy demands of exercise, which can be measured via caloric expenditure, absolute oxygen intake, or metabolic equivalents (METs) [19] (Fig. 5.1). Another alternative is to allow the patient to monitor their heart rate. Moderate physical activity increases HR to 64–76% of maximum while vigorous will increase to 77–95% of maximum (Fig. 5.2).

Current recommendations for moderate-intensity physical activity recommend accumulation of activity via at least 10-min intervals [19]. Lower duration activity has not been associated with similar health outcomes. Those patients who use a "weekend warrior" approach to physical activity, meaning that they accumulate large durations of activity on shorter numbers of days, also seem to benefit, although this has not been thoroughly studied. One large cohort indicated that this likely has mortality benefit for men without cardiovascular risk factors, although it is unclear as to whether this would be applicable to patients with identifiable risk factors [24]. Steps are a popular method of quantifying activity but do not determine the quality of the exercise. Instead of recommending an aggregate number of steps, it may be better to recommend steps per minute combined with recommended duration of exercise (i.e., 100 steps per minute for 30 min) [19].

Primary Prevention of Chronic Disease

Exercise is one of the few lifestyle changes that can impact mortality significantly. Those who are active for 7 h a week have a 40% lower risk of dying early than those who are active for less than 30 min per week. Even low amounts of physical activity can reduce risk of dying prematurely [25] (Fig. 5.3).

Physical activity reduces the risk of developing coronary artery disease, stroke, type 2 diabetes, and some cancers such as colon and breast cancers. Exercise can lower cholesterol, improve blood pressure, improve insulin sensitivity, assist in weight management, and improve mental health including depression and anxiety. In the elderly population, exercise improves bone mass and risk of falling. It is associated with improved cognitive function and lower risk of cognitive decline and dementia. All in all it is associated with enhanced quality of life [19, 26] (Fig. 5.4).

Light <3.0 METs	Moderate 3.0 - 6.0 METs	Vigorous >6.0 METs
Walking Walking slowly around home, store or office = 2.0*	Walking Walking 3.0 mph = 3.3* Walking at very brisk pace (4 mph) = 5.0*	Walking, jogging & running Walking at very very brisk pace (4.5 mph) = 6.3* Walking/hiking at moderate pace and grade with no or light pack (<10 lb) = 7.0 Hiking at steep grades and pack 10-42 lb = 7.5-9.0 Jogging at 5 mph = 8.0* Jogging at 6 mph =10.0* Running at 7 mph = 11.5*
Household & occupation Sitting — using computer work at desk using light hand tools = 1.5 Standing performing light work such as making bed, washing dishes, ironing, preparing food or store clerk = 2.0–2.5	Cleaning - heavy: washing windows, car, clean garage = 3.0 Sweeping floors or carpet, vacuuming, mopping = 3.0-3.5 Carpentry — general = 3.6 Carrying & stacking wood = 5.5 Mowing lawn — walk power mower = 5.5	Shoveling sand, coal, etc. = 7.0 Carrying heavy loads such as bricks = 7.5 Heavy farming such as bailing hay = 8.0 Shoveling, digging ditches = 8.5
Leisure time & sports Arts & crafts, playing cards = 1.5 Billiards = 2.5 Boating — power = 2.5 Croquet = 2.5 Darts = 2.5 Fishing — sitting = 2.5 Playing most musical instruments = 2.0-2.5	Badminton — recreational = 4.5 Basketball — shooting around = 4.5 Bicycling — on flat: light effort (10–12 mph) = 6.0 Dancing — ballroom slow = 3.0; Ballroom fast = 4.5 Fishing from river bank & walking = 4.0 Golf —walking pulling clubs = 4.3 Sailing boat, wind surfing = 3.0 Swimming leisurely = 6.0† Table tennis = 4.0 Tennis doubles = 5.0 Volleyball—noncompetitive = 3.0-4.0	Basketball game = 8.0 Bicycling — on flat: moderate effort (12–14 mph) = 8.0; fast (14–16 mph) = 10 Skiing cross country-slow (2.5 mph = 7.0; fast (5.0–7.9 mph) = 9.0 Soccer — casual = 7.0; competitive = 10.0 Swimming — moderate/hard = 8-11† Tennis singles = 8.0 Volleyball — competitive at gym or beach = 8.0
Ainsworh, et al. 2000 (1). * On flat, hard surface. † MET values can vary substantially from person to person during swimming as aresult of different strokes and skill levels.		

Fig. 5.1 Metabolic equivalents (METs) for common activities (Adapted from Ainsworth et al. [22])

Age	Target HR Zone 50-85%	Average Maximum Heart Rate, 100%
20 years	100-170 beats per minute	200 beats per minute
30 years	95-162 beats per minute	190 beats per minute
35 years	93-157 beats per minute	185 beats per minute
40 years	90-153 beats per minute	180 beats per minute
45 years	88-149 beats per minute	175 beats per minute
50 years	85-145 beats per minute	170 beats per minute
55 years	83-140 beats per minute	165 beats per minute
60 years	80-135 beats per minute	160 beats per minute
65 years	78-132 beats per minute	155 beats per minute
70 years	75-128 beats per minute	150 beats per minute

Fig. 5.2 Target heart rates (Adapted from American Heart Association 2016 [23])

Recommendations for Physical Activity

Adults

The 2008 Physical Activity Guidelines from the US Department of Health and Human Services, the American Heart Association (AHA), the Centers for Disease Control and Prevention (CDC), the World Health Association (WHO), and the American Diabetes Association (ADA) all recommend adults avoid inactivity and perform at least 150 min a week of moderate-intensity or 75 min a week of vigorous-intensity aerobic exercise. For additional health

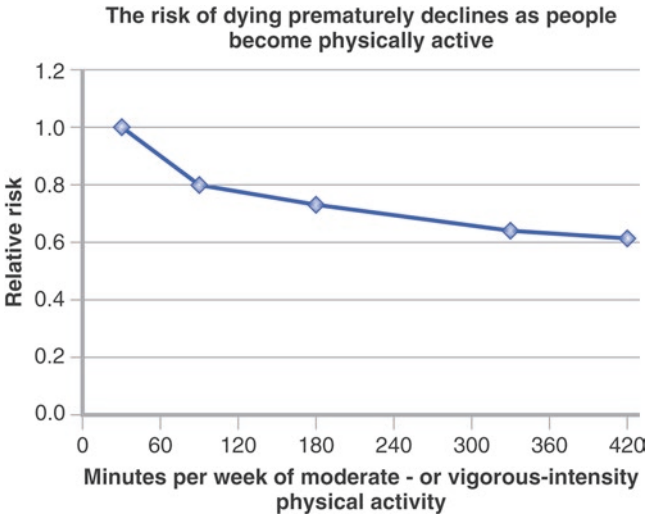

Fig. 5.3 The risk of dying prematurely declines as people become physically active (Adapted from 2008 Physical Activity Guidelines handbook [25])

benefits, they should increase aerobic activity to 300 min a week of moderate-intensity or 150 min a week of vigorous activity. Adults should also do muscle strengthening activity involving major muscle groups 2 or more days a week [25].

The American College of Sports Medicine (ACSM) has similar cardiorespiratory and resistance guidelines but gives additional recommendations to incorporate flexibility training and neuromotor exercise. They recommend flexibility exercises at least 2–3 days each week to improve range of motion. Each stretch should be held for 10–30 s to the point of tightness or slight discomfort. Each stretch should be repeated two to four times, accumulating 60 s per stretch. Neuromotor exercise should occur 2–3 days per week at about 20–30 min per day [20].

Women

Physical activity guidelines for women are consistent with men throughout all age groups, the exception being during pregnancy when there are some additional guidelines. Physical activity in pregnant woman has minimal risks and has been shown to be beneficial to most women. Guidelines recommend 150 min per week of moderate-intensity aerobic activity. Those women who prior to pregnancy were consistently participating in vigorous aerobic activity can continue to do so. Those women who have conditions that are contraindications to exercise should discuss activity with their provider [27] (Boxes 5.1 and 5.2).

The exercise guidelines for peri- or postmenopausal women are similar to exercise guidelines for the general population. Menopausal symptoms are reduced among women who are more active [28].

Health benefits associated with regular physical activity

Children and adolescents

Strong evidence

- Improved cardiorespiratory and muscular fitness
- Improved bone health
- Improved cardiovascular and metabolic health biomarkers
- Favorable body composition

Moderate evidence

- Reduced symptoms of depression

Adults and older adults

Strong evidence

- Lower risk of early death
- Lower risk of coronary heart disease
- Lower risk of stroke
- Lower risk of high blood pressure
- Lower risk of adverse blood lipid profile
- Lower risk of type 2 diabetes
- Lower risk of metabolic syndrome
- Lower risk of colon cancer
- Lower risk of breast cancer
- Prevention of weight gain
- Weight loss, particularly when combined with reduced calorie intake
- Improved cardiorespiratory and muscular fitness
- Prevention of falls
- Reduced depression
- Better cognitive function (for older adults)

Moderate to strong evidence

- Better functional health (for older adults)
- Reduced abdominal obesity

Moderate evidence

- Lower risk of hip fracture
- Lower risk of lung cancer
- Lower risk of endometrial cencer
- Weight maintenance after weight loss
- Increased bone density
- Improved sleep quality

Fig. 5.4 Health benefits associate with regular physical activity (Adapted from 2008 Physical Activity Guidelines handbook [25])

Older Adults

Recommended guidelines for older adults are similar to the younger adult population. However, if they are not able to physically achieve these goals, they should be as physically

Box 5.1 Absolute Contraindications to Aerobic Exercise During Pregnancy

- Hemodynamically significant heart disease
- Restrictive lung disease
- Incompetent cervix or cerclage
- Multiple gestation at risk of premature labor
- Persistent second- or third-trimester bleeding
- Placenta previa after 26 weeks of gestation
- Premature labor during the current pregnancy
- Ruptured membranes
- Preeclampsia or pregnancy-induced hypertension
- Server anemia

Box 5.2 Relative Contraindications to Aerobic Exercise During Pregnancy (Adapted from ACOG 2002 Physical Activity During Pregnancy Position Statement [27])

- Anemia
- Unevaluated maternal cardiac arrhythmia
- Chronic bronchitis
- Poorly controlled type 1 diabetes
- Extreme morbid obesity
- Extreme underweight (BMI less than 12)
- History of extremely sedentary lifestyle
- Intrauterine growth restriction in current pregnancy
- Poorly controlled hypertension
- Orthopedic limitations
- Poorly controlled seizure disorder
- Poorly controlled hypertension
- Poorly controlled hyperthyroidism
- Heavy smoker

active as their fitness allows. It is also recommended to incorporate exercises that improve balance to limit risk of falling [25].

Children

The 2008 Physical Activity Guidelines recommend children and adolescents should do 60 min or more of physical activity daily. Most of the physical activity should be moderate or vigorous-intensity physical activity, and vigorous physical activity should occur at least 3 days a week. Children and adolescents should also include resistance training at least 3 days a week. It is also recommended for children and adolescents to participate in a variety of age-appropriate exercises that they enjoy [25].

The Pre-participation Physical

The risk of a fatality during regular physical activity is less than 0.01 per 10,000 participant hours, although that risk increases slightly with vigorous activity or a new physical activity program in a previously sedentary individual [29]. The risks associated with being physically inactive are higher than those transient risks during and immediately following an acute bout of exercise in both healthy and chronic disease patients [30]. The Office of Disease Prevention and Health Promotion (ODPHP) recommends that individuals with chronic disease participate in regular physical activity and should be screened and monitored by a medical provider when a regular exercise program is undertaken. There are some considerations that need to be taken prior to medical clearance for initiation of a regular exercise program.

As with healthy individuals, the pre-participation evaluation begins with a thorough history, with the cardiovascular and musculoskeletal components being the most common rate-limiting factors for exercise prescription. Exertional symptoms, presence of a heart murmur, symptoms of Marfan syndrome, and family history of premature serious cardiac conditions or sudden death should be assessed [31]. For patients with chronic diseases, special consideration for additional symptoms should be taken. For instance, patients with severe hypoxemia related to COPD or uncontrolled asthma with no known cardiovascular disease (CVD) or musculoskeletal problem may be potentially mistakenly cleared for exercise [32]. Variant CVD symptoms should be assessed in patients with diabetes, such as difficulty completing usual tasks, dizziness with activity, easy fatigability, shoulder pain, or upper back pain [33]. Absolute contraindications to exercise include unstable angina pectoris, aortic aneurysm, severe aortic stenosis, acute myocardial infarction, active myocarditis, uncontrolled ventricular tachycardia, multifocal premature ventricular contractions, and fluid retention suggested by > = 2 kg increase in body mass over 1–3 days, regardless of chronic disease status [29]. Medication history is also critical as aerobic exercise may affect the pharmacokinetics of medications commonly taken for chronic diseases [34]. In the asthmatic population, the risk of adverse events and complications with exercise is related to the level of asthma control and compliance with medication use [35]. For a comprehensive history, providers may use internationally recognized standardized tools for pre-participation evaluation such as the Physical Activity Readiness Questionnaire (PAR-Q), with the follow-up Physical Activity Readiness Medical Evaluation (PARmed-X) form used to address any medical concerns which may arise [30].

The physical examination should at least include assessment of general appearance, vital signs, vision, hearing, and the cardiovascular and musculoskeletal systems [31].

Auscultation of the lungs is of particular importance in patients with respiratory conditions such as COPD, asthma, pulmonary hypertension, or cystic fibrosis. Oxygen saturation should also be obtained. A 6-min walk test may be considered for exertional hypoxemia. The heart should be auscultated and arterial pulses appreciated. The musculoskeletal examination includes range of motion, strength, and tone. Functional musculoskeletal testing including squatting, walking on toes, duck walking, gait observation, balance, and proprioception is useful.

Symptom-directed cardiopulmonary exercise testing is another adjuvant to the pre-participation physical examination that can provide information on the patient's functional capacity, progression of cardiovascular disease, and risk for early death [30, 36]. The risk of a cardiovascular event during maximal exercise testing is less than 1 per 10,000 h of testing including in people with known cardiovascular disease [29]. While pre-exercise health screening is important, the use of exercise testing is not required for pre-exercise clearance in the majority of patients with cancer [37]. The AHA and the American College of Cardiology (ACC) do not recommend exercise stress testing for patients with an established diagnosis of coronary artery disease, including previous myocardial infarction, unless the person desires to participate in vigorous activity [38]. Pharmacologic stress tests or stress echocardiography tests may be preferred to the graded exercise tests in persons with heart failure. An appropriate exercise prescription with minimal risk may be developed for a patient through a thorough history, physical exam, and judicious use of testing modalities.

Secondary Prevention of Chronic Disease

Obesity and Its Relationship with Chronic Disease

Obesity is defined by body mass index (BMI), which is weight in kilograms divided by height in centimeters. An adult with a BMI greater than or equal to 30 is considered obese [39]. In children and adolescents aged 2–19 years old, obesity is a BMI at or above the 95th percentile of the sex-specific BMI-for-age growth charts [39]. From 2011 to 2014, 36% of adults and 17% of youth in the United States were considered obese [39]. There has been a significant linear increase in the prevalence of obesity within the US population since 1999 [39].

Obesity is associated with many chronic diseases and increases the risk of all-cause mortality, hypertension, dyslipidemia, type 2 diabetes, osteoarthritis, depression, sleep apnea, respiratory illness, and many more maladies [40]. The financial ramifications of this are staggering. Direct costs related to the care of these diseases totaled $147 billion dollars in 2008 [41]. Indirect costs related to loss of productivity and employee absenteeism range from 3 to 6 billion dollars [42]. The burdens of obesity are many, and the factors that contribute to this issue are complex. However, physical activity and exercise are simple and effective means by which some of these burdens may be lessened.

Healthy behaviors include healthy diet patterns and consistent physical activity. Balancing net energy intake from calories consumed each day with total energy expenditure used for exercise plays a part in maintenance of appropriate weight [43]. As the scale tips toward more energy consumption than energy expended, unused calories are stored in the body as fat and if left unchecked lead to obesity, which predisposes to a higher risk of metabolic and cardiovascular disorders, such as diabetes, insulin resistance, hypertension, and heart disease [43]. Exercise not only has a direct effect on weight loss and maintenance of healthy weight but also treats the chronic diseases associated with obesity.

The benefits of exercise far outweigh the risks in obese patients. However, there are some points to consider when recommending an exercise prescription to these patients. Gradual increase in duration and intensity level should be recommended [44]. This prevents stress fractures and other overuse injuries and allows for confidence building with each successfully completed level. Avoiding high-impact activities minimizes joint forces and lowers the risk for early osteoarthritis. Obese patients have lowered proprioception sense and joint awareness predisposing them to falls, acute ligament sprains, and muscle tears. Thermoregulation is diminished, so education regarding heat exhaustion and heat stroke are crucial. Appropriate hydration strategies should be advised for before, during, and after exercise. Although the risk is low for a cardiac event during low-intensity exercise, patient's risk factors for cardiovascular disease should be evaluated prior to initiating an exercise regimen [44, 45].

There are basic principles that can be applied to the obese patient in regards to formulating exercise prescriptions. Current recommendations for exercise in adults suggest 150 min or greater of moderate-intensity exercise per week or 75 min per week of vigorous exercise [39, 44]. Health benefits increase as the duration and intensity levels increase. Although exercise alone results in improved health, high-intensity regimens are required to produce significant weight loss. Patients should aim for gradual lessening of daily caloric intake with increasing levels of physical activity [44–46]. For able-bodied patients, 150–200 min of walking per week can prevent weight gain and improve cardiovascular fitness, but to actually lose weight, greater than 60 min of moderate-intensity exercise per day is recommended [44]. Aerobic activity results in improved endurance, weight loss,

and a decrease in abdominal and visceral fat. Resistance training demonstrates improved muscle mass and strength. All of these are important for obese patients; therefore exercise prescriptions should include a combination of these exercise types [44, 45].

Diabetes Mellitus

People with diabetes can lower blood pressure, weight, cholesterol, and risk of cardiovascular disease with exercise. Conversely, patients with poorly controlled diabetes have a three to four times higher risk of stroke and heart disease [47]. Exercise improves glycemic control and cardiovascular fitness [48]. A structured aerobic exercise program that includes resistance training, walking, cycling, or jogging reduced hemoglobin A1c values by 0.6%. As little as a 1% decrease in hemoglobin A1c is associated with a 20% reduction in major cardiovascular events and a 37% reduction in microvascular complications [47]. The combination of both aerobic and resistance exercises is superior to either type of exercise alone in improving hemoglobin A1c, body composition, plasma lipid values, and blood pressure. Still, only 39% of adults with diabetes are physically active compared with 58% of other US adults [49].

The ACSM and ADA recommend patients with diabetes perform 30 min of moderate to vigorous-intensity aerobic exercise at least 5 days a week or a total of 150 min per week. This activity should be spread out over at least 3 days per week without more than 2 days in a row without exercising [50]. Prior to starting a new exercise program, the patient should undergo a physical exam by a physician. The US Preventive Services Task Force advises that stress testing should not be routinely recommended in asymptomatic individuals with a low CAD risk (<10% risk of a cardiac event over 10 years) because of the risk of false positives. Patients who have been sedentary and plan activities more vigorous than brisk walking should have an ECG [51]. ECG stress testing may be indicated in older patients and those with diabetes for more than 10 years or with signs of end-organ disease. Patients with certain complications of diabetes require special consideration [52, 53]. Those with diabetic peripheral neuropathy are at increased risk of falls and should incorporate balance exercises. Stationary bike and swimming may be better alternatives to weight-bearing activities such as walking and jogging. Those with proliferative retinopathy are at risk of vitreous hemorrhage and retinal detachment with exercise and should avoid heavy lifting and vigorous exercise. Biking, walking in a pool, slow hiking, and elliptical machines at low to moderate intensity are advisable. There are no specific restrictions on light to moderate exercise for patients with nephropathy.

Patients may need to check their glucose before exercise and, if exercising over longer periods of time, every 30–60 min until they know how their blood sugar responds to different exercise regimens. A carbohydrate drink or fruit may be consumed before, during, or after activity. Those on insulin should avoid injecting it into exercising muscle and may need to decrease doses of insulin or secretagogues before sessions of activity [52, 53].

Cardiovascular Diseases

Regular physical activity is an effective tool for secondary prevention of cardiovascular diseases [54–57].

Coronary Artery Disease and Hyperlipidemia

There is an increased risk of acute myocardial infarction and sudden cardiac death in people with coronary artery disease (CAD) and hyperlipidemia [58]. The recommended amount of physical activity to lower that risk is three to four 40-min sessions of moderate to vigorous aerobic activity per week [56]. This improves both survival and quality of life [54, 55, 57]. There is an inherent risk of sudden cardiac death and/or acute myocardial infarction with vigorous exercise in patients who have CAD so they should undergo stress testing and assessment of left ventricular function prior to starting a vigorous exercise routine [58]. Clinicians and patients should then engage in shared decision-making regarding results, considering risks versus benefits of exercise.

Hypertension

Hypertension is considered a systolic blood pressure (SBP) >140 mm Hg and/or diastolic blood pressure (DBP) >90 mm Hg in someone over age 18, measured on two or more occasions at least 1 week apart. In those under 18 years of age, hypertension is a systolic or diastolic pressure above the 95th percentile for age/sex/height [59]. Hypertension is the most common modifiable cardiovascular condition among the general population, affecting 80 million US adults [59, 60]. Physical activity is effective as secondary prevention and reduces the incidence of stroke and both all-cause and cardiovascular mortality [59–63]. Both SBP and DBP remain lower for up to 24 h after aerobic exercise [64].

For those with stage 1 hypertension (SBP 140–159 mm Hg or DBP 90–99 mm Hg), there are no restrictions to initiating exercise, provided blood pressure is monitored every few months. Stage 1 patients with sustained hypertension following exercise should have an echocardiogram. Patients with stage 2 hypertension (SBP >160 mm Hg or DBP >100 mm Hg) should avoid high static sports (weight lifting, wrestling, etc.) until blood pressure is controlled [59].

Arrhythmias

There are many variations in heart rate and rhythms that may affect a patient's appropriateness for exercise [65]. Most require risk stratification with history, physical examination, and electrocardiogram (ECG) and occasionally echocardiogram (ECHO), exercise tolerance testing (ETT), and invasive electrophysiology studies (EPS). Patients with asymptomatic bradycardia and no structural disease may exercise as tolerated. Those with symptomatic bradycardia or conduction blocks likely need structural evaluation of the heart with ECHO and even EPS and eventual pacemaker, after which they can usually tolerate exercise. If patients are pacemaker dependent, they should avoid activities with risk of collisions, which could damage the pacemaker. Young or competitive athletes with symptomatic supraventricular tachycardia (SVT) or atrial fibrillation are preferentially treated with permanent catheter ablation rather than pharmacotherapy. Those who are asymptomatic should have stress testing and, if there is a bypass tract with a short refractory period, should have an ablation prior to exercise clearance. Patients with atrial fibrillation for whom rate control and anticoagulation is the selected treatment should avoid contact sports. Patients with premature ventricular complexes (PVCs) need at least an ECG and ETT, and if PVCs increase in frequency or cause symptoms with exercise, or are associated with structural disease, activity should be limited to low intensity. More worrisome rhythms such as ventricular tachycardia require ECHO, ETT, and Holter monitoring. Patients with implantable cardiac defibrillators (ICDs) should only engage in low-intensity exercise, starting 3 months after the ICD was inserted.

Valvular Heart Disease

Moderate-to-severe valvular heart disease (VHD) is present in 2.5% of Americans and can impact quality of life [66]. VHD, even after valve repair or replacement, is a chronic disease and requires evaluation for physical activity, including history and physical exam and consideration of risk stratification with an ECHO or ETT [67, 68]. Some patients have mild disease and/or murmur and may exercise without restriction. Some have intermediate disease and require monitoring. Aortic stenosis (AS) is a more significant condition, can cause exertional death, and is responsible for 4% of exercise-related sudden death in young athletes. Patients with mild disease may exercise if ECG and blood pressure changes during exercise are normal. Patients with moderate-to-severe AS should generally avoid exercise and consider surgical intervention if symptoms are present. Aortic regurgitation may lead to left ventricular (LV) dilation and should be evaluated with echocardiography. If the patient has Marfan syndrome, any amount of aortic dilation should preclude exercise participation. Otherwise, patients with mild-to-moderate disease are able to participate provided that LV end-diastolic diameter is only mildly increased (<6.0 cm) [68]. Severe mitral stenosis (MS) may lead to atrial fibrillation, requiring anticoagulation, which would limit exercise participation. Patients with mild MS have little restriction, whereas patients with moderate MS should be limited to low-to-moderate activity which does not produce symptoms. Patients with asymptomatic mitral valve prolapse with normal LV function and diameter may participate fully in exercise. Mitral regurgitation may be associated with systolic dysfunction; however if no harm is evident, an exercise program is prudent [67, 68].

Chronic Obstructive Pulmonary Disease

Chronic obstructive pulmonary disease (COPD) causes airflow obstruction, prolonged expiratory phase, air trapping, and inflammation [69]. Fourteen million adults have COPD leading to 11 million physician office visits and 1.5 million emergency visits [70]. COPD was the third leading cause of death in the United States in 2014 [71]. Patients with COPD have fatigue, shortness of breath, poor functional status and quality of life, and poor exercise tolerance [72]. All of this improves with exercise, not by improving lung function, but by maximizing the function of other body systems [73]. Gains in muscle strength and endurance allow a patient to work harder with delayed fatigue and decreased ventilation demand, which allows for more time for expiration of air [74]. Psychological factors, such as increased tolerance to dyspnea, are positively affected with exercise [75]. This may be due to the antidepressant effects of exercise, social interaction, and distraction when participating in pulmonary rehabilitation programs with other people having the same condition or education of patients regarding their disease.

Although the benefit of exercise is clearly established in patients with COPD, there are risks. Musculoskeletal injury is a concern as the majority of patients with COPD are debilitated and may need supervision [72]. Exercise-induced bronchospasm is not uncommon, and patients need to have their bronchodilators on hand. Patients with COPD are at increased risk for cardiovascular death and may need stress testing before starting an exercise program [76, 77].

Endurance and resistance exercise for the upper and lower extremities is central to any pulmonary rehabilitation program and improves function [72]. High-intensity workouts are preferred, targeting 60% of $VO2_{max}$ [78], but even low-intensity exercise produces benefit. Health benefits are seen after just 6 weeks of exercise with longer programs likely sustaining benefit [79, 80].

Osteoporosis

Osteoporosis is characterized by low bone mass and microarchitecture deterioration of bone tissue leading to bone fragility and increase in fracture risk [81]. Over 75 million people in Europe, Japan, and the United States alone are currently diagnosed with osteoporosis, which is likely an underestimation [82]. Between 30% and 50% of women and 15–20% of men will suffer an osteoporotic fracture in their lifetime, often as the presenting symptom of the disease [83].

Though there are pharmaceutical treatments for osteoporosis, physical activity is still the first recommendation in the prevention of osteoporosis and fragility fractures. Resistance training and weight-bearing exercises are likely to help build and preserve bone mass. Exercise enhances muscular strength and coordination, which reduces the risk of falling, which is the major risk factor for fragility fractures and the most common cause of mortality and morbidity from osteoporosis [84]. A physically active lifestyle is associated with a 50% decrease of hip fractures, presumably related to a decrease in fall risk [85–87]. Exercises such as Tai Chi focus on posture and weight bearing using low-velocity movements of the body, which increases muscular strength and improves balance, postural stability, and flexibility, reducing the risk of falls in older adults by 50% [88]. Starting physical activity at a young age likely contributes to higher peak bone mass later in life [89]. Even short-term gains in bone density can be measured in children and adolescents [90].

In women resistance training and weight-bearing exercises produce a 2% gain in bone density at the lumbar spine and femoral neck [91–93]. Resistance training improves vertebral bone density, and high-impact training improves femoral neck density with mixed programs that incorporate jogging, walking, or stair climbing with resistance training improving both [91–93, 95]. None of the training regimens have a significant impact on bone strength at either the proximal tibia or the femoral shaft [94]. Walking and endurance training alone have little to no effect on femoral neck or lumbar spine bone density [96–99]. High-impact jumping programs without other exercises were ineffective [100].

Studies on the effects of exercise on bones in men are limited but show that high-intensity progressive resistance training combined with moderate-to-high-impact weight-bearing exercises performed at least three times a week can improve femoral neck bone density [83, 101].

Exercise programs that involve weight-bearing activities that are variable in nature and applied rapidly, such as skipping, dancing, jumping, and hopping, and are performed three to five times a week for up to 45 min per session are most effective in increasing bone strength [102–104]. In older adults where high-impact exercises may be contraindicated, low-to-moderate impact weight-bearing exercise in combination with progressive resistance and/or agility training is safe and effective [100, 101, 105]. In frail elderly patients who are prone to fall, regular low-impact aerobic or dance exercises or resistance training on machines may be a safe option [106–108]. In younger subjects, nonlinear high-impact and high-loading activities at least twice weekly are beneficial and safe [109].

Osteoarthritis

Osteoarthritis (OA) is a chronic degenerative joint disorder and the most frequent cause of disability among adults in the United States [110]. It affects more than 50 million adults and is the fourth most common cause of hospitalization [111]. In 2009, almost a million knee and hip replacements were performed at a cost of over $42 billion [112]. The lifetime risk of OA by the age of 85 is one in two and increases to two in three for those who are obese [113]. Other risk factors are family history, female sex, past trauma, muscular weakness, and advancing age.

OA often asymmetrically affects the hands, knees, hips, and spine. Although any joint can be affected, knees followed by hips are the most affected joints [114]. The disease process involves the whole joint, including cartilage, bone, ligament, and muscle with joint pain the predominant symptom. OA is defined radiographically by joint space narrowing, bony osteophytes, bone contour deformity, and/or sclerosis and clinically by descriptions that take into account age, stiffness, warmth, crepitus, tenderness, and bony enlargement [115]. These symptoms lead to physical and psychological disabilities and impaired quality of life. Despite evidence that exercise is beneficial, most people with OA do not achieve recommended levels of physical activity. This leads to muscle weakness which worsens joint biomechanics, making joints less stable and subject to pathologic shear which causes microtrauma and cartilage degeneration, subchondral bone sclerosis, and malalignment [116].

Exercise and muscle strengthening is the cornerstone of nonsurgical management of OA and reduces pain while increasing physical function, so patients can pursue social, domestic, occupational, and recreational activities [117–119]. Land-based exercises reduce pain and improve physical function in those with knee OA [114]. There is less evidence regarding hip OA.

Weight loss of greater than 5% or at a rate of 0.24% reduction per week leads to significant improvement in disability and reductions in the load placed on the knee in individuals with knee osteoarthritis [120]. In order to avoid muscle wasting, patients with dietary restrictions for weight loss need strength training.

Exercise therapy should be individualized and patient centered, taking into account patient age, mobility, comorbidities, and preferences. Aquatic therapy or seated exercises

may be better tolerated by patients who are deconditioned or obese. Exercise may be effectively delivered via individual treatments, supervised groups, or performed unsupervised [121]. Some supervision may lead to improvement in movement and walking pain long-term [122]. General exercise programs are safe and well tolerated for most people with lower limb OA but are often limited by discomfort at the affected joint, which may require modification to the exercise regimen. Adequate footwear, proper warm-up and cooldown, correct exercise technique, proper clothing, and gradual increases in exercise dose are recommended [123].

Promoting Physical Activity

There are innumerous benefits of physical activity for a host of chronic diseases. A majority of practitioners are at least partially aware of these benefits and the crucial role that exercise can play in a comprehensive treatment plan, yet many consistently fail to incorporate activity recommendations into the plan of care. Only a third of patients report that their physician has advised them to be physically active [124]. Many clinicians are uncertain as to how to write an appropriate exercise prescription or do not know what counseling strategies are effective. Only 6% of medical schools include exercise guidelines in their core curriculum [124]. System factors include lack of time during visits, an emphasis on acute issues rather than preventive medicine, and lack of financial reimbursement for exercise counseling. Although these barriers exist, physicians can significantly influence patients' physical activity. Patients provided with physician advice and written materials had about 1 kcal/kg/day increase in physical activity 6 months after the initial encounter. In an 80kg man, this would translate into almost a 600 kcal/week increase in physical activity [125], the question then becomes how to be effective in counseling on physical activity in a challenging environment. Several successful models are highlighted below.

Exercise as a Vital Sign

In 2009, a Kaiser Permanente outpatient clinic system in Southern California began to routinely ask patients about their weekly physical activity. This was referred to as "Exercise as a Vital Sign," which functioned as part of a larger initiative named "Exercise is Medicine," which encouraged providers to prescribe exercise to patients [126]. In addition to the usual vital signs, the patient was asked "On average, how many days per week do you engage in moderate to vigorous physical activity (like brisk walking)?" and "On average, how many minutes do you engage in physical activity at this level?" The answers were multiplied to obtain the total number of minutes of physical activity per week and recorded in the patient's medical record. This initiated discussions of physical activity, highlighted the importance of exercise, was associated with modest weight loss in overweight patients, and improved glucose control in diabetics. By recording physical activity in an EMR, practitioners are able to track values over time and patient progression toward exercise goals. From a public health standpoint, aggregating physical activity data may be a tool for analysis of health discrepancies by geographical area.

The Exercise Prescription

Providing a written prescription for exercise may be effective in motivating patients to be more active. One effective and simple prescription is known as the FITT model and includes specific recommendations regarding **f**requency (number of days per week), **i**ntensity (moderate or vigorous), **t**ype (modality of activity, often dependent on the resources available to the patient, limitations of the chronic medical conditions, and their personal interests), and **t**ime (length of the session or the number of repetitions) [127]. As patients advance it is important to increase duration or frequency before increasing intensity. Exercise prescriptions should include a recommendation for 2 days/week of strength training. All sessions should include a dynamic warm-up, the main cardiorespiratory phase, and then a cooldown period [128].

Community and Clinic Initiatives

Because of the barrier of cost to many patients, communities or clinics can sponsor and encourage physical activity in local parks or trails. One model is Run/Walk with a Doc where a local physician leads interested participants for a walk or a run. Several communities sponsor mall walking in the morning before stores open. New York City has an initiative called "Make Central Park Your Gym" and allows people to rent bikes or participate in free outdoor group exercise classes several times a month.

New Trends and Alternative Arenas

High-Intensity Interval Training

High-intensity interval training (HITT) is performed at vigorous levels (80–95% of maximum heart rate), alternating work and rest periods. It has similar aerobic benefits as longer workouts but in shorter periods of time with more calories burned. Two weeks of HITT can improve aerobic

capacity as much as 6–8 weeks of endurance training. Participants should have a base fitness level before beginning this type of training with an established form and appropriate level of strength before focusing on intensity and speed, which should be based on their own fitness levels and not on that of others participating with them [129].

Yoga

Yoga is a combination of breath work and movement which can be tailored to focus on strengthening and stretching specific muscle groups. It offers physical, mental, and emotional benefits, including stress reduction. It improves balance which can prevent injury, a process enhanced by instruction from a professional teacher [130].

Tai Chi (Taiji)

Tai Chi is the marriage of traditional Chinese martial arts with meditation. It is a series of slow, focused movements accompanied by breathing and is often to older adults as it can reduce the risk of falls while reducing stress and improving cardiovascular function. One practice is known as Qigong or "energy work" and is a form of meditation done sitting, standing, lying down, and moving and is associated with improvement in executive brain function. Form practice is enhanced Qigong and incorporates choreography. Another form is push hands, which involves contact with a partner and works best when supervised by a trained instructor [131].

Aquatic Therapy

Aquatic therapy is exercise performed in the pool. It can be useful for patients limited by arthritis, obesity, or overall deconditioning as it allows for unloading of joints. Access to a pool or prohibitive membership costs limits the availability of this form of exercise.

Group Training

Group athletic structure is pervasive and formative in the youth population but is harder to find in adulthood. Group training is led by an instructor and offers some of the same benefits found in team sports including a social atmosphere and accountability. Many different types of classes fall into this category, including boot camps, indoor cycling, kickboxing, and circuit training. Workouts are planned by a trained instructor and do not usually require much experience before attending the class. Working out with others and with a group leader may make it more difficult for participants to skip less favored sections of a workout and may encourage participants to engage with consistent intensity. Many group classes require individuals to sign up for ahead of time or pay a fee ahead which can improve accountability but can be a discouraging factor to some populations [132].

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Diet and Weight Management

6

Leah Elizabeth Chapman, Ramine Alexander,
Thomas C. Keyserling, and Alice S. Ammerman

Introduction

Weight gain and obesity result from small changes in daily energy balance over time [1]. Adults ages 20–40 gain on average about 2 pounds per year [2]. While this amount seems small, it adds up over time [3]. A healthy, balanced diet is an important strategy for preventing weight gain and achieving weight loss.

Weight stability requires a balance between calories consumed and calories expended and the traditional advice to "eat less and exercise more" seems straightforward. However, large well-designed studies suggest that the message should be more nuanced [3–5]. Not only should we "eat less," but we should also "eat better," as a healthful diet reduces the risk of chronic disease. Transitioning from a contemporary Western diet (high intake of red and processed meat, refined grains, and sweets) to a pattern of high-quality fats (polyunsaturated and monounsaturated fats from plants and fish) and carbohydrates (fruits, vegetables, and whole grains) is essential for obesity and chronic disease prevention and treatment [6, 7].

The US Preventive Services Task Force (USPSTF) recommends screening all patients aged 6 and older for obesity, and adults with a body mass index (BMI) of 30 kg/m^2 or higher should be offered intensive, multicomponent behavioral interventions [8]. The American Academy of Pediatrics recommends timely recognition of obesity in children stating that it is never too early for a family to make changes that will help a child keep or achieve a healthy weight [9].

L.E. Chapman (✉)
Department of Nutrition, The University of North Carolina at Chapel Hill, Chapel Hill, NC, USA
e-mail: leahchapman@unc.edu

R. Alexander
Department of Nutrition, UNC Center for Health Promotion and Disease Prevention Department, Chapel Hill, NC, USA

T.C. Keyserling
Division of General Medicine and Clinical Epidemiology, Department of Medicine, UNC Hospitals, Chapel Hill, NC, USA

A.S. Ammerman
Center for Health Promotion and Disease Prevention, Department of Nutrition, Gillings School of Global Public Health and School of Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

Obesity and Chronic Disease

Obesity prevalence has dramatically increased over the past 30 years. Global obesity rates have doubled since 1980; nearly 10% of men and 14% of women totaling 500 million adults worldwide are obese (defined as a BMI ≥ 30) [10]. In the United States, obesity rates have steadily increased since 2005 and have more than doubled since 1980 [11, 12]. The prevalence of childhood obesity (BMI ≥ the 95th percentile for children of the same age and sex) has steadily increased in the United States over the past 30 years, doubling among school-aged children and quadrupling in adolescents [13–15]. Nearly 40% of American adults, 20% of adolescents, 18% of school-aged children, and 9% of preschoolers are obese [16]. The prevalence of obesity is lowest among Asian adults (12%) and is increasing in non-Hispanic white (35%), Hispanic (42%), and black (48%) adults.

An unhealthy diet is a risk factor for obesity and certain foods are more "obesogenic" than others [17–19]. Weight gain is strongly associated with intake of potato chips, potatoes, sugar-sweetened beverages, red meats, and processed meats and is inversely associated with the intake of vegetables, whole grains, fruits, nuts, and yogurts [3, 17, 19]. Fast-food consumption is also correlated with obesity [18].

Obesity is strongly associated with incidence of and mortality due to chronic diseases including cardiovascular disease (CVD), type 2 diabetes (T2D), osteoarthritis, and obstructive sleep apnea [1]. Increased BMI is also associated with certain cancers such as colorectal, renal, esophageal, pancreatic, gallbladder, liver, thyroid, non-Hodgkin lymphoma, endometrial, postmenopausal breast, ovarian, aggressive prostate, and multiple myeloma [20]. About 20% of cancer is caused by excess weight [21]. Weight loss may

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be associated with a reduction in this risk with one study showing that successful bariatric surgery reduced cancer incidence over a 10-year period [22].

The link between obesity and CVD incidence or mortality is well established [1]. A high BMI is associated with higher blood pressure and unfavorable cholesterol levels, which increase the risk for CVD [23, 24]. Obesity is also associated with the development of insulin resistance, prediabetes, and type 2 diabetes [25]. Men and woman with BMI ≥ 30 have a 7- and 12-fold higher risk, respectively, of developing diabetes compared with their peers in the normal weight range (BMI < 25). Given this strong link, clinicians should screen all overweight and obese patients for diabetes. Moderate weight loss can prevent or delay the onset of diabetes among high-risk individuals [26–28].

Osteoarthritis (OA) is strongly linked to obesity in both men and women with a five-unit increase in BMI associated with an 11% increased risk of hip OA and a 35% increased risk of knee OA [29, 30].

Obesity is a major risk factor for the development and progression of obstructive sleep apnea (OSA) [31–35]. Patients with mild OSA who gain 10% of their baseline weight are at a sixfold increased risk of progression of OSA, while weight loss results in a >20% improvement in OSA severity [33, 36].

The incidence of obesity and chronic disease is not distributed evenly across the population. African Americans, Hispanic Americans, and people of lower socioeconomic status are more likely to be obese and suffer from chronic diseases [14, 37–39]. This may be due to a variety of reasons, such as higher rates of poverty, limitations in cultural competence among healthcare providers, and lack of access to providers, technology, and procedures [37].

The burden of obesity and chronic disease is significant. According to the Centers for Disease Control and Prevention, 86% of all healthcare spending in 2010 was attributed to people with one or more chronic medical conditions [40]. Medical costs linked to obesity were estimated to be $147 billion in 2008, and annual medical costs for obese individuals were $1429 higher than those for people of normal weight in 2006 [41]. In 2010, costs linked to cancer and heart disease were $157 billion and $315 billion dollars, respectively [42, 43]. The total estimated medical costs of diagnosed diabetes in 2012 were $176 billion [44]. In addition to these direct medical costs, in 2012 diabetes caused a $69 billion loss due to decreased productivity associated with absence from work, decreased productivity, or disability [43].

Dietary Patterns and Chronic Disease

In addition to the influence of diet on obesity, eating patterns also play a role in the development and management of common chronic diseases. There are robust associations between dietary pattern and CVD risk, and replacing saturated fats with unsaturated fats, especially polyunsaturated fats, lowers cholesterol and reduces that risk [5, 45–52]. Consumption of red and processed meat is associated with increased incidence of CVD [53]. Sugar-sweetened drinks are similarly problematic, and women who drank more than two servings of sugary beverages each day had a 40% higher risk of heart attack or death from heart disease than women who rarely drank sugary beverages [54]. A dietary pattern of high-quality fats and carbohydrates decreases the risk of CVD [4].

There are also strong associations between dietary pattern and risk for diabetes [55, 56]. A plant-based diet that includes whole grains, fruits, vegetables, nuts, and legumes is linked with a substantially lower risk of diabetes, while a diet high in red and processed meat or sugar-sweetened beverages is associated with an increased risk [57–61].

A link between diet and cancer is likely but less established than the links between diet and diabetes [62]. Women who adhered to a Mediterranean diet supplemented with extra-virgin olive oil and nuts had a lower incidence of breast cancer compared to the control group [63]. Adults who consume more fruits during adolescence (2.9 servings) compared to those who consume less (0.5 servings per day) have a lower risk of breast cancer [64]. There is also a link between red and processed meat and mortality from cancer [65].

Approaches to Managing Obesity

Screening for Obesity

Healthcare providers play a role in identifying and clarifying the importance of a healthy diet and weight management, and their advice to patients can have positive effects [66]. When providers initiate weight-related discussions, patients are more likely to perceive themselves as overweight and to then report wanting to lose weight [67–69].

Since obesity is associated with increased mortality, chronic diseases, and an array of other deleterious effects, the US Preventive Services Task Force (USPSTF) recommends clinicians screen all adults for obesity [70]. The most common tool used to screen for excess body weight is body mass index (BMI). BMI is easy to measure, highly reliable, and closely correlated with adult body fat. Waist circumference and waist-to-hip ratio can also be used. However, BMI is the favored measure because it is linked with the broadest range of health outcomes and entry criteria for most treatment studies, and weight-related trials are based on BMI [71].

Interventions for Weight Loss

If a patient does not have a healthy weight, providers should consider comorbidities such as depression, sleep problems,

chronic pain, stress, eating disorders, and other psychiatric problems that can influence weight. Weight loss attempts that do not take into account psychiatric and medical comorbidities result in a higher rate of failure [72]. Another consideration is the patient's readiness for change. Factors such as low self-efficacy, financial problems, or other life circumstances can affect a patient's motivation to lose weight. In these cases, the provider can help the patient outline a plan to address weight with the understanding that the patient may pursue this when he or she is ready. Providers should also inquire about success or failure with past and current strategies related to weight loss while praising those previous attempts, even if they are not reflected in their current BMI.

The most effective interventions in treating obesity are comprehensive and high intensity. Multicomponent behavioral interventions such as group or individual sessions, setting goals, improving diet or nutrition, physical activity sessions, addressing barriers to change, self-monitoring, and maintaining a healthy lifestyle are effective management strategies that help people lose weight [8]. Participants in behavioral interventions lose about 6% of their body weight in a year with 12–26 treatment sessions compared to little or no weight loss in control group patients. Behavioral interventions also improve immediate health outcomes, such as blood pressure, waist circumference, and glucose tolerance.

Intensive behavioral treatment should involve a multidisciplinary team. Such teams, combined with quarterly physician oversight visits, are more likely to produce clinically significant weight loss than physician counseling alone [73, 74]. These teams usually include nurses, medical assistants, dietitians, psychologists, and health educators. If this is not available, physicians can partner with the local health department or private practices of healthcare providers who offer these services. Intensive behavioral counseling in person or by telephone can help patients from primary care facilities have clinically meaningful weight loss [74]. Most obesity guidelines recommend face-to-face contact, but telephone counseling can be just as effective and is also convenient, is less costly, and can reach patients in underserved areas [75–77].

Weight loss outcomes improve when behavioral strategies complement reductions in caloric intake and physical activity [78–81]. Motivational interviewing can effectively change behaviors that influence weight [82]. The 5As model for weight management counseling in primary care is another effective approach (Fig. 6.1) [72]. The treatment algorithm is based on the 5As framework (Assess, Advice, Agree, Assist, and Arrange) and improves the odds of increasing patients' motivation to lose weight, improve their diet, and increase their physical activity [69, 71, 83]. Combining a multidisci-

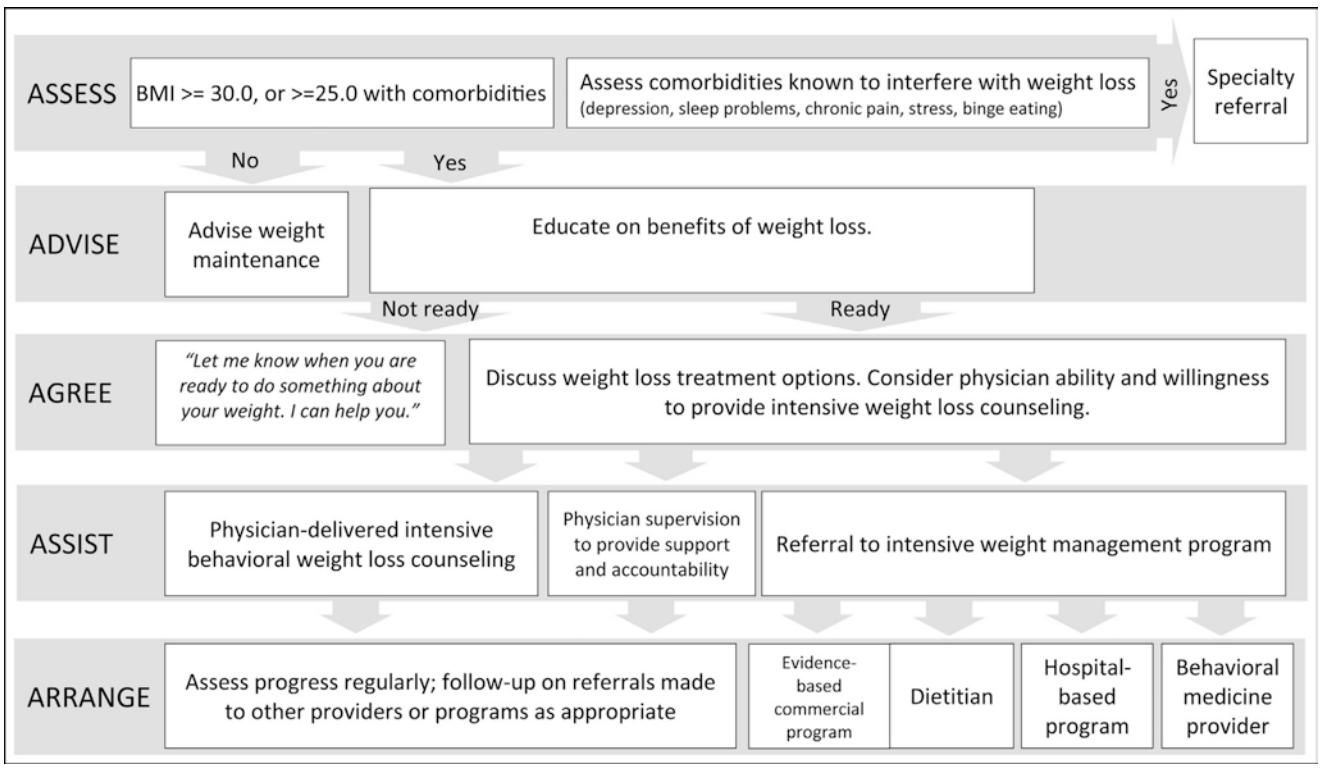

Fig. 6.1 Flowchart for 5As model of obesity management in primary care. The flowchart allows for the categorization of patients according to their readiness to lose weight within the 5As model. Of note, the physician is able to consider comorbid conditions that may interfere with weight loss and provide appropriate referrals for other professionals as needed within this model. BMI 1⁄4 body mass index

plinary team and the 5As model helps patients lose weight and maintain weight loss [73, 74]. It can also be used by individual clinicians.

Physicians and other healthcare professionals can partner with local health departments, the YMCA, federal- and community-based programs, or other resources in the community that may offer affordable services for patients referred from local clinics [72]. The YMCA offers an intensive behavioral treatment program for obesity called the Diabetes Prevention Lifestyle Intervention [72]. Effective commercial-based programs include Weight Watchers and Take Off Pounds Sensibly (TOPS) [84]. There are also a variety of commercial mobile applications available for dietary and physical activity self-monitoring [85]. Patients can review the data collected on their devices with their physician and discuss progress and barriers [86].

Social support is also an important factor in achieving and maintaining health behavior change. Family members, friends, colleagues, churches, and other social communities are a regular part of a patient's life and can play a role in support efforts to change lifestyle [87].

Bariatric Surgery

Bariatric surgery is associated with early and sustained weight loss and a reduction of chronic disease incidence and mortality. Bariatric surgery is a surgical procedure performed on the stomach or the intestines to induce weight loss [88]. It is approved for people with extreme obesity (BMI $\geq$ 40) or people with moderate obesity (BMI $\geq$ 35) who also have an obesity-related health problem, such as diabetes, high blood pressure, or sleep apnea [89]. The two most common surgical options for bariatric surgery are Roux-en-Y gastric bypass surgery and gastric sleeve surgery [88]. Gastric sleeve surgery, which accounts for approximately 70% of bariatric surgeries, removes 80% of the stomach. The gastric sleeve procedure causes weight loss by reducing the size of the patient's stomach, so he or she will not be able to eat as much, and by reducing the stomach's secretion of the hunger hormone ghrelin, which then suppresses the patient's appetite. Roux-en-Y gastric bypass surgery, which was previously the most common form of bariatric surgery, converts the upper stomach into an egg-sized pouch and reroutes the small intestine to the pouch. Mechanistically, this procedure yields weight by restricting caloric intake (small stomach) and increasing malabsorption (bypass component of procedure). Both gastric sleeve and surgery are performed laparoscopically.

The number of people undergoing bariatric surgery has soared in recent years, increasing from 101,645 surgeries in 2011 to 154,276 surgeries in 2013 in the United States and Canada (a 51% increase) [90]. This is likely due to several factors, including a growing number of extremely obese people, improved surgical techniques, and bariatric surgery success stories from high-profile figures such as American television personality Al Roker, who lost 100 lb from bariatric surgery in 2002 [91, 92]. Women are more likely than men to undergo bariatric surgery, while African Americans are less likely than people of other ethnicities to have this surgery [93].

Bariatric surgery is consistently associated with short- and long-term weight loss. BMI loss within 5 years postsurgery is within the range of a 12–17 unit drop (kg/m^2) [94]. However, the surgery is associated with substantial risk. The complication rate is 17% and includes bleeding, stomal stenosis, leak, vomiting, reflux, gastrointestinal symptoms, and nutritional and electrolyte abnormalities. The reoperation rate is 7%. The mortality rate within 30 days after surgery is 0.08% with a mortality rate after 30 days of 0.31%. Roux-en-Y gastric bypass is more effective in weight loss compared to adjustable gastric banding but associated with more complications. Adjustable gastric banding has lower mortality and complication rates than Roux-en-Y gastric bypass surgery, but the reoperation rate is higher and weight loss less substantial. Sleeve gastrectomy is more effective in weight loss compared to adjustable gastric banding and is comparable with weight loss from Roux-en-Y gastric bypass.

Postoperative diet and physical activity change in addition to bariatric surgery predicts more successful short- and long-term weight outcomes, compared to people who undergo bariatric surgery and do not make diet and physical activity changes. Patients who exercise (defined as exercising in any form for at least 30 min per session three or more times a week) show a 28% higher loss of fat mass and an 8% higher gain in lean body mass than the non-exercise group at 18 months postoperatively [95]. Postoperative uncontrolled eating is another important detrimental indicator of short- and long-term weight outcomes of bariatric surgery patients [96].

Bariatric surgery improves bodily pain and physical function. One year after bariatric surgery, 58% of patients have improvement in bodily pain, 76% improve their physical function, and 60% have better "walk time" endurance (ability to walk several blocks). Larger improvements are associated with younger age, higher household incomes, fewer depressive symptoms before surgery, greater weight loss during follow-up, and absence or resolution of diabetes [97, 98]. These gains decline over time, and by 3 years postoperatively, bodily pain improvements dropped from 58% to 49% and improved physical function decreased from 76% to 70%, but improvement rates for walk time did not decrease.

In addition to weight loss and improvements in pain and bodily function, bariatric surgery is associated with a decreased incidence of and mortality due to chronic diseases [99]. Even cancer incidence and mortality rates decrease fol-

lowing bariatric surgery [100]. In the Swedish Obese Subjects study, there was a 40% reduction of total cancer incidence in women who had bariatric surgery, but no effect on total cancer incidence in men who had similar procedures [22]. Certain cancers, such as endometrial and breast cancer, are associated with estrogen, so this association for women may be driven by reduction in body fat mass (and therefore estrogen, which is produced in part by fat cells) from bariatric surgery [101, 102]. The Utah Cancer Registry study found that total cancer incidence was 24% lower in people who had Roux-en-Y gastric bypass surgery compared to severely obese controls, though these improvements were again only evident in women [100]. Cancer mortality was 46% lower in the surgery group compared to the control group for women.

Bariatric surgery is also associated with a decreased risk of diabetes. Two years after surgery, bariatric subjects experience significantly higher diabetes remission rates (74%) compared to nonsurgical subjects (7%) [103]. Other studies report that diabetes resolves in 78% of patients after surgery and improves or resolves in 87% of patients [104].

An improvement in cardiovascular risk factors, including hypertension, dyslipidemia, inflammation, and type 2 diabetes, as well as reductions in the risk of myocardial infarction, stroke, and death, has been observed among patients who undergo bariatric surgery [105]. Bariatric surgery is associated with a significantly reduced risk of composite cardiovascular adverse events including myocardial infarction and stroke [106].

Though bariatric surgery affords many benefits, it is also associated with side effects and adverse outcomes. Increased fracture risk, development of gallstone disease, and alcohol abuse are associated with bariatric surgery. Postoperative fracture risk is higher among patients who had bariatric surgery compared to obese controls and nonobese controls [107]. Rapid weight loss increases the risk of gallstone formation, to as high as 53% after 1 year [108–111]. Bariatric surgery is also associated with an increased incidence in alcohol abuse in some patients [112]. Macro- and micronutrient deficiencies can also occur in postoperative patients, and lifelong nutritional supplementation is usually required [113, 114]. In addition to these concerns, bariatric surgery is expensive. Roux-en-Y gastric bypass costs $25,000–$30,000 per patient, including the surgery and postoperative care [115]. Due to cost and lack of acceptability to most obese people, bariatric surgery is not likely to have a major impact on population obesity rates.

Weight Loss Medication

There are six weight loss medications approved by the Food and Drug Administration (FDA) for use in the United States: orlistat, combined phentermine/topiramate, lorcaserin, naltrexone/bupropion, liraglutide, and phentermine [116]. All six medications have shown weight loss efficacy versus placebo, and the five medications approved for long-term weight management (all except phentermine, which is only approved for short-term use) have also been associated with improvements in weight-related comorbidities, such as hypertension, high cholesterol, diabetes, and other cardiovascular risk markers. With the exception of low-dose orlistat, there is a lack of evidence for the effectiveness of non-prescription medications on weight loss and weight-related comorbidities.

According to the American Association of Diabetes Educators, people with a BMI of ≥30, or people with a BMI of ≥27 with an obesity-related condition, such as diabetes or high blood pressure, are candidates for weight loss medication [117]. Women are more likely than men to take prescription weight loss medication [118]. Though effective, weight loss medications can be costly for patients with expected annual costs of $1743 for lorcaserin, $1518 for orlistat, and $1336 for combined phentermine/topiramate extended release [119].

Weight loss medications work through a variety of physiologic mechanisms and cause several side effects (Table 6.1).

Weight loss medications are consistently associated with weight loss among obese individuals. A large review showed that the percentage of patients who successfully lost at least 5% of their weight was 44% for orlistat, 75% for phentermine/topiramate, 49% for lorcaserin, 55% for naltrexone/bupropion, and 63% for liraglutide, with 23% of those taking placebo also losing this percentage of weight [129]. An analysis using data from 22,927 obese people in the 2012 US National Health and Wellness Survey showed that those who took weight loss medication were more satisfied than those who attempted weight loss with diet, exercise, and weight loss supplements [130]. Data from the National Health and Nutrition Examination Survey (NHANES) found that using prescription weight loss medications was associated with losing ≥10% weight [131]. A variety of clinical trials have demonstrated that weight loss medications are associated with weight loss and improvements in weight-related comorbidities. Results from clinical trials for each of the six FDA-approved weight loss medications are listed below.

Orlistat Both prescription and non-prescription orlistat are associated with weight loss and improved health outcomes. The XEBDIS clinical trial found that orlistat (120 mg three times daily) produced significantly greater weight loss compared with placebo after 4 years [121, 122]. This weight loss was accompanied by approximately a 50% risk reduction in progression to diabetes in those with impaired glucose tolerance at baseline. Improvements in blood pressure, waist circumference, total cholesterol, and LDL cholesterol were

Table 6.1 Physiologic mechanisms and side effects of approved weight loss medications

Medication	Mechanisms	Side effects
Orlistat	Reversible gastric and pancreatic lipase inhibitor. Reduces fat absorption by approximately 30% [116]	Fecal leakage and a decrease in the absorption of fat-soluble vitamins, which can be addressed by taking a daily multivitamin containing vitamins A, D, E, and K and beta-carotene [116, 120–122]
Phentermine/ topiramate extended release	Combination of phentermine, a sympathomimetic amine anorectic that acts as an appetite suppressant and stimulant, and topiramate, an anticonvulsant that has weight loss side effects [116, 123]	Paresthesia, dry mouth, constipation, dysgeusia, insomnia, and dizziness [116, 123]
Lorcaserin	5-Hydroxytriptamine (serotonin, 5-HT) 2C receptor agonist [116]	Headaches, dizziness, nausea, fatigue, constipation, dry mouth, and hypoglycemia in patients with diabetes [116, 124]. Additionally, in a small amount of study participants, lorcaserin was associated with cognitive impairment (2.3% vs. 0.7% placebo) [116, 124]
Naltrexone/ bupropion	Sustained-release combination of naltrexone (an opioid receptor antagonist) and bupropion (a catecholamine reuptake inhibitor) [116]	Nausea, constipation, headache, vomiting, and dizziness [116, 125]
Liraglutide 3.0 mg	GLP-1 receptor agonist [126]	Nausea, hypoglycemia in those with T2D, diarrhea, constipation, vomiting, headache, decreased appetite, dyspepsia, fatigue, dizziness, abdominal pain, and increased lipase [127]. Liraglutide is also associated with gastrointestinal disorders, increased heart rate, pancreatitis, acute gallbladder disease, and in animal studies, thyroid tumor [116]
Phentermine	Sympathomimetic amine anorectic [116]	Primary pulmonary hypertension, palpitation, tachycardia, elevation of blood pressure, overstimulation, restlessness, dizziness, insomnia, euphoria, dysphoria, tremor, headache, rare psychotic episodes, dryness of the mouth, unpleasant taste, diarrhea, constipation, other gastrointestinal disturbances, impotence, changes in libido, urticaria [128]

greater with prescription orlistat than with placebo. Non-prescription orlistat (60 mg three times daily – brand name alli®) led to improvements in body composition, lipid profiles, and blood pressure [132].

Combined Phentermine/Topiramate Extended Release In the EQUIP trial, the maximum dose of 15 mg/92 mg produced a weight loss of 11% (versus 1.6% with placebo) after 1 year among study participants with a BMI ≥ 35 [123, 133]. This was associated with significant improvements in waist circumference, blood pressure, lipid profiles, and fasting serum glucose compared with placebo [133]. The CONQUER trial demonstrated that weight loss after 1 year was 7.8% with the "midrange" dose of phentermine/topiramate extended release (7.5 mg/46 mg once daily) and 9.8% with the maximum dose (15 mg/92 mg once daily) compared with 1.2% with placebo [123, 134]. Similar to the EQUIP trial, improvements in waist circumference, blood pressure, lipid profiles, and fasting serum glucose accompanied this weight loss. In an extension phase of the CONQUER trial, phentermine/topiramate extended release also hindered progression to diabetes over 108 weeks with the maximum dose of 15 mg/92 mg once daily compared with placebo [135].

Lorcaserin The BLOOM and BLOSSOM trials assessed the association between lorcaserin, weight loss, and additional health outcomes. After a 1-year period, lorcaserin (10 mg twice daily), in conjunction with a diet and exercise program, was associated with weight loss of 5.8% (compared with weight loss of 2.5% with placebo) [124, 136, 137]. Improvements in blood pressure and lipid levels occurred as well. Lorcaserin was associated with a decrease in the concurrent use of medications to treat hypertension and dyslipidemia.

Naltrexone/Bupropion The COR-I and COR-BMOD studies found that among obese individuals without diabetes, two 8 mg naltrexone/90 mg bupropion tablets taken twice daily were associated with a mean weight loss of 5.4% at week 56 (COR-I) and 8.1% (COR-BMOD) from baseline [125]. The COR-Diabetes study had similar findings; among obese individuals with diabetes, there were a significant reduction in weight (3.7% versus 1.7%) and a significant increase in the proportion of participants achieving ≥5% weight loss (36% versus 18%) at week 56, compared with placebo [125, 138]. Naltrexone/bupropion also improved certain cardiovascular risk markers, such as hemoglobin A1c, weight circumference, HDL cholesterol, and triglycerides in people with diabetes.

Liraglutide The SCALE Maintenance Trial **e**valuated liraglutide 3 mg in overweight or obese individuals without dia-

betes (the dose increased in increments of 0.6 mg over 4 weeks). These individuals had already lost ≥5% of their weight through low-calorie diets and exercise counseling during a 12-week run-in period. Individuals in both treatment arms continued to receive diet and exercise counseling after randomization. Study participants who were randomized to liraglutide 3 mg averaged an additional 6.2% reduction in body weight over 56 weeks, while weight in the placebo arm remained relatively unchanged over the same period [127, 139, 140]. The SCALE Trial also found that liraglutide 3 mg was associated with significant improvements in cardiovascular risk markers, such as waist circumference, hemoglobin A1c, systolic blood pressure, triglycerides, and high-sensitivity C-reactive protein.

Phentermine A meta-analysis of six randomized clinical trials found that participants who received phentermine lost an additional 3.6 kg of their body weight compared with those who received placebo [141].

Although pharmacological therapies are associated with weight loss and improvements in weight-related comorbidities, they are not "magic pills" for obesity treatment. Weight loss medications often have significant side effects, and most have not been studied with regard to long-term clinical outcomes such as heart disease and stroke. Weight loss medications should be used in combination with lifestyle changes in diet and exercise.

Putting It All Together

Mediterranean Diet

Consuming a diet with healthful components but without significant weight loss has a positive health impact on multiple chronic diseases including CVD, diabetes, and some cancers. This healthful dietary pattern, perhaps best characterized and studied as the Mediterranean diet [142], includes generous consumption of high-quality fats (polyunsaturated and monounsaturated fats primarily from plant sources and fish) and high-quality carbohydrates (fruits, vegetables, and whole grains) [143–145]. A Mediterranean diet supplemented with nuts or olive oil reduced CVD events (heart attack and stroke) by approximately 30% [4]. This reduction in CVD events is similar in people with diabetes who can reduce their risk of diabetes by 50% [56]. For women, there is a substantial reduction in breast cancer incidence [63]. The Women's Health Initiative showed a 20% reduction in hip fracture in those following a Mediterranean diet [146]. There is emerging evidence that a Mediterranean diet may decrease the risk for cognitive decline and dementia [147–149]. Consuming a diet with lower fat content and more carbohydrate (without a major focus on carbohydrate quality) does not reduce the risk of CVD, shown convincingly in the Women's Health Initiative trial ($n = 48{,}835$) [150].

Dietary Pattern More Important Than Weight Loss

Some have argued that any weight loss diet is acceptable if it leads to weight loss [151]. However, if patients are at increased risk for CVD, as is typically the case for most patients with obesity, and particularly so for those with diabetes [152], consideration should be given to advocating a weight loss diet that also reduces CVD risk. Some lower fat and higher carbohydrate diets that have yielded significant weight loss have not been associated with a reduction in CVD risk. Intensive lifestyle intervention for weight loss does not decrease CVD morbidity and mortality among overweight and obese people with diabetes [79]. Even when following the diet recommended by the Diabetes Prevention Program [153], with a focus on reducing fat intake to less than 30% of total calories and successful weight loss after 10 years, there was no significant improvement in CVD events.

A Mediterranean diet can lower CVD risk even without meeting the 5% weight loss threshold recommended by the American Diabetes Association [154, 155]. The Mediterranean diet is also easier to follow, and those that do lose weight find it easier to maintain than those on a low-fat diet [4, 156]. Hence, this is the recommended dietary pattern to advocate.

Weight Loss Interventions in Primary Care

Despite national guidelines endorsing intensive weight loss interventions, research in the primary care setting is limited and suggests only modest effects [8, 157–159]. This may feel discouraging, but patients can be presented with options. First, if a patient meets criteria for, is willing to accept, and has adequate insurance coverage, bariatric surgery is an effective option. Second, weight loss medications are an option. Third, if a patient is motivated, an intensive, multicomponent behavioral intervention that promotes a Mediterranean diet and physical activity is likely to help. Even if sustained weight loss is not achieved, this lifestyle is associated with a substantial reduction in the risk of several chronic diseases.

While it is difficult to achieve meaningful change in diet and weight through the primary care setting alone, referral to resources implementing evidence-based programs can help.

Clinicians should provide advice and encouragement to patients, which can be reinforced at subsequent visits. Both office-based and community-wide efforts can promote healthy lifestyle choices for patients which will improve both individual and population health.

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Alcohol and Drug Use Disorders

7

Sarah E. Wakeman and Richard Saitz

Introduction

Alcohol and drug use disorders can be considered as chronic diseases, conditions which are frequently seen in general medical settings and are associated with other health disorders. Although substance use is not a disease – it is a factor that can lead to an adverse health outcome (e.g., first use of cocaine can result in ventricular fibrillation and death) – substance use disorder is a disease that can be chronic. For some, the illness is episodic and short-lived and can resolve without formal treatment. However for many others, particularly individuals with a more severe disorder, the disease can have chronically recurrent symptoms. In 2015, over 66 million people in the USA reported that they had at least one heavy drinking episode (i.e., "binge drinking") in the prior month, and 27 million people reported having used illicit drugs or prescription drugs for a nonmedical purpose. Nearly 21 million Americans report an alcohol or drug use disorder, and 2.7 million had both an alcohol and drug use disorder [84].

Substance use disorders (SUD) include a spectrum of disease graded from mild to severe and are defined by the continued use of alcohol and/or other drugs which results in clinically and functionally significant impairment, impacting health, employment, and relationships [84]. Unintentional drug overdose is the leading cause of accidental death in the USA, and in 2014, there were 47,055 drug overdose deaths, more than any year on record [68]. The impact of SUD on health cannot be underestimated, and an unprecedented recent rise in the mortality of white Americans has been attributed to alcohol and other drug use [10, 87]. In addition, alcohol is responsible for even more deaths – 88,000 each year – and is responsible for one in ten deaths among working adults [81]. The associated cost of alcohol and other drug use is also staggering, with $400 billion spent annually on crime, health, and lost productivity due to alcohol or other drug use [87].

There are several categories of alcohol and drug use, and these are described with their associated prevalence in Table 7.1 [84].

Alcohol or other drug use disorders can be chronic diseases that are independent of other conditions; however there are many chronic diseases that are a byproduct of substance use. For example, alcohol is the etiology for alcohol-related cardiomyopathy, cirrhosis, pancreatitis, and polyneuropathy [77]. In addition, there are over 200 diseases and conditions in which the risk of disease development or death has a dose-response relationship with alcohol. These alcohol-associated diseases range from malignancies, including breast, oropharyngeal, esophageal, laryngeal, and liver cancers, to hypertension and diabetes [77].

Several types of drug use can result in, or exacerbate, a range of chronic diseases, including cardiovascular disease, stroke, cancer, HIV/AIDS, hepatitis, and lung disease. The medical consequences of drug use can occur after one episode of use or with repeated heavy use [57]. Chronic disease may attributed to the route of drug administration, as evidenced by the infectious complications associated with injection use, such as HIV, hepatitis B or C, endocarditis, and skin, soft tissue, and joint infections [6]. In addition, the type of substance that is used can trigger emergent conditions and complications in long-standing chronic diseases. Methamphetamine use, for example, can result in hypertension, aortic dissection, acute coronary syndromes, pulmonary arterial hypertension, and methamphetamine-associated cardiomyopathy [62].

Alcohol and drug usage affects the delivery of healthcare services. Among hospitalized patients, 22% have a current drug or alcohol use disorder and 50% have a lifetime history of substance use disorder (SUD) [7]. Among community-

S.E. Wakeman (✉)
Department of Medicine, Massachusetts General Hospital, Boston, MA, USA
e-mail: swakeman@partners.org

R. Saitz
Department of Community Health Sciences (CHS), Department of Medicine, Boston University Schools of Public Health and Medicine, Boston Medical Center, Boston, MA, USA

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Table 7.1 Prevalence of alcohol and other drug use disorders in the USA (Source: [84])

Category of use	Description	Prevalence (#)	Prevalence (% of population)
Risky alcohol use	Includes heavy episodic or "binge" use, defined as drinking five (males)/four (females) or more standard drinks* on the same occasion (i.e., at the same time or within a couple of hours of each other) on at least 1 day in the past 30 days	84 million	31.4
Alcohol use disorder	Compulsive alcohol seeking and use, despite harmful consequences	15.7 million	5.9
Risky drug use	Any illicit drug use (including cannabis) or use of a prescription medication for a nonmedical purpose	47.7 million	17.8
Drug use disorder	Compulsive drug seeking and use, despite harmful consequences	7.7 million	2.9

*Standard drink defined as: roughly 14 grams of pure alcohol, which is found in: 12 ounces of regular beer, which is usually about 5% alcohol. 5 ounces of wine, which is typically about 12% alcohol. 1.5 ounces of distilled spirits, which is about 40% alcohol

based primary care clinics, one study found that 22% of patients reported drinking above recommended limits, 5% met DSM-IV criteria for alcohol dependence, 5% reported current illicit drug use, and 20% reported using illicit drugs five or more times [48]. Despite the prevalence of SUD, a survey of general internists found that the majority do not feel very prepared to provide screening, brief counseling, and referral to specialty care or to discuss treatment options with a patient, and few frequently provide SUD treatment to patients [88].

This chapter provides a grounding in alcohol and other substance use disorders (SUD). The first section outlines screening approaches and diagnostic criteria for SUD that can be used in clinical settings. This content is followed by a review of treatment options, including behavioral modalities, peer-based programs, and pharmacotherapy. The subsequent section describes SUD treatment strategies in general medical settings and an overview of specialty addiction treatment programs. The chapter closes with future directions and some promising innovative models to promote addiction treatment within primary care.

Screening Approaches and Diagnostic Criteria

Unhealthy alcohol use can be reliably identified by screening with a single question, which is known as the single-item screening question (SISQ): "How many times in the past year have you had X or more drinks in a day?" where X is 5 for men and 4 for women. A response of at least one time is considered positive. This single-question screening approach has been found to be 81.8% sensitive and 79.3% specific for the detection of unhealthy alcohol use and 87.9% sensitive and 66.8% specific for identifying a current alcohol use disorder [79]. These test properties are comparable to the AUDIT-C, a three-item screener which uses alcohol consumption questions from the Alcohol Use Disorders Identification Test.

There is also a SISQ for drug use: "How many times in the past year have you used an illegal drug or used a prescription medication for nonmedical reasons?" A response of at least one time is considered positive. This screening question has been found to be 100% sensitive and 73.5% specific for the detection of a drug use disorder with test properties that are comparable to the longer ten-item Drug Abuse Screening Test (DAST-10). The SISQ is less sensitive for the detection of self-reported current drug use (92.9%) and drug use detected by toxicology (81.8%) [80].

A self-administered SISQ for alcohol and drug use is also a valid approach for detecting unhealthy alcohol and drug use in primary care. Although the accuracy is slightly lower than interviewer-administered screening, this instrument may be more readily adopted in these settings [51]. With state-by-state changes in the legal status of marijuana, the term "illegal" may be dropped from the single item, and a separate question can ask about prescription drug usage beyond the medical indication or use for the feeling it causes (e.g., to get high) to clarify the term "nonmedical."

Since the SISQ has low specificity for identifying an alcohol or drug use disorder, positive responses are followed up with an additional screening tool such as the DAST-10, or the AUDIT-C, or an interview. The AUDIT-C (Table 7.2) is a three-question alcohol screening tool that can identify patients with unhealthy alcohol use, such as risky/hazardous use, or those who have alcohol use disorder [8]. Of note, the DAST (Table 7.3) may no longer be an optimal instrument due to a failure to specify the drug of choice, poor discrimination of the type of disorder, and limited validation in primary care settings; however there are few alternative short tools to assess severity. The Short Inventory of Problems is one measure that may help quantify the level of consequences for monitoring [3].

The Alcohol, Smoking, and Substance Involvement Screening Test (ASSIST) can be used as a more comprehensive screening tool, and it can be self-administered and provide risk levels for each drug [58]. ASSIST results can indicate severity or risk levels and help inform if brief or more extended treatment is required.

The diagnosis of a substance use disorder is based on 11 criteria from the Diagnostic and Statistical Manual of Mental Disorders (Table 7.4) (DSM–5). A person must meet two criteria to receive the diagnosis, and severity is graded based on

Table 7.2 AUDIT-C

Q#1: How often did you have a drink containing alcohol in the past year?
Never (0 points)
Monthly or less (1 point)
Two to four times a month (2 points)
Two to three times per week (3 points)
Four or more times a week (4 points)
Q#2: How many drinks did you have on a typical day when you were drinking in the past year?
1 or 2 (0 points)
3 or 4 (1 point)
5 or 6 (2 points)
7–9 (3 points)
10 or more (4 points)
Q#3: How often did you have six or more drinks on one occasion in the past year?
Never (0 points)
Less than monthly (1 point)
Monthly (2 points)
Weekly (3 points)
Daily or almost daily (4 points)

Scoring: A score of 4 for men and 3 for women is used as the threshold for unhealthy use. A score of 8 or higher is highly correlated with a diagnosis of alcohol use disorder. Patients can screen positive even if they are drinking below the recommended limits. For example, a woman who drinks one drink four times per week is below the recommended NIAAA limits (men, no more than 14 drinks a week, 4 drinks per occasion; women, no more than 7 drinks a week, 3 drinks per occasion) but would screen positive. In this case, the provider should review the patient's alcohol intake to confirm accuracy and medical history to ensure there are no medical contraindications to drinking and advise the patient to stay below recommended limits

Table 7.3 DAST-10

1. Have you used drugs other than those required for medical reasons?
2. Do you use* more than one drug at a time?
3. Are you always able to stop using drugs when you want to?
4. Have you had "blackouts" or "flashbacks" as a result of drug use?
5. Do you ever feel bad or guilty about your drug use?
6. Does your spouse (or parents) ever complain about your involvement?
7. Have you neglected your family because of your use of drugs?
8. Have you engaged in illegal activities in order to obtain drugs?
9. Have you ever experienced withdrawal symptoms (felt sick) when you stopped taking drugs?
10. Have you had medical problems as a result of your drug use?

Scoring: Score 1 point for each question answered "Yes," except for question 3 for which a "No" receives 1 point
Drug screening total score: (calculation)
Drug screening score and interpretation: 0–2, low risk; 3–5, moderate risk; 6+, high risk
*The original questionnaire used the word "abuse" however this is inaccurate and stigmatizing and modernizing the item with the change to "use" is thought to not affect performance of the questionnaire

Table 7.4 DSM-5 criteria (paraphrased) for substance use disorder (Source: DSM–5)

Using larger amounts or over longer period than intended
Persistent desire or unsuccessful efforts to cut down/control use
Great deal of time spent obtaining, using, recovering from use
Craving
Recurrent use resulting in a failure to fulfill major role obligations
Continued use despite persistent or recurrent social or interpersonal problems caused or exacerbated by substance
Important activities given up because of use
Recurrent use in situations in which it is physically hazardous
Continued use despite knowledge of having a persistent or recurrent physical or psychological problem caused or exacerbated by use
Tolerance
Withdrawal

the number of criteria met. A minimum of two to three criteria is required for the diagnosis of mild SUD, while four to five is moderate, and six or more is severe. The diagnosis is substance specific, so an individual could have a severe opioid use disorder and a moderate alcohol use disorder simultaneously. In general, those with a moderate to severe disorder can benefit from medications and other specialized and longitudinal treatments.

The diagnosis of an SUD is based primarily on patient interview rather than a specific test result, although some laboratory results such as toxicology can provide important collateral information. There are several diagnostic instruments which have demonstrated reliability and validity [22]; however these tools have strengths and weaknesses, particularly when considering practical usage in clinical settings and the training and time requirements for the interviewer.

The National Institute on Drug Abuse Clinical Trials Network reviewed the five most commonly used instruments in developing a consensus recommendation regarding a single diagnostic instrument in both clinical and research settings. The group reviewed the SUD section of the Structured Clinical Interview for DSM-IV (SCID); the SUD section of the Composite International Diagnostic Interview, 2nd ed. (CIDI-2); the SUD section of the Diagnostic Interview Schedule for DSM-IV Diagnosis (DIS-IV); the Diagnostic Statistical Manual-IV Checklist (DSM-IV Checklist); and the Substance Dependence Severity Scale (SDSS). The SCID received the highest overall score; however the ultimate consensus of the group was to recommend the CIDI-2, since it required less interviewer training, used ICD-10 coding, and provided past year and lifetime diagnoses [22]. Despite this recommendation, these instruments were predominantly developed for research and are too time-intensive to be adopted in medical settings, except perhaps a DSM symptom checklist [73].

The Tobacco, Alcohol, Prescription Medication, and Other Substance Use (TAPS) tool was developed more

recently to address the need for a brief instrument that could readily be incorporated into clinical workflows for both screening and to gauge disease severity. The TAPS tool covers all substances and has comparable psychometric properties when administered by an interviewer or when self-administered [52]. There is a two-step process for administering the instrument, starting with a screening component (the TAPS-1), followed by an assessment component, the TAPS-2. The TAPS-1 component asks about past 12-month use of tobacco, alcohol above recommended daily limits, illicit drug use, or prescription medication use for nonmedical purposes. The TAPS-2 component asks two or three follow-up items which are specific to each substance class that screened positive. A score of 1 was used as the cutoff for "problem use" and 2+ for SUD [52].

This tool was compared to the CIDI and found to have reasonable specificity for diagnosing SUD although it does not perform meaningfully better than shorter tools. TAPS varied depending on the type of SUD: for alcohol the sensitivity was 70%, specificity 85%; for marijuana the sensitivity was 71%, specificity 95%; for cocaine and other stimulants the sensitivity was 57%, specificity 99%; for heroin the sensitivity was 66%, specificity 100%; for prescription opioids the sensitivity was 48%, specificity 100%; and for sedatives the sensitivity was 54%, specificity 99% [52].

Treatment Options for Substance Use Disorders

The goals of SUD treatment are similar to chronic disease, reducing disease symptoms and enhancing health and quality of life [87]. Cure is not a goal, but rather remission and prevention of relapse. Relapse rates for substance use disorders (40–60%) are comparable to those for chronic diseases, such as diabetes (20–50%), hypertension (50–70%), and asthma (50–70%) [50]. SUD treatment can be effectively provided across a range of inpatient or outpatient care settings and generally includes a combination of behavioral therapies and pharmacotherapy. For some, attention to social circumstances and networks can be very helpful, and the intensity of the treatment setting (e.g., inpatient vs outpatient) must be determined by the severity of the substance use disorder and individual patient needs and preferences.

Once a diagnosis of SUD has been made, it is important to determine the appropriate type of treatment using an individualized and patient-centered approach. Effective SUD treatment includes a combination of pharmacotherapy, behavioral modalities, and recovery supports. Developing an optimal treatment plan requires an assessment of the biopsychosocial needs of the patient and is intentional about incorporating patient preferences. Motivational counseling interventions can be particularly important for engaging patients in care since individuals may not be ready to begin or maintain treatment due to the effect that substance use has on brain functioning around decision-making. Treatment plans should also consider patient age, gender identity, race and ethnicity, language, health literacy, religion/spirituality, sexual orientation, culture, trauma history, treatment history, and comorbid physical and mental health problems [87].

Pharmacotherapy

There are three FDA-approved medications for the treatment of opioid use disorder (methadone, buprenorphine, naltrexone) and three for alcohol use disorder (acamprosate, naltrexone, and disulfiram). Currently, there are no medications approved to treat stimulant, sedative, or cannabis use disorder, although some medications have shown modest effects in research studies; topiramate has shown the most promise for cocaine use disorder [4, 78] and N-acetylcysteine has shown promise for cannabis use disorder [26]. The evidence base for medication treatment of opioid use disorder with methadone, an opioid full agonist, and buprenorphine, an opioid partial agonist, is the most robust [5]. There is more than half a century of research documenting the efficacy of methadone maintenance treatment in reducing opioid use, drug-related health complications, overdose, and healthcare costs, while improving treatment retention, social functioning, and health [5, 14, 15, 19, 49]. With proper dosing, buprenorphine is similarly effective, although methadone maintenance treatment has higher retention rates [32]. Each medication has its unique advantages and disadvantages and access remains a challenge for both [2]. In the USA, methadone must be administered in an opioid treatment program (OTP) with daily dosing initially, integrated counseling, and often support through case management. This organizational structure can support treatment adherence for some individuals; however it can be practically and logistically challenging. Some patients cite the barrier of daily clinic visits as a reason why methadone is less appealing as a treatment option [91]. In contrast, buprenorphine can be prescribed in a physician's office and taken at home, offering greater flexibility. As a partial agonist, buprenorphine has a dose ceiling effect, which limits the likelihood of causing overdose.

Buprenorphine has been associated with a marked reduction in overdose as well as a reduction in HIV prevalence among people who use injection drugs [9, 74]. Having both methadone and buprenorphine treatment options available for patients is important to maximize patient-centered treatment and engagement. One study found that 28% of individuals who select buprenorphine report they would not have accessed treatment with methadone [63]. In recognition of the evidence supporting both methadone and buprenorphine maintenance

treatment, the World Health Organization (WHO) has added these two medications to its list of essential medications.

Another medication option for opioid use disorder is the opioid antagonist, naltrexone, which is available in a once daily oral formulation or in an extended release monthly intramuscular injection. Oral naltrexone is ineffective for opioid use disorder due to exceedingly poor adherence; extended release naltrexone is more effective than placebo in reducing opioid use [44]. Extended release naltrexone had not beendirectly compared to opioid agonist therapy until recently. Two trials were published in 2017 comparing injectable naltrexone with buprenorphine as this text was going to press. Results suggest that a substantial minority of patients are not successfully begun on naltrexone, but that outcomes for those who receive the treatments are similar in the short term [92, 93]. While the evidence to date suggests antagonist therapy is likely to be inferior to agonist therapy due to treatment retention, there are certain populations who may do well on antagonist therapy. In particular, individuals under correctional supervision, who prefer not to be on agonist therapy, do better on extended release naltrexone than those on no medication [46].

The decision of which of medications to initiate first should be guided by patient preference, treatment history, and the treatment setting that would best meet the individual's needs. For example, a patient may have greater success in an office-based setting versus in an OTP depending on the individual's psychosocial context and co-occurring disorders [37]. Most importantly, the absence of counseling should not be a barrier to medication administration, particularly since controlled trials have often failed to show any incremental benefit.

Naloxone is another important medication for individuals with opioid use disorder. Like naltrexone, naloxone is a pure opioid antagonist; however its rapid onset of action makes it an effective and often life-saving antidote to opioid overdose. While it does not treat the disease of opioid use disorder, it does immediately reverse the effects of an opioid overdose, including respiratory depression [40]. Broad access to this medication for all individuals with opioid use disorder and their caregivers is crucial and analogous to ensuring someone with a history of anaphylaxis has epinephrine readily available.

Pharmacotherapy for alcohol use disorder can increase abstinence and reduce heavy drinking, although it has had mixed success when compared to treatments for opioid use disorder. This class of FDA-approved medications is safe, easy to prescribe, and underutilized [35]. Table 7.5 presents the medications, mechanisms of action, and dosing regimens.

Naltrexone and acamprosate are more effective than disulfiram, which is no better than placebo unless administered as directly observed treatment [1, 23]. Topiramate is not FDA-approved for alcohol use disorder, but randomized trials have found efficacy for reducing heavy drinking, increasing abstinence, and improving medical outcomes (such as blood pressure) [23, 28, 36]. Combination therapy has not been shown to be more effective than single therapy, but treatment regimens may often combine these medications since their mechanisms of action can be complementary.

Acamprosate and oral naltrexone decrease alcohol consumption with equal efficacy [23]. Naltrexone can decrease craving and pleasurable effects of alcohol, while acamprosate may help with protracted symptoms of withdrawal but has a disadvantage of multiple daily dosing. The evidence supporting injectable naltrexone over oral naltrexone is limited, but it has the theoretical advantage of better adherence due to the longer half-life [1]. A limitation is that the injection must be administered in a clinical setting. There are several national and international guidelines for pharmacotherapy in alcohol use disorder [12, 55, 86]. Guidelines recommend that all individuals with moderate or severe alcohol use disorder be offered either oral naltrexone or acamprosate, combined with behavioral interventions. When bundled with medication, behavioral counseling that is delivered by medical clinicians, such as primary care physicians, has demonstrated efficacy comparable to more intensive therapies. This type of counseling involves validating abstinence and alcohol use; checking on consequences of alcohol usage, medication adherence, and side effects; and providing supportive advice.

Behavioral Modalities

Several types of evidence-based behavioral interventions help individuals with SUDs. The goal of these interventions is to engage people with SUD in treatment, change their attitudes and behaviors related to substance use, and increase their skills to manage stress, cravings, and cues that put them at risk for recurrence [56]. Some treatments emphasize complete abstinence while others focus on reduced use if abstinence is not achievable or initially desired. Both approaches can be effective and can be approached using skills development or incentives as ways to sustain individuals in treatment. The most widely studied and utilized therapies include cognitive-behavioral therapy (CBT), motivational enhancement therapy (MET), and contingency management (CM). CBT and MET can be combined into one behavioral intervention (i.e., combined behavioral intervention) for alcohol use disorder.

Cognitive-behavioral therapy focuses on building skills to enhance a person's ability to manage cravings, identify and avoid high-risk situations, and utilize self-monitoring to identify cravings early and prevent circumstances that put the person at risk of using. Motivational enhancement therapy utilizes the principles of motivational interviewing to

Table 7.5 Medications for alcohol use disorder (Source: [1]; Johnson 2010)

	Mechanism of action	Dosing regimen
Acamprosate	Thought to modulate hyperactive glutamatergic NMDA receptors	Oral: 666 mg three times per day
Disulfiram	Inhibits ALDH2, causing accumulation of acetaldehyde during alcohol consumption, resulting in unpleasant effects such as nausea, dizziness, and flushing	Oral: 250–500 mg per day
Naltrexone	Opioid antagonist blocking the effects of ethanol-induced endogenous opioid release	Oral: 50–100 mg per day Intramuscular injection: 380 mg per month
Topiramate	Normalizes GABA neuronal activity and suppresses ethanol-induced dopamine release	Oral: 200–300 mg per day

help people with SUD resolve their ambivalence about initiating treatment and stopping substance use through eliciting reasons for change, strengthening motivation, and developing a plan for change. Contingency management gives individuals rewards for engaging in treatment or not using substances. An example would be the use of vouchers for activities that support recovery (e.g., movie tickets, gift cards) given for each toxicology test that is negative. These vouchers would increase in value with each passing test, or the value would be reset to zero if the person has a positive toxicology [56]. Contingency management is not widely available but is particularly applicable in cocaine use disorder for which there are few other known efficacious treatments.

Peer-Based Recovery Support

Peer-based recovery support is nonprofessional, nonclinical assistance provided by people who have the shared experience of substance use disorder and can support the mutual goal of long-term recovery from alcohol- and drug-related problems [90]. Mutual help organizations are an example of peer-based recovery support services and are generally free, community-based groups, such as the 12-step groups of Alcoholics Anonymous (AA), Narcotics Anonymous (NA), and SMART Recovery. Alcoholics Anonymous (AA) is the most well known and well studied of these and is available in virtually every community. A central tenet of AA's philosophy and founding text is that recovery is achieved through religious or spiritual means, which continues to spark controversy and can be a barrier for patients who are not religious.

The benefits of AA can be attributed to the social support and therapeutic mechanisms, which strengthen cognitive skills and is similar to mechanisms found in more formal treatment [39]. In terms of effectiveness, research has demonstrated an association between mutual help organization involvement and reduced substance use, improved psychosocial functioning, and decreased healthcare costs [33]. However, a meta-analysis of eight trials involving 3417 people failed to show conclusive efficacy of AA, but there may be a self-selection bias among those who are willing to participate in these types of programs [20].

Patients with drug use disorder respond well to either AA or NA [38]. Weekly or frequent attendance at AA or NA meetings after completing residential addiction treatment is associated with less opioid and alcohol use, but not reduced stimulant use [25]. For some patients, a factor that limits AA/NA attendance is a stigma about medication treatments for SUD, particularly opioid agonist therapy. A mixed method analysis of the experiences and outcomes of patients with opioid use disorder treated with buprenorphine attending 12-step groups found a strong correlation between NA meetings attended and treatment retention. However, the stigma around medication treatments was a barrier for many patients, and being required to attend NA meetings did not lead to improved outcomes [54]. There are other mutual help groups that may be effective (e.g., SMART Recovery, Rational Recovery, Women For Sobriety) but have not been well studied.

Monitoring of Treatment Effectiveness

A historical assumption of SUD treatment was that a defined amount of treatment would be adequate for a successful outcome [50]. This was evidenced in the dictum that individuals "graduated" from treatment and that physicians and other health professionals viewed treatment as a specific time course until completion. As SUD has grown in understanding as a chronic disease, treatment and monitoring have been reframed in a longitudinal and ongoing fashion as "concurrent recovery monitoring," with "recovery management checkups." This framework involves frequent reevaluation regarding clinically relevant symptoms, functional status, and treatment adherence [69]. An approach utilizing recovery management checkups provides an evidence-based strategy for managing people with SUD over time, grounded in the knowledge that people with this disease require ongoing monitoring.

One studied protocol involves recovery management checkups occurring every 3 months for the first 4 years [75]. At each of these checkups, individuals are asked about past

90-day substance use, problems in their life related to substance use, withdrawal, and whether the person feels the need for intensified treatment. Individuals who report no substance use undergo toxicology testing, and any discrepancy is addressed with a reminder of no punishment or judgment for drug or alcohol use, but rather as an opportunity for enhanced care. The ongoing management for SUD in this model is comparable to chronic disease surveillance involving symptom management, treatment adherence, laboratory testing, and individualized treatment modification as needed.

Treatment in General Medical Settings

There is evidence demonstrating that general medical settings including primary care, acute care hospitals, and emergency departments can be effective venues to deliver SUD treatment. This care continuum ranges from identifying risky use or an SUD through screening, intervening for individuals with risky use, and providing treatment for those with SUD.

These care sites may be more likely to provide effective treatment for comorbid medical, mental health, and substance use conditions simultaneously and in an integrated fashion. Providing this type of care in general medical settings may be effective and can be less stigmatizing than care settings focused solely on addiction care.

The integration of addiction medicine into general medical settings should be guided by evidence-based principles and practice. Screening for alcohol and other drug use disorders can be effective in primary care, with single-item screening questions demonstrating validity comparable to longer screening tools [79, 80]. Although risky alcohol use can be addressed by brief counseling (i.e., brief intervention) in primary care with modest reductions in self-reported consumption, the evidence does not support brief intervention as effective for individuals with alcohol use disorder [70]. In addition, brief intervention has been shown to be ineffective for individuals identified by screening with any level of drug use [72].

Treatment for both alcohol and other drug use disorders can be effectively provided in primary care. A study comparing primary care-based treatment (i.e., an embedded behavioral health specialist working with the primary care physician) with specialty clinic referral found that retention and engagement were significantly higher and heavy drinking lower in the primary care treatment arm [60]. A study of medication treatment of alcohol use disorder with naltrexone in primary care demonstrated equivalent outcomes when compared to patients who also received specialty addiction care [59]. Similarly, treatment with buprenorphine for opioid use disorder is effective when delivered in primary care; there was no demonstrated benefit of adding specialized addiction counseling [21]. In recent years, there has been growing support for embedding addiction treatment in acute medical settings, such as non-treatment seeking hospitalized patients or those presenting to the emergency department [18, 47, 76].

Incorporating addiction treatment in general medical settings improves not only SUD outcomes but also other health outcomes. For example, patients are more likely to achieve evidence-based preventive services when they receive addiction treatment, and more do so when that care is delivered by their primary care physician, rather than a specialist [29]. Although chronic disease management has generally not been found to improve outcomes when provided to patients with a wide range of addictions [94], one study has suggested possible small benefit of collaborative care, largely on alcohol consumption, though results of that trial are difficult to interpret. Treatment of co-occurring SUD can improve chronic disease outcomes, such as HIV medication adherence and viral load suppression [61]. In hospital settings, patients are less likely to leave against medical advice and are more likely to complete their medical treatment when their underlying addiction is addressed [85].

The stepped care model is another approach that can be adopted in primary care settings. The model initiates treatment at low intensity and advances to higher levels of treatment for patients who do not respond to less intensive services [41]. For some patients, an SUD diagnosis may be uncertain at the start of therapy, and one advantage to stepped care is that the diagnosis can become clarified based on the treatment response. For example, a treatment plan may start with brief counseling for abstinence or reduced use. If there is no improvement, the patient could be started on medication, such as buprenorphine for opioid use disorder. If the patient achieves remission, the patient would continue with that treatment plan. However if the patient continues to have symptoms, as measured by toxicology (e.g., positive for illicit substances, not for buprenorphine, or both) and nonadherence to monitoring and follow-up, treatment would be intensified. This strategy could include more frequent visits, the addition of counseling, consideration of a medication change to methadone, care in a specialty treatment program, or residential admission [82].

Specialty Addiction Treatment Programs

Historically, SUD treatment programs and associated reimbursement models have been independent from general medical care and limited to specialty addiction settings or opioid treatment programs. When SUD is severe or complex, specialized treatment settings can be preferred options. Specialty addiction treatment is often organized by the intensity and resources of the care setting, which range from outpatient to medically managed inpatient care. The most broadly utilized

classification system is the American Society of Addiction Medicine (ASAM) levels of care, which describes settings based on intensity of treatment and is depicted in Fig. 7.1 [53]. The ASAM placement criteria offer an approach to developing treatment plans, identifying the appropriate level of care in an individualized way, and continuing to monitor progress [53]. The placement criteria utilize six dimensions to determine an individual's risk, needs, and strengths in order to match the patient to the right level of care. The six dimensions include (1) acute intoxication and/or withdrawal potential, (2) biomedical conditions and complications, (3) emotional/behavioral/cognitive conditions and complications, (4) readiness to change, (5) relapse/continued use/continued problem potential, and (6) recovery environment.

Across this continuum of care, patients should enter care at the clinically appropriate level. Programs within treatment systems can be organized in a linear, integrated model (e.g., early intervention to medically managed intensive inpatient services), or they may offer one level of care or treatment option at a specific level (e.g., intensive outpatient services). A traditional path through the treatment system would begin with short-term, medically managed detoxification, followed by one or more months of intensive residential treatment, followed by continuing care in an outpatient treatment program, with or without additional recovery supportive housing [87]. Despite this recognized approach to treatment, the evidence supporting residential treatment over outpatient treatment is unclear [64]. However, residential treatment may be necessary for individuals with limited social resources (e.g., homelessness or a social network limited to those using substances regularly) or for those for whom outpatient programs have failed.

Opioid treatment programs (OTPs) are treatment programs certified by the Substance Abuse and Mental Health Services Administration (SAMHSA) that provide supervised assessment and medication treatment for patients with opioid use disorder [11]. All OTPs offer counseling in addition to pharmacotherapy, as well as a range of other services. About half of OTPs offer screening for other mental health disorders and 21% prescribe psychiatric medications for co-occurring disorders. Treatment options are largely driven by regulatory requirements and reimbursement models. The majority of OTPs offer testing services for hepatitis B and C as well as HIV though medical and psychiatric treatments are often not offered on site [83].

While OTPs are able to offer medications approved to treat opioid use disorder, methadone can only be prescribed in an OTP setting; many programs offer methadone and no other medications. Of the 10,144 outpatient-only SUD treatment facilities in the USA in 2012, 10% (1026 facilities) were OTPs and 51% of these offered buprenorphine in addition to methadone [2, 83]. Across the country, 306,440 patients receive methadone treatment and 25,656 patients receive buprenorphine treatment in OTPs [2]. A study which randomized OTP patients to either methadone or buprenorphine found higher treatment retention in the meth-

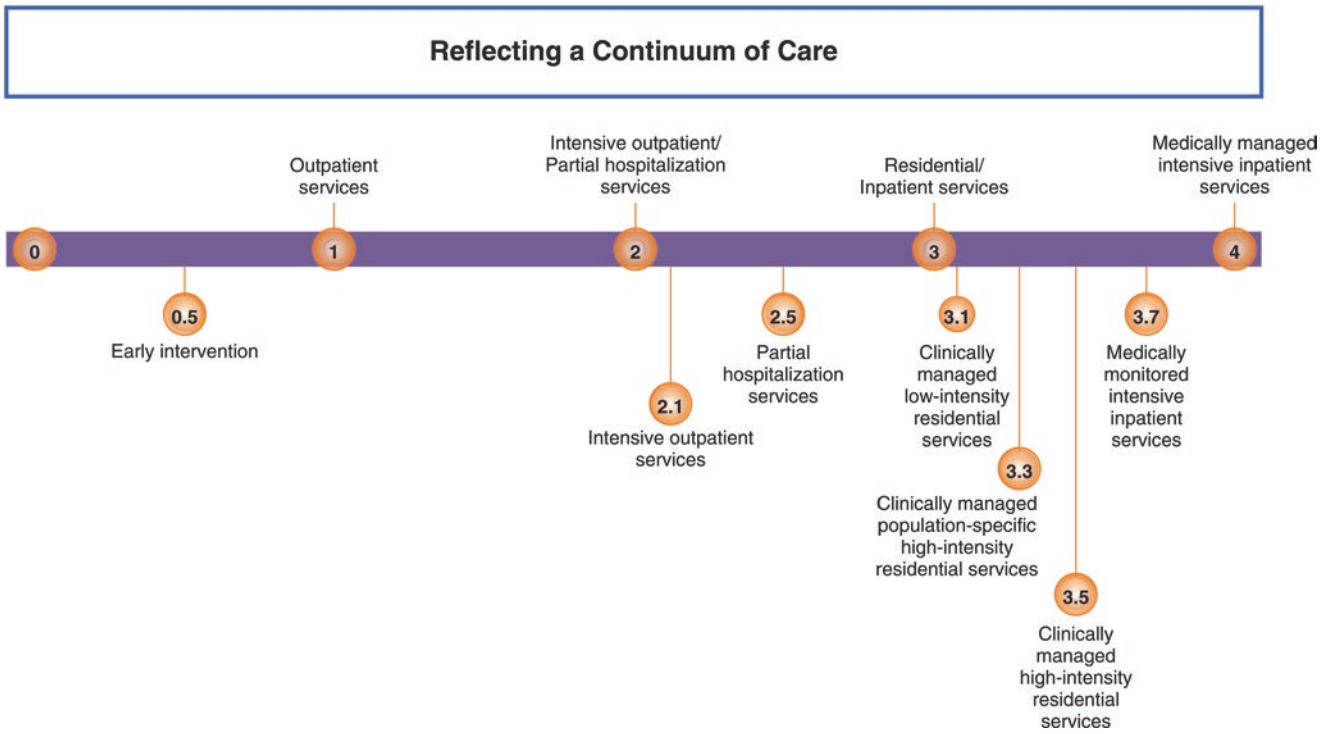

Fig. 7.1 ASAM levels of care for adults (Adapted from: asamcontinuum.org/knowledgebase/what-are-the-asam-levels-of-care/)

adone group but greater abstinence in the buprenorphine group among those retained in treatment [31].

Wait times are one of the many barriers to care, and treatment must be readily available on demand, since the longer the wait time for program entry is, the less likely an individual is to enter treatment [30]. Lack of integration between addiction treatment programs and medical care results in care pathways that are challenging for patients and families to navigate. A qualitative study of individuals with alcohol use disorder revealed several barriers to treatment, including multiple appointments, burdensome assessments that are poorly linked to treatment plans, abstinence requirements prior to initiating care, and coordination challenges with multiple clinicians and service agencies [24]. These hurdles are particularly problematic for individuals with active SUD whose motivation for treatment can vary and who may have limited organizational and coping skills.

Additional barriers to accessing care in OTPs include insurance status and proximity to facilities. While 98% of OTPs accept cash, only 62% accept Medicaid and 43% accept private insurance [83]. Only 18 state Medicaid programs and the District of Columbia cover all levels of addiction treatment as well as medications to treat opioid use disorder [27]. While private insurers have progressed in coverage of addiction pharmacotherapy, prior authorization is common and may be associated with relapse due to interruptions in care [13, 65]. Lack of local access to programs can also be a challenge. A national study of 23,141 patients in 84 OTPs found that 6% of individuals had to travel between 50 and 200 miles to attend an OTP and 8% had to travel across state lines [67].

In the context of the current opioid crisis, the timeliness of treatment is crucial since each day of ongoing use puts an individual at greater risk of overdose and death. Individuals with opioid use disorder who are on a waiting list for medication treatment have a tenfold risk of death, when compared to individuals who started therapy [15]. Additionally, a study of young individuals with non-injection opioid use found that those who sought, but were unable to access, addiction treatment were over two times more likely to initiate injection drug use [16].

Future Directions

Although the adoption of addiction treatment into general medical settings has been slow, there are several innovative models that may guide addiction treatment within primary care and community-based settings. Passage of the Drug Abuse Treatment Act allowed physicians of any specialty to receive a waiver to treat patients with opioid use disorder with buprenorphine. Despite hopes that this would enhance access to addiction treatment within primary care, few have opted to get the waiver. Among primary care physicians, only 3% have a waiver, leaving most counties in the USA with no qualified physician to offer this treatment [66]. Numerous studies have explored reasons for the lack of adoption of buprenorphine within primary care, and common barriers include the perceived lack of knowledge, time, staff support, or access to behavioral health or addiction specialty consultation or services [17, 34, 89].

The requirement for special certification and training restricts new treatment adoption in primary care settings. Nevertheless, two innovative models have been developed to address these barriers and to support the integration of addiction treatment into primary care: the Massachusetts Collaborative Care Model, also known as the Nurse Care Manager Model, and Project ECHO [43].

Collaborative Care Model

The Massachusetts Collaborative Care Model began at Boston Medical Center and was subsequently disseminated to community health centers across the state as part of an initiative to increase access to office-based opioid treatment with buprenorphine. The model centers around a team-based approach with nurse care managers working with physicians to provide evaluation and monitoring of patients. This collaboration allows sharing of the care of patients, ideally addressing many of the barriers physicians report, including a lack of time and support to do this work. The expansion of this model increased the number of physicians with buprenorphine waivers by 375% within 3 years [45]. In addition, annual treatment admissions for buprenorphine treatment in the health centers increased dramatically from 178 in 2007 to 1210 in 2012, with 67% of the patients across all programs remaining in treatment for more than 12 months in 2013 [45].

Project ECHO

Project ECHO is a model which began in New Mexico as a strategy for providing specialist support and training to primary care physicians using video conferencing [42]. The project was initially designed for hepatitis C treatment and has been expanded to other chronic diseases including SUDs. The ECHO model for SUD, called the Integrated Addictions and Psychiatry (IAP) TeleECHO Clinic, has been in operation since 2005 and has focused predominantly on opioid use disorder treatment, including buprenorphine management. In the ECHO model, teams of specialists at academic medical center "hubs" provide clinical case support and didactic teaching to rural primary care clinics on a range of SUD-related topics. Since the IAP TeleECHO Clinic launched, the number of waivered physicians across the state grew from 36 to 375,

and New Mexico went from ranking 13th nationally to 4th for its number of waivered physicians [42].

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Quality of Life and Patient-Centered Outcomes

8

Margaret C. Wang and Jim Bellows

Introduction

Patient-centeredness is one of the six attributes of high-quality healthcare identified in the Institute of Medicine report, *Crossing the Quality Chasm: A New Health System for the Twenty-First Century*. Patient-centeredness encompasses "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" [1, p. 6]. Although patient-centered care is a major design feature of twenty-first-century healthcare, actionable strategies are needed to operationalize it in clinical practice [2].

An approach that promotes patient engagement and supports patient-centered care, particularly among chronically ill patients, is the use of patient-reported outcome (PRO) data [3, 4].

Healthcare providers routinely ask patients about their health and experiences; however, until relatively recently, this information has not been systematically collected, recorded, or used in a measurable way. The chapter first describes commonly used terms in PRO before turning to applications of patient-reported outcomes in practice. The next section provides selected examples of the use of patient-reported outcomes and explores the impact of the data they provide on care processes and outcomes. Key milestones in the intellectual development of PRO are provided before the final section outlines current challenges to and future trends in the widespread use of patient-reported outcomes in healthcare.

M.C. Wang (✉) • J. Bellows
Kaiser Permanente, Care Management Institute, Oakland, CA, USA
e-mail: margaret.c.wang@kp.org

Defining and Understanding Patient-Reported Outcomes

The rigorous, research-based development of standardized questionnaires that solicit information on patients' symptoms, functional status, quality of life, and health behaviors has promoted the use of patient-centered information in clinical care and quality improvement. The US Food and Drug Administration, for example, defines patient-reported outcomes as "any report of a patient's (or person's) health condition, health behavior, or experience with healthcare that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else" [5]. When integrated into clinical care, the use of PRO data complements clinical indicators and physiological markers obtained through physical examinations, laboratory tests, and imaging studies [3]; improves patient engagement [3]; facilitates shared decision-making between patients and providers [3]; and improves quality of care [6–12]. According to a Cochrane classification of the outcomes of clinical trials, PROs are among the outcomes that are most important to patients, along with survival (e.g., 5-year disease-free rates), morbidity events such as stroke, and caregiver-reported outcomes such as caregiver burden and stress [13].

Patient-reported outcome is an umbrella term and often encompasses three meanings. The first is patient experiences and perceptions that exist separately from any systematic attempt to measure them; this meaning is characterized by a patient who reports "I feel better" to a healthcare provider. The second meaning refers to measurement tools, typically questionnaires and related tools such as visual analog scales, that aim to systematically capture patient experiences and perceptions. These may be considered as PRO questionnaires, and they are most suited to assessing subjective patient experiences that cannot be measured by a lab test or imaging study. Table 8.1 displays the major PRO domains and examples of questionnaires in each. The third meaning is PRO data collected by questionnaires, referred to as PRO measures. Aggregating these data at the level of populations

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Table 8.1 Classification of patient-reported outcomes and example measures

Domain	Purpose	Example PRO questionnaires
Symptoms	Evaluate the frequency, severity, and impact of symptoms	Brief Pain Inventory (BPI) [14]
		MD Anderson Symptom Inventory [15]
		Distress Thermometer [16]
		SF-36 Vitality Scale [17]
Functional status	Assess the ability to carry out daily activities such as walking, working, or attending social events	Arthritis Impact Measurement Scales [18]
Health-related quality of life	Assess the extent to which usual or expected physical, emotional, and social well-being is affected by a medical condition and/or treatment	Functional Assessment of Cancer Therapy (FACT) core plus symptom modules [19]
		European Organization for Research of Cancer Quality of Life Questionnaire Core-30 (EORTC QLQ-C30) plus symptom modules [20]
Non-preference	Evaluate functioning relative to minimal and maximal levels of performance for each concept; can be used with any group of individuals	SF-36 [17]
Preference	Assign a relative value or utility to levels of health based on patient preferences	EuroQoL (EQ-5D) [21]
		Health Utility Index (HUI) [22]
		Quality of Well-Being Scale [23]
Health behaviors		
Health-directed behavior	Evaluate engagement in behaviors aimed at disease prevention and/or health promotion	Health Education Impact Questionnaire (heiQ) [24]
Adherence	Assess the extent to which the agreed-upon mode of treatment continues under limited supervision and in the face of conflicting demands, as distinguished from compliance or maintenance	Simplified Medication Adherence Questionnaire [25]
Satisfaction with care	Assess satisfaction with received care	Consumer Assessment of Healthcare Providers and Systems (CAHPS) [26]

Adapted from Ahmed et al. [65]

creates PRO performance measures that can be used to assess quality of care for healthcare organizations and systems [27].

The components of patient-reported outcomes vary across existing classifications. A National Quality Forum report includes domains such as health-related quality of life (HRQoL), which encompasses health and functional status, symptoms and symptom burden (e.g., pain and fatigue), care experiences such as those measured by the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey, and health behaviors such as adherence, smoking, diet, and physical activity [27]. Other classifications that are based on the premise that outcomes represent only the effects of care and do not include health behaviors and care experiences; these are viewed as patient-reported information from healthcare interactions [28]. It is debatable whether reports by proxies such as caregivers and family members should be considered PRO [13, 27, 28].

PRO questionnaires can be disease-specific, condition-specific, or generic. Disease-specific questionnaires assess severity, symptoms, or functional limitations that pertain to a particular disease or diagnostic grouping, such as arthritis or diabetes. Condition-specific questionnaires capture patient symptoms or experiences related to a single condition (e.g., low back pain) or intervention, such as coronary artery bypass surgery. Generic questionnaires are designed for use with any patient population [13].

Patient-reported outcomes that are assessed systematically with standardized questionnaires have three key features. They are patient-centric because they capture information that most patients consider important; they are outcomes-oriented, as opposed to assessing processes of care such as screening rates; and they are consistently measured over time, unlike descriptions of symptoms documented in patients' health records. For example, a patient who complains of "feeling blue" prompts a provider to use the Patient Health Questionnaire (PHQ-9) to screen her for depression (Fig. 8.1) [29]. Over time, the clinician may monitor her symptoms using the PHQ-9 summary score and response to individual questionnaire items.

Applications of Patient-Reported Outcomes in Clinical Practice

A theory-driven taxonomy developed by Greenhalgh in 2009 described six applications of patient-reported outcomes in clinical practice and summarized evidence of their impact on the processes and outcomes of care [30]. The taxonomy describes applications along two dimensions: the level at which PRO data are aggregated—individual patients and populations of patients—and whether the application takes place during a patient-provider encounter.

Fig. 8.1 The Patient Health Questionnaire (PHQ-9) (Permission to reprint confirmed)

The Patient Health Questionnaire (PHQ-9)

Patient Name _____ Date of Visit _____

Over the past 2 weeks, how often have you been bothered by any of the following problems?	Not At all	Several Days	More Than Half the Days	Nearly Every Day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed or hopeless	0	1	2	3
3. Trouble falling asleep, staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself - or that you're a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or, the opposite - being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3
Column Totals	_____	+ _____	+ _____	
Add Totals Together	_____			

10. If you checked off any problems, how difficult have those problems made it for you to Do your work, take care of things at home, or get along with other people?

☐ Not difficult at all ☐ Somewhat difficult ☐ Very difficult ☐ Extremely difficult

Table 8.2 contains a taxonomy adapted from Greenhalgh and several other sources [3, 31–33] that incorporates more recent developments. It describes current PRO applications in clinical practice. Each application is described separately below; in practice, the same PRO measure is often used in multiple applications.

Individual-Level PRO Data Used During Patient-Provider Encounters

Screening

Screening is one of the most common applications of PRO. Questionnaires are frequently used in behavioral health to detect depression or anxiety [34–36] and, more broadly, to detect physical, functional, social, and emotional issues [37, 38]. Without specific assessment during clinical encounters, some problems may be overlooked because patients are reluctant to disclose symptoms or unware of their importance. Data from PRO questionnaires can alert providers to the need to address previously undetected conditions, potentially reducing their severity. For example, a patient completes the PHQ-9 as part of a routine visit. His/her primary care provider is alerted to a high score that may indicate depression and initiates a conversation with the patient to confirm the diagnosis, investigate possible causes, and identify ways to mitigate symptoms.

Treatment Monitoring

Monitoring is another common application of PRO, widely used within psychotherapy to facilitate patient-focused research and outcomes-informed care [30, 39, 40]. Repeated use of PRO questionnaires for the same patient over time allows providers to assess treatment effectiveness and to adjust treatments and care management as needed. Returning to the example just above, the patient completes

Table 8.2 Taxonomy of applications of patient-reported outcome measures in clinical practice

Purpose	Used at provider-patient interface	Description
PRO data aggregated at the level of individual patients		
Screening	Yes	Response to PRO measures helps identify undetected problems or non-reported symptoms
Monitoring	Yes	Repeated PRO measurements help track progress over time, response to treatment, or both
Facilitating patient-centered care	Yes	Review of PRO data helps prioritize patient-provider encounters to address issues and concerns important to the patient
Enabling patient engagement in self-care	No	Feeding back PRO data to the patient enables data-driven self-care management
Facilitating communication within care teams	No	Systematically collected PRO data provide a common language for providers to align patient goals with multidisciplinary team's care management strategies
PRO data aggregated at the level of populations		
Decision aids	Yes	Comparative studies of outcomes, including PROs, from various treatment options provide evidence informing and facilitating shared decision-making between patient and provider
Monitor and manage population health	No	Aggregated PRO data support monitoring and managing populations of patients with specific conditions
Assess and improve quality of care	No	Analyses of aggregated PRO data help identify quality improvement opportunities
Public reporting and pay for performance	No	Organization-level PRO data are reported to external agencies to meet regulatory requirements or for reimbursement or marketing purposes

Adapted from Greenhalgh [30]

another PHQ-9 on a follow-up visit after starting antidepressant medication. His/her primary care provider compares scores from the first and second questionnaires to assess whether symptoms have improved and, finding no improvement, adjusts treatment. By trending the results of PRO questionnaires the patient completes at office visits and over the phone during scheduled telephone appointments, his primary care provider can compare the patient's course of depression to normative recovery curves and adjust therapy as needed.

Facilitating Patient-Centered Care

Primary care clinicians are expected to do more in a typical visit than can possibly be accomplished [41]. Time pressure may preclude patient-centered care as providers focus on pressing biophysical issues, such as hemoglobin A1c control, and appointments end before they can address symptoms that are important to patients, like fatigue and neuropathic pain. PRO questionnaires can efficiently identify issues that are most important to patients and help providers and patients agree on which outcomes to prioritize. When patients and providers anchor discussions to these issues, patients are empowered as partners in shared decision-making and become more engaged in their own care, which improves adherence to treatment and preventive care [42, 43]. For instance, a patient completes a Short-Form Health Survey (SF-36) assessing physical, social, and emotional well-being and functional status before an annual visit [17], and the results are used to create a personalized list of priorities. While reviewing the results, the patient and her primary care provider discuss the adverse effect that her recent divorce has had on her diet and adherence to physical therapy treatments and identify strategies for better self-care.

Individual-Level PRO Data Used Outside of Patient-Provider Encounters

Enabling Patient Engagement in Self-care

Self-care is a cornerstone of managing chronic conditions. With the explosive growth of technology that includes online portals to patients' electronic health records (EHRs) and consumer wearable devices, PRO data are widely anticipated to become part of the "big data" that help inform healthy decisions and self-care. Examples of applications can be found in rheumatology, primary care, and postoperative recovery [3, 44, 45]. Access to easily understood data promotes self-awareness of gaps between current and goal states. Combined with tools and tips, this awareness motivates individuals to work toward achieving health goals. For example, combining trended PHQ-9 data with diaries can help patients both identify stressors triggering depression symptoms and develop coping strategies to reduce their impact.

Facilitating Communication Within Multidisciplinary Care Teams

Patients with chronic conditions are often cared for by a team consisting of members from diverse professional backgrounds. PRO measures have been advocated as providing a common language for multidisciplinary healthcare providers [30, 46]. When PRO questionnaires collect structured information about patients that is systematically documented in

an EHR system accessible to all team members, it is less likely that important symptoms or experiences will go unnoticed. More importantly, data from PRO questionnaires provide a common basis for collaboratively setting goals with the patient and a common platform to gauge treatment effectiveness. For example, the team caring for a patient recovering from stroke could involve a neurologist, primary care provider, physical therapist, speech therapist, social worker, and occupational therapist, each of whom has unique training. The Stroke Impact Scale captures the most prevalent aspects of post-stroke recovery and helps multidisciplinary team members use a common language to assess the patient's health, function, and well-being [47].

Population-Level PRO Data Used During Patient-Provider Encounters

Assisting in Decision-Making

Patient-reported outcomes are increasingly used in comparative effectiveness research to assess the impact of treatments on outcomes that are centered on patient preferences and values [48]. In surgical care, pain and functional status outcomes can help patients and providers make informed choices about treatment timing, selection, and adjustment, including decisions about surgery [49, 50]. Population-level normative PRO data can clarify treatment risks and benefits in terms of outcomes such as HRQoL and the probability that a treatment will deliver the outcomes that a patient prefers, based on his or her clinical profile. By helping patients and providers evaluate treatment options in terms of the most important outcomes, decision aids incorporating PRO data help engage patients in shared decision-making and improve adherence and self-care. They also help patients set realistic expectations about treatment effectiveness and postoperative recovery by comparing themselves to normative data from other similar patients [3]; this improves their health and satisfaction and can save healthcare costs [49].

Population-Level PRO Data Used Outside Patient-Provider Encounters

Monitoring and Managing Population Health

Aggregated PRO data can provide insights on prevalent HRQoL issues for groups of patients with similar conditions [51]. Recognizing HRQoL issues at the department, practice, or organizational level enables the allocation of appropriate resources to help patients address them [32]. For example, data showing that a large proportion of patients in an oncology clinic report high levels of distress after receiving a cancer diagnosis can help clinic administrators decide to hire a social worker or psychologist to be available on site. Trended over time, group- or population-level PRO data can assess whether allocated resources have helped ameliorate identified issues.

Assessing and Improving Quality of Care

PRO data collected from individual patients can be aggregated to the appropriate level and used with other indicators to improve quality of care. At the provider level, academic detailing via sharing successful clinical practices can lead to better outcomes; at the department level, a quality improvement infrastructure using plan-do-study-act (PDSA) cycles can improve processes associated with measured outcomes; at the organizational level, data from PRO measures help monitor performance, identify best practices to spread, and direct resources for performance improvement. Using PRO data as part of performance assessment and improvement, coupled with dedicated quality improvement resources, increases the likelihood of improving outcomes. Wu and colleagues describe many cases of using aggregated PRO data to drive quality improvement [32]. For example, in combination with other HRQoL measures, pain scores can guide the design, implementation, and monitoring of quality improvement efforts to improve the management of pain that affects patients' function.

Public Reporting and Pay for Performance

PRO data can be used for policy purposes, based on the idea that requiring public reporting and incentivizing superior outcomes through pay for performance or reputational gains will motivate organizations and providers to improve these outcomes. Publicly reported data include surgical outcomes reported by the Dartmouth Hitchcock Spine Center and the California Total Joint Registry website [52, 53]: both aim to help patients choose among providers by providing them with comparative data on the outcomes that are most important to them. Health plan performance on Healthcare Effectiveness and Data Information Set (HEDIS) measures is also publicly available; the 2016 measure set includes monitoring depression symptoms for adults and adolescents with the PHQ-9 [54]. Figure 8.2 illustrates applications of PRO across healthcare encounters to facilitate patient-centered care for a hypothetical patient with osteoarthritis of the knee.

Key Milestones in the Development of Patient-Reported Outcomes

Current thinking about PROs can be traced to Donabedian's structure-process-outcome model [55]. Structural attributes of the context in which care occurs, processes of care, and

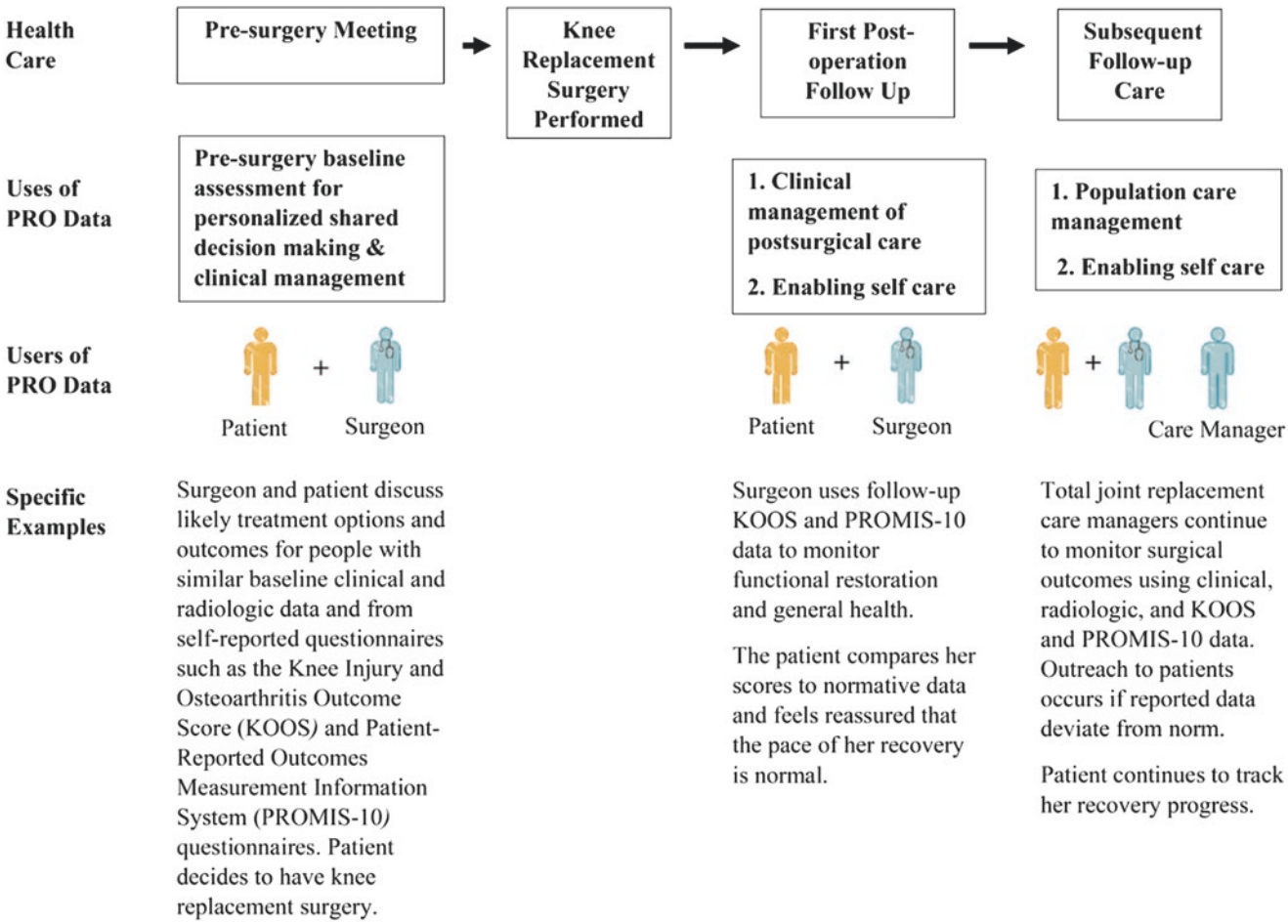

Fig. 8.2 Illustration of PRO applications at healthcare encounters for a patient with knee osteoarthritis

care outcomes are interrelated dimensions by which healthcare quality can be assessed [56, 57]. In this model, outcomes are the effects of healthcare on patients and populations; examples include changes in intermediate outcomes (e.g., blood pressure), adverse events, morbidity, survival, recovery and restoration, and improvements in function and HRQoL.

The development, validation, and application of PRO questionnaires and measurement approaches began in the 1940s [58]. By the end of the 1990s, many PRO questionnaires were available [59]. They included several instruments assessing HRQoL:

- The multidimensional Medical Outcome Study Short-Form Health Survey (SF-36) [17]
- The EuroQol (EQ-5D) [21]
- Disease-specific questionnaires such as the Diabetes Quality of Life Questionnaire [60] and the Asthma Quality of Life Questionnaire [61].

Hundreds of HRQoL generic and diagnosis-, condition-, or symptom-specific questionnaires have subsequently been created [62]. The most recent development is the Patient-Reported Outcomes Measurement Information System (PROMIS) initiative funded by the National Institutes of Health [63]. A repository for publicly available PRO questionnaires, PROMIS uses a computer adaptive testing approach to collecting data that customizes questionnaires to individuals.

Despite the proliferation of PRO questionnaires, they have been incorporated into research to a limited, although expanding, degree. A 2009 report found that 14% of interventional clinical trials registered in 2004–2007 included some PRO measures, up from 4.2% in 1980–1997 [64]. Recognizing PRO as crucial endpoints to assess efficacy, the Food and Drug Administration (FDA) promotes their use in guidelines for the approval of pharmacological products and medical devices [5]. Similar arguments have been made for using PRO in comparative effectiveness research [65].

Recent changes continue to shape PRO measures. Chief among these is the involvement of patients in the research development of questionnaires; providers and researchers cannot adequately represent patients' perspectives and preferences. Active solicitation of patient input during research development is limited but increasing [66]. Awareness is growing that patient-centered care and, by extension, patient-centered research and redesign would benefit greatly from partnering with patients. In this emerging paradigm, patients partner with researchers in shaping research questions and the methods by which they are asked, selecting outcomes that matter, interpreting results, and applying findings [66, 67].

Impact of PRO Applications on Care Processes and Outcomes

In general, evidence of the impact of PRO on care processes and outcomes is mixed because of heterogeneous applications and a variety of methodological issues [30, 68]. Nelson and colleagues recently provided two examples of using PRO data to improve outcomes [45]. In the Swedish Rheumatology Quality Registry, data are used in a structured way to guide treatment, facilitate shared decision-making, and enable self-care; clinical outcome measures, including disease severity as measured by C-reactive protein, appear to improve. Another example is the HowsYourHealth online system, which asks about functions, symptoms, health habits, preventive care needs, capacity for self-care, and care experiences. Its use in some primary care practices supports the idea that when patients' PRO data are embedded into routine care and accompanied by management strategies, sustained improvement occurs among patients with pain and emotional problems [45].

In contrast, a randomized controlled trial of assessing HRQoL in clinical oncology practice found that the data, coupled with helping providers interpret the results, did not improve quality of life for patients with cancer [69]. The authors suggested that the use of HRQoL data should be augmented with specific recommendations for changes in clinical management. Similarly, a systematic review of trials investigating the effect of providing PRO data at the patient and group levels found weak evidence supporting its use as a screening tool. However, studies showing the greatest effect used PRO data as a management tool in outpatient care for specific patient populations [70]. PRO data, when used in isolation, may have a limited effect on outcomes. Their most effective use is likely as part of a comprehensive system of care and follow-up.

To guide learning from existing evidence and assessing future studies, Santana proposed a conceptual model of the mechanisms and effects of using PRO in routine care [68]. The model posits that the use of PRO improves communication among patients, multidisciplinary providers, and caregivers. Better communication facilitates identifying important issues, patient preferences, and treatment goals, thus empowering patients to cocreate care plans and manage self-care and enhancing shared decision-making. These effects collectively contribute to better outcomes, although the model does not explain how they relate to each another and the relative contribution of each to improved patient outcomes.

Despite inconclusive evidence about the effect of PRO, many promising practices exist. Lavallee and colleagues provide specific examples of applications that add value in the care of patients with cancer, HIV, arthritis, depression, gastrointestinal disorders, and depression [3]. For example, the Orchestra Project, an innovative approach in which patients and providers partner to manage inflammatory bowel disease, provides evidence that patient outcomes improve when PRO data are used to facilitate ongoing patient-provider learning, shared decision-making, and goal setting and to support patient behavioral change and care management. Between 2007 and 2015, remission rates increased from 60% to 79% among patients treated at more than 70 pediatric gastroenterology care centers in the ImproveCareNow network [71, 72]. Wu and colleagues provide ten in-depth case studies showcasing healthcare organizations that have embedded PRO into EHR systems and integrated their use into clinical workflows [32].

Examples of PRO Use in Clinical Care

Patient-Reported Outcomes in Depression Care

At Group Health Cooperative in Seattle, providers in primary care and behavioral health services consistently use the PHQ-9 to assess, diagnose, manage, and monitor the severity of depression. The PHQ-9 is a well-validated nine-item questionnaire that incorporates diagnostic criteria and other symptoms of major depression [73] (Fig. 8.1). Patients rate the frequency of specific symptoms over the previous 2 weeks. Possible overall scores on the PHQ-9 range from 0 to 27; scores of 5, 10, 15, and 20, respectively, indicate mild, moderate, moderately severe, and severe depression [74]. A short form of the instrument, the PHQ-2, screens for depression. Possible scores on the PHQ-2 range from 0 to 6; a score of 3 or higher indicates a need for further evaluation [75].

Patients complete the PHQ-2 at every wellness visit at Group Health. Medical assistants review patients' EHRs before they arrive for appointments, identifying which patients need to complete a PHQ-2 or PHQ-9. They enter scores into the EHR, where primary care providers assess them during the visit. Primary care providers may also identify the need to screen a patient for depression and administer the PHQ-9. Registered nurse case managers give the PHQ-2 or PHQ-9 to all patients with new or uncontrolled chronic conditions. Patients complete an electronic version of the PHQ-2 on the patient portal to the EHR as part of an annual health risk assessment. A high score triggers an automated message to the patient's primary care provider to follow up. Group Health also contracts with a third-party health coaching vendor that reaches out to patients with high PHQ-2 scores to encourage them to schedule a visit with their primary care provider for evaluation.

Primary care providers diagnose and care for most patients with depression with consultation as needed from behavioral health providers for mild-to-moderate depression. Behavioral health providers typically manage patients with severe or treatment-resistant symptoms. The PHQ-9 provides a common language for primary care and behavioral health providers to discuss the care of patients with depression. Patients with diagnosed depression who are managed in primary care complete follow-up PHQ-9 questionnaires over the phone, through the patient portal, or in person, even if office visits are for another condition. Patients whose depression is managed in behavioral health complete a PHQ-9 at every visit. Between appointments, patients complete questionnaires by phone during follow-up calls from registered nurses or by secure messaging through the patient portal.

Group Health uses transparent performance data to monitor the use of the PHQ-9. In primary care, use is reviewed at the department level every month and at the senior leadership level every quarter. Leaders at all organizational levels round in clinics and review performance data. Group Health assesses the effectiveness of its approach to depression care by tracking PHQ-9 use at diagnosis and at reassessments and 6-month symptom improvement and remission rates.

Patient-Reported Outcomes Supporting Patient Registries

PRO data collected in clinical encounters can be aggregated, along with other data elements, into a registry to track population-level outcomes and care management and support research. Paxton and colleagues describe the development and use of the Total Joint Replacement Registry among 350 surgeons at 43 Kaiser Permanente medical centers [76]. In addition to clinical outcomes, such as complications, hospital readmissions, revisions, reoperations, mortality, and radiographic assessment, patients' preoperative and postoperative self-reported pain levels are collected via a visual analog scale. Patient satisfaction with surgical outcomes is also assessed postoperatively. Ninety percent of surgeons performing total joint replacement procedures voluntarily contribute data to the registry, which has expanded from its initial purpose as a tool for contracting and research to a powerful organizational learning tool promoting quality and patient safety. It assists in the timely identification of patients with recalled implants, tracks and monitors total joint arthroplasty revision and complication rates, monitors surgical site infections, helps identify patient risk factors associated with surgical revisions and complications, and enables the identification and sharing of best practices through internal and external benchmarking.

Engaging Caregivers with Patient-Reported Outcomes

Many patients with chronic conditions rely on caregivers in the daily management of disease. PRO data can also be used to enhance communication among patients, caregivers, and providers and facilitate caregiver engagement. In June 2016, the neurology department at a Kaiser Permanente Southern California medical center piloted the use of the Parkinson's Disease Questionnaire (PDQ-39) as part of ongoing efforts to provide best-in-class care to patients with Parkinson's disease. The PDQ-39 assesses HRQoL, function, and health across eight domains [77]. Patients, typically accompanied by caregivers, receive the PDQ-39 when they arrive for outpatient appointments and complete it in the waiting room; during the visit, the physician, patient, and caregiver discuss the results.

PRO data help caregivers understand patients' functional status, HRQoL, and disease-related symptoms that patients may have difficulty talking about. This information engages caregivers and helps them work with patients and providers to meet patients' self-care needs at home. As one caregiver stated, "I can use that [information] to improve the quality of care I provide to him and to let him know what he can do himself to improve without my help. We both learn."

Current Challenges to the Use of Patient-Reported Outcomes

Challenges associated with collecting and using PRO data in routine clinical practice are well-documented and pertain to providers, patients, and healthcare practices and organizations. Providers may not be confident that patient-reported outcomes add value to existing care processes. They may

believe that incorporating the use of PRO questionnaires into practice will add to their workload without creating substantial efficiency gains or care improvements; providers routinely spend time talking with patients to understand their symptoms, state of health, and concerns [45]. Providers may have concerns about the reliability of information self-reported by patients [3]; PRO questionnaires assess subjective experiences and patients' responses to the same question may vary widely. For example, one patient's 9 out of 10 on a pain scale may be another patient's 5. Providers may also doubt the validity of capturing clinical information with a form, as opposed to questions such as "How is your walking/pain/mood/level of energy since I last saw you?" [62]. Nor are suitable PRO measures available in all clinical areas; no comprehensive and clinically relevant measures exist in fields such as geriatrics, palliative care, and complex care [78].

Providers may find it challenging to interpret and act on PRO data. For many existing PRO measures, no easily accessible reference data exist to help providers identify whether and by how much a patient's reported value is outside of normal limits. A contrasting example is reference ranges for hemoglobin A1c that allow providers to easily determine whether a patient has prediabetes, diabetes, or severe diabetes [78]. Finally, most existing PRO measures are not clinically relevant enough to support and enhance clinical decision-making or trigger clinical actions [78–80].

From the perspective of patients, the burden of responding to PRO questionnaires may be excessive due to lengthy instruments and accessibility issues among patients with specific conditions. For instance, patients with limited vision may require questionnaires with larger text. General literacy and health literacy affect patients' ability to complete PRO questionnaires, and validated translations may not be available for patients who cannot read English [78, 79]. Most importantly, patients want to understand how the information they provide is used for their benefit; if this is not clear, they may be less willing to invest time in responding to PRO questionnaires [62, 79]. These may be especially true for patients whose baseline preference is to share less personal information.

Healthcare organizations and practices lack incentives or regulatory requirements to systematically collect and widely use PRO data for clinical purposes, and the value proposition for their use lacks strong evidence. Integrating PRO into clinical practice requires several steps: generating buy-in from multiple stakeholders, demonstrating feasibility and value to end users, and putting appropriate infrastructure and processes into place to support workflow integration. The latter can include information technology, building time into clinical workflows for collecting PRO data, using data for shared decision-making discussions and clinical decision-making, and documenting clinical actions related to PRO data [32, 62, 79].

Barriers to organizational use of PRO may include costs related to licensure and registration. Some proprietary PRO questionnaires require payment of a licensing fee (e.g., the EQ-5D quality of life instrument). Many require registration, such as the Functional Assessment of Cancer Treatment (FACT) suite of questionnaires [19]. Managing licensure and registration necessitates staffing with associated costs [32, 62].

The Future of Patient-Reported Outcomes

As we look toward the future of patient-reported outcomes, several trends emerge.

Public and Private Organizations Mandating and Supporting PRO Use

The first trend is increasing efforts across governmental and nongovernmental entities to support broader meaningful use of PRO measures. The Oncology Care Model of the Centers for Medicare and Medicaid Services (CMS) includes PRO measures [81], and the Comprehensive Care for Joint Replacement Model from the Center for Medicare & Medicaid Innovation includes voluntary reporting of generic and procedure-specific PRO data that will be used to link the quality of total hip and knee arthroplasty procedures to hospital payments [82]. The National Quality Forum and National Committee on Quality Assurance endorse PRO measures in their performance measurement sets [27, 54]. The International Consortium for Health Outcomes Measurement, a nonprofit advocacy organization, routinely includes PRO measures in recommended standard measurement sets; the standard set for primary and preventive care for older persons includes four PRO measures [83]. A final example is the inclusion of screening for psychosocial distress in the 2012 Cancer Program Standards of the American College of Surgeons [51].

Advances in Information Technology, Data Collection Platforms, and Analytic Capabilities

Wu and colleagues describe state-of-the-art features observed across ten case studies that improve the collection and use of PRO data [32]. Some features make collecting PRO data more efficient, flexible, and patient-centered. Computer adaptive testing customizes PRO questionnaires based on patient-specific information, increasing the precision and efficiency of data collection. Delivering PRO questionnaires by tablet or secure patient portals rather than on paper reduces EHR data entry; however, data collection platforms should be based on patient preferences [32, 79].

Other features enhance clinical decision support to help providers understand PRO data and act on them. Displaying a patient's PRO data alongside annotated normative data or thresholds helps providers identify levels of impairment or dysfunction that warrant intervention. Clinical decision support systems integrate PRO data, threshold values, and best practice alerts to ensure that providers address identified issues; it is critical to identify "panic values" that require immediate action and build in workflows to ensure it occurs. For example, at Group Health, an elevated score on the PHQ-9 item assessing suicidal ideation triggers a more detailed suicide risk assessment. Some systems using PRO data, including Kaiser Permanente, use standard documentation templates, or SmartSets, to reduce the time providers need to document related interventions.

Organizations will improve business intelligence by identifying improvement opportunities from aggregated PRO data, enhanced by the use of standardized PRO questionnaires and a consistent approach to administration. As user-friendly analytic tools such as SAS Enterprise Business Intelligence and Tableau become more available, PRO data will become an essential part of the "big data" that organizations routinely collect and analyze to inform organizational performance and identify opportunities for improvement. Finally, state-of-the-art applications of PRO data will eventually facilitate and streamline reporting for regulatory or accreditation requirements.

A Growing Need to Pilot Test Research-Developed Questionnaires in Routine Practice

More user testing and post-pilot assessments are needed to ensure that PRO data has value for all users, including providers, patients, caregivers, department administrators, and healthcare executives. Key qualities of PRO questionnaires that need to be assessed include feasibility, usability, and acceptability. Feasibility refers to how readily a questionnaire can be incorporated into existing clinical workflows [84]. Usability refers to the extent to which an intended user can use the resulting PRO data effectively and satisfactorily to support identified use cases [85]. Acceptability is a function of a questionnaire's perceived accuracy and reliability [59]. Other important factors affecting the implementation of PRO questionnaires in clinical practice are the required level of health literacy and optimal modalities (paper or electronic) for data collection. A typical PRO questionnaire includes 20 or more questions [78], and the feasibility and intended applications of lengthy questionnaires must be established before they are broadly implemented. In addition to the burden they pose to respondents, long questionnaires can overwhelm providers with patient-reported data if they lack specific guidelines for using them.

However, the integration of PRO questionnaires from research into routine care must primarily be considered from the perspective of patients. Several issues need to be addressed [62], including the value of using multiple questionnaires. As questionnaires move from research into practice, a pivotal question is how much PRO data is required to understand patients' experiences and needs.

Many PRO questionnaires are in routine use in clinical practice, such as single items or scales assessing pain levels and a variety of questionnaires assessing behavioral health, cognitive functioning, and psychosocial well-being; they include measures of depression, anxiety, dementia, and stress [62]. As new PRO questionnaires spread from research to clinical settings, the number and complexity of questionnaires that patients, particularly those with multiple conditions, are asked to complete will likely grow. Respondent burden may be an issue. Finally, the sustainability of using PRO data as intended must be examined. A key question is whether providers continue to use data as intended over time. This may depend on how valuable they find the data. PRO questionnaires targeting specific groups of patients appear to be more useful for managing care than more general ones [70], but this finding needs validation across PRO questionnaires and patient populations.

PRO Data Improve Population Health

Population-level PRO data may be increasingly used for broad population health improvement. Moving the policy discussion from health to well-being would distinguish between healthcare policy and health policy and embrace broader determinants of health [86]. Well-being is a subjective experience; in the future, population health will be assessed in part by PRO measures. This movement is exemplified by the Institute of Health Improvement (IHI) 100 Million Healthier Lives initiative, a cross-sectoral collaboration aimed at achieving global health, well-being, and equity [87]. Person-reported outcomes are an essential part of the measurement strategy; IHI is piloting a seven-item health and well-being questionnaire in 24 US communities.

Patients as Full Partners in PRO

Patients will become increasingly involved in PRO design and selection. Healthcare is belatedly becoming more attuned to the preferences and values of the individuals who are its consumers. At Kaiser Permanente, for example, patients are active partners in the design of programs and services and of the measures with which we evaluate their effectiveness. Shared decision-making about the most important outcomes of care is essential to ensuring a focus

on what is most important to patients. PROs have a great potential to support innovating and redesigning new ways of working and communicating with patients.

The International Consortium for Health Outcomes Measurement solicits patients' input on key outcome measures, including PRO, when developing condition-specific standard measurement sets [88]. Similarly, Selby and colleagues describe the approach at the Patient-Centered Outcome Research Institute (PCORI) to ensuring patient-centeredness while developing research proposals and reviewing funding [66]. This approach may be seen in the KP environment, where quality improvement leaders focus on "measures that matter to members" and view partnering with patients as shared decision-making about important outcomes.

Individual patients have a rapidly expanding ability to monitor the outcomes that are most important to them by using devices that track data like caloric intake, daily steps, and sleep patterns. The "democratization of metrics" is modifying patients' expectations about how the effectiveness of healthcare should be assessed. Although the use of standardized PRO measures is a large step in the right direction, providers must also know which outcomes among the many assessed by a questionnaire are most important to the patient sitting in the examination room.

Conclusion

Many PRO questionnaires are available to measure the experiences and outcomes that matter most to patients—and their number is growing. It is critical to ensure that patients' investment of time and energy in providing PRO data has clear value to them. Patient-reported outcomes have the potential to increase the degree to which healthcare is patient-centered, and realizing that potential requires achieving balance between the distribution of PRO questionnaires to patients and the use of the collected data to improve outcomes. It matters to patients that we ask about their experiences; it matters even more that we use what they tell us to improve their health and well-being.

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Part II

Family and Social Support

Family and Other Caregivers

9

Megan Gately and Keren Ladin

Ultimately, caregiving is about doing good for others, and doing good in the world, as naive as it may sound, is what medicine is really about. –Arthur Kleinman [1]

Introduction

The impact of chronic conditions cuts across age, gender, racial, ethnic, and socioeconomic lines affecting a wide variety of populations at all stages of the life span. As people live longer, the burden of chronic diseases increases, affecting older adults and their social network of family members and friends who provide day-to-day support. A caregiver, often referred to as informal caregiver, unpaid caregiver, or family caregiver, can be defined as a family member, partner, friend, or neighbor of a person with a chronic or disabling condition, with whom the caregiver often has a significant and personal relationship and for whom he or she provides a wide range of assistance [2]. The provision of care, which is often complex, time-consuming, and without financial remuneration, can affect the physical and mental health, financial savings, productivity, and well-being of the caregiver [3–5]. Providing care for persons with chronic conditions often involves a multitude of caregivers operating within a dynamic, ever-shifting network [6, 7]. By contrast, formal caregivers are individuals paid to provide care in one's home or in a care setting (day care, residential facility, long-term care facility), who can be either medically trained (skilled) or a lay provider.

Unpaid adult caregivers provide the majority of the support for those living with chronic conditions and are an integral, yet often overlooked, piece of the healthcare system. The USA relies on informal caregiving to support the graying population due to low uptake of long-term care insurance and lack of coverage for most home- and community-based services (HCBS). Data extrapolated from the national American Time Use Survey values the total economic value of unpaid caregiving, including opportunity costs, at $522 billion [8]. As healthcare provision has shifted from inpatient settings to care in the home for more complex conditions, family caregivers are assuming more prominent roles in disease management, performing medical tasks often with little to no training. Demographic shifts, including more women in the labor force, families living at greater distances from each other, and couples having fewer children, are shaping the caregiving landscape. Governmental and workplace policies are evolving in response to the recognition of the role that family caregivers provide, including some programs that offer compensation and protected leave to caregivers such as the Family and Medical Leave Act [7, 9, 10]. However, such programming remains a patchwork, with insufficient effort and structure to meet the growing demands.

Much research has been devoted to understanding the nature and scope of caregiving, which has both deleterious and positive effects. As individuals live longer with chronic diseases, the experience and needs of care recipients and caregivers become more complex and increase in duration, necessitating a shift in approach. Caregiving is now widely understood as a reciprocal relationship and even a co-occupation whereby the caregiver and care recipient's health and well-being are inextricably linked [11]. Despite this recognition of the vital role that caregivers play as partners in health maintenance, much remains to be done to support families as they confront the multifaceted demands of chronic disease management. This chapter outlines the scope

M. Gately
Departments of Occupational Therapy and Community Health, Tufts University 574 Boston Avenue, Suite 216, Medford, MA, USA

VA Medical Center, Geriatric Research and Clinical Center, Bedford, MA, USA
e-mail: megan.gately@tufts.edu

K. Ladin (✉)
Departments of Occupational Therapy and Community Health, Tufts University 574 Boston Avenue, Suite 216, Medford, MA, USA

Research on Ethics, Aging, and Community Health (REACH Lab), Medford, MA, USA
e-mail: keren.ladin@tufts.edu

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of caregiving, its role in healthcare provision within the USA, risks and benefits of caregiving, and management of caregivers as patients.

Caregiving Is a Vital Component of American Healthcare

Informal caregivers provide as much as 90% of the in-home long-term care needed by adults with chronic illnesses [3, 12]. Approximately 66 million individuals in the USA served as unpaid family caregivers to an adult or child in 2009; of these, two-thirds provided care for older adults. Approximately 20% of the US population (an estimated 44 million adults) identify as a caregiver to an older adult with a disability or illness, most commonly a relative [7]. On average, caregivers spend 20 h per week on caregiving activities, with one-fifth of caregivers providing over 40 h of weekly care [7].

Caregiving tasks include providing assistance with activities of daily living (ADLs), such as bathing and dressing; help with instrumental activities of daily living (IADLs), such as arranging medical appointments and household tasks (e.g., cooking and housecleaning); and offering emotional support to care recipients. In some cases, caregiving may include proxy decision-making and support in choosing the treatment plans that best reflect patient preferences. Caregivers also perform medical tasks ranging in complexity from administering medication and checking blood pressure to providing wound and incontinence care. Many caregivers report having received little training in these tasks [7]. Advanced age, dementia, and wound care are the leading conditions for which caregivers provide unpaid care [4, 7].

While caregiving may be episodic and of short duration in response to an acute crisis or health condition, most of it is for a long-term condition. Longer durations of caregiving are associated with higher rates of burden [7]. High caregiver burden is experienced by 32% of caregivers and 19% have moderate caregiver burden, which is directly related to the time spent providing care and the care recipient's degree of dependency [3].

Caregivers are a heterogeneous group that includes a range of ages, cultures, and socioeconomic backgrounds, though middle-aged women constitute the majority (60%) of self-described caregivers. The typical caregiver is a 49-year-old woman who works full-time and provides more than 20 h a week of care to her aging mother. Men make up 40% of caregivers; however, there are gender differences in the distribution of care provided. The duration of care provided by women is longer than that provided by male caregivers, and men tend to provide fewer hours of care per week than women. Women also assist with ADL care (e.g., bathing and dressing) more than men. On the other hand, married male caregivers are employed at a higher rate and work more hours than either female caregivers or their unmarried male caregiver counterparts [3, 7].

Older adults who identify as lesbian, gay, bisexual, or transgender (LGBT), and those from sexual and gender minority groups, have faced historic marginalization both in society and within the healthcare system and may be more comfortable with informal caregiving. Distrust of the medical system and perceived discrimination have resulted in lower utilization of preventative services and chronic disease management for these individuals resulting in higher rates of psychiatric, medical, and substance abuse problems [13]. Highlighted in the Healthy People 2020 initiative as a population in need of further research and intervention, LGBT individuals are distinct also in the manner in which they provide and receive care [14]. For this population, the most commonly identified caregivers are partners or friends, not family members. Clinicians should ask the patient directly about preferences, as the most important caregivers and proxy decision-makers may not be those who are next of kin. This underscores the importance of the context of caregiving, as the relationship between caregiver and care recipient may dictate changing norms and expectations [15].

The Consequences of Caregiving

Caregiver burden is well-documented, including its effects on caregiver health, decision-making, and the timing of institutionalization or long-term care placement of the care recipient [4, 16]. Increasingly understood as a multifactorial construct, there is no diagnostic criterion for caregiver burden, yet it is broadly understood to mean the strain experienced by someone caring for a person with a disability, illness, or advanced age. Caregiver burnout occurs when the burden is so great that its negative impact on caregiver and recipient outweighs the benefits [17]. The degree of caregiver burden differs among certain populations, and understanding the risk factors and symptoms of caregiver burden and burnout can assist with targeting assessment and intervention to support higher-risk caregivers.

Caregivers for persons with chronic conditions are at substantively higher risk of burden than those with acute conditions, given the long-term and often unpredictable nature of chronic illness. Caregivers of those with chronic illnesses often encounter multiple co-occurring stressors due to the care recipient's fluctuating health status, stressors that manifest as demands on their time. Caregivers who provide care for long periods of time are more likely to report poorer health themselves [7]. Caregiving may also be emotionally rewarding, strengthening family bonds and conserving family resources. The experience of caregiving is highly individualized and multidimensional, and caregivers have different thresholds for caregiver burden.

Risk Factors for Caregiving Burden

Demographic factors may contribute to an increased risk of caregiving burden, such as being female or having limited education. Social factors also contribute to burden, such as living with the care recipient, being socially isolated, or reducing social activity [4, 18]. Psychological contributors to burden include caregiver stress, anxiety, and poor coping strategies, as well as depression in either the caregiver or care recipient. Problem behaviors in the care recipient increase caregiver burden and are the main predictor of institutionalization [4, 18]. Spousal caregivers of older adults are at higher risk because of their own comorbidities and frailty, their likelihood of cohabitating with the care recipient, and the limited agency they have over assuming the caregiving role. Caregivers who provide care to persons with dementia, advanced cancer, and end-of-life care needs, as well as those experiencing care transitions, face disproportionate risk of caregiver burden. High caregiving demands are related to higher rates of caregiver burden, though caregivers' understanding of their caregiving responsibilities predicts burden and not the level of caregiving alone, indicating that a caregiver's sense of having choice and control, or lack thereof, contributes to their perceived burden [19].

Physical Consequences of Caregiving

Given the range of tasks that caregivers perform, many experience physical strain. Over half of caregivers report some difficulty assisting care recipients with ADLs such as bathing and dressing, with greater difficulty reported by those caring for someone with a chronic, long-term condition such as dementia [7]. Musculoskeletal conditions such as back pain may result from lifting the care recipient, such as is needed for transfers in and out of bed [20]. Caring for people with cancer, regardless of the age of the patient, decreases immune functioning in caregivers [21–23]. Caregivers often experience stress-related physical ailments such as headaches and acid reflux. The risk of developing chronic conditions such as heart disease and diabetes may be exacerbated by negative health behaviors such as smoking and poor eating habits, found to be more common in caregivers than non-caregivers [24]. Caregivers also tend to have higher mortality rates pursuant to these and other ramifications of caregiving, including less adaptive emotional functioning [2].

Psychological Consequences of Caregiving

Caregiving can have a profound effect on the emotional well-being of caregivers, with 64% of caregivers reporting moderate to high levels of emotional stress [7]. Emotional stresses may relate to caregiving demands themselves or from the distress of facing a chronic condition in a loved one, especially a degenerative or terminal disease, like Alzheimer's disease or cancer. Anticipatory grief encompasses not only the emotions experienced by caregivers prior to a loved one's death but also the feelings associated with the experience of chronic conditions as a series of losses that change the landscape of families' hopes and plans for the future [25]. Caregivers and care recipients may grieve the loss of function and autonomy, as well as the changing dynamics within relationships, which may alter long-standing roles. Caregivers who perceive they have no choice in their caregiving responsibilities report high levels of emotional stress, as do those performing medical tasks for their care recipient [7].

Psychological symptoms such as anxiety and depression are often the most prevalent symptoms of caregiver distress [21], and up to 50% of family caregivers meet the diagnostic criteria for clinical depression. Caregivers experiencing such clinical symptoms may have difficulty successfully completing their caregiver tasks, which could have a detrimental effect on the care recipient [26]. Caregiving may negatively affect an older caregiver's own cognitive function [17]. There is also an association between care recipients' cognitive function and symptoms of depression in spousal caregivers [27]. Similarly, caregiver stress has been associated with depressive symptomatology in the care recipient, highlighting the complex and interrelated health effects of the caregiving relationship [28].

A summary of symptoms and conditions common to caregivers is listed in Table 9.1.

Positive Effects of Caregiving

Though the impact of burden and burnout is real, increasingly there is a movement toward emphasizing the positive aspects of caregiving as potential mediators of burden. Acknowledging the caregiver's contribution and commitment can allow caregivers to fulfill their caregiving role especially if they also have access to support services such as respite

Table 9.1 Symptoms and conditions common to caregivers

Medical problems	*Psychosocial problems*
Back pain	Depression
Decreased immune function	Anxiety
Headaches	Limited coping strategies
Acid reflux	Social isolation
	Suicide
Negative health behaviors	*Clinical outcomes*
Smoking	Increased mortality
Poor eating habits	Weight gain or loss
	Poor self-care
	Sleep deprivation

care [16, 29]. Beneficial aspects of the caregiver-care recipient relationship include increased closeness, opportunities for resolution of prior relationship conflicts, finding meaning in the caregiving role, and increased caregiver strength and efficacy [30, 31]. Individuals providing care to patients with Alzheimer's disease identified engaging in positive behaviors and a positive attitude as factors that contributed to a more positive caregiving relationship [32]. Successful adaptation to the caregiving role in those who are caregivers to chronically mental ill patients increases the likelihood of caregiver reward [33]. Caregivers to people with multiple sclerosis defined "meaning-making" in caregiving to involve acceptance, relationship ties, and a spiritual component [34]. Arthur Kleinman depicts caregiving as a moral imperative both for himself and for society at large as a way of imbuing even the most mundane of caregiving tasks with meaning [1]. Caregiver self-efficacy, or competence in the caregiving role, mediates caregiver stress in high-stress dementia caregivers, particularly when coupled with spirituality [35].

Linking the caregiving experience to a higher or more transcendent understanding may alleviate caregiving stress. This may help to transmute long-standing models used to describe the caregiving experience, such as stress-coping theory which posits that a person under stress first weighs the seriousness of the consequence of stress and then the available resources to address it, with each aspect influencing the other. The person then responds to the stress by choosing a passive or active coping strategy. Depending on the circumstances and choice of coping strategy, the process can have a positive or negative effect [18]. As an alternative to this approach, the healthy caregiver hypothesis builds upon data finding more positive health outcomes in older adult caregivers than non-caregivers. Recent data applying this theory to cognitive function in older adult female caregivers suggests that continuous caregiving may help to maintain cognitive status. The increased physical activity due to caregiving and the cognitive complexity of caregiving tasks may be the mechanisms for these findings [17].

Financial Consequences of Caregiving

Estimates of the economic value of unpaid caregiving vary widely, but likely exceed $500 billion, including opportunity costs such as time lost from activities or employment in which the caregiver previously participated [7, 8]. The financial impact of caregiving is directly felt by individual caregivers, nearly 20% of whom report financial strain as a result of their caregiving duties. On average, family caregivers spend nearly $7000 in out-of-pocket expenses per year related to caregiving, corresponding to 20% of their annual income. Although most caregivers are employed full-time while providing care, many miss work, must alter work schedules, and even turn down promotions. Approximately 80% of middle-aged workers at the peak of their careers face the prospect of caring for parents or in-laws who need long-term support, forcing difficult choices that may have significant financial implications [7]. Though many caregivers receive workplace accommodations for caregiving, including paid sick days or flexible schedules, most employers do not offer employee assistance programs or telecommuting as options for caregivers.

An unevenly distributed caregiving burden perpetuates existing health and socioeconomic disparities. An estimated 20% of older workers who are providing care leave the workforce entirely, with lost wages and benefits averaging $304,000 per individual [7]. Women who stop work to provide care often experience a long-term impact on their financial security. Women generally earn less than men during their working years, resulting in decreased contributions to retirement plans and Social Security which is compounded by early retirement. Given that women tend to live longer than men, this puts them at increased risk of poverty when they are older themselves.

Financial strain from lower earnings due to reduced hours, unemployment, or underemployment is exacerbated by greater expenses due to caregiving. This risk is even higher for caregivers from ethnic and racial minority groups, such as African-Americans and Hispanics [2]. Hispanic and low-income caregivers face disproportionate burdens, spending an average of 44% of their annual income on caregiving. Forty-one percent of these caregivers' out-of-pocket expenditures are associated with home maintenance costs and home modification (e.g., ramps, handrails, railings), while medical needs account for 25% of expenditures, including nursing support and insurance [36]. For caregivers of persons with Alzheimer's disease or dementia, out-of-pocket expenses are typically higher ($10,700 annually). For Hispanic caregivers, this is nearly half of their annual income, while for African-American caregivers, this is 34% of their income. For white and Asian-American caregivers, this averages to 14% and 9% of annual income, respectively. Care for dementia is typically more expensive due to the higher level of care needed which, when coupled with the long duration of illness, can financially cripple caregivers. As a result of lost wages and greater expenditures related to caregiving responsibilities, many caregivers report decreasing leisure and social participation, including putting off vacations or being unable to spend time with their own children or friends [3].

Caregivers as the Invisible Patient

Caregivers are an underserved population with unmet needs. Most caregivers report not having conversations with healthcare providers about their responsibilities even though more than 80% desire more information regarding their caregiving role. Caregivers especially want advice on strategies for keeping their loved one safe, ways to manage the stress and emotional impact of caregiving, and guidance on decision-making, including end-of-life care. Caregivers also desire training that will increase their skill level in performing medical or nursing tasks [7]. Caregivers of patients with chronic obstructive pulmonary disease (COPD) report needing more information about their loved one's health condition as well as additional support from the healthcare team [37]. Proactive intervention for caregivers is imperative, given that caregivers of individuals with chronic conditions, particularly those caring for Alzheimer's disease, may wait to seek help until symptoms of burden and burnout are already present [29].

Assessing the Caregiver

Providers should evaluate a caregiver's sense of well-being, confidence in ability to provide care, and need for additional support. A multidisciplinary team approach can achieve this and includes collaboration with social workers, psychologists, community agencies, and palliative care services to support both caregivers and recipients. This starts by asking about the caregiving situation and progresses to the provision of prognostic information and counsel about the likely scope of future caregiving needs.

Though evidence clearly demonstrates a link between caregiver and care recipients' health and well-being, healthcare providers infrequently assess and address caregiver needs. Clinicians should be aware of risk factors for caregiver burden, using these to spark discussions with the caregiver. Assessing caregiver burden and available supports, such as backup and secondary caregivers, is essential to ensuring quality care and can be achieved by asking specific questions about how the caregiver is coping (Table 9.2). Addressing any physical, emotional, behavioral, financial, social, and occupational implications to the caregiver is essential to the health and well-being of the care recipient.

Guidelines provided by the National Center on Caregiving encourage the integration of caregiver evaluation into the routine care of frail elders and those with chronic, disabling conditions. Underlying this approach is the importance of a culturally appropriate, family-centered focus that factors in the needs and preferences of both patient and caregivers and leads to the collaborative development of an intervention plan that includes training and education. This process should be supported by governmental agencies and third-party payers as part of the care of older adults and those with chronic, disabling conditions [2].

Formal assessment of caregivers should reflect the complex and context-specific nature of caregiving, including critical caregiving domains such as caregiver well-being, skills and knowledge for caregiving tasks, and potential resource needs. Caregiver-specific concerns such as burden and strain can be measured using the Zarit Burden Inventory [38] and the Modified Caregiver Strain Index [39]. Tools such as the Patient Health Questionnaire help identify depression in the caregiver [40]. Caregiver confidence and self-efficacy can also be assessed, as can caregiver self-rated health and life satisfaction, all of which contribute to a more thorough understanding of the caregiver [41].

Other aspects of a caregiver assessment include asking questions about the caregiver's relationship to the care recipient, duration of care, and living arrangements, as well as questions about the caregiver's perspective of the care recipient, including cognitive and overall health status, level of function, and goals of care. The caregiver's values around caregiving should be understood, particularly given the known association between perceived lack of choice in assuming the caregiver role and level of burden [7].

The Tailored Caregiver Assessment and Referral (TCARE) program is an evidence-based protocol developed for use with military personnel that is widely used in the assessment of adults who provide care to either chronically or acutely ill older adults [42]. TCARE is based on a caregiver identity theory which posits that caregiving is a dynamic process that changes over time with caregiver stress resulting from a dissonance between personally held values, roles, and norms and caregiving behaviors. Delivered over multiple sessions by a trained case manager, nurse, social worker, or other members of the healthcare team, TCARE includes an assessment and intervention process designed to empower caregivers in decision-making. TCARE leads to a care plan that can be monitored and adjusted over time and can be used in community-based settings with adults of all ages. It has also been adapted to serve individuals with developmental disabilities and for those from diverse racial and ethnic populations. TCARE reduces caregiver burden and depressive symptoms.

Support for Caregivers

Primary care teams and other frontline providers are well-situated to assist patients and families dealing with chronic illness [21]. Initiatives to support caregivers are broad and expanding, representing a paradigm shift from an acute, reactionary stance to a proactive and planned approach.

Table 9.2 Topics and selected questions for caregiver assessment (Adapted from Adelman et al. [4])

Context of care	
Caregiver relationship to care recipient	What is the caregiver's relationship to the patient?
	How long has the caregiver been in this role?
Family caregiver profile	What is the educational background of the caregiver?
	Is the caregiver employed?
Additional caregivers	Are other family members or friends involved in providing care?
	Are paid caregivers (e.g., home health aides) involved?
Living arrangements	Does the caregiver live in the same household as the care recipient?
Physical environment	Does the care recipient's home have grab bars and other adaptive devices and necessary equipment to assist with care?
	Is the care recipient homebound?
Caregiver's perception of care recipient's overall health	
Cognitive status	Is the patient cognitively impaired?
	How does this affect care provision?
Health, functional status, prognosis, and goals of care	What medical problems does the care recipient have?
	What is the caregiver's perception of the care recipient's medical problems, prognosis, and goals of care?
	What are the goals of care according to the care recipient?
Caregiving needs	Is the care recipient totally dependent 24/7 or is only partial assistance required?
	Is there evidence that the caregiver is providing adequate care?
Assessment of caregiver values	
Willingness to provide and agree to care	Is the caregiver willing to undertake the caregiver role?
	Is the care recipient willing to accept care provision?
Cultural norms	What types of care arrangements are considered culturally acceptable to this family?
Assessment of caregiver health	
Self-rated health	How does the caregiver assess his or her health?
Health profile	Does the caregiver have any functional limitations that affect the ability to act as a caregiver?
Mental health	Does the caregiver feel she or he is under a lot of stress?
Quality of life	How does the caregiver rate his or her quality of life?
Impact of caregiving	Is the caregiver socially isolated?
	Does the caregiver feel his or her health has suffered as the result of caregiving?
Assessment of caregiver knowledge and skills	
Caregiving confidence	How knowledgeable does the caregiver feel about the care recipient's condition?
Caregiving competence	Does the caregiver have the appropriate medical knowledge required to provide care (wound care, transferring patient, health literacy for administrating complex medical regimen, etc.)?
Assessment of caregiver resources	
Social support	Do friends and family assist the care recipient so the caregiver has time off?
Coping strategies	What does the caregiver do to relieve stress and tension?
Financial resources	Does the caregiver feel financial strain associated with the caregiving?
	Does the caregiver have access to all financial benefits and entitlements for which the care recipient is eligible?
Community resources and services	Is the caregiver aware of available community resources and services (caregiver support programs, religious organizations, volunteer agencies, respite services?)

Caregiver support may be offered at either the provider or system level, but individualized and multidisciplinary approaches are recommended. Programming should reflect key principles of chronic illness management for both caregivers and patients, including recognition of the emotional impact of chronic illness, such as acceptance, grief, and assumption of new roles. Family caregiving concepts to be integrated include the transactional nature of caregiving, the importance of well-being on the part of caregivers and patients, the desire for guidance in decision-making, and the need for family cohesion and adaptability, given the ongoing and shifting demands of chronic illness [43].

Caregivers should be included in decision-making and devising goals of care, such as having their names in the medical chart of care recipients. Caregivers should be trained in the safe and effective delivery of care tasks at home, including utilizing proper body mechanics. An occupational therapist can evaluate and offer suggestions to improve the home environment [44]. Social work professionals may assist with establishing community-based supports, including food programs such as Meals on Wheels or caregiver support groups. Referral for a psychological evaluation may be indicated, if depression is suspected. Respite care, either short-term relief of caregiving responsibilities by a friend of family member staying with the care recipient or of longer duration where the care recipient stays in an inpatient facility, may allow for continued caregiving duties and decrease caregiver stress [22]. Day care or home-based services may assist families. Caregivers should be encouraged to take care of their own health needs and to recognize the signs and symptoms of burnout, such as withdrawal from social relationships and trouble sleeping [7, 9].

Policy-Related Issues and Concerns

Federal and workplace policies influence family caregivers contending with chronic illness. Access to health insurance and support programs is vitally important, such as can be found in the UK where the National Health Service recognizes the impact of health and wellness on both patients and caregivers [45]. Even where services are provided, caregivers often underutilize healthcare resources due to barriers such as language differences and lack of information [46]. The lack of any supportive services, such as in developing countries, increases the physical demands of caregiving and may increase caregiver strain, particularly for caregivers of children with disabilities [20]. Programs that provide tax breaks and other incentives may assist families with the financial burden of caregiving including transportation costs. Progressive workplace policies on leave and time off for caregiving may assist with maintaining work-life balance for many caregivers, given the substantial number of caregivers who are still in the workforce [9].

Examples of Interventions

There are numerous examples of caregiver support programs. The Guided Care Program for Families and Friends supports older adults with multiple comorbidities and their caregivers. Delivered through a primary care setting, Guided Care provides ongoing education and support and increases the quality of care to care recipients [47]. Primary Health Care is a psychological intervention that includes cognitive behavioral therapy for caregivers of dependent relatives and those with disabilities and improves caregivers' mental health [48]. A German multidimensional program supports patients and family members and emphasizes the contextual needs of caregivers given that chronic disease changes and can include acute flare-ups as well as long-standing rigors of day-to-day disease management [49]. The timing of the provision of information and activation of resources should be adjusted accordingly.

Supporting Parents with Chronically Ill Children

Providing care to a child with a chronic illness poses unique challenges for parents and other family members. Besides the emotional distress, these caregivers may also be trying to maintain employment or be simultaneously responsible for the care of an aging parent or relative, both of which exacerbate caregiving strain [22]. Parents may be raising multiple children and need to divide attention and modulate their parenting style to accommodate different stages of their children's development. Caregiving for a child with a chronic condition is often lifelong and includes planning a future for a child who may outlive her parents but still require assistance with daily living. Long-term caregiving by a parent, particularly to a child who is medically fragile, can have health effects, such as decreased immune function [23]. Physical demands associated with caring for a dependent child may result in strain and injury, such as when a child requires assistance with transfers [20]. Single parents and those from lower socioeconomic backgrounds may be at particular risk of negative effects of caregiving [22].

Interventions to support parents can be offered at the institutional level, e.g., school- or hospital-based support services, or in the community. Assistance with care tasks such as help from others or the provision of equipment can

facilitate children's school attendance or improve function. Training on proper body mechanics and positioning for the more physically demanding aspects of caring for a child with a chronic illness, such as lifting, may be helpful. Broad-based policies that reduce financial strain such as leave and workplace accommodation, as well as access to affordable housing, can support parents of children with a chronic condition. Respite care and caregiver support groups are helpful. An approach that considers the entire family, including well siblings, best meets the needs of the patient and caregivers [22].

Supporting Caregivers of People with Dementia

Caregivers of people with dementia face unique challenges due to behavioral problems and decreasing cognitive function of the care recipient. These caregivers often assume decision-making responsibility for the patient, which necessitates a dyadic approach by healthcare providers. Interventions such as psychoeducational programming, cognitive-behavioral therapy, case management, caregiving training, and respite to caregivers of people with dementia all had statistically significant but modest positive effects on caregiver burden, subjective well-being, depression, knowledge, and negative symptoms of the care receiver [50]. An individualized approach that targets specific caregiver domains has the best likelihood of being helpful.

Numerous programs support caregivers' desire to help their loved one with dementia to stay at home. Resources for Enhancing Alzheimer's Caregiver Health (REACH) is a program that uses a behavioral approach for family caregivers of veterans with dementia and results in positive effects to both caregivers and patients. Widely implemented within Veterans Health Administration, the largest healthcare service provider in the USA, REACH offers a model of intervention implementation within the broader healthcare system [51]. MemoryCare is a community-based nonprofit program that augments the medical management of patients with dementia. Using a chronic disease model, the program provides caregiver and patient education, counseling, and support, and has been shown to reduce the rate of hospitalization for these patients [52]. An excellent resource for caregivers of people with Alzheimer's disease or related dementia is available at www.SunriseRiverPress.com. It contains information on more than 50 medical and behavioral conditions that caregivers often address and provides information on how caregivers can take care of their own health.

Supporting Caregivers of People with COPD

Chronic obstructive pulmonary disease (COPD) is a chronic and often disabling condition that poses distinct challenges for patients and caregivers. As with other chronic conditions, caregiver burden increases and quality of life decreases in direct relation to the disease severity [37, 53]. Caregivers of patients with COPD must often assist with activities due to disease-related fatigue. They may also complete medical tasks that involve complex technologies such as portable oxygen, suction, and the use of various machines that aid in breathing or the administration of medication. Disease progression, exacerbations, and unpredictable flare-ups are challenging and often necessitate increasing caregiver involvement. Caregivers are often deficient in their understanding of the disease and management strategies [37]. Useful interventions include those that provide ongoing case management, education, information about support services, and the option for palliative care [54].

Technological Support

Technology may increase access to education and services for both the caregiver and care recipient. Telehealth, a growing area of service delivery that provides healthcare remotely by means of telecommunications technology, may be of particular benefit for the sizeable number of chronically ill or older adults who live in rural areas or have mobility challenges [55]. Mobile technologies and video telehealth increase the options for receiving care at home, and monitoring and surveillance technologies may decrease caregiving demands. Many caregivers utilize health information technology to assist with care, and educational videos and caregiver support groups are available online [4, 56, 57]. More research is needed to identify the barriers and facilitators to telehealth, including ethical and privacy considerations.

Telehealth solutions are increasingly utilized to support caregivers of patients with dementia. Video telehealth in the home provides group psychosocial interventions for caregivers [57, 58]. The Internet-based Tele-Savvy is a psychoeducational tool for dementia caregivers that shows positive preliminary results [59]. The In-Home Care Coordination and Intensive Caregiver Support for Veterans with Dementia program offers an innovative model of dementia care utilizing home telehealth to provide caregiver support. Surveillance technologies have also been implemented to create a safer home environment for veterans with dementia [60, 61]. A Home Clinical Video Telehealth program supports veterans with dementia at home and decreases caregiver isolation [62]. These technologies will continue to

develop and add to the efforts that support caregivers in their important role of providing care to the growing number of people with chronic diseases.

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Domestic Violence, Abuse, and Neglect

10

Samantha Schilling and Adam J. Zolotor

Introduction

The Centers for Disease Control and Prevention defines intimate partner violence (IPV) as "physical violence, sexual violence, stalking, and psychological aggression (including coercive tactics) by a current or former intimate partner (i.e., spouse, boyfriend/girlfriend, dating partner, or ongoing sexual partner)" [1]. Specifically, physical violence is defined as the intentional use of physical force with the potential for causing death, disability, injury, or harm and includes scratching, pushing, shoving, throwing, grabbing, biting, choking, shaking, hair-pulling, slapping, punching, hitting, burning, use of a weapon (gun, knife, or other object), and use of restraints or one's body, size, or strength against another person. Sexual violence is defined as a sexual act that is committed or attempted by another person without freely given consent of the victim or against someone who is unable to consent or refuse. Stalking is a pattern of repeated, unwanted, attention and contact that cause fear or concern for one's own safety or the safety of someone else (e.g., family member, close friend), and psychological aggression is the use of verbal and nonverbal communication with the intent to harm another person mentally or emotionally and/or exert control over another person [1].

Over the course of a lifetime, more than one in three women and more than one in four men in the United States experience rape, physical violence, and/or stalking by an intimate partner [2]. Approximately one third of homicides of women are committed by intimate partners [3]. Because victims of IPV tend to have high rates of physical and mental health morbidity, they are frequent users of the health-care system. Intimate partner violence is thus a condition that physicians and other providers can expect to encounter frequently in their care settings.

The US Government enacted the Child Abuse Prevention and Treatment Act in 1974, which defines child maltreatment as "any recent act or failure to act on the part of a parent or caretaker, which results in death, serious physical or emotional harm, sexual abuse or exploitation, or an act or failure to act which presents an imminent risk of serious harm" [4]. While federal legislation sets minimum standards for states, each state provides its own definitions of maltreatment within civil and criminal statutes. Each year in the United States, Child Protective Service (CPS) agencies receive more than three million reports of suspected child maltreatment and investigate more than two million of these reports; more than 650,000 children are substantiated by child welfare as maltreatment victims [5]. Most maltreated children are victims of neglect (78.5%), 17.6% are victims of physical abuse, and 9.1% are victims of sexual abuse. More than 1500 child deaths are attributed annually to child abuse or neglect [5].

A substantial body of research and associated clinical experience indicate that child maltreatment and IPV are public health problems with lifelong health consequences for survivors [6]. A landmark study known as the Adverse Childhood Experience study demonstrated a gradient risk among adults for both health risk behaviors and chronic diseases based on the number of childhood adversities and traumas. For example, those with greater adversity had 4–12 times greater risk, compared to those with less adversity, for alcoholism, drug abuse, and suicide attempt. Similarly, those with greater adversity had higher rates of cancer, heart disease, lung disease, and liver disease compared to those with less adversity [7]. Much has been learned about the factors that contribute to family violence and about characteristics that may prove protective.

At the other end of the life course is elder mistreatment. An expert panel convened by the National Academy of Sciences defines elder maltreatment broadly as the intentional actions

S. Schilling (✉)
University of North Carolina, Department of Pediatrics, Chapel Hill, NC, USA
e-mail: samantha_schilling@med.unc.edu

A.J. Zolotor
University of North Carolina School of Medicine, Department of Family Medicine, Chapel Hill, NC, USA

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that cause harm or create a serious risk of harm (whether or not harm is intended), to a vulnerable elder by a caregiver or other person who stands in a trusted relationship to the elder, or failure by a caregiver to satisfy the elder's basic needs or to protect the elder from harm [8]. Multiple types of elder maltreatment exist including physical abuse, psychological abuse, sexual assault, neglect, and financial exploitation. Estimates of elder abuse vary between 2% and 10%. In a probability sample of elderly people not in institutions living in Boston, MA, the overall abuse rate was 3.2% [9]. The extent of elder abuse is sufficiently large that physicians who serve elderly adults are likely to encounter it routinely.

Physicians and other care providers play a key role in identifying and treating maltreatment and family violence, as well understanding physical and mental health problems in pediatric and elderly patients in the context of challenging life events, such as chronic illness. This chapter will first provide general guidelines for clinicians who may encounter child abuse, intimate partner violence, and elder mistreatment. The next section will outline evaluation approaches for patients who may present for medical care and will be followed by management strategies. The chapter will close with future trends in this important area.

General Guidelines

Because maltreatment and family violence are widely prevalent, all physicians and other health-care providers will encounter patients who experience these problems. Furthermore, although there are subspecialists with expertise in the evaluation and management of child maltreatment and family violence, the vast majority of identification and treatment occurs by primary care clinicians. The identification of abuse can be difficult for many reasons; abuse is rarely witnessed, disclosure by the perpetrator is uncommon, and victims are often nonverbal, too severely injured, or too frightened to disclose. Furthermore, injuries may be nonspecific in the case of physical abuse or absent in the case of sexual abuse.

Child Abuse

Existing instruments designed to screen for social determinants of health often inquire about parental concern for child abuse [10]. Asking a caregiver about abuse is important and underscores the centrality of these problems to child health. A negative response, however, should not preclude an evaluation for abuse if other concerns are identified. Indeed, the best available screen for child abuse at this time remains a high index of suspicion and a thorough physical examination.

Once a concern for child abuse has been identified, a report to child protective services must be made and consultation with a specialist for further evaluation, diagnosis, and treatment may be indicated. Child abuse pediatricians are responsible for the diagnosis and treatment of children and adolescents who are suspected victims of child maltreatment and participate in multidisciplinary collaborative teams within the medical, child welfare, law enforcement, and judicial arenas. Social workers and domestic violence counselors are also critical team members in addressing family violence concerns. Multidisciplinary child maltreatment evaluations also take place in child advocacy centers which are child-friendly facilities in which law enforcement, child protection, prosecution, mental health, medical, and victim advocacy professionals work together to investigate abuse, help children heal from abuse, and help families navigate the judicial systems to hold offenders accountable and optimize family outcomes [11].

Although the maltreatment of children has been recognized for decades, there are ongoing challenges to deliver high-quality medical care to children with suspected abuse. Identifying and ensuring the health and safety of abused and neglected children is challenging. There is abundant evidence that physicians often miss opportunities for early intervention of injuries that are concerning for physical abuse [12–14]. Previous sentinel injuries are minor injuries such as bruises or intraoral injuries that are noted before a diagnosis of child abuse. Such injuries are often identified by physicians, but are incorrectly attributed to accidental trauma or not reported to CPS for investigation despite physician suspicion for abuse [12, 13, 15].

There is considerable variability in the diagnostic evaluation for physical abuse. All children younger than 2 years of age in whom physical abuse is suspected, for example, require a skeletal survey, the standard tool for detecting occult fractures [16]. However, race and socioeconomic status appear to influence a physician's decision to obtain skeletal surveys when children younger than 2 years present with skeletal trauma or traumatic brain injury, leading to both the over reporting and under reporting of abuse in different populations [17–19].

Studies have also shown that many physicians have not been properly trained in anogenital examination of children [20, 21]. Variability has also been observed in performing recommended testing for STIs and pregnancy, and administering recommended prophylaxis and emergency contraception when adolescents present to pediatric emergency departments following acute sexual abuse [22].

Although neglect is the most widespread form of child maltreatment and results in significant morbidity and mortality, the focus of public and professional attention is largely on physical and sexual abuse. A greater and ongoing challenge is that neglect is difficult to define. For instance,

although a health-care provider might view repeated nonadherence to medications as neglect, this may not meet a state's CPS statute for neglect unless harm has resulted from this inaction.

Intimate Partner Violence (IPV)

Assessing for IPV in the clinical setting can be universal or selective, based on presentation or risk factors. The US Preventive Services Task Force (USPSTF) recommends screening all women of childbearing age and referring any women who screen positive for intervention services [23]. This recommendation is based on evidence that IPV can be accurately detected using currently available screening instruments, that effective interventions can mitigate the adverse health outcomes of IPV, and that screening causes minimal harm [23].

Physicians and other providers should be aware of the clusters of symptoms that are common in victims of IPV. When patients present with signs and symptoms suggestive of IPV (e.g., frequent somatic complaints, unexplained injuries, injuries to the face or trunk, frequent mental health complaints), clinicians should inquire about IPV since an intervention may not only be beneficial but also because knowledge of IPV can inform the treatment plan or help the clinician understand barriers to treatment. A physician perception of poor adherence to medical recommendations may in fact be associated with the abuse a patient is experiencing since impeding access to health care may be part of the control that abusers exert in their partners' lives [24]. Physicians who diagnose IPV, and therefore begin to understand the barriers that their abused patients face, may be able to develop more effective therapeutic relationships. Identifying IPV also provides an important opportunity for providing the patient with empathic support, educating her regarding the dynamics of IPV and the future risks it poses to her and her children.

Several questionnaires for assessing for IPV have been validated in a variety of settings and are practical in primary care, such as HITS, Woman Abuse Screening Tool (WAST), the Ongoing Violence Assessment Tool (OVAT), and the Partner Violence Screen [25]. Whether a clinician uses a structured instrument or simply asks questions informally in the context of a patient interview, several principles are important to follow. Physicians should ensure a private setting, without friends or family members present. They should assure patients of confidentiality but notify them of any reporting requirements. It is often helpful to preface questions about IPV with normalizing statements, for example, "Because violence is a common problem, I routinely ask my patients about it" or "Many people with [condition] have worse symptoms if they have been physically, emotionally or sexually abused in the past."

Prevention of family violence can be targeted to the individual/family level, community level, and societal/policy level. Interventions at the level of the family have been the best studied and have been widely deployed. Newborn education, primary care education, screening and brief intervention, and intensive home visiting are among the most evaluated programs for family-level interventions [26–29]. Intensive home visiting has a substantial evidence base in the prevention of child maltreatment. Despite this demonstrated track record, it remains poorly disseminated, engagement and retention in this type of program is limited, and outcomes are hard to reproduce. Community-based programs that seek to change social norms around parenting and family dynamics have also been shown to be successful [30]. These programs are often implemented in combination with some level of individual or family-level intervention. Finally, two policies, paid family leave and earned income tax credit, have been shown to decrease child maltreatment [31, 32].

Toxic Stress, Child Maltreatment, and IPV

The lifetime consequences of early trauma are substantial and enduring. Researchers have found that most causes of morbidity and mortality, including obesity, heart disease, alcoholism, and drug use, are directly associated with child maltreatment and childhood exposure to IPV [7, 33, 34]. Children need an environment in which a responsive, attentive caregiver meets their basic needs including nurturance, love, and protection for normal growth and development. In this fundamental caregiver–child relationship, the child also depends on the caregiver to mediate and buffer life's stressors [34]. When stressors are overwhelming, or when caregivers are unable to help children buffer them, significant adversities can challenge the normal development of healthy coping mechanisms, learning, emotional health, and physical health [33, 34].

Stress that is unbuffered and overwhelming leads to potentially maladaptive neuroendocrine changes that impede a child's capacity to protect herself/himself from threats that are experienced and perceived in their world. When a child faces profound and chronic adversity such as abuse, neglect, and household IPV, significant biologic changes can occur. Excessive activation of the physiologic stress response system can lead to changes to hypothalamic–pituitary–adrenal gland axis activation, epigenetic gene translation, altered immune response, and impaired neurodevelopment involving brain structures responsible for cognition, rational thought, emotional regulation, activity level, attention, impulse control, and executive function [34]. These biological processes are made manifest in specific behavioral, learning, and health problems which are seen in many children who have been maltreated or exposed to IPV.

In the health-care setting, physicians and other providers may address some of the changes in bodily function associated with trauma's influence on the brain. Sleep problems may include difficulty initiating or maintaining sleep or experiencing nightmares. Children who have experienced trauma may demonstrate rapid eating, lack of satiety, food hoarding, or loss of appetite. Toileting problems include constipation, encopresis, enuresis, and regression of toileting skills [35]. Neuroendocrine changes can impact the immune and inflammatory response. In addition, an increased risk of infection and rates of asthma and allergy and an increased risk of metabolic syndrome can all be linked to trauma [36, 37].

Elder Mistreatment

There are no validated instruments for the screening or evaluation of elder mistreatment. Clues about potential mistreatment frequently come from ancillary staff members or home care nurses who observe the abuser–victim dyad away from the health-care provider [38]. A general sense that something is displaced in the patient's environment such as an abrasive interaction between the elder and the caregiver, poor hygiene, frequently missed medical appointments, or failure to adhere with a clearly designated treatment strategy can all be important indicators.

There are no diagnostic signs or symptoms of elder abuse presentation, and clinicians need to consider elder mistreatment in the differential of many clinical presentations they encounter. Significant injuries and severe neglect are obvious, but many prevalent chronic diseases that afflict the elderly also have clinical manifestations of abuse and vice versa. For instance, fractures may result from osteoporosis or physical abuse. Malnutrition may be the result of progressive malignancy or the withholding of nourishment. Most often, chronic disease and elder abuse co-occur making the identification of elder mistreatment one of the most difficult clinical challenges in geriatric medicine.

Patient Evaluation

Suspected Child Abuse

Child abuse and neglect result from a complex interaction of child, parent, and environmental factors. Most often multiple factors coexist and are interrelated and increase the child's vulnerability to maltreatment [39]. Even if there is no single factor that overwhelms the caregiver, a combination of several stressors may precipitate an abusive crisis [40] (see Fig. 10.1).

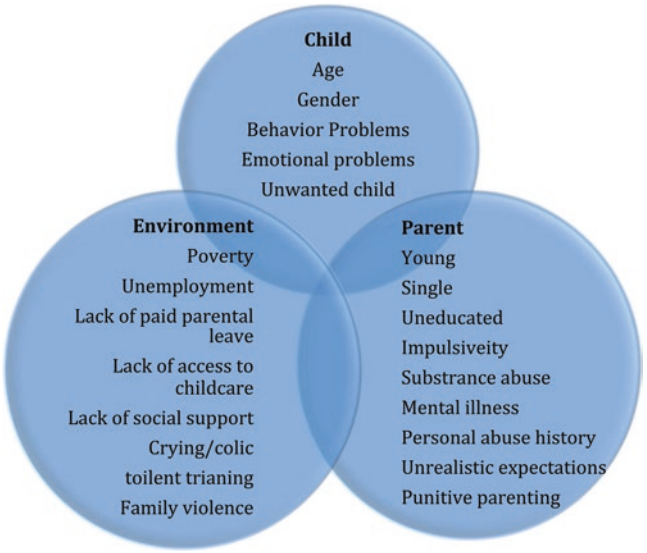

Fig. 10.1 Factors that place a child at risk for maltreatment

Individual characteristics that predispose a child to maltreatment include those that make a child more difficult to care for or may be at odds with parental expectations. Adolescents are more likely than younger children to suffer physical abuse and neglect; however infants and toddlers are particularly vulnerable to severe and fatal maltreatment because of their smaller size and developmental phase [41]. Girls may be at higher risk for sexual abuse, although this may be in part because boys are more likely to delay disclosure of sexual abuse [42]. Children with physical or developmental disabilities, special health-care needs, or chronic illnesses may also be at increased risk [43]. Physical aggression, resistance to parental direction, and antisocial behaviors also more commonly characterize maltreated children [44]. These children exhibit poor emotional regulation, distractibility, negative affect, and a resistance to following directions [45].

There are parent characteristics associated with child maltreatment, and these include young age, being a single parent, and low educational achievement [46]. Factors that decrease a parent's ability to cope with stress and increase the potential for maltreatment include low self-esteem, poor impulse control, substance abuse, and mental illness [47]. In addition, parents who were themselves victims of child maltreatment are more likely to have children who are abused or neglected [48]. Parents who maltreat their children are more likely to have unrealistic developmental expectations for child behavior and to have a negative perception of normal behavior. In addition, parents with punitive parenting styles are more likely to maltreat their children [48].

Poverty and unemployment are also associated with maltreatment [49]. Even when parents are employed, the absence of paid family leave policies increases the risk of maltreatment

[31]. Additionally, when low-income working parents have challenges accessing affordable and safe childcare, substandard childcare can present an elevated risk for child abuse [50]. The absence of a robust family social support system places the child at increased risk for maltreatment [49]. Young children who live in households with unrelated adults are at exceptionally high risk for abuse [51].

High-stress situations can increase the potential for child abuse. Circumstances that occur during the course of normal child development, including colic, nighttime awakenings, and toilet training, are potential triggers for maltreatment [39]. In particular, crying is a common trigger for abusive head trauma [52]. Infant crying generally peaks between 2 and 4 months, and the incidence of abusive head trauma parallels this crying trajectory [53]. Accidents surrounding toilet training are another potential trigger. Immersion burns may be inflicted in response to encopresis or enuresis when a caregiver believes that children should be able to control these bodily functions [54]. The average age of children who have been intentionally burned is 32 months, by which time abusive parents may have expected their children to have mastered bodily functions [39].

Children living in homes with IPV are at increased risk of being physically abused, in addition to suffering the negative emotional, behavioral, and cognitive consequences from exposure to this family violence [55–57]. Although IPV affects all ages, races, ethnicities, and socioeconomic strata, young women and individuals with low incomes are at greatest risk [58, 59].

Physical Abuse

Almost no injury is pathognomonic for abuse or accident without careful consideration of the history, a thorough physical examination, and targeted radiographic or laboratory analysis. When abuse is suspected as the cause of an injury, the clinician may conduct tests to screen for other injuries and to identify potential medical etiologies in the differential diagnosis of abuse. The extent of diagnostic testing depends on several factors, including the severity of the injury, the type of injury, and the age and developmental level of the child. Table 10.1 summarizes tests that may be used during a medical assessment for suspected physical abuse.

Table 10.1 Laboratory and radiologic testing for the evaluation of suspected physical abuse

Injury	Laboratory testing	Radiologic testing
Bruises	CBC	Skeletal survey for non-ambulatory infants with bruises
	PT, INR, PTT	
	VWF antigen, VWF activity	Skeletal survey for children <2 years with suspicious bruising
	Factor VIII level, factor IX level	CT head/MRI head for infants <6 months or infants with suspicious bruising
Fractures	Calcium, phosphorous, ALKP	Skeletal survey
	Consider 25OHD, PTH	CT head/MRI head for infants <6 months
	Consider serum cooper, vitamin C, ceruloplasmin	
	Consider DNA analysis for osteogenesis imperfecta	
Abdominal injury	AST, ALT, amylase, lipase, urinalysis	CT abdomen with contrast
		Skeletal survey in children <2 years
Head injury	CBC	CT head
	PT, INR, PTT	MRI head and spine
	Factor VIII level, factor IX level	Skeletal survey in children <2 years
	Fibrinogen, d-dimer	
	Review newborn screen	
	Consider urine organic acids	

Skin Injuries

Bruises are universal in active children and bruises are also the most common injury resulting from physical abuse. Patterned bruises, such as slap marks or marks caused by a looped extension cord, are highly suggestive of abuse. Bruises in healthy children tend to be distributed over bony prominences; bruises isolated to the torso, ears, or neck should raise concern [60]. Bruises in non-ambulatory infants are unusual and are highly concerning for physical abuse [61]. Many diseases are associated with bruises, including coagulopathies and vasculitides, and children who present with suspicious bruises may require screening for diseases that are included in the differential diagnosis of abuse [62]. Bite marks are characterized by ecchymoses, abrasions, or lacerations that are found in an elliptical or ovoid pattern [63]. Bite marks can be inflicted by an adult, another child, an animal, or the patient.

Approximately 6–20% of children hospitalized with burns are victims of abuse [64]. Abusive scalds due to neglect outnumber those due to intentional injury by a factor of 9:1 [65]. Inflicted burns can be the result of contact with hot objects, such as irons, radiators, stoves, or cigarettes, and from immersion injuries. Although both inflicted and accidental contact burns may be patterned, inflicted contact burns are characteristically deep and leave a clear imprint of the hot instrument. In contrast to accidental scald injuries, inflicted scald burns have clear demarcation, uniformity of burn depth, and a characteristic pattern [66]. Dermatologic and infectious diseases can mimic abusive burns, including

toxin-mediated staphylococcal and streptococcal infections, impetigo, phytophotodermatitis, and chemical burns of the buttocks from laxatives [67].

Fractures

Unexplained fractures, fractures in non-ambulatory infants, and the presence of multiple fractures raise suspicion for physical abuse [68]. Certain fracture types also have a higher specificity for abuse, such as rib fractures and classic metaphyseal lesions. Skeletal survey is the standard tool for detecting occult fractures in possible victims of child abuse [16]. Repeating skeletal surveys 2–3 weeks after an initial presentation of suspected abuse improves diagnostic sensitivity and specificity for identifying skeletal trauma in abused infants [69, 70]. Vitamin deficiencies, mineral deficiencies, and genetic diseases may be considered in the differential diagnosis of unexplained fractures when appropriate [71].

Abdominal Injuries

Abdominal injury is the second leading cause of mortality from physical abuse [72]. Compared with children who sustain accidental abdominal trauma, victims of abuse tend to be younger, more likely to have hollow viscera injury, more likely to have delayed presentations to medical care, and have a higher mortality rate [73, 74]. Symptomatic children can present with signs of hemorrhage or peritonitis, but many children will not display overt findings. Therefore liver and pancreatic enzymes are important to obtain in all children who present with serious trauma, even if they do not display acute abdominal symptoms [75]. Contrast-enhancing computed tomography (CT) is warranted if these screening laboratory tests indicate possible abdominal trauma and in all cases of symptomatic injury. Surgical consultation is required for children with inflicted abdominal injury [76].

Head Injuries

Abusive head trauma is the leading cause of mortality and morbidity from physical abuse [77]. Multiple mechanisms contribute to the cerebral, spinal, and cranial injuries that result from inflicted head injury including both shaking and blunt impact [77]. For symptomatic children, CT of the head will identify abnormalities that require immediate surgical intervention and is preferred over MRI for identifying acute hemorrhage and skull fractures and scalp swelling from blunt injury. MRI is the optimal modality for assessing intracranial injury, including cerebral hypoxia and ischemia, and is used for all children with abnormal CT scans and asymptomatic infants with non-cranial abusive injuries [78]. Severe retinal hemorrhages are highly associated with abuse, particularly in young infants [79].

An examination using indirect ophthalmoscopy is indicated in the evaluation of abusive head trauma, preferably by an ophthalmologist with pediatric or retinal experience. Conditions that may be confused with abusive head trauma include accidental/birth trauma and metabolic, genetic, or hematologic diseases associated with vascular or coagulation defects [80]. Many of these can be ruled out through careful medical, developmental, and family history and thorough physical examination.

Suspected Neglect

Neglect occurs when a child's basic needs are not adequately met. Physical neglect, the most common form of neglect, includes failure to provide food, clothing, stable housing, supervision, or protection. Educational neglect occurs when a child's educational needs have not been met, often by failure to enroll a child in school or by chronic truancy. Emotional neglect refers to exposing a child to conditions that could result in psychological harm such are ignoring a child's need for stimulation, isolating a child, threatening a child, or verbally ridiculing a child. Medical neglect refers to lack of appropriate medical or mental health care or treatment. The general examination, including careful measurement of growth parameters, may reveal evidence of neglect, including malnutrition, extensive dental caries, or neglected wound care.

Sexual Abuse

Many communities have child advocacy centers where children can be referred when concerns of sexual abuse arise. Depending on the community services available, the physician should be prepared to conduct a basic medical interview with a verbal child when there is a concern regarding sexual abuse. Any disclosure should be recorded word for word in the medical record [81]. If the sexual abuse occurred in the distant past and the asymptomatic child is going to be referred to a specialty center for medical evaluation, examination might be deferred. However, if the abuse is recent and the child is reporting genital or anal pain or bleeding, thorough examination should be performed to rule out injury.

For girls, separation of the labia and gentle labial traction while the child is supine with knees bent and hips abducted (i.e., frog-leg position) will adequately expose the genial structures. Speculum examinations are contraindicated in prepubertal children and are most often not needed in adolescents in the absence of signs or symptoms of genital disease [82]. For boys, the examination of the genitals consists of inspecting the penis and scrotum for evidence of trauma or scarring. Most sexually abused children have normal anogenital examinations [83]. The sexual abuse of children may not result in injury and when injury does occur the anogenital tissue often heals quickly and completely [84]. A normal examination of the genitalia and anus does not rule out sexual abuse [85].

Sexually abused adolescents should be tested for chlamydia, gonorrhea, trichomonas, and pregnancy [82, 86]. In addition, the CDC suggests hepatitis B testing in unimmunized victims and consideration of human immunodeficiency virus (HIV) and syphilis testing in populations in which there is a high incidence of infection or when the victim requests these tests [87]. Sexually transmitted infections (STIs) in prepubertal children evaluated for abuse are rare, and thus a targeted approach is recommended [88]. Factors that may prompt testing include vaginal or anal penetration, abuse by a stranger, abuse by a perpetrator infected or at risk of infection with an STI, having a household contact with an STI, or signs or symptoms of an STI. Positive results should be confirmed using additional tests in populations with a low prevalence of the infection or when a false-positive test could have an adverse outcome. If diagnosed with an STI, the child should be treated promptly. Children who have had recent sexual contact should be immediately referred to a specialized clinic or emergency department capable of forensic evidence collection [89]. Most states recommend that forensic evidence be collected in less than 72 or 96 h since the assault.

Suspected Intimate Partner Violence

When IPV is detected in the clinical setting, clinicians should respond in a way that builds trust and sets the stage for an ongoing therapeutic relationship. Key components of an initial interaction should include validation of the patient's concerns, education regarding the dynamics and consequences of IPV, safety assessment, and referral to local resources. A growing body of evidence suggests that a variety of counseling and advocacy interventions are effective at reducing violence and mitigating its negative health effects [90]. IPV is usually a chronic problem that will not be mitigated in one or two visits, but rather can be worked on over time [91].

An initial response to a disclosure of IPV should include listening to the patient empathically and nonjudgmentally, expressing concern for her/his health and safety, and affirming a commitment to help her/him address the problem. Women who have long been subjected to abuse may believe that the abuse is their fault. Health-care providers can help counter this belief, reassuring patients that although partner violence is common, it is unacceptable and not the fault of the victim. Clinicians should also convey respect for IPV victims' choices regarding how to respond to the violence. Victims of IPV may have a clearer understanding than their health-care providers about what courses of action may result in increased danger. If patients need to move slowly, frequent office visits can be helpful by providing ongoing support and addressing medical problems.

Suspected Elder Mistreatment

Spouses and adult children are the most common perpetrators of elder abuse [92]. Living with another adult is a major risk factor for elder abuse, perhaps due to increased opportunities for contact and conflict in a shared living arrangement [9, 92]. An exception to this pattern is financial abuse, for which victims are more likely to live alone [93]. Several studies have reported higher rates of physical abuse in patients with dementia [94, 95]. A likely mechanism is the high rate of disruptive and aggressive behaviors of patients, which are a major cause of stress and distress to caregivers. Social isolation has been identified as a risk factor for elder abuse [96]. There are certain perpetrator-specific risk factors as well, including mental illness and alcohol misuse [94, 97]. Finally, elder abusers tend to be heavily financially dependent of the person they are mistreating [98].

Once the possibility of elder abuse has been raised, a comprehensive assessment is necessary. If there are no cognitive limitations, the patient should be interviewed alone and asked directly about the etiology of any concerning findings [99]. Often patients are initially unwilling to speak openly about being an elder abuse victim due to embarrassment, shame, or fear of retribution from the perpetrator who is frequently a caregiver [99]. Interview of the suspected abuser is a potentially hazardous undertaking and not necessary [99]. Elder abusers who are presented with an empathetic, nonjudgmental ear to describe their stresses and actions will sometimes describe their situations at great length and in great detail. However, all forms of domestic abuse share a pattern wherein abusers gain and control access to their victims. An elder abuser confronted with allegations of mistreatment may move to sequester a victim in such a way that a fragile, isolated adult loses access to critically needed medical and social services [99].

Management Strategies

Mandated Reporting

In every state, health-care providers are mandated by law to identify and report all cases of suspected child abuse and neglect. Yet, much of the abuse that is recognized by physicians does not get reported to CPS for investigation [13]. In part this is because clinicians may incorrectly believe that making a report requires certainty in their diagnosis of child abuse, rather than having a *reasonable suspicion* for maltreatment as the law requires. In addition, many clinicians believe that reporting to CPS is not an effective intervention and distrust the ability of the child welfare system to protect children [14]. Reports should be made when there is reasonable cause to suspect abuse. In all states, the law provides

some type of immunity for good faith reporting. However, failing to report may result in malpractice suits, criminal offenses, licensing penalties, and, most importantly, continued abuse to the child. Mandated reporters must become familiar with their state-specific reporting procedures and laws.

Health-care provider cooperation with CPS investigations is critical to effective decision-making by investigators. Health Insurance Portability and Accountability Act (HIPAA) rules allow disclosure of protected health information to CPS without authorization by a legal guardian when the clinician has made a mandatory report, but state laws differ regarding the release of health information during and after investigations are complete [100]. Some states require mandated reporting of IPV exposure to CPS, and clinicians should know their specific state's reporting requirements before screening and inform the caregiver accordingly. In most states cases of elder abuse must be reported to adult protective services. Websites such as www.endabuse.org, http://www.childwelfare.gov, or http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx provide information on state-specific laws about mandated reporting and available resources.

Enhanced Health-Care Needs of Maltreated Children

Maltreated children, particularly those in foster care, exhibit high rates of acute and chronic physical, developmental, and mental health conditions [101–104]. In fact, nearly 80% of children in foster care have significant physical, mental, and developmental health-care needs [105]. Exposures such as insufficient prenatal care, prematurity, or in utero toxins as well as chronic abuse/neglect have direct and indirect effects on the health and well-being of this population.

The interplay of chronic or prolonged stress, physiologic response to that toxic stress, and behavioral adaptations to this stress impact the health of children over the life course. Maltreated children may require more frequent preventive health visits due to multiple environmental and social issues that can adversely impact their health. Furthermore, this medically vulnerable population requires intensive, integrated behavioral and medical care.

Approach to Child Maltreatment

The treatment of child maltreatment is complex and challenging. Many of the approaches developed by child welfare agencies, health-care providers, therapists, and others have not been rigorously tested, and many families suffer from chronic dysfunction and a multitude of challenges that require broad approaches to management. Several treatment strategies have shown promise.

Abuse-focused cognitive behavioral therapy (AF-CBT) and parent–child interaction therapy (PCIT) are considered "best practice" intervention protocols for the treatment of physical abuse [106]. Both are dyadic interventions designed to alter specific patterns of interaction found in parent–child relationships. AF-CBT represents an approach to working with abused children and their offending caregivers based on learning theory and behavioral principles that target child, parent, and family characteristics related to the maltreatment [107]. The approach is designed to promote the expression of appropriate/prosocial behavior and to discourage the use of coercive, aggressive, or violent behavior. PCIT is a highly specified, step-by-step, live-coached behavioral parent training model. Immediate prompts are provided to a parent by a therapist while the parent interacts with their child. Over the course of 14–20 weeks, parents are coached to develop specific positive relationship skills, which then results in child compliance to parent commands [108, 109].

When abused children or children who have witnessed IPV develop posttraumatic stress disorder symptoms, trauma-focused cognitive behavioral therapy (TF-CBT) is also effective [110]. TF-CBT is a structured individual and parent trauma-focused model that includes initial skills-based components followed by more trauma-specific components with gradual exposure integrated into each component [110].

Physicians should become familiar with programs in their geographic area of practice, which provide evidence-based interventions for children who have experienced abuse or IPV exposure. Additional information on trauma-informed care resources is listed in Table 10.2.

Approach to Intimate Partner Violence

Clinicians should educate patients on the dynamics of partner violence and potential effects on victims and their children, helping them understand that once violent dynamics are established in a relationship, the violence generally

Table 10.2 Trauma resources

Resource	Website
AAP Healthy Foster Care America	www.aap.org/fostercare
AAP Cope with Trauma Guide	www.aap.org/traumaguide
AAP Medical Home for Children and Adolescents Exposed to Violence	www.aap.org/medhomecev
National Child Traumatic Stress Network	http://nctsn.org
SAMHSA National Center for Trauma-Informed Care	www.samhsa.gov/nctic/trama.asp

continues and escalates over time. In a nonjudgmental way, health-care providers can convey concern to patients regarding the negative physical and mental effects that IPV may have on patients and their children. Although addressing IPV is usually a long-term process, health-care providers should be alert to crisis situations that indicate imminent danger (e.g., escalating violence, use of or threat with a weapon, drug or alcohol use). Assessing for these risk factors provides an opportunity to educate patients about what situations indicate increased risk.

Health-care providers should refer victims of IPV to local resources that can provide advocacy and support. Physicians and others should be familiar with organizations in their communities that provide assistance to victims of IPV, including organizations' capacity to accommodate specific populations such as immigrants, specific ethnic or cultural groups, teens, lesbian, gay, bisexual or transgender clients, or persons with disabilities. Resources can also include community-based advocacy groups, shelters, law enforcement agencies, or social workers. The National DV Hotline (800-799-SAFE) can serve as an information source. If immediate concerns for safety exist, the health-care providers can offer to contact these resources for the patient directly from the office. A follow-up visit should be scheduled, and IPV should be readdressed at future visits.

Table 10.3 Interventions to consider for elder abuse

Abuse trigger to target	Potential interventions
Alleviating caregiver stress	Respite services
	Adult daycare
	Caregiver education program
	Recruitment of other family, informal, or paid caregivers to share burden of care
	Social integration of caregiver to reduce isolation
Treating specific caregiver deficiency	Treatment for caregiver depression or mental illness
	Referral to alcohol or drug misuse rehabilitation program
Aggressive symptoms in patient with dementia	Geriatric medical assessment of causes of underlying behavior and treatment of aggressive symptoms
Longstanding spousal violence	Marital counseling
	Support groups
	Shelters
	Orders of protection
	Victim advocacy
Financial exploitation by family member	Guardianship proceedings
	Power of attorney
	Adult protective services
Financial exploitation by paid caregiver	Legal services
	Law enforcement
	Adult protective services

Approach to Elder Mistreatment

There are no evidence-based interventions regarding treatment for elder abuse, and clinicians should view elder abuse as multifactorial rather than as a homogeneous condition. However clinicians can offer interventions likely to be effective in mitigating the impact of the abuse. Table 10.3 lists potential interventions to be considered in the treatment of elder maltreatment. Resources for clinicians and families who are dealing with elder mistreatment can be found at National Association of Area Agencies on Aging (http://www.n4a.org).

Future Directions

Child abuse, family violence, and elder mistreatment are tied to substantial burdens of suffering and associated costs to our communities (e.g., health care, criminal justice, mental illness, substance use). These conditions and maladaptations should ultimately be viewed as problems of the individuals involved, as well as the family, the community, and the greater policy environment. For health-care providers, there is ample opportunity to (1) identify families at risk, (2) provide resources and referral, (3) treat the sequelae, and (4) advocate for the most constructive programs and policies to reduce the burden of suffering.

The most important frontiers in research will be the development, adoption, and sustained implementation of new programs – prevention and intervention – for families across the life course who are at risk of and victimized by violence. The most effective type of intervention for child maltreatment, for example, is intensive home visiting [29, 111]; however, these programs are available to relatively few families who may benefit, and recruitment and retention rates are low. In addition, although these approaches require significant resources per person, they need to be adapted and scaled across a broader range of settings, such as primary care, early care and education, schools, and long-term care. Finally, research is needed on how to most effectively engage and retain families in effective prevention and treatment programs.

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Peer Support

11

Edwin B. Fisher, Patrick Y. Tang, Maggy Muchieh Coufal, Yuexing Liu, and Weiping Jia

Introduction

Peer support (PS) provided by "community health workers," "lay health advisors," "promotores," "patient navigators," "peer supporters," and individuals with a number of other designations has been shown to play influential roles in health and the health-care delivery system [1]. Although medical care and self-management programs may help individuals understand what to do to stay healthy, people often find themselves disconnected from resources and left on their own to enact and manage a complex set of factors to initiate and sustain behavior change. For example, current standards for diabetes education and support of the American Diabetes Association and American Association of Diabetes Educators call for diabetes self-management support to help those with diabetes implement and sustain the behaviors needed to manage their illness [2].

In particular, PS links people living with a chronic disease or condition – people who share knowledge and experience that others, including many health workers, do not have – for practical and emotional support of behavior change [3]. PS approaches can offer the kind of emotional, social, and practical assistance for how to achieve and sustain complex behaviors that are critical for managing conditions and staying healthy [4–8]. This strategy can complement and enhance other health-care services to help people follow management plans in daily life, stay motivated and cope with the stressors chronic disease so often provides, and stay connected to their health-care providers to get the care they need, often in a cost-effective manner [9–12]. In sum, PS interventions have been shown to be an effective disease management strategy to enhance linkages to care and attend to the dynamic and evolving conditions of real-world environments and circumstances that influence health behavior [13–21].

The average patient may spend approximately 6 h a year in a health professional's office or consulting room. That leaves about 8760 h a year in which patients are responsible for all the things they need to do to manage their health conditions, 24/7 for the rest of their lives. This reality points to why patients, especially those with chronic illness, need multiple sources for patient education programs, such as community resources for healthy lives, supportive family and friends, and web-based sources. The importance of 8760 is recognized, for example, in the standards for diabetes self-management education and support that have been developed by the American Diabetes Association, the American Associations of Diabetes Educators, the American Dietetic Association, and several other organizations [22]. These groups acknowledged that the effects of time-limited education programs are, themselves, time limited and diminish after about 6 months, which led to recognizing the importance of diabetes self-management support in addition to self-management education.

This chapter provides an introduction to peer support (PS). The first section defines PS and outlines the key historical and intellectual developments in this area. Next, the evidence base of PS is presented with a particular focus on diabetes mellitus. The subsequent section outlines implementation

E.B. Fisher (✉) • P.Y. Tang
Peers for Progress, Department of Health Behavior, Gillings School of Global Public Health, University of North Carolina-Chapel Hill, Chapel Hill, NC, USA
e-mail: edfisher@unc.edu

M.M. Coufal
Peers for Progress, Department of Health Behavior, Gillings School of Global Public Health, University of North Carolina-Chapel Hill, Chapel Hill, NC, USA

Asian Center for Health Education, Plano, TX, USA

Y. Liu
Shanghai Diabetes Institute, Shanghai Jiao Tong University Affiliated Sixth People's Hospital, Shanghai, China

W. Jia
Shanghai Diabetes Institute, Shanghai Jiao Tong University Affiliated Sixth People's Hospital, Shanghai, China

Department of Endocrinology & Metabolism, Shanghai Clinical Center for Diabetes, Shanghai Jiaotong University Affiliated Sixth People's Hospital, Shanghai, China

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and dissemination approaches for PS and highlights integration strategies using the Chronic Care Model. Also included is the experience of peer support in China, which emphasizes the cultural aspects that need to be considered in program development. The next section identifies fiscal and reimbursement considerations before the chapter closes with how PS may contribute to the emerging health-care workforce.

Definition and Scope of Peer Support

Peer support has been broadly applied across different patient populations, health conditions, stages of disease, and settings to achieve a variety of health outcomes. Employing a range of modalities (e.g., face-to-face, group-based, telephone-based, digital health), peer support may be adapted to the unique needs of its organizational home and population focus. Peer support can occur organically in group medical visits and patient education classes as patients take advantage of opportunities to share their experiences. Organized peer support, with volunteers or state-certified community health workers, can provide individual counseling, support daily self-management of chronic diseases, connect patients with social services, and provide a basic level of care coordination. In each case, peer support provides assistance and emotional support in chronic care and chronic disease management in addition to helping to connect individuals with appropriate care and resources in their community [23, 24].

The Peers for Progress program initiated a consultation that was organized through the World Health Organization in 2007 [25]. Representatives from over 20 countries emphasized that key aspects of PS could be generalizable across differences in settings, although PS programs would have to be tailored to individual health systems, cultures, and patient populations. The output of this consultation resulted in a strategy of defining PS not by specific implementation protocols or details, but according to four key functions of support [26, 27]. This follows a strategy of standardization by function, not content [28, 29]. The four key functions are (1) assistance in daily management, (2) social and emotional support to encourage management behaviors and coping with negative emotions, (3) linkage to clinical care and community resources, and (4) ongoing support because chronic disease is for the rest of one's life [27]. With tailoring according to the needs and strengths of a specific setting or health goal, these become a template for planning and evaluating PS programs [26]. The hardiness of this approach was demonstrated by its application in programs in Cameroon, South Africa, Thailand, and Uganda and the benefits achieved across clinical, self-management, and quality-of-life indicators [26].

One example of PS includes a weight management social networking site, which provides a platform for the formation of a health buddy network in which participants self-select their online buddies [30]. Another model is the SafeMed program in Tennessee, which expanded the role of pharmacy technicians to act as community health workers to help improve transitions of care with an emphasis on medication management [31]. Still another example among school-aged cancer patients with extended hospital stays is the RESPECT program that mobilizes classmates to provide in-hospital support for better rehabilitation outcomes [32].

Peer support is ideally extended over time and is not a time-limited intervention. Although using peers to teach time-limited courses [33], or to promote health behaviors such as screening or immunizations [34], is important, the focus of a peer is to support and encourage the ongoing behaviors and patterns that are central to healthy living for the rest of an individual's life.

Key Intellectual and Historical Developments

The historical development of organized peer support can trace its roots to pioneers in mental health and substance abuse. In the late eighteenth century, Bicêtre Hospital in Paris was the first documented case of employing recovered patients as hospital staff. These peer staff were praised for being "gentle, honest, and humane," "averse from active cruelty," and "disposed to kindness" [35]. In the modern era, the notion of peer-facilitated recovery commenced with Alcoholics Anonymous in 1935 and has been adopted by multiple other peer groups [36]. Approximately two decades later, a group of consumers calling themselves We Are Not Alone developed a clubhouse approach to provide mutual support for those with serious mental illness who were discharged from state hospitals. The program was adapted by professionals to build an intentional therapeutic community comprising both people who had a serious mental illness and staff who worked within the clubhouse setting [37].

Community mental health professionals advocated for lay counselors to help mentally ill patients in the late 1960s [38]. This philosophy was widely adopted by mental health consumers in the 1970s as state mental hospitals were being shuttered, releasing patients into the community without adequate support. Simultaneously, patients began to speak out about systematic mistreatment and denial of civil liberties while under the care of state mental hospitals. Once released, former patients sought relief through autonomous peer and mutual support groups, which helped empower individuals as well as the community. Mental health advocates were at the vanguard, as demonstrated by peer support specialists in the mental health field being among the first to be certified and to qualify for state and Medicaid reimbursement [39, 40].

Fig. 11.1 Picture from studies of Harry Harlow and colleagues demonstrating the fundamental preference for "contact comfort" provided by a terry-cloth-covered surrogate mother, relative to a wire surrogate providing food. As described in the text, this and other studies of Harlow showed that the value of contact comfort from one's own species is fundamental among primates, not derivative of other needs, such as for food (Image reprinted with permission from Harlow [41])

Research on social influence and social support date back to Harry Harlow's classic study in the 1950s who showed that, although a wire surrogate mother was the source of food, young monkeys spent more time on a warmer, more cuddly terry-cloth surrogate (Fig. 11.1). Counter to thinking that affectional bonds are based on association with food and other necessities, Harlow argued that this and a series of similar studies made clear that "contact comfort" and the relationships that provide it are of value in and of themselves, not derivative of other needs [41].

A large amount of subsequent research reinforces the idea that social support has direct impacts on objective indices in health; it is important in and of itself, not just because it may be associated with other good things, such as education, and access to care. Among healthy volunteers exposed to rhinoviruses and quarantined in a laboratory setting for 1 week, for example, Cohen showed that variety of social ties predicted symptom response [42]. Among women with ovarian cancer, high levels of reported social support were associated with lower levels of factors associated with invasive and metastatic growth [43]. Such demonstrations of the fundamental roles of social connections are reflected in major epidemiological reviews [44, 45] showing the effects on mortality of social isolation to be similar to cigarette smoking.

Social support is of value and directly influences important biological processes, which has important implications for PS programs. In addition to benefits through improved health behaviors, social support may provide benefit through direct influences on disease processes. Thus, in addition to training supporters in skills for promoting self-management and behavior change, it may often be of value to encourage their simple availability and emotional support of those they help [46]. These aspects of "being there" may be of substantial value in health as well as quality of life.

Evidence Base

Although a number of reviews have examined PS programs, most of these have focused on a specific health problem, area of prevention and health care (e.g., promoting breastfeeding), or modality (e.g., telephone support). A review by Viswanathan and colleagues [47] focused on PS through community health worker interventions to create a bridge between community members, especially hard-to-reach populations, and the health-care system. It found moderate evidence in impacts on knowledge, health behaviors, utilization, and cost/cost-effectiveness. Gibbons and Tyus [1] reported efficacy in enhancing outcomes across mammography, cervical cancer screening, and a variety of other health/prevention objectives in reviewing PS for underserved groups and on US-based programs. A more recent review by Perry and colleagues [48] identified contributions of community health workers to basic health needs in low-income countries (e.g., reducing childhood undernutrition), to primary care and health promotion in middle-income countries, and to disease management in the USA and other countries with developed economies.

A comprehensive review conducted by the Peers for Progress program [49] included PS interventions from around the world, addressing a wide variety of prevention and health objectives entailing sustained behavior change and using a broad definition of PS entailing assistance and encouragement for self-management behaviors as well as linkage to appropriate care. The review included 65 papers from the USA (34 papers); Canada (7); Bangladesh, England, Pakistan, and Scotland (4 from each); and Australia, Brazil, Denmark, Ireland, Mozambique, New Zealand, South Africa, and Uganda (1 from each). Fifty-three were from World Bank-designated high-income coun-

tries and 12 from low-income, low-middle-income, and high-middle-income countries. The 65 papers addressed a variety of health conditions including drug, alcohol, and tobacco addiction (3 papers), cardiovascular disease (10), diabetes (9), HIV/AIDS (6), other chronic diseases (12), maternal and child health (17), and mental health (8). The papers also addressed both prevention (26) and disease management (39).

Across all 65 papers, 54 (83.1%) reported significant impacts of PS, 40 (61.5%) reported between-group differences, and another 14 (21.5%) reported significant within-group changes. When limited to papers reporting randomized controlled trials or other controlled designs, and utilizing objective or standardized outcome measures, results were similar. Among the 43 studies meeting these criteria, 31 (72.1%) reported significant between-condition effects favoring PS, and an additional 5 (11.6%) reported significant within-condition effects. Combining these, 36 of 43 (83.7%) of controlled designs using objective or standardized measures reported significant effects of PS. Among the 19 reviews of peer support included in this systematic review, a median of 64.5% of studies reviewed reported significant effects of PS.

A subsequent, extended review conducted by Peers for Progress [50] on diabetes used the same criteria for paper selection and coding, with the exception of limiting the search to papers on diabetes. Across all 30 studies, 17 (56.7%) reported significant, between-group differences favoring PS. An additional nine studies (30.0%) reported significant within-group changes indicating effects of PS among those who received it. Among the 24 diabetes studies utilizing controlled designs and either objective or standardized outcome measures, 16 (66.7%) reported significant between-condition effects favoring PS, and an additional 4 (16.7%) reported significant within-condition effects. Among the 30 diabetes studies, 23 reported an average HbA1c decrease of 0.76 among those receiving PS [51–72].

In addition to clinical trials, 14 evaluation and demonstration projects in PS for diabetes management have been conducted in nine countries around the world. Among the findings of these projects [73], a PS program implemented as an extension of clinical teams caring for low-income and ethnic minority patients with diabetes in a large community health center in San Francisco showed significant reductions in HbA1c measures relative to controls [71]. Another program along the Mexican border in southern California engaged individuals, of whom 41% had sixth grade education or less [63], and reported that HbA1c values declined from 8.7% to 8.3% over 12 months. In Argentina, diabetes education and ongoing support implemented by peers were comparable to those that were implemented by professionals in terms of clinical, self- management, and psychosocial indicators [62].

Approaches to Implementation and Dissemination

Based on the evidence noted above, the priority now in PS should no longer be verifying its efficacy, but how it works, how it works best, and for whom. There are a number of ways in which PS may contribute to expanding access, reducing health disparities, and increasing the quality and efficiency of care.

Engaging the Hardly Reached

Those who experience disproportionate, avoidable, and high-cost care are often not reached by clinical and preventive services. PS may be most successful among these "hardly reached" groups with whom one might expect least success. For example, asthma coaches were able to engage nearly 90% of mothers in a population of Medicaid-covered children who were hospitalized for asthma. The coaches sustained that engagement, averaging 21 contacts per parent over a 2-year intervention and reducing rehospitalization by 52% [9]. Among ethnic minority patients of safety net clinics in San Francisco [71], the impact of PS over usual care alone was greatest among those initially identified as having low medication adherence and self- management [74]. In veterans with diabetes that had PS dyads [53], improvements in blood glucose were greatest among those with initially low levels of diabetes support or health literacy [75]. In Pakistan, PS for postpartum depression was most effective relative to controls among women with household debt and/or relatively low levels of economic empowerment [76]. Most notably, a systematic review of these and 44 additional studies of PS for those often challenged to engage in health care found that 94% reported significant changes favoring peer support [77].

Reaching Populations

Most studies of PS are based on selected samples, shedding little light on the challenge of reaching the entire populations. A collaboration of Alivio Medical Center, a federally qualified health center in Chicago, the National Council of La Raza, Peers for Progress, and the former TransforMed℠ sought to reach the population of an estimated 3500–4000

Latino adults with type 2 diabetes in the Alivio catchment area [78]. The program, *Compañeros en Salud,* reached 88% of 471 patients categorized as high need (i.e., elevated HbA1c values and/or distress or depression and/or judged by their primary care providers as especially likely to benefit). Patients initially received biweekly phone calls, reduced to monthly and then quarterly as progress warranted. *Compañeros* also engaged 82% of 3316 assigned to regular care that included group classes and activities and quarterly contacts via phone or during regular clinical appointments. Across all 3787 Alivio patients with diabetes, HbA1c declined from 8.22% to 8.14% over 2 years. Among high-need patients, HbA1c declined from 9.43% to 9.16%, and the proportion with moderate to good HbA1c control (≤8%) increased from 19% to 26%. Modest in comparison to larger changes in smaller samples, these outcomes indicate PS may benefit populations of those with diabetes and other health problems.

Integrating Behavioral Health and Peer Support

Chronic diseases are often accompanied by psychosocial and mental health problems, including depression and anxiety disorders [79]. A broad range of factors influence psychological and physical health, from epigenetic effects of early maternal care to social and economic contexts of family and social relationships and organizational, economic, and cultural factors. Those disadvantaged across the complex of developmental, biological, and psychosocial determinants [79] are likely to experience both physical and psychological problems and disproportionate emergency and hospital care. The importance of social contact and emotional support [80] suggests that simple, frequent, and affirming PS may be especially helpful to those with emotional distress. For example, a meta-analysis found a pooled, standardized mean difference between PS for depression and usual care of −0.59 favoring PS [81].

In a striking program in Pakistan, "Lady Health Workers" implemented a cognitive-behavioral, problem-solving intervention that greatly reduced depression through 12 months postpartum [82]. In India, PS achieved a 30% decrease in prevalence of depression and other common mental disorders, 36% reduction in suicide attempts or plans, as well as reductions in days out of work [83]. In a Hong Kong study, PS also reduced distress and related hospitalizations among adults with diabetes. Among the 20% of patients who reported heightened depression, anxiety, and/or stress, PS improved distress scores relative to controls and reduced overall hospitalizations (relative risk = 0.15) to the normal level of those low on distress measures [69]. A striking aspect of this PS intervention was that it was designed to assist diabetes management, not to reduce emotional distress. It may be that intrinsic aspects of PS reduce emotional distress and problems associated with it.

Peer Support and Digital Technologies

Several digital health modalities (e.g., computer, mobile, and web-based technology) have been studied for their potential to enhance, extend, and scale up peer support. These platforms create environments for the exchange of unstructured and/or structured peer support, provide patient education, encourage self-management behaviors, and collect and analyze patient data to deliver personalized messages and guide clinical decision-making. Digital health technologies are able to respond in real time, delivering support that is contextual, accessible, and convenient. Some people prefer digital modalities because they allow for the exchange of rich, thoughtful information and are unique avenues of self-expression. Additionally, digital health can facilitate PS across geographic distances, enabling those with rare diseases to find others with the same condition, improving access to support and affordability of care.

In remote areas of Australia, for example, telephone-linked care [84] provided messages and reminders that were personalized according to individual self-management and clinical measures, all monitored through data entered in patients' smartphones. HbA1c values declined from 8.8% to 8.0% and were accompanied by improvements on quality-of-life indicators that exceeded those in a control condition. Medication costs were lower as well ($1542 versus $1821 on average). Users reported substantial social and emotional support; 79% strongly agreed that it gave them confidence to manage their diabetes better [85].

Online communities (e.g., forums, social media) are frequently consumer-driven networks whose purpose is to facilitate the exchange of peer support while providing linkages to health-care professionals [86]. These online communities can be responsive to the needs of their members, leading to high levels of satisfaction. One review concluded that computer-mediated environments enhance an individual's ability to interact with peers while increasing the convenience of obtaining personalized support [87]. The latest developments in mobile phone interventions (e.g., text messaging, mobile apps) can offer interactive features, monitoring tools, and personalized feedback to enhance the quality of peer support interactions [88].

A recent pilot test of a lay health coaching intervention was enhanced with a diabetes self-management application (BlueStar™) [89]. The intervention involved health coaches who provided telephone-based diabetes self-management

support and encouraged the routine use of BlueStar for day-to-day self-management tasks. Patient-generated data in BlueStar was shared with the health coaches and the care coordinators to guide highly personalized care. Both intervention components proactively engaged with participants to achieve high rates of retention and overall program satisfaction. Patients that participated in this intervention made behavior changes and experienced a significant drop in HbA1c. One finding from this project was the significant correlation between total entries in BlueStar and total coach contacts, which suggests complimentary roles between health coaching and the diabetes application.

High tech complements, but does not replace, the soft touch of PS. Offering both peer support and digital health can promote patient choice, depending on the support they need or prefer. Digital health technologies can address the routine tasks and monitoring needed for chronic disease self-management, leaving peer supporters to provide highly individualized support for more complex problems. These platforms can extend peer support to more people and integrate the efficiencies of high tech with the humanizing force of personal contact [90]. Investigators are particularly interested in integrating digital health technologies for peer supporters that have the capacity to generate actionable data; prompt timely, context-sensitive outreach; and guide decision-making [91]. Such programs may have the capacity to reach the entire populations while maximizing the efforts of peer supporters and clinical staff.

Peer Support and the Chronic Care Model

The Chronic Care Model (CCM) has become a major framework for the delivery of chronic care services and includes several components: (1) the organization of health care, (2) delivery system design, (3) decision support, (4) clinical information systems, (5) self- management support, and (5) community resources [92, 93]. In this way of thinking, it is important to change approaches to care to meaningfully respond the care needs of chronically ill patients [94]. If clinical teams are unable to transition from a view of care that centers exclusively around medical management to one that places an emphasis on the individual and self-management, the adoption and implementation of CCM will be modest.

The view that patients are central to their own care is the focus of most peer support (PS) interventions. PS can encourage individuals to fulfill an active role in care; provide clinical teams a practical, feasible way to support the patient's role and self-management; and reinforce the shift to care that is integrated around the individual. This effective role of PS can be applied for each of the CCM components. Whether as part of the clinical team or as a closely linked resource, developing PS services can include grounded representatives of communities who receive care from those service areas. Incorporating PS can sharpen the focus of the respective delivery system to one that is dedicated to patients' perspectives and concerns. Through frequent interaction with patients and by understanding their needs, PS can enrich the perspectives of other members of the clinical team, particularly in decision-making.

As detailed throughout this chapter, PS is a robust strategy for encouraging self- management and for supporting and sustaining that self-management over the many years that individuals live with chronic conditions. If PS is situated in community organizations or settings, it can provide organizational linkages between clinical care, providing information for patients and clinicians regarding available community resources. PS is frequently provided through community settings so that individuals experience education and ongoing support as part of the settings of their daily lives – churches, community centers, schools, playgrounds, and parks – rather than decontextualized in clinical settings.

Examples of Peer Support and the Chronic Care Model

One example of how the CCM can provide a platform for PS is a program of the Baylor Health Care System, the *Diabetes Equity Project*. This project used the CCM to integrate community health workers (CHWs) into primary care teams in order to address inequities in five community clinics serving low-income Latino adults with diabetes [58, 95]. As part of system redesign, CHWs were recruited from medical assistants, were trained in general peer support skills and diabetes-specific information, and were embedded within clinical teams. Although they were part of those clinical teams, they reported to an offsite nurse manager who coordinated their work. Development of the CHW role included taking on tasks from primary care providers as well as adding new tasks, as displayed in Fig. 11.2.

The combination of embedding CHWs within clinical teams, but having distinct, independent reporting relationships, as well as the task responsibilities, illustrates the complementarity of the PCP and CHW roles and the potential for synergistic collaboration between them. System redesign also included locating CHWs in the practice setting, facilitating regular and routine interactions, including as needed on-the-spot consultations in contrast to referrals with potential delays and often uncertain completion.

In addition to the Baylor Health Systems model, other programs have demonstrated ways that peer support can be integrated into health-care service delivery through the CCM. A review of primary care approaches to preventing chronic kidney disease identified a number of contributions

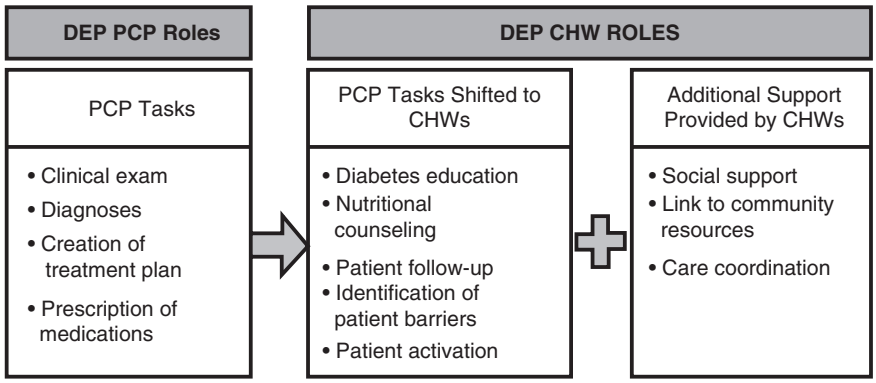

Fig. 11.2 Redesign of primary care in the Diabetes Equity Project (DEP): shifting of roles from primary care providers (PCPs) to community health workers (CHWs) (Modified from Collinsworth et al. [95])

of peer support into multidisciplinary teams to improve the health of ethnic/racial minority and low SES populations [96]. PS can deliver culturally competent education and facilitate the adoption of self-management skills to enhance treatment adherence. The review documented that PS, for those at risk for chronic kidney disease, improves blood pressure control, knowledge, self-management behaviors (e.g., appointment keeping), and appropriate utilization of health services.

A multifaceted intervention to test the CCM model for patients with macular degeneration focused on reorganization of care around trained Chronic Care Coaches (CCCs) [97, 98]. In participating clinical sites, the CCC was a practice assistant [98] trained to monitor the treatment, including telephone reminders, patient information, and direct self-management support. Patients were instructed in self-management by the CCCs, including patients' weekly self-administration of the Amsler test for monitoring vision and an action plan that helped them manage symptoms and estimate their severity and response strategies in the case of deterioration.

In rural areas of northern Australia, indigenous health workers were included in health-care teams to facilitate PCPs' and patients' mutual development of management action plans and manage the coordination of care [99]. Training content included chronic disease guidelines, education and engagement strategies, medication management, client self-management, care planning, care coordination, and work planning. Ongoing professional support for the indigenous workers included weekly reflective practice sessions by telephone with an indigenous clinical support team member, monthly video-linked meetings, and in-service training in a central location for 1 week every 6 months.

In an intervention to reduce coronary heart disease risk among African-Americans with hypertension, patients with well-controlled hypertension provided peer-based self-management support for reducing blood pressure and cardiovascular risk through three phone calls among six monthly contacts, with three staff visits on alternate months. The content of calls included healthy diet, exercise, medication adherence, and smoking cessation [100]. Another smoking cessation intervention employed nurses to provide initial education and counseling to hospitalized patients who, after discharge, received follow-up telephone counseling from a quitline counselor [101]. For those patients who were ambivalent about quitting, the counselor focused on increasing motivation to quit. For those patients who remained committed to quitting, the counselor focused on relapse prevention.

A comprehensive program in a Federally Qualified Health Center was developed for a population of mostly Latino adults with diabetes [102]. Assistance in daily management took place through a variety of activities that included the following: weekly breakfast club that included demonstration of cooking skills using healthy modifications of traditional Puerto Rican recipes; a weekly drop-in afternoon snack club in which patients were taught how to prepare healthy snacks and interact with other patients and staff to reinforce problem-solving and self-management skills; diabetes education classes; chronic disease self-management classes [103] facilitated by CHWs; daily, on-site exercise class; and bilingual/bicultural CHW services provided directly to patients. Additional services included home visiting, accompanying patients to their medical visits, and providing telephone and in-person counseling and support.

The CCM is also responsive to individuals' needs for social and emotional support in the management of chronic conditions. A widely recognized model for addressing psychological distress, depression, and other mental health problems within primary care is the Collaborative Care Model of Katon and colleagues [104]. This model provides an approach for integrating peer support as extenders of the care manager and health-care providers. One program used this model in New Orleans after Hurricane Katrina. A collaboration of professionals, community representatives, and CHWs developed a curriculum to train community-based CHWs in building awareness, screening, referral for collaborative care, and problem-solving interventions. Training included an overview of depression and PTSD, techniques for building trust with clients, instruction in use of depres-

sion screening tools, community resources for referring depressed patients, skills for problem-solving and behavioral activation, self-care for community health workers, and tools for tracking client services and outcomes ([105], p. S1–47).

Peer support has the capacity to effectively link clinical care and community resources, a key feature of the CCM. The earlier described program involving macular degeneration using Chronic Care Coaches included planning and arranging contact between patients and physicians and a monthly structured follow-up call with the patients [97, 98]. Similarly, the indigenous health workers in Australia were required to manage care coordination and provide advocacy to enhance access to medical, allied health, and community-based services [99]. In the program for Latino adults in Massachusetts [102], CHWs accompanied patients to their medical visits and contacted patients who had not been seen regularly in outpatient care. The review of CCM in primary care for preventing kidney disease noted several contributions of peer support to linkage to and coordination of care [96]. These included coordination of needed health-care services, minimizing barriers to care due to health beliefs and values, overcoming patient barriers (including lack of access to transportation), addressing health system barriers, and overcoming language and literacy barriers.

A project to improve pediatric asthma care through practice redesign that used the CCM included quarterly well-asthma visits, appropriate controller as well as responder medication, and attention to trigger exposure. CHWs were used for outreach and follow-up, encouraging engagement in care [106]. Similarly, the intervention for smoking cessation during hospital stays deployed quitline counselors to provide follow-up with primary care providers [101].

In addition to helping individuals identify and gain access to care, peer support also facilitates the relationships between individuals and their care providers. As noted in the model from the Baylor Health Care System, CHWs provided useful information to PCPs regarding their patients' needs; patients reported that the intervention had improved their relationships with those providers [95]. Similarly, in the intervention for African-American patients with hypertension [100], peer supporters left voicemail messages to clinical staff reporting concerns to be addressed in patients' clinical visits.

Cultural Considerations: The Example of China

Peer support (PS) programs need to account for, and respect, the social and cultural factors that impact the delivery of health care. An emphasis on the four key functions of PS, rather than a concrete product, has established a respect for indigenous preferences, as evidenced by the planning, development, and implementation of programs in China. In conjunction with leaders of the Chinese Diabetes Society and in health-care settings in several cities, over 600 program managers, clinicians, and diabetes educators have been trained to develop and implement programs [78]. Importantly, training includes ongoing consultation by conference call to facilitate coping with problems in developing and implementing PS programs. Formative and process outcomes have included over 35 programs being developed, the expansion of the section on patient education and management of the Chinese Diabetes Society, and a demonstration project of the Beijing Diabetes Prevention and Treatment Association that touches 50 hospitals and community health centers and over 5000 individuals with diabetes [78].

A demonstration project in community health centers in Anhui province set an adaptation model of PS in China [107]. The program trained adults with diabetes, most of whom were retired, to colead monthly informational and educational meetings with staff of community health centers. The peer leaders also led discussion groups that provided greater opportunity for participants to talk about self-management plans, obstacles encountered, and successes. The peer leaders also promoted informal groups within housing complexes such as for tai chi, morning walking, shopping, and even fishing. The program achieved significant benefits relative to controls ($ps < 0.05$) for knowledge, self-efficacy, body mass index, blood pressure, and both fasting and 2-h postprandial blood glucose [107].

The Shanghai Integration Model

The Shanghai Sixth People's Hospital (S6PH) has developed a robust version of the CCM that enhances care workflows and improves clinical outcomes through the integration of primary and specialty care for diabetes. In 2015, the Shanghai Municipal Government initiated a major project for diabetes as part of a 3-year action plan for strengthening the public health system in Shanghai. The major components of this 3-year plan are being rolled out through the Shanghai Integration Model (SIM), which includes a city-wide prevention and treatment center at the S6PH that can provide guidance to the project, training, and subspecialty treatment of difficult or intractable cases.

A key feature of the work in Shanghai is the training of professional staff regarding the peer support program and their roles in supporting it [105, 107]. Clinicians and professional staff have critical roles in collaborating with the peer supporters and in encouraging their patients to take full use of them [108]. The training of professional staff in Shanghai is based on experience in training over 500 nurses and physicians in developing peer support programs through training programs developed with the Chinese Diabetes Society and colleagues at Southeast University and Zhongda Hospital in Nanjing. Ongoing consultation with program managers by conference calls facilitates program develop-

ment [78, 109]. In current programs in Shanghai, peer supporters and CHC clinical staff are trained through both separate and joint sessions over a 2-day training period. As in the broader work in China, ongoing conference calls and group chats with clinical staff advise in program development and tailoring to the needs of individual health centers and their patients.

Organizational and Fiscal Approaches to Peer Support

The Affordable Care Act and associated health-care reform in the USA emphasize primary care and preventive services, effective chronic disease management, timely acute care, and evidence-based and cost-effective medical and surgical interventions. This transformational focus moves health-care service delivery away from a production-based approach to one that is grounded in value. The patient-centered medical home (PCMH) and PS as provided by community health workers and others will play critical roles in achieving this goal.

The organization of PS in the PCMH can begin with clinicians and team members identifying patients who may be well suited to providing PS. Care must be taken, though, to avoid focusing on model patients who may demonstrate the successful mastery of their medical conditions, rather than coping strategies that are most effective in promoting new behaviors [110] and with whom others can identify. Peer supporters may be organized within the PCMH through clinical teams and/or as extensions of care managers [108]. Another approach is to introduce them through group patient education programs [111] or through group medical visits. In a number of settings, peers use skills learned in training for the Chronic Disease Self-Management Program [112] to provide a number of other PS services. Another approach is for the PS program to be based in community settings but with close ties to clinical providers [113]. In New York, researchers and clinicians at Columbia University and NewYork-Presbyterian health system have developed a program that funds community-based organizations to offer PS services that are then coordinated with clinical care at the university health center [114]. Additional approaches to organizing PS through the PCMH may utilize telehealth and digital health methodologies, which were discussed in greater detail later in this chapter.

Financial models are critical to the sustained adoption of PS in the PCMH, and there is broad evidence for the cost-effectiveness of PS and several models for its financing [115]. Most notably, the Affordable Care Act (ACA) included a number of provisions for the reimbursement of PS (generally referred to as provided by "community health workers" (CHWs) in the ACA). The organizational framework includes the Health Home or Chronic Health Home [116] that provides financing for a variety of supportive services for those with two chronic conditions (or one with risk for a second) and/or a serious and persistent mental health problem. Many of the services outlined in the legislation can be carried out by peer supporters; however there is flexibility in how services can be organized, creating the opportunity for a variety of approaches and strategies in clinical and community settings.

The experience of PS projects in Mingo County, Georgia, provides important, preliminary information about such organizational frameworks [115]. One program was community based in a social service agency, while the other was sited in a health-care system. The former reached more people but with more modest average improvements in glucose control, while the clinic-based program reached fewer people but with greater average impacts. Clearly, the successful approach will depend on the objectives and strategies for the program and its role within the organizations or communities that host it.

Other approaches to PS fiscal models [108] include value-based reimbursement, in which clinical providers support PS services in order to enhance quality and reduce avoidable care and costs. The Centennial Care initiative is one example in New Mexico that utilizes capitated payments to stratify Medicaid beneficiaries into Level I (individuals with good to excellent health), Level II (those with long-term chronic disease or high-cost conditions), or Level III (those with very complex health needs such as multiple chronic conditions, high hospitalization rates, high prescription drug use rates, and high emergency department usage) [117]. Using an algorithm, PS services are tailored to each level and address health literacy and other barriers to care, such as navigating the health-care system, understanding the importance of medication adherence, and non-clinical support such as assistance with transportation or obtaining food stamps. The highest-need individuals receive intensive individualized patient support services. Per member per month costs ranged from $321 for those receiving the intensive intervention to $5.75 for Level I and II individuals receiving less intense, community-based services. The long-term savings have been significant with an estimated ROI for a 3-year program of 1.5:1.

Peer Support and the Health-Care Workforce

There is continuum of lay health advisors (LHAs) from natural helpers embedded in their communities to certified paraprofessionals [118]. At the informal end are LHAs who meet qualifications set by a community and have a reputation for good judgment, sound advice, and being discreet. The advantages for those at this end of the continuum include a community-based system of care and social support that com-

plements the more specialized functions of the health professionals [119]. At the other end of the continuum, paraprofessional LHAs can act as extenders of the service delivery system [118]. Although LHAs may benefit from stability provided by a health-care system's support and the linkage between community members and the formal system that peer supporters may provide, a disadvantage is that the accountability of the LHAs is shifted to the service delivery system [118].

Despite these differences, calls-to-action [120] and policy recommendations [40, 121] have repeatedly emphasized the importance of CHWs, LHAs, and other designations of peer supporters in chronic disease care. The World Health Organization's Global Health Workforce Alliance, for example, has emphasized the essential role of CHWs in health care and the need for stronger integration at local and national levels [122]. In the USA, key agencies such as the Centers for Disease Control and Prevention [123] and the Health Resources and Services Administration [124] encourage the adoption of CHW interventions to address some of the country's most pressing public health concerns. As noted earlier, the Affordable Care Act includes several provisions for supporting services of CHWs [125]. The challenge going forward lies in the implementation and integration of this workforce within health-care settings.

According to the US Bureau of Labor Statistics, there were roughly 52,000 people working as CHWs in 2016 [126]. Mental Health America estimates that there are over 24,000 mental health peer specialists in the USA [127]. For comparison, there were 649,300 social workers in the USA in 2014 [128]. The peer workforce is expanding annually, but without national directives and oversight, much of the work is left to the states and nonprofit organizations, with the exception of peer specialists employed through the Department of Veterans Affairs.

Formal training programs, such as degree-granting programs through post-secondary education, are gaining popularity as an approach to increasing the peer support workforce. Just as with other professionals and recognized members of the health-care team, credentialing of CHWs will enhance the recognition and legitimacy, not only of individuals credentialed but of the field itself and the services it encompasses. There are concerns with this emphasis, which include the importance of maintaining the "peerness" of those providing PS, and the flexibility in under-resourced organizations to recruit, deploy, and reimburse for this service. Furthermore, individuals that volunteer or work part-time may face challenges in gaining and maintaining credentials, barriers that can limit PS to those at the professionalized end of the PS continuum. The Peers for Progress program has proposed model guidelines for accrediting PS programs as a complement to individual credentialing [129]. The guidelines note that programs should be able to document the quality of their training, supervision, and services and then access financial support for those services, without individuals working in the programs having to achieve certification or licensing. Additionally, the credentialing of programs can promote high-quality implementation, deployment, and integration of PS that credentialing of individuals cannot provide. The Council on Accreditation of Peer Recovery Support Services has already begun to pursue program accreditation on a national level [130]. These types of structures are needed to ensure that organizations have the flexibility to employ a range of peer supporters and the ability to deploy them effectively.

This approach to credentialing both peer supporters and peer support programs is being developed in North Carolina (NC). A NC Community Health Worker (CHW) Initiative coordinated through the NC Department of Health and Human Services includes CHWs, as well as a range of stakeholders from across the state. It is exploring the competencies, training, and certification of individual CHWs and of CHW programs. To that end, the group has developed recommendations that outline a broad set of roles, specific competencies, and a certification process that lays the foundation for both types of certification [131]. The intent of the NC CHW Initiative is to create a sustainable infrastructure that supports CHW efforts within health-care teams and other organizations to address the needs of all – especially of underserved populations – and to decrease costs and improve outcomes.

Final Comments

The evidence base of peer support (PS) clearly demonstrates its efficacy in chronic illness care, and emerging research shows that PS is broadly feasible and sustainable. This chapter has pointed to ways that would support the broad dissemination of PS, factors key to its success, and strategies in which it can make a difference in achieving value-based health care. Future directions need to address how to tailor PS to different problems, populations, and settings, what organizational and management structures it requires, and how to pay for it [115]. The fundamental importance of social connections in human behavior and health and the bulk of evidence on PS make it clear that the contributions can be substantial.

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Government Agencies and Community-Based Organizations

12

Sherry S. Hay

Introduction

The number of Americans living with chronic disease, which is both preventable and associated with high costs of care, continues to increase. Individuals with high social needs and multiple chronic conditions (MCCs) represent approximately 20% of this population but generate 80% of overall healthcare costs [1]. The Centers for Disease Control and Prevention reported that in 2012, almost half of US adults—117 million people—had at least one chronic health condition, and more than 50% of these individuals had an MCC, which is defined as 2 or more chronic conditions [2]. This prevalence had markedly risen from 2010, per the Agency for HealthCare Research and Quality, which reported that the percentage of the US population living with MCCs was 31.5% [3]. Although there may be differences in case identification across the 2010 and 2012 studies, it is clear that the number of individuals with MCC is increasing as Americans live longer.

Approximately 71% of all US healthcare spending goes to caring for individuals living with MCCs [3]. The cost of care increases proportionally with the number of chronic conditions, straining the budgets of consumers, health insurance carriers, and healthcare systems [3]. In addition to addressing patients' medical needs, there is growing awareness that social determinants exert a powerful influence on individual health. Social determinants of health are the physical and social factors in the larger environment where people live, learn, play, pray, and work [4]. These factors include areas such as availability of healthy food, adequate housing, exposure to crime, and air quality, all which impact individual health and quality of life.

Community-level factors are part of the fabric of patient lives. Social scientists may describe communities based on social norms or shared connections, while epidemiologists, in contrast, could view communities as groups of individuals over time with a shared disease state such as diabetes. Each understanding of community has a place in considering how an individual is able to manage their chronic disease and to what extent social determinants impact health and healthcare. Most people receive care from a primary care physician about two times a year [5], and the average time for an outpatient visit is 18.5 min [6]. In consequence, most patients and caregivers spend more time where they live, work, pray, and play rather than in healthcare settings, and an understanding of governmental agencies and community-based organizations is critical to the provision of individual patient care and population health.

There is growing evidence pointing to government agencies and community organizations as key resources in effective chronic disease management. The chronic care model has identified partnerships with community resources, the mobilization of these resources, and advocating for policy change as key domains in providing high-quality chronic disease care [7]. In addition, the patient-centered medical home model is characterized by the delivery of personalized care from an interdisciplinary team that is under the direction of the patient's personal physician. The interdisciplinary team consists of a number of health professionals, including social workers and pharmacists, who work in partnership with the patient and provider to address the patient's medical and social needs [8, 9].

This chapter is an introduction to government agencies and community organizations that interface with chronic illness care. The first section provides some background to governmental agencies and voluntary organizations that have promoted the advancement of care for chronically ill patients. This section is followed by an inventory of specific federal and state agencies and community-based organizations and resources. An approach to identifying and engaging with community organizations is described in the subsequent section before the chapter closes with strategies and models for healthcare practices that are considering linkages with these organizations.

S.S. Hay (✉)
UNC of Family Medicine, Community Health Initiatives, Chapel Hill, NC, USA
e-mail: Shay@med.unc.edu

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Overview to Government and Community Organizations

For many years in the USA, the focus of public health, biomedical research, and healthcare delivery stakeholders was on treating acute, largely infectious diseases, rather than on chronic disease and health promotion. The shift to an emphasis on chronic disease and health promotion was the result of several influences converging over time: a decline in the infectious disease death rate due to vaccinations and effective antimicrobial therapies, an aging population, increased healthcare expenditures, a decline in the birthrate, and emerging evidence that behavioral risk factors play a role in disease onset [10].

Both government and community-based institutions and organizations have changed in response to this refocus on chronic disease and health promotion. The US Public Health Service (PHS) was established in 1887 and was primarily missioned to address the prevention of infectious disease. Organizationally, the PHS remained a division in the Department of Health, Education, and Welfare in the 1950s, and it remained there until the early 1980s. Since that time it has been a unit within the Department of Health and Human Services (HHS) and includes eight divisions and three human service agencies. Today the primary responsibility of the PHS is on coordinating the work of other federal agencies with a mission of helping to prevent chronic disease [10].

In addition to federal and state agencies, a number of private organizations have promoted the advancement of chronic disease prevention and health promotion. The American Cancer Society, American Lung Association, and the American Heart Association, for example, have worked with the US Department of Health and Human Services to develop and disseminate health information to the public [10]. For example, in 1971 these partners designed and distributed antismoking public service announcements and advocated for the ban on cigarette advertising in television and radio [10]. In response to the evidence that documented the hazards of secondhand smoke, these organizations supported the 1988 Department of Transportation's regulation that eliminated smoking on all domestic flights of less than 2 h [10].

Several philanthropies, such as the Henry J. Kaiser Foundation, Robert Wood Johnson Foundation, and the Commonwealth Fund, have used their resources to promote advancements in chronic illness care. The Commonwealth Fund, for example, seeks to be a catalyst for change by identifying promising practices and contributing to solutions to promote a high-performing health system in the USA. The Fund has supported independent research that focuses on improving healthcare practice and policy [11] and, over the past 10 years, has expended more than $345 million to advance this mission.

In addition to organizations, individuals can play an important role in supporting patients who live with chronic disease. Peer support is an evidence-based approach to cost-effective care for people living with chronic disease. This strategy is individualized to a person's care and includes offering emotional support, home visiting, and personal care services [12]. Peer supporters generally live in the community where they often share ethnicity, language, and socioeconomic status with the mentees they serve [13]. These individuals can be volunteers or paid members of a care team and may be designated in a variety of ways: community health workers, promotores de salud, lay health advisors, health coaches, patient navigators, and doulas [14].

The Patient Protection and Affordable Care Act acknowledged the importance of peer support by including community health workers as integral members in an evolving healthcare system [15]. Legislation also earmarked funding to support this type of care model, especially among vulnerable populations [16]. Identifying resources for individuals who are living with complex medical and social needs can be challenging since services are available through a variety of organizations at the federal, state, and local levels.

Government Agencies

US Department of Health and Human Services (HHS)

The US Department of Health and Human Services (HHS) was officially established as a separate agency in May 1980 [17]. It became the principal governmental agency in the USA charged with protecting the health of all Americans and providing essential human services [18]. HHS, as required by law, develops a strategic plan every 4 years for how it will address the health issues facing the nation [18]. Its mission is fulfilled through the provision of effective health and human services and by fostering sound, sustained advances in the sciences underlying medicine, public health, and social services [19].

HHS's top leadership position, the secretary, is nominated by the president and then voted on by Congress. The secretary oversees all of the divisions within HHS, several of which interface with chronic illness care. There are 11 operating divisions that include 8 agencies in the US Public Health Service and 3 human service agencies that administer a wide variety of health and human services and that fund and conduct biomedical and health services research. The 11 HHS operating divisions include Administration for Children and Families (ACF), Administration for Community Living (ACL), Agency for Healthcare Research and Quality (AHRQ), Agency for

Toxic Substances and Disease Registry (ATSDR), Centers for Disease Control and Prevention (CDC), the Centers for Medicare and Medicaid Services (CMS), Food and Drug Administration (FDA), Health Resources and Services Administration (HRSA), Indian Health Service (IHS), National Institutes of Health (NIH), and Substance Abuse and Mental Health Services Administration (SAMHSA) [20]. HHS is responsible for almost 25% of all federal outlays and administers more grant dollars than all other federal agencies combined [18].

Centers for Medicare and Medicaid Services (CMS)

The Centers for Medicare and Medicaid Services (CMS) is the federal agency that is responsible for administering Medicaid, Medicare, Children's Health Insurance Program (CHIP), and the Health Insurance Marketplace [21]. Individuals must apply and meet certain eligibility guidelines to qualify for benefits or financial support for Medicaid, CHIP, and the Health Insurance Marketplace. Medicare is a health insurance program available to individuals who are 65 or older or who are under 65 with certain disabilities or people of any age with end-stage renal disease [22]. There are three parts to the Medicare benefit: hospital insurance (Part A), medical insurance (Part B), and a drug benefit (Part D). Part A covers inpatient costs, skilled nursing, hospice, and some home health costs, while Part B will cover outpatient physician costs, some occupational and physical therapy, and some home health that Part A does not cover. Part D is provided by private companies and individuals may pay a penalty if they do not enroll [22].

The benefits for Medicaid and CHIP can vary between the states although there are defined, mandatory Medicaid services that all states are required to cover [23]. Medicaid provides health coverage to low-income adults, children, pregnant women, elderly adults, and people with disabilities. Medicaid is administered by states, according to federal requirements [24] and the program is funded jointly by states and the federal government. States can elect to cover optional benefits, such as dental care, under their Medicaid program, if approved by their legislature and outlined in their state Medicaid plans.

An important set of services for children is Early, Periodic, Diagnosis, and Screening (EPSDT), which was enacted into law in 1967 in response to high rejection rates for new military draftees who had untreated childhood illness [24]. The goal of EPSDT is the early identification of conditions that could impede a child's growth and development and the service package for children and includes coverage for comprehensive health and developmental assessments, vision, hearing, and dental services [25].

Program for All-Inclusive Care for the Elderly (PACE)

The Program for All-Inclusive Care for the Elderly, or PACE, is a Medicare and Medicaid program that helps older adults, who would otherwise qualify for nursing home care, to stay and receive healthcare in community-based settings. PACE organizations provide care and services in the home, the community, and the PACE center and contract with many healthcare service providers, such as physicians, allied health, and hospice care [26]. PACE organizations are required to meet state and federal safety requirements and are reimbursed via capitation for the total care that they provide [26].

Home and Community-Based Services (HCBS)

Home and community-based services (HCBS) provide options for Medicaid beneficiaries to receive services in their own home or community settings rather than in institution, such as assisted living facilities and nursing homes. These programs serve a variety of Medicaid recipients with special needs, such as intellectual, developmental, or physical disabilities and/or mental illness. HCBS first became available in 1983 when Congress added section 1915(c) to the Social Security Act giving states the authority to request a waiver of Medicaid rules governing institutional care [27]. Later in 2005, HCBS became a formal Medicaid State Plan option. Today 47 states and the District of Columbia operate at least one 1915(c) waiver.

Lead agencies and other service providers are responsible for HCBS care. A lead agency, such as a county's department of human and social services, acts as the primary care coordinator for a defined area. Service providers contract with the lead agency in their area to provide services [28]. HCBS are usually organized within Departments of Health and Human Services, and programs can offer any or all services from the categories [28]. Table 12.1 lists an inventory of health services and human services that are often provided through HCBS.

HCBS programs provide many benefits to both individuals and communities; however, there are several challenges with administering this type of program, which are listed in Table 12.2.

Centers for Disease Control and Prevention (CDC)

The Centers for Disease Control and Prevention (CDC) was established in 1946 as the communicable disease center that arose from the work of the Malaria Control in War Areas (MCWA). The mission of CDC is to create expertise, information, and tools that people and communities need to protect their health [29]. Figure 12.1 below depicts the CDC's chronic disease prevention system.

Table 12.1 Health and human services provided through home and community-based services [28]

Health services	Human services
• Home healthcare, such as – Skilled nursing care – Therapies: occupational, speech, and physical – Dietary management by registered dietician – Pharmacy • Durable medical equipment • Case management • Personal care • Caregiver and client training • Health promotion and disease prevention • Hospice care (comfort care for patients likely to die from their medical conditions)	• Senior centers • Adult day cares • Congregate meal sites • Home-delivered meal programs • Personal care (dressing, bathing, toileting, eating, transferring to or from a bed or chair, etc.) • Transportation and access • Home repairs and modifications • Home safety assessments • Homemaker and chore services • Information and referral services • Financial services • Legal services, such as help preparing a will • Telephone reassurance

Table 12.2 Benefits and challenges of home and community-based services [28]

Benefits	Challenges
• Cost-effectiveness: usually less than half the cost of residential care • Culturally responsive: spiritual and cultural activities and support available • Familiarity: patient enjoys the comfort of their own home or small residential facility in the community • Can provide counseling or clergy to assist with bereavement • Some waivers permit family members to be paid caregivers	• Access to providers • Availability of qualified caregivers • Caregiver burnout • Lack of 24/7 medical professional availability • Nonfamily caregivers may have limited access in remote locations, especially during winter • Potential cultural bias or barriers in the acuity assessment process • Skilled nursing care includes only medical services performed by a registered nurse. Other daily tasks fall primarily to family members • Those needing care do not always want family members to act as their caregivers due to potential for abuse or financial manipulation • Tribes need to complete processes that are often long and complex, such as creating an elder abuse code or establishing a memorandum of understanding with the state, to create an HCBS program

The Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) is a division of the CDC that supports a variety of activities that improve the nation's health by preventing chronic diseases and their risk factors. Program activities include one or more major functions: supporting states' implementation of public health programs; public health surveillance; translation research; health communication; and developing tools and resources for stakeholders at the national, state, and community levels [30]. The center works with partners to strengthen health for states, tribes, localities, and territories through four primary strategies:

- *Tracking* chronic diseases and risk factors through surveys and research
- *Improving* environments to make it easier for people to make healthy choices
- *Strengthening* healthcare systems to deliver prevention services that keep people well and diagnose diseases early [30]
- *Connecting* clinical services to community programs that help people prevent and manage their chronic diseases and conditions [30]

Administration on Aging (AoA)

The Administration on Aging (AoA) is the federal agency responsible for implementing provisions of the Older Americans Act of 1965. The Act empowers the federal government to distribute funds to states for supportive services for individuals over the age of 60. The AoA provides services and programs designed to help older adults live independently in their homes and communities [31]. There are several divisions within the AoA:

Office of Supportive and Caregiver Services provides home and community-based services to millions of older persons through the programs funded under the AoA. Services provided include transportation, adult day care, caregiver supports, and health promotion programs [31].

Office of Nutrition and Health Promotion Programs manages health, prevention, and wellness programs for older adults, including behavioral health, chronic disease self-management education programs, diabetes self-management, disease prevention and health promotion services, falls prevention programs, HIV/AIDS education, nutrition services, and oral health promotion [31].

Office of Elder Justice and Adult Protective Services manages programs specific to elder abuse prevention, legal assistance development, and pension counseling. It also leads the development and implementation of comprehensive Adult Protective Services systems that provide a coordinated response to adult victims of abuse and to prevent abuse [31]. This unit also develops standards to improve delivery and effectiveness of these types of services and provides support for the Elder Justice Coordinating Council.

Office for American Indian, Alaska Natives and Native Hawaiian Programs administers programs for the provision of nutrition and supportive services for Native Americans (American Indians, Alaska Natives, and Native Hawaiians), as well as caregiver support services.

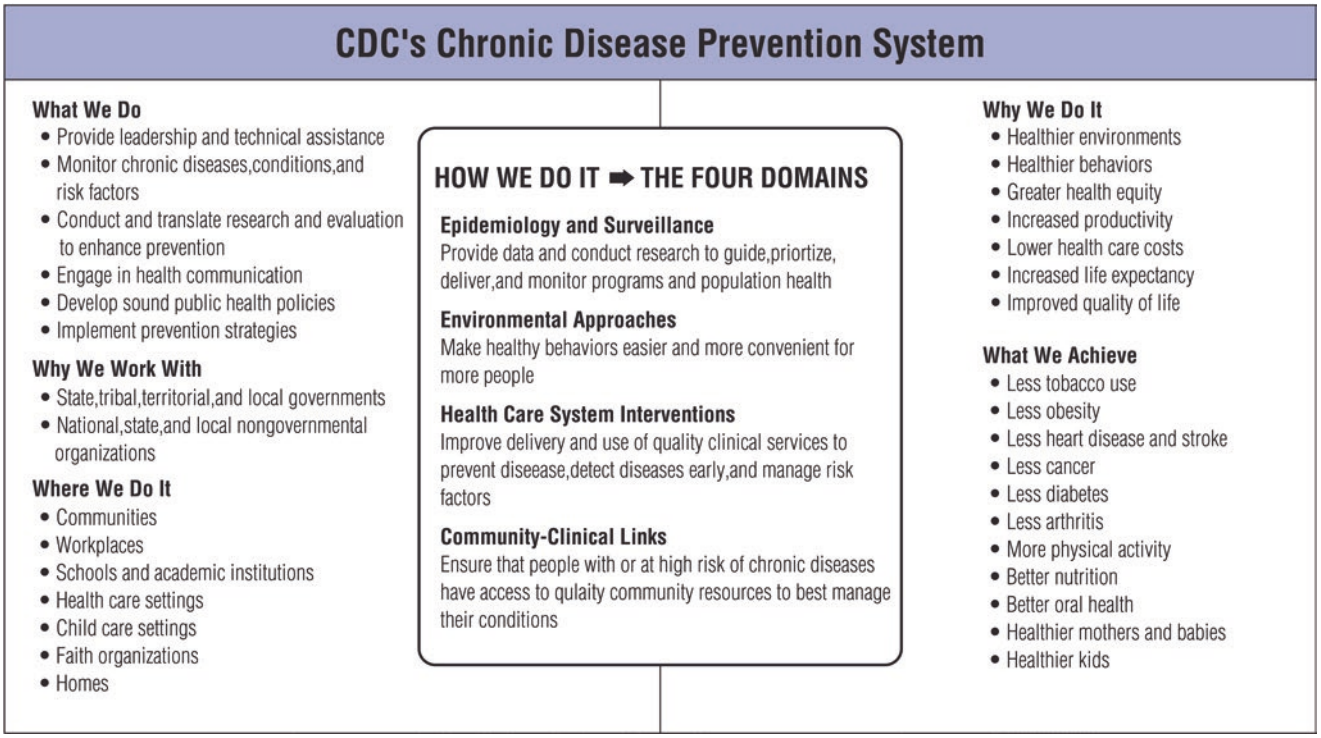

Fig. 12.1 CDC's chronic disease prevention system

Eligible [31] tribal organizations are eligible for grants that support home and community-based services for their elders, including nutrition services and support for family and informal caregivers.

Office of the Long-term Care Ombudsman Programs began as a demonstration program in 1972 and now operates in all states, the District of Columbia, Puerto Rico, and Guam [31]. Each state has an Office of the State Long-Term Care Ombudsman, headed by a full-time state ombudsman. As part of statewide programs, thousands of local ombudsman staff and volunteers assist residents in long-term care and their families by providing a voice for this vulnerable population.

Administration for Children and Families (ACF)

The Administration for Children and Families (ACF) was established in 1991 and aims to promote the economic and social well-being of families and children through funding, training, and technical support [32]. ACF programs have several aims: (1) to empower families and individuals to increase their economic independence and productivity; (2) to encourage strong communities that have a positive impact on quality of life and the development of children; (3) to create partnerships with service providers in order to identify and implement solutions that transcend traditional program boundaries; (4) to improve access to services through planning, reform, and integration; and (5) to address the needs, strengths, and capacities of vulnerable populations, such as people with developmental disabilities, refugees, and migrants [33].

There are 13 programs administered by the division, which are organized around specific areas, such as early childhood development, adolescent pregnancy prevention, and childcare [34]. For example, Head Start is an ACF childcare service that collaborates with childcare centers and in-home childcare in local communities to provide free learning and development services to children and pregnant women from low-income families [35]. Candidates for these services apply to a Head Start or Early Head Start program in their community, where the local program determines eligibility.

There are resources for adults within family households, such as family violence prevention, adoption, and Temporary Assistance for Needy Families (TANF). TANF is designed to help low-income families achieve self-sufficiency [36]. TANF can provide monthly cash assistance payments to low-income families with children, as well as a wide range of services that align with TANF's four broad purposes [37]: work, education, training activities, and childcare.

Health Resources and Services Administration (HRSA)

The Health Resources and Services Administration (HRSA) is the primary federal agency for improving health and achieving health equity through access to quality services, a skilled health workforce, and innovative programs [37].

HRSA's programs provide healthcare to people who are geographically isolated and economically or medically vulnerable, which includes people living with HIV/AIDS, pregnant women, mothers, and their families, and those in need of high-quality primary healthcare [37]. HRSA also supports the training of health professionals, the distribution of providers to workforce shortage areas, and improvements in healthcare delivery.

There are five bureaus in HRSA. The Bureau of Health Workforce administers programs to strengthen the healthcare workforce and to connect skilled professionals to rural, urban, and tribal underserved communities nationwide [38]. The Bureau of Primary Health Care oversees the Health Center Program, which is comprised of a national network of community health centers that provide healthcare services to economically challenged patients. The Healthcare Systems Bureau focuses on protecting the public health and improving the health of individuals, including solid organ, bone marrow, and cord blood transplantation; poison control center services; countermeasure and vaccine injury compensation; Hansen's disease direct patient care, provider education, and research; the Medical Claims Review Panel; and the 340B Drug Pricing Program [38].

The HIV/AIDS Bureau is responsible for the Ryan White HIV/AIDS Program, which provides a comprehensive system of care for people living with HIV [38]. The Program works with cities, states, and local community-based organizations to support HIV treatment services. The Maternal and Child Health Bureau's (MCHB) programs serve more than 50 million women, children, and families each year, including half of all pregnant women and one-third of all infants and children in the USA [38]. MCHB provides Title V block grants to states to help focus on six focus areas: maternal/women, child, adolescent/young adult, perinatal/infant, children with special healthcare needs, and a cross-cutting life course [39].

Substance Abuse and Mental Health Services Administration (SAMHSA)

The Substance Abuse and Mental Health Services Administration (SAMHSA) is the federal agency that leads public health efforts to promote the behavioral health of the nation. SAMHSA's mission is to reduce the impact of substance abuse and mental illness on America's communities [40]. SAMHSA's initiatives seek to (1) inform the behavioral health field with data from national surveys and surveillance; (2) build public awareness of the importance of behavioral health; (3) support innovation and practice improvement by evaluating and disseminating evidence-based, promising behavioral health practices and engaging in activities that support behavioral health system transformation; (4) collect best practices and develop expertise around prevention and treatment for people with mental illness and addictions; and (5) assist local entities build and improve system capacity by encouraging innovation, supporting more efficient approaches, and utilizing evidence-based programs and services.

US Department of Agriculture (USDA)

The Food and Nutrition Service (FNS) is an agency of the US Department of Agriculture's (USDA) Food, Nutrition, and Consumer Services. FNS is committed to ensuring access to healthy and safe food, especially expecting mothers, infants and children in childcare and school, low-income families going to food banks, local farmers' markets, and local supermarkets [41]. FNS addresses hunger and obesity through the administration of 15 federal nutrition assistance programs including WIC, Supplemental Nutrition Assistance Program (SNAP), and school meals [41]. In partnership with state governments, these programs work with public, private, and nonprofit partners, to increase food security and reduce hunger by providing children and low-income people access to food, a healthful diet, and nutrition [41].

Supplemental Nutrition Assistance Program (SNAP)

SNAP is the largest program in the federal hunger safety net and offers nutrition assistance to millions of eligible, low-income individuals and families [42]. FNS works with state agencies, nutrition educators, and neighborhood and faith-based organizations to ensure that those eligible for nutrition assistance can make informed decisions about applying for the program and can access benefits. To receive SNAP benefits, households must meet certain tests, including resource and income tests [43]. FNS also works with state partners and the retail community to improve program administration and ensure program integrity.

Special Supplemental Nutrition Program for Women, Infants, and Children (WIC)

The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) provides federal funding to states for supplemental foods, healthcare referrals, and nutrition education for low-income pregnant, breastfeeding, and non-breastfeeding postpartum women and to infants and children up to age 5 who are at nutritional risk [44]. The program is administered through the Food and Nutrition Service (FNS) of the US Department of Agriculture and is not an entitlement program, but a federal grant program which Congress authorizes a specific amount of funds each year for the program [45]. WIC is organized through 90 WIC state agencies, with approximately 47,000 authorized retailers.

Child Nutrition Programs

FNS also administers several programs that provide healthy food to children, including the National School Lunch Program, School Breakfast Program, Child and Adult Care Food Program, Summer Food Service Program, Fresh Fruit and Vegetable Program, and Special Milk Program [46]. These programs are administered by state agencies and target hunger and obesity by reimbursing organizations such as schools, childcare centers, and after-school programs for providing healthy meals to children [46].

State and Local Health Agencies

The organization and governance models of state public health agencies are variable and can either be an independent agency or a unit of a larger agency [47]. Local health departments are units led by local governments, which make most of the programmatic and fiscal decisions. In a mixed model, some local health departments are led by state government and some are led by local government; no one arrangement predominates. A central model subsumes all local health departments as units of state government.

State health agencies often assume programmatic and fiscal responsibility for a variety of federal initiatives, many of which were described earlier [47]. These agencies often provide technical assistance to a variety of partners in different areas, most commonly on quality improvement, performance, and accreditation [47]. For example, nearly all state health agencies provide training to local health agencies on disease prevention and tobacco control. The majority of state health agencies engage in activities to promote access to healthcare, particularly health disparities and minority health initiatives and rural health, and also report providing financial support to primary care providers.

There are a number of services related to population-based primary prevention, screening, and treatment of diseases and conditions that are provided by state agencies. Most of these services are tied to tobacco, HIV, and sexually transmitted disease counseling [47]. State health agencies provide variety of functions related to surveillance, data collection, and laboratory functions, primarily in the areas of bioterror agent testing, foodborne illness testing, and influenza typing [47].

Nongovernment Organizations

American Heart Association (AHA)

The American Heart Association (AHA) was founded in 1924 by six cardiologists and is the nations' oldest voluntary organization fighting heart disease and stroke [48]. The organization funds research, advocates for stronger public health policies, and provides tools and information for professionals and consumers. The AHA provides public health education as the nation's leader in CPR education training and promotes the importance of healthy lifestyle choices. For clinicians, the AHA provides evidence-based treatment guidelines to help them care for their patients. At the policy level, the AHA educates lawmakers, policymakers, and the public for changes to protect and improve the health. The AHA has a large grant portfolio and has funded more than $3.8 billion in heart disease and stroke research, more than any organization outside the federal government [48].

American Cancer Society (ACS)

The American Cancer Society (ACS) is a nationwide, community-based voluntary health organization dedicated to eliminating cancer [49]. The ACS is engaged in many areas that are focused on cancer: (1) encouraging prevention; (2) providing support for cancer patients and caregivers; (3) funding and conducting lifesaving research to better understand, prevent, and find cures for cancer; (4) working with policymakers and lawmakers to promote cancer care; and (5) promoting access to cancer care for millions of underinsured and uninsured Americans and supporting multicultural communities to help reduce the risk of cancer. The ACS has a local presence in over 5000 communities, and regional and local offices are organized to engage communities in their work, delivering potentially lifesaving programs and services and raising money at the local level [50].

American Diabetes Association (ADA)

The American Diabetes Association (ADA) is an organization comprised of volunteers, health professionals, and staff that leads the fight against the deadly consequences of diabetes and advocates for those affected by diabetes [51]. The ADA funds research to prevent, cure, and manage diabetes, provides services to hundreds of communities, and disseminates health information. In addition to 76 offices across the USA, there are online resources that support the clinical practice and patient education [51].

Legal Aid

Legal Services Corporation (LSC) is an independent nonprofit established by Congress in 1974 to provide financial support for civil legal aid to low-income Americans [52]. LSC promotes and provides funding to 134 independent

nonprofit legal aid programs in every state, the District of Columbia, and US territories and serves thousands of low-income individuals, children, families, seniors, and veterans in every congressional district [52]. LSC is a grant-making organization and awards grants through a competitive process and currently funds 134 independent legal aid organizations.

LSC grantees handle the basic civil legal needs of the poor, addressing matters involving safety, subsistence, and family stability [52]. Most legal aid practices are focused on family law, including domestic violence and child support and custody, and on housing matters, including evictions and foreclosures. LSC ensures grantee compliance with statutory and regulatory requirements, and with sound financial management practices, LSC conducts regular on-site fiscal and programmatic compliance reviews and investigations. LSC also assesses the quality of legal services its grantees deliver and provides training and technical assistance to them.

Legal aid services are provided through a variety of public law firms and/or community legal clinics. In addition to legal aid services in the community, medical-legal aid partnerships are available in many states. The mission of the partnerships is to improve the health and well-being of people in communities by leading health, public health, and legal sectors in an integrated, upstream approach to combating health-harming social conditions [53]. The partnership embeds lawyers and/or paralegals in healthcare settings who work as an extension of the care team to (1) train healthcare teams in identifying health-harming social conditions, (2) assist patients in addressing the identified social issues which range from triage and consultations to legal representation, (3) transform clinic practice and institutional policies to better respond to patients' health-harming social conditions, and (4) prevent health-harming social conditions broadly by detecting patterns and improving policies and regulations that have an impact on population health [54].

United Way

The United Way is a worldwide nonprofit organization that is focused on creating community-based and community-led solutions that strengthen the cornerstones for a good quality of life: education, financial stability, and health [55]. It is a coalition of public and non-for-profit partners who identify and resolve issues facing communities and has 1200 local offices located throughout the USA. Much of United Way's work is in triaging individuals to local resources, particularly in the areas of education, financial stability, and health. In the area of health, the United Way promotes healthy eating and physical activity, expanding access to quality healthcare and integrating health for all people [55].

Identifying and Engaging with Community Organizations

As noted earlier, both the chronic care and patient-centered medical home models have identified partnerships with community resources as a key domain in providing high-quality chronic disease care [56]. The movement to patient-centered medical homes and team-based care extends the healthcare reach, and an approach is to take advantage of incorporating services through government and community organizations. There is a continuum of engagement that healthcare providers may have with community organizations. This can range from an awareness of these organizations' services and capacities to variable degrees of engagement (e.g., referral for services) and to full healthcare-community partnerships that address population health needs.

There are two approaches that healthcare providers and practices can undertake as they consider engaging with community partners. The first approach begins with an understanding and description of the patient population (e.g., demographics and disease burden) of interest in the practice. Many electronic medical records have developed capacities to aggregate patient population-based specified parameters (e.g., patients with diabetes), which can guide candidate community organizations. Once this population is identified, one to two community organizations or government agencies—whose work is aligned with the respective patient population—are identified to explore resources that these organizations can provide, such as funding to design and implement interventions aimed at impacting the patient population. In many areas, for example, a first point of contact would be the director of the local health department. Another option would be an organization which serves as a central triage point to local resources and serves every demographic in the community, such as the United Way.

Once identified, clinical stakeholders should reach out and connect with organizational stakeholders to learn about their identified needs, local resources, and existing coalitions. The focus of initial meetings should be on determining mission concordance of the respective organizations and relationship building. Once these critical tasks have been achieved, move to identifying a specific project that has a high likelihood of success. Use this project as a pilot work to develop and test governance, communication, and resource allocation for larger partnership with the respective organizations.

The second approach involves participating in existing local health coalitions and/or advisory boards as a way to engage with community organizations. Table 12.3 outlines principles of community engagement, which were developed by the CDC Task Force on Community Engagement within the Agency for Toxic Substances and Disease Registry [57].

Table 12.3 Principles of community engagement [58]

Principle	Key elements
Set goals	• Clarify the purposes/goals of the engagement effort • Specify populations and/or communities
Study community	• Economic conditions • Political structures • Norms and values • Demographic trends • History • Experience with engagement efforts • Perceptions of those initiating the engagement activities
Build trust	• Establish relationships • Work with the formal and informal leadership • Seek commitment from community organizations and leaders • Create processes for mobilizing the community
Encourage self-determination	• Community self-determination is the responsibility and right of all people • No external entity should assume that it can bestow on a community the power to act in its own self-interest
Establish partnerships	• Equitable partnerships are necessary for success
Respect diversity	• Utilize multiple engagement strategies • Explicitly recognize cultural influences
Identify community assets and develop capacity	• View community structures as resources for change and action • Provide experts and resources to assist with analysis, decision-making, and action • Provide support to develop leadership training, meeting facilitation, skill building
Release control to the community	• Include as many elements of a community as possible • Adapt to meet changing needs and growth
Make a long-term commitment	• Recognize different stages of development and provide ongoing technical assistance

Sustaining Community-Healthcare Partnerships

Once a partnership has been established with a community-based organization, there are several strategies that healthcare systems and practices can use for sustaining linkages with these organizations.

- *Create a community resource station in the practice*: Secure space in the practice and designate as a community resource area for patients [59]. The area would have health information in the form of posters, brochures, or videos on disease self-management, as well as community-based resources and contact information for respective agencies. Some areas would have a dedicated phone that links directly to an agency or a computer for Internet searches [59]. A staff person from the practice would be designated to keep information in this area up to date [59].
- *Colocate community resource staff in the practice:* Have dedicated practice space to house staff from community organizations [59]. The space can be shared with other resources (e.g., care manager) in the practice and can include a rotation of community staff from a range of services [59], such as legal aid through a medical-legal partnership, Medicaid assistance services through a local department of social services worker, or nutrition services by a medical nutrition therapist employed by the local health department. Seek to integrate the community resource staff as a member of the practice staff by incorporating in staff meetings.
- *Include as part of care management services:* Care management services are increasing in clinical practice settings and can be provided by individuals, such as social workers or nurses, or through a team approach. These services usually include comprehensive care planning, accessing community resources, and coordinating care. Care managers can also help keep resource directories current for the practice whether they are electronic, "hard copy," or embedded in the clinic electronic health record.
- *Create a resource directory*: Map out existing resources through community agencies (e.g., United Way as a central triage agency) [59] or local hospital/healthcare system for existing resource lists. Add resources to the directory based on the needs of the clinic population [60] and organize based on type of assistance needed, such as chronic disease, financial, or transportation. Designate a staff person [59] to add eligibility information, costs, referral process, and other pertinent information to the directory.
- *Build functionality in the electronic health record (EHR)*: Work with health information technology to gain an understanding of the practice's EHR functionality and capacity for building resource directories, making electronic referrals, and longitudinal care planning. These functionalities would ideally include fields that capture community resources and services that have been provided to patients. Also, it is important to think about how these resources will be updated and refreshed in the EHR.
- *Evaluate the system*: Create evaluation systems that can collect, analyze, and report process and outcome data. Candidate measures include feedback from staff and families [59] on the functionality of the community-healthcare

partnership, health indices (e.g., hemoglobin A1c for diabetic patients), and healthcare utilization (e.g., hospitalization rates). Data collection systems can be implemented in electronic surveys via email [59] or through staff or patient meetings. In addition, patient advisory boards can provide feedback from the larger practice patient population.

Community-Based Partnership Models

The ARCHES project and community-centered health home model are representative of community-based partnerships with healthcare providers.

ARCHES Project

The ARCHES project is a collaborative of clinical and community stakeholders in the Philadelphia area who have partnered to improve the health and well-being of individuals living in Philadelphia [57]. The collaborative works together to identify and address community health needs around six common themes: access and advocacy; research and evaluation; community partnership; health education, screening, and prevention; educations of health providers and students; and service delivery systems innovation. A key to their success is collaboration—identifying health needs and interventions within the group rather than meeting to review and approve a predetermined intervention [57]. This collaborative has fostered several community programs aimed at managing chronic disease, which are displayed in Table 12.4 and provide a description of each of the ARCHES projects, partners, outcomes, and funding sources [57].

Community-Centered Health Homes

Community-centered health home (CCHH) is a model that was developed at the Prevention Institute [60] and seeks to bridge community prevention and health service delivery. The model is rooted in finding solutions for improving health of people in local communities as well as healthcare systems, while providing individual patient care. Clinicians are trained to collect data, diagnose a problem, and develop a treatment plan for individual patients. CCHH has parallel activities, which are termed inquiry, analysis, and action [60]. The inquiry step is collecting data on prevalence of disease and other social and economic factors in the community. The analysis step involves setting priorities and strategies with community partners, while the action step involves both implementing coordinated strategies and making policy change for better health in the community [60].

This process is fueled by innovative leadership, diverse staff, and staff education in the clinic. Leadership creates a culture of innovation and continual quality improvement while providing staff with the tools and resources it needs to understand and work with patients to improve the adverse impacts of social determinants on health [60]. The diversity of staff speaks to the need of having the right mix of skills within the clinic to meet the needs of the community. Strategies for identifying and convening partners outside of the clinic walls will also be key. The Prevention Institute has created an interactive tool, the Collaboration Multiplier, which can be used to identify and engage with community partners [61].

A case study of the model is St. John's Well Child and Family Center in California. Clinicians at St. John's noticed a growing number of patients coming to the clinic with lead poisoning, cockroaches in the ears, and rodent bites [60]. The staff identified a potential association of these findings with area housing, and a patient survey was conducted which included questions about housing [60]. This data provided the foundation for a partnership between the clinic and housing and human rights organizations to develop a strategic plan to improve local housing conditions. An evaluation of this intervention showed both improved housing and health outcomes [60].

Future Directions

Chronic disease management has been difficult for many reasons: the lack of integrating clinical care and preventative services, the degree to which social determinants adversely impact health, and the increased number of Americans who are aging and living with chronic disease. In recent years, there have been new ways of thinking about care delivery models that are incorporating government and community-based organizations. Innovations in care delivery models are now being seen in healthcare reimbursement, as evidenced by CMS and private foundations supporting pilot payment models for healthcare services which include chronic disease management [62]. For example, the rise of Accountable Care Organizations (ACO), which seeks to provide coordinated, high-quality care to a defined population of Medicare patients, offers a glimpse to how local, organized networks of healthcare providers and community-based organizations may manage the care of populations.

As ACO models continue, there will be ongoing incentives to connect with community partners who have different and complementary expertise and resources in managing the health and social needs of individuals. There are opportunities and challenges with building capacity to engage with community partnerships. The opportunities lie in breaking down the silos that exist between the delivery of preventive and clinical care services and developing

Table 12.4 ARCHES community-based partnerships for improving chronic disease

Program	Community partners	Description	Outcomes	Funding sources
JeffHOPE	Salvation Army Resources for Human Development Prevention Point Acts of the Apostles II Bethesda Project	• Jefferson Medical Student outreach program [9] • Provides free healthcare, health education, and social advocacy to medically underserved individuals	• 2000 visits per year • Screened 300 men for CV disease [10], colorectal cancer, prostate cancer, and hepatitis C	• Student fundraising • TJUH contribution • American Assoc. of Medical Colleges • Caring Community Grants • TJUH Women's Board • Civic Foundation
Wellness Center	Project H.O.M.E. Wellness Center Ridge Avenue Business Association Women Against Abuse Pro-Act Council for Relationships	• Primary medical care, behavioral healthcare, nutrition education, rehabilitative services, case management, and peer-led health promotion • Direct linkage to supportive housing, neighborhood-based affordable housing, economic development, access to employment opportunities, adult and youth education	• 800 visits/year • Implementation of diabetes registry	• Independence Blue Cross Foundation • Medicaid managed care
Pathways to Housing	Pathways to Housing-PA	• Housing First model which ends chronic homelessness for individuals with serious mental illness [10] • Scattered-site permanent supportive housing • Trans-disciplinary care management team [10] • Novel integrated care program through a unique partnership with the DFCM	• Chronic disease registry [10] • Ongoing tracking of standard health indicators • Integrated health record • Medication management and e-prescribing • On-site adult vaccines	• Housing: Philadelphia Office of Supportive Housing • Intensive care management: Philadelphia Department of Behavioral health
Center for Refugee Health	Nationalities Service Center (NSC) Lutheran Family and Children's Services Hebrew Immigrant Aid Society	• Partnership facilitates communication between the resettlement agencies and DFCM to assist refugees navigate through the healthcare system (labs, imaging, specialists, pharmacies, etc.)	• Since 2009, more than 700 refugees have received comprehensive screening and follow-up at DFCM	• Barra Foundation • Pennsylvania Refugee Coordination Center
SHAPE-IT (Stroke, Hypertension, and Prostate Evaluation and Intervention Team)	DFCM Center for Urban Health Philadelphia Department of Health Health Promotion Council Community Partners	• Reduce the incidence of stroke and morbidity and mortality from prostate cancer high-risk AA men • Development of Project Advisory Council (PAC)	• Screening/education for 7019 men in high-risk zip codes • Targeted population linked to primary care services	• Pennsylvania Department of Health

effective, long-term solutions for improving the health of people living with chronic disease. The challenge is that this work will not be easy, requiring time, resources, and expertise. Yet a future direction that is characterized by capacity building and collaboration will create and sustain community partnerships which jointly define health issues, connect interventions, advocate for policy change, and provide healthcare solutions for everyone.

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Part III

Providing Chronic Illness Care

Screening for Chronic Disease

13

Alexander Kaysin and Margaret L. Gourlay

Introduction

Screening is defined as the early diagnosis of presymptomatic disease among well individuals in the general population [1]. The goal of screening is to identify individuals without recognized symptoms of the target condition, in whom early intervention can produce meaningful long-term health benefits. Screening is a form of prevention that is frequently misunderstood and misused, even among knowledgeable clinicians and health policy experts. Primary care practitioners benefit from understanding the history, general tenets, and challenges of screening.

History of Screening

In 1968, Wilson and Jungner published a World Health Organization monograph summarizing ten principles for evaluation of screening programs [2]. This includes the principle that screening must address an important health problem with a significant burden on public health. Other principles include an understanding of the natural history of the disease being targeted by screening and a recognizable latent or preclinical stage to the disease. There must also be an acceptable test with adequate sensitivity, specificity, and predictive value, and the benefits of the screening test must exceed the harms. There must also be an acceptable and effective treatment. Lastly, the screening program must be cost-effective.

By the 1980s, the practice of screening was increasing, despite the lack of evidence-based standards. In 1984, the US Preventive Services Task Force (USPSTF) developed a standard approach for developing clinical practice guidelines for screening and other preventive interventions in primary care, based upon rigorous systematic reviews of original research using a formal evidence grading system [3]. Because of its rigorous evidence standards exercised by an independent panel of preventive medicine and primary care experts, the USPSTF is a trusted and respected source of clinical practice recommendations.

By the late 2010s, overuse of and overdiagnosis from screening, especially in the USA, led experts in the field to propose new evidence criteria for evaluating screening programs. A focus on high-value strategies for which benefits clearly justify the harms and costs of screening was encouraged along with a call for population-based, longer-term health outcome studies [4, 5]. The conceptualization of value focuses on accurate classification of disease risk and weighing the benefits and harms of screening. Highly sensitive tests can lead to potential harms from overdiagnosis of clinically unimportant conditions, so increased test sensitivity does not imply a better screening test in the new schematic.

Rational use of screening remains a challenge in the current setting of wide availability of a growing number of screening tests in the setting of conflicting screening recommendations from numerous public and private organizations. Longitudinal studies of common cancer screening tests have documented common misbeliefs about screening that promote overdiagnosis and overtreatment in the USA [5–7]. Misunderstandings often occur because of overestimation of potential benefits and confusion over or disregard of potential harms of screening. At the same time, underuse of screening occurs in underserved populations with higher baseline risk for disease than higher-income individuals with better access to care. US clinicians must substantially improve their efforts to provide high-value and cost-effective screening targeted to populations with a level of disease risk where benefits are likely to outweigh harms.

A. Kaysin (✉) • M.L. Gourlay
Department of Family Medicine, University of North Carolina, Chapel Hill, NC, USA
e-mail: alexander_kaysin@med.unc.edu

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Screening Concerns

Overdiagnosis and Overtreatment

Given the frequency of screening overuse in the USA, overdiagnosis and overtreatment are key concerns. Overdiagnosis occurs when earlier diagnosis (due to screening) compared with later diagnosis (due to clinical detection) leads to increased labeling, diagnostic evaluation, or treatment that has potential adverse effects on health [8]. To illustrate this concept, consider tumor B in Fig. 13.1 in which there are multiple opportunities for detection by screening, even though its natural course does not lead to the patient's death (e.g., slow-growing prostate cancers). This is in contrast to tumor D which is a more aggressive cancer that goes undetected despite screening. An example of overdiagnosis in breast cancer screening is seen in a large prospective cohort study from Denmark, which examined the effect of screening on the incidence of advanced invasive breast cancer over a three decade period [10]. The findings show no significant change in the incidence of advanced tumors in screen-eligible versus screen-ineligible populations of women but a substantial increase in the detection of non-advanced tumors and ductal carcinoma in situ, which have a much lower risk of causing metastatic disease. The authors note that one in every three breast tumors detected in women aged 50–69 was probably overdiagnosed, suggesting that the benefits of some widely accepted cancer screening programs may be overstated. The women diagnosed with these less aggressive tumors were likely subjected to overtreatment, with little to no benefit derived from intervention as these overdiagnosed conditions would likely remain stable.

Low-Value Screening

Screening is a double-edged sword and potentially harmful if implemented in a misguided manner. Figure 13.2 demonstrates how screening initiates a cascade of events which can

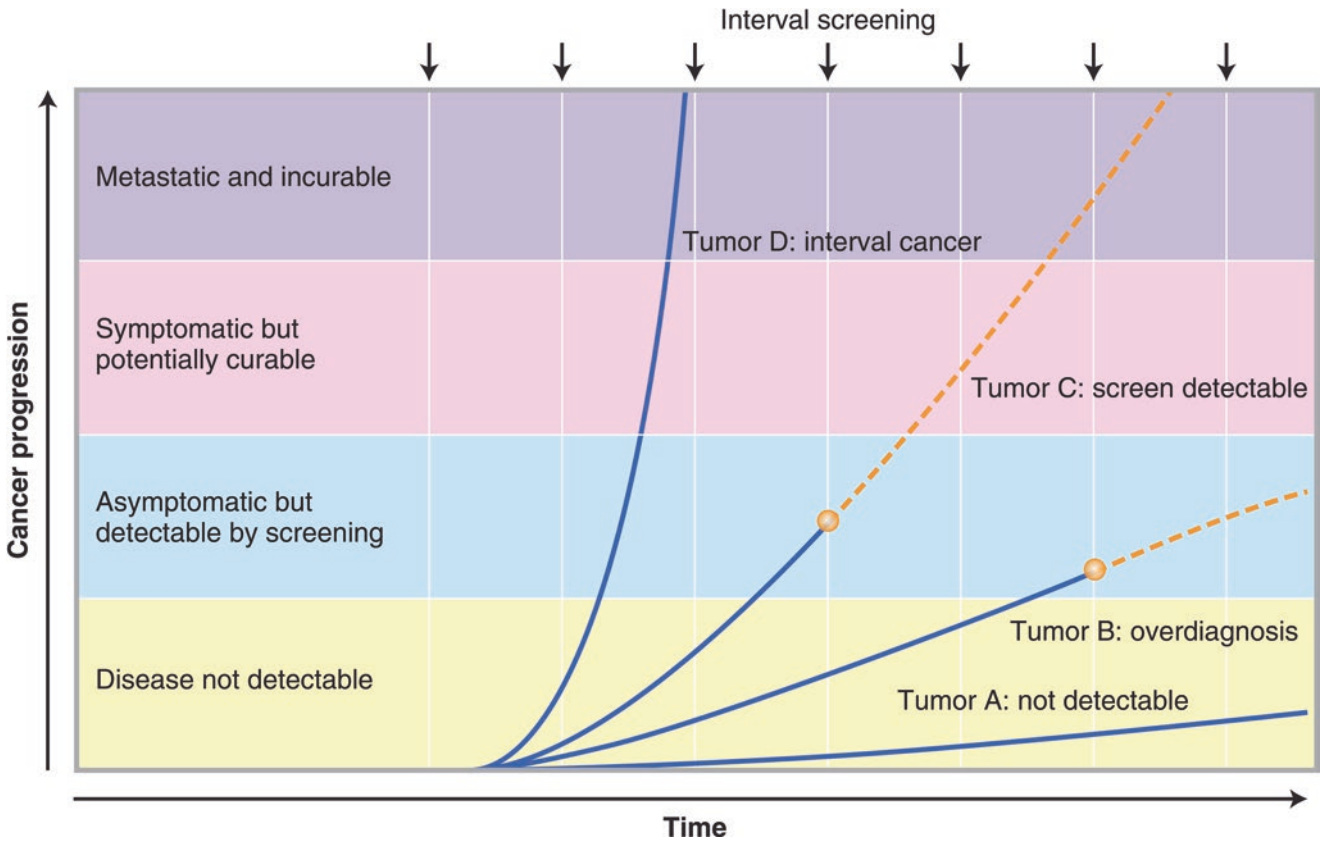

Fig. 13.1 Overdiagnosis in cancer screening. In this hypothetical example, the probability of detecting disease is related to the growth rate of each tumor. *Tumor A* remains microscopic and undetectable with the current screening test. *Tumor B* eventually becomes detectable by screening (*orange circles*), but its growth rate is so slow that it will not cause symptoms during the life of the individual; its detection will result in overdiagnosis. *Tumor C* (the only cancer with potential to benefit from screening in this example) is capable of metastasizing, but it grows slowly enough that it can be detected by screening (*orange circles*); for some, this early detection will result in survival. *Tumor D* grows very quickly and therefore is usually not detected by screening. This will present in the interval between screening examinations and has a poor prognosis. Red dashed lines represent the natural history of these tumors in the absence of detection by screening (Modified from Gates [9])

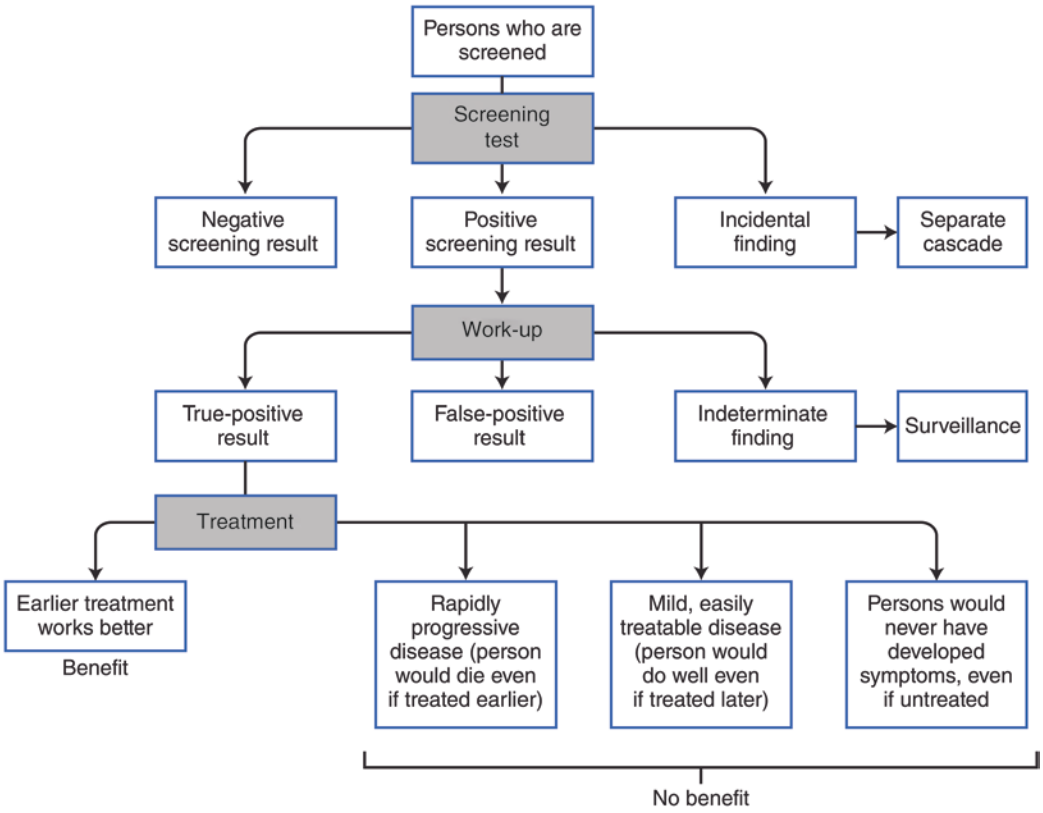

Fig. 13.2 Screening cascade (Modified from Harris et al. [11])

lead to benefit from earlier detection and treatment of a disease or to less desirable outcomes such as false-positive results with resultant potentially harmful or expensive diagnostic procedures, detection and intervention for diseases with no effective treatments, or finding conditions which would never lead to symptomatic disease (overdiagnosis) [11].

High-intensity screening involves testing a broad population more frequently or with more sensitive tests [11]. Such undertakings must take into account potential benefits (morbidity and mortality reduction) as well as harms (adverse events associated with diagnostic procedures, anxiety from false-positive results, overdiagnosis, and cost) [4, 11]. Examples of high-intensity screening in the USA are common and do not always follow these tenets. For example, one in five women aged 30–39 were advised by a physician to obtain a screening mammogram and of these women, as many as one in three underwent mammography, despite the fact that this is not a recommended screening test in this younger age group [12]. Similarly, one in three primary care clinicians include MRI and ultrasound in addition to mammography for routine breast cancer screening, despite recommendations to the contrary and the significant expense this imposes on the healthcare system [13]. To optimize value, clinicians must optimize screening intensity, benefits, harms, and costs [4].

Potential harms of screening are often poorly studied and inappropriately downplayed in discussions with patients. Because physiological and psychological harms can be inflicted upon an otherwise healthy individual, screening should never be undertaken unless adequate quality evidence supports the notion that benefits outweigh harms [14]. Potential harms are an essential discussion point during counseling regarding screening, especially in younger individuals who benefit less from screening or with elderly patients who have a higher risk of complications and lower likelihood of benefit due to shorter life expectancy. For instance, survival data from population-based randomized controlled trials of breast and colorectal cancer (CRC) screening clearly demonstrate that the time lag to benefit from screening in achieving a 1 in 1000 mortality reduction (screened versus unscreened cohorts) is 10.3 years for CRC and 10.7 years for breast cancer [15]. In other words, patients undergoing CRC and breast cancer screening must live for 10.3 and 10.7 years, respectively, in order to expect a 1 in 1000 chance of benefitting from the given screening tests.

Implementation of a Screening Program

A screening program may be considered if adequate and consistent evidence supports, with at least moderate certainty, that the benefits of screening outweigh potential harms [16]. Many detectable conditions are not amenable to screening due to failure of this criterion. For example, although selective screening may be considered in high-risk patients, pancreatic cancer is not amenable to mass screening in the general population because of very low disease prevalence, increased risk of harms due to limited accuracy of available screening tests, invasive diagnostic tests, and generally poor outcomes of treatment [17].

Screening almost always occurs in primary care practices. Specialists may order the same tests, but usually not for the purpose of screening. For example, dual-energy X-ray absorptiometry (DXA) bone density testing is used both for screening and diagnosis of osteoporosis, which is the condition of very low bone density that predisposes patients to increased fracture risk. While primary care clinicians use DXA in asymptomatic patients with average baseline risk of fracture in order to diagnosis early osteoporosis, subspecialists are likely to use DXA to monitor bone density loss in patients who use oral glucocorticoids, have rheumatoid arthritis, or had a prior hip fracture. These latter patients are at higher baseline risk of fracture, and these uses of DXA are not screening but rather methods of disease surveillance.

Evidence Base for Screening Policy

Experimental (RCTs) Versus Observational Evidence

A variety of study designs provide evidence to support (or not support) routine screening. Multiple high-quality population-based longitudinal studies of screening tests that demonstrate mortality reduction and/or disease incidence reduction can strengthen the evidence base for clinical recommendations. High-quality randomized controlled trials (RCTs) are valuable to demonstrate proof of screening efficacy. Due to the length, ethical considerations, large size, and difficulty of high-quality execution, RCTs may not be available, especially during early implementation of a screening test. When RCTs are not available, the USPSTF states that multiple large, well-conducted observational studies with consistent results showing a large effect size that does not change markedly with adjustment for potential known confounders may be judged sufficient to determine the magnitude of benefit and harm of a preventive service [18].

Perhaps the best example of an effective and successful screening program predominantly based on observational evidence is cervical cancer screening. The Papanicolaou (Pap) test for precancerous cervical cell abnormalities reduces cervical cancer and cervical cancer mortality in multiple large observational studies worldwide [19, 20]. Once the leading cause of cancer deaths among women in the USA, cervical cancer now ranks 14th with the decrease attributed to early detection, mass screening, and treatment programs [19]. Based on the amount and consistency of the evidence supporting net benefits, the USPSTF considers routine cervical cancer screening in women aged 21–65 years to be supported by Grade A evidence with a high degree of certainty [21].

Early in the course of a screening program, operational characteristics such as age to start, screening interval, and age to stop are not specified. These parameters are not easily studied in a randomized controlled trial because they would require an unfeasibly large number of trial arms for fair comparison. Instead, longitudinal secondary analyses of data may help inform such screening decisions. In the absence of independent studies on these topics, the USPSTF commonly uses statistical modeling with decision analysis on pooled data from individual trials with adequate quality to estimate age ranges and intervals for screening [18].

US Preventive Services Task Force Evidence Grades

Based on the consistency, quality, and quantity of published evidence, the USPSTF assigns an evidence grade to summarize the benefits versus harms of a screening program or other preventive services. The grades range from *A* for a recommended service with high certainty that the net benefit is substantial to *D* for moderate or high certainty that the service has no net benefit or that the harms outweigh the benefits or *I* indicating that evidence is insufficient to assess the balance of benefits and harm (Table 13.1) [23]. Clinicians can utilize a point-of-care mobile decision tool on their computer or smartphone by downloading the USPSTF electronic preventive services selector app at http://epss.ahrq.gov/PDA/index.jsp [24].

Table 13.1 US Preventive Services Task Force (USPSTF) grading criteria for strength of recommendation

Grade	Definition	Suggestion for Practice
A	The USPSTF recommends the service. There is high certainty that the net benefit is substantial.	Offer or provide this service.
B	The USPSTF recommends the service. There is high certainty that the net benefit is substantial.	Offer or provide this service.
C	The USPSTF recommends selectively offering or providing this service to individual patients based on professional judgment and patient preferences. There is at least moderate certainty that the net benefit is small.	Offer or provide this service for selected patients depending on individual circumstances.
D	The USPSTF recommends against the service. There is moderate or high certainty that the service has no net benefit or that the harms outweigh the benefits.	Discourage the use of this service.
I Statement	The USPSTF concludes that the current evidence is insufficient to assess the balance of benefits and harms of the service. Evidence is lacking, of poor quality, or conflicting, and the balance of benefits and harms cannot be determined.	Read the clinical considerations section of USPSTF Recommendation Statement. If the service is offered, patients should understand the uncertainty about the balance of benefits and harms.

Source: U.S. Preventive Services Task Force. Grade definitions after July 2012 [22]

Counseling Patients Regarding Screening for Chronic Illness

A 2008 analysis of National Ambulatory Medical Care Survey data reported that between 1997 and 2005, the number of clinical items addressed per primary care clinical visit increased from 5.4 to 7.1, while visit duration increased from 18 to 21 min [25]. It is estimated that 7.4 h per working day would be needed solely for preventative services counseling and coordination for a primary care physician to fully satisfy all USPSTF recommendations for an average patient panel [26]. This estimate is conservative given that new preventive care recommendations have been added since the release of that analysis. With substantial time pressure and the competing demands of acute and inpatient care, clinicians must continually weigh the opportunity costs (cost of foregone alternatives) and appropriate timing of discussions regarding screening. Systems can expand and improve patient decision-making by shifting much of this work away from the clinician and onto a multidisciplinary team of nurse educators and/or community health workers. To maximize the value and efficiency of discussions of screening with patients, providers should follow these guidelines:

Emphasize Screening Tests with USPSTF A and B Evidence Grades

The USPSTF is a trusted and respected source of clinical practice recommendations that are based on rigorous reviews of the evidence by a panel of preventive medicine and primary care experts.

Explain Age-Appropriate Benefits and Harms of Screening

A discussion of appropriate versus inappropriate screening can help curtail requests for testing among patients who are least likely to derive benefit and more likely to be harmed. The likelihood of net harms is higher for younger patients (due to lower prevalence and incidence of symptomatic disease) and older patients (due to lower life expectancy and increased risk of harms from screening and diagnostic procedures or treatment). For patients with average risk of disease and a limited expected remaining life span, screening discussions should focus on whether screening will make any difference or whether it may even shorten survival. In older individuals with serious comorbid illnesses, clinicians often forget to end habitual screening. For example, a sizeable proportion of patients with advanced cancer receive routine screening tests, despite a low likelihood of meaningful benefit [27]. Older adults need a 5- to 10-year life expectancy to have at least a small probability of survival benefit from screening programs such as breast and colorectal cancer screening, and the probability of benefit is considerably greater if life expectancy is longer than 10 years [15, 28]. Although life expectancy is difficult to predict accurately, several publicly available tools can prognosticate the patient's likelihood of reaching a certain age [29–31].

Providers should follow the recommendations from the USPSTF and other organizations regarding the starting and stopping ages and intervals for screening. If the patient insists on testing outside the recommended demographic and medical risk groups, the provider should elicit the patient's beliefs about screening and engage in an informed and culturally appropriate discussion of harms versus benefits. With tact and respect, the clinician can help dispel or reframe any popular myths and erroneous beliefs regarding screening.

Choose the Best Test for Screening

Many conditions have several options for screening, which vary in the degree of technical difficulty, duration, expense, and inconvenience to the patient. For example, patients may prefer fecal occult blood (FOBT) or fecal immunochemical tests (FIT) for colorectal cancer screening after hearing that 2 additional deaths are averted, but 4 to 5 additional complications are caused per 1000 screened by colonoscopy compared to FOBT or FIT (Table 13.2). Practical challenges such as inability to complete the colonic prep for a colonoscopy or insurance coverage may also influence a patient's choice of testing.

Individual Considerations

A strong family history of a detectable and treatable disease warrants consideration of selective screening on an earlier or more frequent schedule (greater intensity of screening). American Cancer Society guidelines on breast cancer screening suggest consideration of breast MRI and/or tomosynthesis when a woman's lifetime risk of breast cancer exceeds 20–25% and there is a strong family history of breast and/or ovarian cancer or in women who received treatment for Hodgkin disease [32]. However, the use of risk calculators is problematic in that available tools have significant discrepancies in whom they identify as high risk, are largely based on modeling studies, and are usually proposed for clinical use before they have been validated prospectively [33]. It is therefore important for the clinician and patient to discuss the limits of risk estimates rather than automatically initiating higher intensity screening protocols based on insufficient evidence [34].

Table 13.2 Screening for colorectal cancer (CRC): USPSTF recommendation statement of benefits vs harms[a]

Screening method and frequency	CRC deaths averted per 1000 screened	Complications per 1000 screened[b]
Flexible sigmoidoscopy every 5 years	20 (17–21)	10 (9–12)
FIT-DNA every 3 years	20 (19–22)	9 (9–10)
FIT every year	22 (20–23)	10 (10–11)
High-sensitivity gFOBT every year	22 (20–23)	11 (11–11)
CT colonography every 5 years	22 (20–24)	10 (10–11)
Flexible sigmoidoscopy every 10 years plus FIT every year	23 (22–24)	11 (11–12)
FIT-DNA every year	23 (22–24)	12 (12–13)
Colonoscopy every 10 years	24 (22–24)	15 (14–15)

Adapted from Bibbins-Domingo et al. [37]

CT computed tomography, *FIT* fecal immunochemical test, *FIT-DNA* multitargeted DNA stool test, *gFOBT* guaiac-based fecal occult blood test, *USPSTF* US Preventive Services Task Force, *CRC* colorectal cancer

[a]Models present median (low-high) estimates for benefits and harms

[b]Complications defined as gastrointestinal and cardiovascular events from screening and follow-up testing

Examples of Screening for Cancer

Using evidence drawn primarily from the most recent systematic reviews prepared by the USPSTF, screening considerations for four common cancers are discussed below.

Screening for Breast Cancer

Mammography is used to screen for breast cancer based on RCT data (USPSTF Grade B) [35].

Conventional mammography is given a Grade C, while ultrasonography, digital breast tomosynthesis, breast MRI, and other adjunctive tests are Grade I in the 40–49-year age group [36].

Potential Benefits

The USPSTF concludes that based upon available RCT evidence, there is moderate certainty (see Table 13.3 for details on the USPSTF levels of certainty) that the benefit of breast cancer screening among women 40–49 years is small. Potential benefits include a mortality reduction of 3 per 10,000 over a 10-year period compared to 8 per 10,000 in the 50–59-year age group [35]. Older women in the 60–69-year range have a mortality reduction of 21 per 10,000. Screening women aged 50–74 earns a Grade B recommendation. The actual time period to realize these mortality benefits requires at least 10 and preferably 15–20 years of longitudinal study [4, 15].

Potential Harms

Among the more serious consequences of breast cancer screening include overdiagnosis and overtreatment, which involves the treatment of tumors that would never result in invasive disease or directly cause mortality. Beginning mammography screening at a younger age and screening more frequently (i.e., increased screening intensity) increase the risk of overdiagnosis and overtreatment. Data from RCTs indicate that 19% of breast cancers are overdiagnosed over a 10-year period, an estimate that is likely low given enhanced sensitivity of modern digital mammography techniques and lack of inclusion of ductal carcinoma in situ (DCIS), which now accounts for one in four diagnosed cases of breast cancer [35]. By definition, DCIS is confined to the mammary-lobular system and is thus noninvasive. The natural history of screen-detected DCIS is poorly understood making it difficult to ascribe a mortality benefit to the treatment of DCIS given that a significant proportion of these cases do not progress to invasive cancer [35, 38]. Another issue that deserves discussion with patients is the lifetime attributable risk of breast cancer as a result of radiation directly from mammography, which is estimated to be 4 per 10,000 if biennial screening is initiated at age 40 [35].

False-positive results with associated biopsies, anxiety, and time away from work and family are other associated disadvantages. False-positive rates are highest for younger women aged 40–49 (121 per 1000 women) compared to 93 per 1000 among women aged 50–59, which continues to decline up to age 90 [39].

Individual Considerations

Five to ten percent of women with a first-degree relative (sister or mother) affected by breast cancer develop breast cancer themselves. For these women, informed discussion and shared decision-making is encouraged beginning at age 40 [36, 39]. The clinician can estimate the individual breast cancer risk using a breast cancer prediction model available through the National Cancer Institute (NCI) at https://www.cancer.gov/bcrisktool/Default.aspx [40]. For example, a 47-year-old asymptomatic woman with no prior history of breast disease but whose mother was diagnosed with breast cancer at age 60 has a 5-year risk of 1.2% and lifetime risk of 11%, compared to the average 5-year risk of 1% and lifetime risk of 9.3% with matching demographics but no history of maternal breast cancer. The NCI breast cancer prediction tool only applies to average-risk women, not women with a strong family history of early-onset or BRCA-1-associated breast cancer. Recommendations for screening high-risk women such as those with a higher likelihood of genetic mutations predisposing to breast cancer may warrant individualized approaches to screening compared to average-risk women [32].

Clinicians must consider other individual characteristics when discussing screening. Weight gain (regardless of absolute BMI), presence of diabetes mellitus, and history of menopausal hormone therapy for women older than 60 or after 10 years of menopause onset are all independently and significantly associated with increased risk of breast cancer among postmenopausal women [41–43]. Assessment and management of these associated health conditions can decrease the risk of breast cancer independently from screening.

Screening for Colon Cancer

Both invasive and noninvasive methods of colorectal cancer (CRC) screening have been developed and widely implemented. Table 13.3 lists these screening modalities along with their benefits and harms. The outcomes were derived from modeling studies that estimate deaths averted and complications caused by each modality of colorectal cancer screening per 1000 average-risk people screened. The modeling studies assume routine screening between the ages of 50 and 75 with follow-up continuing throughout an individual's remaining life span [37]. Other tests with significantly less supporting evidence include double-contrast barium enema, computed tomography colonography, magnetic resonance colonography, and capsule endoscopy. These tests are not recommended by the USPSTF and should not be routinely offered based on current (early 2017) evidence [37]. Because of the limited number and quality of head-to-head comparative trials among screening strategies, the USPSTF does not recommend one test over another. It encourages informed decision-making about a screening strategy that would most likely result in completion and better acceptance for the patient. Clinicians should adequately address cost and insurance coverage issues for colonoscopy and flexible sigmoidoscopy including time requirements for colon prep and recovery.

Table 13.3 US Preventive Services Task Force (USPSTF) levels of certainty regarding net benefit

Level of certainty	Description
High	The available evidence usually includes consistent results from well-designed, well-conducted studies in representative primary care populations. These studies assess the effects of the preventive service on health outcomes. This conclusion is therefore unlikely to be strongly affected by the results of future studies
Moderate	The available evidence is sufficient to determine the effects of the preventive service on health outcomes, but confidence in the estimate is constrained by such factors as:
	The number, size, or quality of individual studies
	Inconsistency of findings across individual studies
	Limited generalizability of findings to routine primary care practice
	Lack of coherence in the chain of evidence
	As more information becomes available, the magnitude or direction of the observed effect could change, and this change may be large enough to alter the conclusion
Low	The available evidence is insufficient to assess effects on health outcomes. Evidence is insufficient because of:
	The limited number or size of studies
	Important flaws in study design or methods
	Inconsistency of findings across individual studies
	Gaps in the chain of evidence
	Findings not generalizable to routine primary care practice
	Lack of information on important health outcomes
	More information may allow estimation of effects on health outcomes

Source: U.S. Preventive Services Task Force. Grade definitions after July 2012 [22]

The USPSTF defines certainty as "likelihood that the USPSTF assessment of the net benefit of a preventive service is correct." The net benefit is defined as benefit minus harm of the preventive service as implemented in a general, primary care population. The USPSTF assigns a certainty level based on the nature of the overall evidence available to assess the net benefit of a preventive service

Potential Benefits

In 2016, new CRC diagnosis is estimated to impact 134,000 persons in the USA and cause 49,000 deaths (median age 68) [44]. Based on RCT data and observational studies, the USPSTF concludes with high certainty that screening reduces colorectal cancer mortality in individuals aged 50–75 years (Grade A). For individuals aged 76–85, there is moderate certainty of only a small benefit, especially of first-time screening compared to previously screened, among individuals without comorbidities that significantly limit life expectancy (Grade C). Regardless of the method, CRC screening has not been shown to lower all-cause mortality [37].

Potential Harms

Table 13.2 describes the estimated harms from screening individuals aged 50–75 years based on the screening method used. In all methods, problems associated with colonoscopy represent the primary source of complications given that a positive noninvasive test will need to be followed by a diagnostic colonoscopy. In addition to the discomfort of bowel prep and associated potential dehydration and electrolyte abnormalities (particularly among older individuals), there is an incidence of colonic perforation of 4 per 10,000 and 8 per 10,000 for major intestinal bleeding from screening colonoscopy [45]. Other harmful effects of colorectal cancer screening include the psychosocial consequences of receiving a false-positive result, the potentially significant complications of colonoscopy mentioned above, a false-negative result, the possibility of overdiagnosis leading to unnecessary investigations or treatment, and the complications associated with treatment [46]. These risks need to be considered in the context of the screening interval of the chosen method. Existing evidence suggests little benefit and significant harm in continuing to screen average-risk patients older than 75 years for CRC when consecutive prior screening tests have been negative.

Underuse Issues

CRC screening is a notably underused preventive strategy with one in three age-eligible adults in the USA never screened for colorectal cancer [47, 48].

Individual Considerations

Although the absolute difference is very small, colorectal cancer in African Americans has an increased incidence and mortality relative to whites, and African Americans are less likely to have undergone colorectal cancer screening [49]. Smoking is a risk factor and should be considered in the discussion, assuming a life expectancy of at least 10 years [50]. Tobacco cessation, addressing obesity, and dietary changes such as reducing consumption of red and processed meats and moderating alcohol intake may also reduce the risk of colon cancer [51].

Screening for Cervical Cancer

Based on observational data, the USPSTF gives cervical cancer screening a Grade A recommendation [52]. The testing consists of cytology (Papanicolaou smear) every 3 years for women aged 21–65 years or screening with a combination of cytology and human papillomavirus (HPV) testing every 5 years for women aged 30–65 years [21]. Given the higher sensitivity and lower specificity of stand-alone HPV testing compared to cytology in the detection of cervical intraepithelial neoplasia (CIN) 2–3, this form of screening should not

be offered due to high false-positive rates [53, 54]. To view comprehensive screening and management algorithms as well as access the mobile app from the American Society for Colposcopy and Cervical Pathology (ASCCP), visit http://www.asccp.org/asccp-guidelines [55].

Potential Benefits

Observational studies in North America and Europe have shown a very significant reduction in the incidence of invasive cervical cancer along with cervical cancer-related mortality reductions ranging from 20% to 60% since the institution of widespread screening [21]. The USPSTF reports high certainty that screening women aged 21–65 years with cytology every 3 years or women aged 30–65 years every 5 years with cytology and HPV co-testing outweighs potential harms and substantially reduces cervical cancer incidence and mortality (Grade A). The USPSTF recommends with moderate certainty against screening of average-risk women aged 65 and older who have had adequate prior screening (Grade D).

Potential Harms

The harms of cervical cancer screening outweigh benefits among average-risk women younger than 21 (regardless of their sexual history), women older than 65, and women with a history of hysterectomy for indications other than dysplasia or cancer. Screening in these groups results in no significant reduction in cervical cancer mortality or years of life gained but does expose these women to false-positive results with subsequent colposcopies and biopsies and even unnecessary treatment that may increase the risk of adverse future pregnancy outcomes for younger women. Women aged 65 and older may still benefit if they have not had adequate lifetime screening, especially if they emigrated from countries where routine cervical cancer screening is not performed.

Cervical cancer screening should follow evidence-based guidelines to avoid the harms associated with overtesting and overutilization of resources. Future studies will need to address the screening recommendations for women who have completed the HPV immunization series as adequate long-term follow-up data is not yet available.

Individual Considerations

The standard recommendations do not apply to women who have existing high-grade precancerous cervical lesions or cervical cancer, women with in utero exposure to diethylstilbestrol (DES), or women who are immunocompromised.

Screening for Prostate Cancer

In 2012, the USPSTF recommended against prostate-specific antigen (PSA)-based screening for prostate cancer (Grade D) [56]. A 2013 Cochrane combined meta-analysis of five RCTs concluded that prostate cancer screening did not significantly decrease prostate cancer-specific mortality and caused major harms such as overdiagnosis and overtreatment, infection, blood loss requiring transfusion, pneumonia, erectile dysfunction, and incontinence [57]. Patients should be counseled regarding these potential harms of PSA testing but also consider that African American men have a higher risk of prostate cancer than white men and that smoking and family history are risk factors for the disease [58]. Although nearly one-third of participants in the Prostate Cancer Intervention Versus Observation Trial were African American [59], African American men have been underrepresented in prostate cancer screening trials as a whole [60–64].

The American Urological Association advises clinicians to exercise shared decision-making among men 55–69 and men younger than 55 who are considered at higher risk of prostate cancer based on family history or African American ethnicity, citing a mortality benefit of 1 man with prostate cancer for every 1000 screened [65]. The US Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial failed to demonstrate any mortality benefit from PSA testing in any age group [66]. In a large European trial, five out of seven countries failed to demonstrate a statistically significant benefit of PSA testing in terms of prostate cancer mortality, while all-cause mortality was essentially identical in the screened and non-screened groups within the trial as a whole [67, 68].

Conclusions

Healthcare professionals require an understanding of screening tests and an ability to discuss and individualize screening decisions with patients. The most important issue to discuss is the balance of benefits versus harms of a screening procedure. This balance changes over an individual's lifetime according to age, disease risk, and potential for successful treatment. High-intensity screening including the use of high-sensitivity tests performed more frequently does not necessarily lead to better patient outcomes. Instead, such practices may lead to overdiagnosis of clinically inconsequential conditions, iatrogenic harms from overtreatment, and increased healthcare costs. The clinician's judgment of the patient's capacity for safe and potentially beneficial screening includes an assessment of an appropriate age to stop screening in light of the patient's estimated life expectancy. Candidates for screening ideally have a life expectancy of 10 years or longer, so they can live long enough to recognize benefits.

Even in settings that have standard clinic protocols, clinicians must individually weigh the quality and quantity of evidence surrounding a screening test as they assist patients in making informed choices on whether or not to participate.

The USPSTF is a key source of information on screening because of its use of objective and comprehensive systematic reviews for the development of clinical practice recommendations. Clinicians should augment their review of policy statements by reading current original research that may have findings that change screening practice.

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Medication Management and Treatment Adherence

14

Emily M. Hawes

Introduction

It is estimated that 82% of adults in the USA take at least one medication (i.e., prescription drug, herbal supplement, or over-the-counter drug) and almost 30% take five or more medications [1]. Errors can occur with any type of medication across all care settings, including long-term care facilities, hospitals, and ambulatory care clinics. The frequency of medication-related problems (MRPs), including medication errors and adverse drug events (ADEs), is a serious public health problem which contributes to morbidity and mortality [2]. Each year, 700,000 emergency department (ED) visits and 120,000 hospitalizations are due to ADEs [3] and at least $3.5 billion is spent on medical treatment of ADEs annually. One quarter of the ADEs are preventable, resulting in unnecessary cost and harm [2]. In 2003, one study, for example, conservatively estimated 530,000 preventable ADEs in outpatient Medicare patients, while another placed the cost in 2000 per preventable ADE at $1983, with national annual costs at $887 million [3, 4]. Of note, approximately $200 billion worth of expenditures were attributed to MRPs in 2000; while in 2009 the retail drug costs were about $250 billion [5, 6]. Regrettably, the USA spends almost as much on complications associated with medications (e.g., adverse drug events) as it does for the medications itself [7].

Individuals 65 years and older continue to be the largest consumers of medications, with almost 20% taking at least ten drugs weekly [1, 8]. The greater number of medications, as well as age-related physiologic changes, contributes to a disproportionate effect of ADEs in this population. These older adults are more than twice as likely to be treated emergently for an ADE and nearly seven times as likely to require hospitalization than individuals younger than 65 years [8]. In fact, two thirds of unintentional overdoses and one third of ED-treated ADEs in patients aged 65 years or older were due to toxicity associated with medications commonly used to treat chronic illnesses [8]. Unintentional overdoses are one of the most common causes of ADEs contributing to hospitalizations. High-risk drugs used for chronic disease management (i.e., warfarin, insulin, and digoxin) are frequently associated with ADEs and require routine monitoring to prevent complications.

Medications prescribed in outpatient settings will continue to increase due to an aging population, the development of new drugs with more indications for approved medications, the transition of prescription to OTC availability, enhanced coverage of medications, and more frequent use of medications for disease prevention [8, 9]. The greater quantity of medications used in the ambulatory setting increases the likelihood of MRPs, such as mixing problematic OTC and prescription medications, stopping a needed medication, administering the wrong dose, using incorrect technique, and consuming interacting foods with certain medications [2, 9].

People are living longer with chronic conditions which require more time to discuss treatment options, greater complexity in coordinating care, and a higher risk of complications in a clinical environment that is moving to value-based care. Healthcare professionals and patients need to be trained and prepared to effectively manage medications [2], and although much attention has been focused on identifying, resolving, and preventing MRPs in hospitalized patients, less effort has been directed to MRPs occurring outside of hospital settings [8]. This chapter seeks to assist physicians and other care providers in a better understanding of medication management. The first section provides an overview to the nomenclature used in medication management, while the remainder of the chapter reviews applied strategies and approaches for effectively managing medications in multiple chronic conditions, especially in the ambulatory care setting [2].

E.M. Hawes (✉)
Department Family Medicine, University of North Carolina School of Medicine, Chapel Hill, NC, USA

UNC Eshelman School of Pharmacy, Chapel Hill, NC, USA
e-mail: emily_hawes@med.unc.edu

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Understanding Medication Management

Pharmaceutical care involves the provision of medication-based treatment for the purpose of achieving measureable therapeutic outcomes that improve a patient's quality of life. Such therapeutic outcomes include curing disease, eliminating or reducing symptoms, stopping or slowing disease progression, and preventing disease or symptomatology. Managing medication-related problems (MRPs) involves three major domains: (1) identifying potential and actual MRPs, (2) resolving actual MRPs, and (3) preventing potential MRPs [10].

Medication-Related Problems (MRPs)

An MRP, also known as a drug-related problem or drug therapy problem, is an event or circumstance involving medication that actually or potentially interferes with an intended health outcome [10–12]. MRPs can include medication errors as well as ADEs, and these are described in Table 14.1 [2, 13, 14].

While determining the nature of the MRP is an important component of medication management, a universally accepted classification system has not been adopted [14]. Classification systems generally include at minimum the MRP categories listed in Table 14.2 [11, 14–16].

Patient nonadherence is key MRP factor that impacts chronic illness care. Less than half of patients actually remain adherent to their medications after 1 year [17, 18], and nonadherence has been attributed to 125,000 deaths annually, 10% of hospitalizations, and an estimated $100 billion in direct and indirect costs [19]. Polypharmacy also contributes significantly to the likelihood of MRPs, especially adverse reactions and drug interactions, and, subsequently, increased mortality [2, 20]. Prescription and OTC drug use are increasing, as is the growing prevalence of herbal supplements and alternative medications in the USA. Although more patients are requesting that these agents as part of their therapy regimens, many of these products are not evaluated, monitored, and regulated to the same degree as prescription and OTC drugs. This can contribute to side effects that are exacerbated in those with renal and hepatic impairment, which is more common in older adults or those with chronic illnesses [2].

Table 14.1 Typology of medication-related problems

Medication-related problem (MRP)	An event or circumstance involving medication that actually or potentially interferes with a desired health outcome
Error	The failure of a planned action to be completed as intended or the use of a wrong plan to achieve an aim
Medication error	Any error occurring in the medication-use process
Adverse drug event (ADE)	Any injury resulting from a medication
High-alert medications	Medications that have a higher risk of causing significant harm when used in error. Although mistakes may or may not be more likely with these medications, the consequences of an error are more devastating to patients
Polypharmacy	The use of multiple medications by a patient, generally considered to be at least five to ten medications. It can include not only prescriptions, but over-the-counter medications and herbal supplements

Effective Medication Management

The Institute of Medicine (IOM) advocates that healthcare should be safe, individualized, timely, and effective to meet the needs of patients and that patients should be actively involved in their healthcare to prevent MRPs [2]. Effective medication management consists of medication reconciliation, comprehensive medication reviews to identify and resolve MRPs, and patient education [2, 21–23]. A basic framework for medication management in patients with chronic diseases involves understanding the recommended components for medication reconciliation, a comprehensive medication review, and patient education.

Medication Reconciliation

Medication reconciliation is the process of creating and maintaining a valid and verified list of medications and using that list to guide therapy decisions and patient education. An up-to-date, accurate, and available medication list is critical

Table 14.2 Common medication-related problems

Untreated indications	The patient has a medical problem that requires pharmacotherapy but is not receiving a drug for that indication
Improper drug selection	The patient has an indication but is taking the wrong pharmacotherapy
Subtherapeutic dosage	The patient is being treated with too little of the correct medication
Failure to receive medication	The patient has a medical problem that is the result of not receiving a medication
Overdosage	The patient is being treated with too much of the correct medication
Adverse reactions	The patient has a medical problem that is due to an adverse drug reaction or adverse effect
Drug interactions	A drug-drug, drug-food, or drug-laboratory test interaction is present
Medication use without indication	The patient is taking a medication for no valid indication

to ensuring safe medication use across all healthcare settings [2, 21, 24]. Outpatient visits may result in no changes or modifications to the list; however after hospital discharge, medication reconciliation can be time-consuming and often complicated. The goal in each setting is to provide a ledger of correct medications, including drug name, dosage, frequency, and route, to the patient and other care providers.

It is critical to understand what medications the patient is actually taking to reconcile medications. Information sources can be obtained from patient report, medication refill history, as well as reviewing the patient's pill box and medication bottles. The Institute for Healthcare Improvement (IHI) has recommended a three-step process involving (1) verification (i.e., obtaining the medication history), (2) clarification (i.e., ensuring that the regimens are appropriate), and (3) reconciliation (i.e., documentation of changes). At patient care encounters, every drug should be reviewed and noted as continued, discontinued, held, or modified (e.g., dose adjustment). Successful reconciliation also ensures that medication modifications, and ultimately an updated list, have been communicated to the patient as well as other providers [21].

Patients should be counseled to maintain an updated medication list in some proximity and to give a copy to their emergency contact. This list can be useful when picking up prescriptions at the pharmacy, as well as when attending healthcare appointments. The list should include allergies (such as drugs, food, dyes, and insects) and a description of the adverse reaction, if any, that the patient has experienced from prior medicines. The list should also document the patient's primary care provider name and phone number, as well as the pharmacy name, phone number, and location. The elements of the medication should include the brand and generic name of each medicine, dose, route, (e.g., by mouth, under tongue, injection) and frequency of administration. Over-the-counter, herbal, vitamin, and diet supplement products as well as all formulations, such as tablets, patches, drops, ointments, and injections, need to be included, even if they are only – "as needed" – those taken only on an intermittent or periodic basis. Ideally, an updated medication list should accompany a patient when they leave a healthcare setting [24].

Comprehensive Medication Review

According to the Centers for Medicare and Medicaid Services, a comprehensive medication review is comprised of a detailed evaluation of a patient's medications, including prescriptions, OTC medications, and herbal and dietary supplements, that guides pharmacotherapy and optimizes patient outcomes [22]. The review is a systematic process of collecting patient-specific information, assessing medication therapies to identify MRPs, developing a prioritized list of MRPs, and creating a plan to mitigate MPRs. Medication reviews should be tailored to the individual needs of the patient and may include the following actions [22, 25]:

- Obtaining patient data including demographic information, general health and activity status, past medical history, medication history (including adherence and past drug trials), allergy history, immunization history, and patient's thoughts or perceptions about their health conditions and medication use
- Assessing medications according to relevant clinical indications, as well as the patient's physical and overall health status, including current and previous conditions
- Understanding the patient's values, preferences, quality of life, and goals of therapy
- Assessing the patient's cultural context, education level, language barriers, literacy level, and other communication factors
- Interpreting signs and symptoms that could be due to adverse events from current medications
- Interpreting, monitoring, and evaluating laboratory results
- Identifying, evaluating, and prioritizing MRPs including but not limited to appropriateness of each medication, including efficacy, tolerability, safety, and ease of use; dosing, which includes consideration of indications, contraindications, potential side effects, and interactions; duplication or other unnecessary medications; adherence; untreated conditions; cost; and access considerations
- Developing a strategy to mitigate each MRP
- Providing education and training on the appropriate use of medications and medication delivery devices
- Coaching to empower patients to self-manage their medications
- Monitoring and evaluating the response to therapy, including safety and efficacy
- Communicating needed information to other healthcare professionals

Assessing medication use and identifying MRPs "behind the scenes" sometimes involve calling the community pharmacy regarding refill histories and can be a helpful piece of a comprehensive medication review. An interactive, face-to-face encounter with the patient can facilitate a comprehensive assessment of the patient's needs and goals and assess actual use and identify MRPs.

Patient Counseling

Effective education about medications can empower patients to be active partners in their care and promote treatment adherence. Establishing a therapeutic relationship built on trust is key to promoting learning and encouraging self-

management. Counseling involves assessing the patient's understanding about his or her health problems and medications, the capacity to use the prescribed medications correctly, and attitudes toward the health-related issues and associated pharmacotherapy [2, 23].

Open-ended questioning is a strategy that can be used to gauge patient understanding, reinforce important concepts, and determine what information is required for patients [23]. For example, "what questions do you have for me?" instead of "do you have any questions?" can invite richer dialogue [26]. When starting a new medication, an inquiry about each medication's purpose and the patient's expectations, as well asking the patient to demonstrate self-administration, will facilitate the communication process. This approach can be repeated during follow-up visits, to possibly uncover medication-related problems or concerns that arise.

Visual aids and demonstration devices can fill gaps in knowledge for patients and their caregivers. Opening medication bottles, for example, can visually display to patients the pill color, size, and shape. For injectable medications, this may involve showing patients the dosage marking on the measuring devices. Devices such as inhalers and pens may require a demonstration of the assembly of the device and the correct use of administration. The direct observation of medication use can also gauge correct usage and reinforce important concepts. Written handouts can supplement more complex medication regimens and help patients recall information.

The agenda for the counseling session may include the information listed below and can be dependent on each patient's regimen and monitoring plan and based on the educator's professional judgment.

- The medication's brand and generic name, common synonym, or other descriptive name(s) and, when needed, its therapeutic class and efficacy.
- The medication's indication and expected benefits. This may include whether the medication is intended to cure a disease, eliminate or reduce symptoms, arrest or slow the disease, or prevent the disease or symptom.
- The medication's anticipated onset of action and what steps to take if the expected result does not occur.
- The medication's route, dosage form, dose, and administration schedule.
- Directions for preparing and using the medication, which may include adapting to patients' schedule.
- Steps to take in case of a missed dose.
- Precautions to look for when using the medication and the potential risks in relation to benefits.
- Common side effects that may occur, actions to prevent or minimize their occurrence, and actions to take if they occur, including notifying the prescriber, pharmacist, or other healthcare providers.
- Strategies for self-monitoring.
- Potential drug-drug (including OTC), drug-food, and drug-disease interactions or contraindications.
- The medication's relationships to procedures, such as radiologic, laboratory, or surgical.
- Prescription refills authorized and the process for getting refills.
- Proper storage and disposal.
- Any other helpful information unique to the specific patient or medication.

Understanding patients' cultural context, especially health and illness beliefs, attitudes, and practices, can help individualize educational strategies. Healthcare professionals should adapt their teaching content and style to patients' communication skills, often with the use of teaching aids, interpreters, or cultural guides. Assessing a patient's cognitive abilities, health literacy, learning style, and physical status can also help tailor information and educational methods to meet the patient's needs. Some patients may learn best by listening to information, by seeing a picture or model, and/or by feeling the medications and devices [23, 26].

Some patients may lack the visual acuity to read prescription labels on bottles, find syringe markings, or follow written educational material. An impaired ability to read instructions printed on medication bottles or package inserts increases the likelihood for errors in self-managing medications. These patients may need special services such as blister packaging provided by a community pharmacy. In addition, they may rely on family members, friends, or caregivers to read instructions on bottles or leaflets, memorize how the pill feels in their hand, or use enhanced lighting devices and magnifiers. Others may use technological devices (such as talking pill bottles, glucometers, or scales) or computer software that converts printed information to Braille.

Arthritis or other functional limitations can reduce patient dexterity or strength in a way that challenges the use of devices such as child-resistant containers and special lids for medication bottles. Patients may also have hearing impairments which can limit an understanding of oral instructions and force reliance on a written format. Other impediments to verbal communication between healthcare professionals and patients can lead to misunderstandings in the execution of the prescribed regimen. Although approaches for meeting the medication safety needs of patients with hearing or visual impairment are challenging, strategies should focus on tailoring self-management to each patient's limitations [2, 23].

For patients, medication management requires physical and cognitive skills, including higher-level cortical processing and integration. With cognitive impairment, parts of the brain responsible for thinking and executive functions (such as memory, reasoning, learning) can be compromised and

may interfere with daily activities including self-management of medications. Even memory changes associated with normal aging can be an impediment to effective medication use, especially for chronic diseases such as type 2 diabetes that require problem-solving. Various intervention such as behavior modification, caregiver involvement, and utilizing weekly pill boxes, can be helpful in managing medications in patients with cognitive impairment. These individuals may variably rely on informal caregivers for medication management and error prevention. Such caregivers require adequate training and emotional support to carry out this role for chronic conditions that are often long-term. Given that caregiver burnout increases the risk for medication errors, efforts should be made to simplify the medication regimen for each patient and his or her support system [2].

Assessment Tools for Nonadherence and Health Literacy

Nonadherence

Medication adherence is the extent to which patients take medications as prescribed by a healthcare provider [2, 27]. For many chronic medical conditions, medication adherence has been associated with enhanced disease control, reduced symptoms, and decreased hospitalizations and mortality. A review of over 500 studies of chronically ill patients reported a nonadherence rate of 24.8% [27, 28]. Studies in other populations have reported nonadherence rates of approximately 50%, suggesting that one in every two medication doses for chronic conditions is missed [27, 29].

Both subjective and objective measures of adherence are useful in clinical practice. Objective measures, such as tracking clinical outcomes, pill counts, dispensing pharmacy records, electronic monitoring of pill administration (e.g., MEMS, the Medication Event Monitoring System), and drug concentrations, provide the most accurate measure of patient adherence. Subjective measures, including reports by family members, as well as use of self-report adherence scales, have less accuracy but greater potential to gain understanding around the reasons for nonadherence. These measures are simple to use and are less expensive and time-consuming than objective assessments, but they are prone to recall bias, the potential that respondents may provide answers that conform to their perceived expectations of the interviewer [27, 29].

There are a large number of well-validated adherence scales, including the Brief Medication Questionnaire, Morisky Medication Adherence Scale (MMAS-8), Adherence Self-Report Questionnaire, Adherence Visual Analogue Scale (VAS), Self-Efficacy for Appropriate Medication Use Scale (SEAMS), and Medication Adherence Questionnaire (MAQ) [27, 29–34]. The MMAS-8 remains one of the most widely used instruments to assess patient adherence for chronic illnesses.

Table 14.3 includes an example of the MMAS-8 questions used in the SPRINT trial, a recent landmark hypertension study [35].

Validated self-report measures are not routinely used in clinical practice to assess medication adherence, despite the capacity to provide actionable information for the medical team. Many clinicians believe they can accurately estimate medication adherence, but research demonstrates that clinician assumptions of adherence are often inaccurate [36]. In consequence, assessment of adherence is an important strategy for managing chronic illness, and brief and validated self-report measures of adherence should be considered for use in clinical practice [27, 36].

Health Literacy

Health literacy is the degree to which individuals have the ability to obtain, process, and understand basic health information in order to make appropriate health decisions. Health literacy is routinely classified by reading level as low or inadequate (i.e., sixth grade or less), marginal (i.e., seventh to eighth grade), or adequate (i.e., ninth grade and above) [26]. Almost half of high school graduates have low health literacy, and most patients do not reveal this limitation to their healthcare providers [26, 37]. Low health literacy is frequently under-recognized in clinical practice since there is a common assumption that patients can accurately read and comprehend prescription labels, in addition to understanding

Table 14.3 Morisky Medication Adherence Scale (MMAS-8) items used in the SPRINT trial

	Response choices
Do you sometimes forget to take your high blood pressure pills?	Yes or no
Over the past 2 weeks, were there any days when you did not take your high blood pressure medicine?	Yes or no
Have you ever cut back or stopped taking your medication without telling your doctor because you felt worse when you took it?	Yes or no
When you travel or leave home, do you sometimes forget to bring along your medications?	Yes or no
Did you take your high blood pressure medicine yesterday?	Yes or no
When you feel like your blood pressure is under control, do you sometimes stop taking your medicine?	Yes or no
Do you ever feel hassled about sticking to your blood pressure treatment plan?	Yes or no
How often do you have difficulty remembering to take all your blood pressure medication?	Never; almost never; sometimes; quite often; always

medical information. Practice-level barriers include a compressed and busy work environment, which can compromise the ability of providers to gauge the health literacy of their patients.

Low health literacy results in worsened health outcomes and increased cost. It contributes to medication nonadherence via missed medication refills, problems understanding prescription instructions and warning labels, inappropriate dosing or administration times, and failure to recognize side effects or drug interactions [26, 38–40]. In a study enrolling 400 English-speaking patients across 3 large primary care clinics, patients with low literacy had difficulty understanding label instructions for the medications that they were prescribed. Although two thirds of patients with low literacy correctly read the instructions, "Take two tablets by mouth twice daily," only one third of those patients could show the correct number of pills to be taken in a day. Although this may reflect a deficiency in mathematical skills rather than reading proficiency, numeracy is an aspect of functional health literacy [40].

Functional literacy is the ability to use literacy to complete a task. It includes speaking and comprehension (e.g., reporting symptoms, describing medication use), reading and writing (e.g., reading and understanding a label on a prescription bottle, completing a questionnaire), and basic math skills (e.g., calibrating a medical device at home, calculating the correct dose of a drug) [2]. One study reported that almost half of patients (including those with adequate skills) misunderstood one or more of the prescription label instructions and that lower literacy and a high number of medications are independently associated with misunderstanding of prescription instructions [40].

An additional study evaluated the impact of literacy in anticoagulated patients and found that low health literacy was associated with deficits in warfarin-related knowledge. Of those with limited health literacy, 70% of the patients understood that warfarin was a "blood thinner," and only half of these patients understood that bleeding and bruising were the most common side effects [41]. In addition to creating barriers in medication-related comprehension, low health literacy may contribute to non-prescribing of indicated therapy, such as anticoagulation, especially in the elderly and ethnic minority subgroups who are at increased risk for poor health literacy [41, 42].

Signs of low health literacy can include patients who ask for instructions to be repeated; ask fewer questions overall; do not use medical terminology; do not know the name of the medications; rely on the shape, size, and color to identify their medication; "forget their glasses"; are nonadherent; and have difficulty explaining their concerns [26, 43]. Objectively assessing health literacy is an important step in accurately gauging literacy level and better tailoring medication education for patients. The Rapid Estimate of Adult Literacy in Medicine (REALM), the most widely used measure of health literacy, is a 66-item word recognition and pronunciation test using common terms from the healthcare setting. Raw scores can be converted into one of three reading levels: sixth grade or less (score, 0–46, low literacy), seventh to eighth grade (score, 45–60, marginal literacy), and ninth grade and above (score, 61–66, adequate literacy) [26].

The REALM-Short Form (REALM-SF) is a 7-item word test that provides a quicker assessment of health literacy and has excellent agreement with the 66-item REALM test [44]. The interviewer prompts the REALM-SF test as follows [44]: "Providers often use words that patients don't understand. We are looking at words providers often use with their patients in order to improve communication between health care providers and patients. Here is a list of medical words. Starting at the top of the list, please read each word aloud to me. If you don't recognize a word, you can say "pass" and move on to the next word." The interviewer then gives the participant the word list, which includes the following words: behavior, exercise, menopause, rectal, antibiotics, anemia, and jaundice. If the patient takes more than 5 s to respond to the word prompt, the interview moves on to the next word [26, 44–46]. Other validated literacy tools include the Short Assessment of Health Literacy – Spanish and English (SAHL-S&E) and Short Assessment of Health Literacy for Spanish Adults (SAHLSA-50) [26, 47, 48].

Communication Strategies

When interacting with patients, physicians and other healthcare providers should explain concepts in nonmedical jargon. Terms such as *use* vs. *utilize*, *side effect* vs. *adverse reaction*, *blood pressure* vs. *hypertension*, *low sugar* vs. *hypoglycemia*, *when you need it* vs. *PRN*, *and on the skin* vs. *topical* are generally easier to understand for patients [26]. Standardized instructions about medication dosing schedules (e.g., morning, noon, night, and bedtime) promote patient understanding and reduce medication errors. Imprecise and vague information about dosing frequency (e.g., every 4–6 h) should be avoided for those patients with low health literacy. A prescription label that has explicit instructions such as "Take one tablet in the morning and one at 4 PM" instead of "Take one tablet twice daily" significantly reduces the possibility of improper dosing frequency and administration [26, 40, 49].

Providers should be mindful of their pace of speech and content and volume of medical information, especially when communicating to patients with limited health literacy. For example, "take on an empty stomach" instead of "take 2 hours before lunch or 2 hours after lunch" may have greater relevance for patients. The communication focus should be on one to three key concepts, and important information

should be repeated with succinct explanations for common chronic disease and potential side effects [26, 40].

Patient-centered educational material is an important adjunct to communicating medication administration. Unfortunately, drug information sources (e.g., pharmacy and package inserts) that are intended to supplement provider-patient communications and self-management are inadequate for this purpose, since they are often inconsistent, complex, incomplete, and written at a college reading level [2]. Creation of a medication list, using graphics or simple phrases to show the medicine, its indication, how much to take, and when to take it, can be a useful resource. There are software applications available and Fig. 14.1 displays an example of a pill card [26, 57].

A "teach back" or "show me" technique is an effective strategy to evaluate patient understanding, clarify important points, and close any communication gaps between the patient and provider or health educator. In this approach, patients are asked to repeat instructions to demonstrate their understanding. A provider, for example, may prompt by saying: "I want to make sure that I have explained everything clearly. If you were trying to explain to your partner how to take this medication, what would you say? I want to make sure that I mentioned the main side effects of this new medicine. Could you tell me what you plan to watch out for? Please show me how you would use this inhaler so I can make sure that I explained it well" [26].

The provider or health educator confirms understanding when the patient is able to correctly demonstrate use or explain how to use the medication with his or her own words. If a patient cannot remember or accurately repeat what was presented, the information is presented and clarified, and the patient is invited to teach back again. This process continues until the patient can satisfactorily describe the directions. Misinformation and other errors can be corrected with further targeted teaching and/or revaluating comprehension again [23, 26]. The teach back may be a valid approach to identify potential errors in medication administration, since studies have found a gap between a patient's ability to correctly verbalize instructions and his or her ability to correctly show the correct number of pills to be taken daily [26, 40].

Strategies to Promote Treatment Adherence and Medication Management

There are several principles that underlie strategies to promote treatment adherence and medication management. One basic principle is that the patient should be fully involved in the decision-making and that family caregiver support needs to be encouraged to improve treatment adherence and effectively manage medications. Establishing a patient-provider relationship that is based on a mutually beneficial exchange, in which the patient gives authority to the provider and the provider gives competence and commitment to the patient, is fundamental to effective medication management and adherence [2, 10, 23]. Patients should be empowered as partners in their care, with appropriate communication, teaching, and resources in place to support them. In turn, healthcare professionals should engage in meaningful discussions regarding the safe and effective use of medications at multiple points in the medication-use process [2]. Finally, the healthcare environment should be representative of a patient-centered culture [2].

The largest barrier to patient education and adequate medication self-management is lack of knowledge about the safe and effective use of medications. Both prescribers and patients are often required to make decisions by weighing pros and cons of medication regimens with knowledge limitations in the context of real-time practice. Physicians and other healthcare providers are often under time constraints that limit time spent with patients, and most prescriptions are written in the last minute of the encounter with limited time for counseling regarding the medication [2]. Prescribing requirements associated with various formularies are another practical barrier impacting providers in practice. Some aspects of managing different formulary requirements can be alleviated with the use of information technology, but such programs are not always accurate and comprehensive [2].

A rapidly growing strategy to promote medication management is found in health information technology applications that identify areas around medication safety and the use of this information to inform patients and providers. Many healthcare systems and institutions are seeking ways to implement these technologies in a way that enables providers to readily access evidenced-based resources, effectively communicate medication-related information to patients, use automated decision-support tools and best practice alerts, run drug-drug interaction screens, and assess the safety of medication use through monitoring and run reports [2]. Medication reminders, such as smartphone apps, adherence aids (e.g., pill boxes or blister packages), medication calendars, as well as appointment reminders – both telephone and computer-based – are useful tools. Promoting the use of a weekly pill box and encouraging patients to bring it to clinic appointments can help improve adherence and can assist the provider in confirming that the patient is administering medications as prescribed [19, 26, 50].

Patient access to the electronic medical record (EMR), which includes a medication list and provider access to patient adherence data (including EMR alerts), can also increase compliance. Telephone, mail, or video support and counseling has also been piloted [19]. Maintaining contact with patients through more frequent follow-up appointments and telephone calls; encouraging self-reporting, such as daily weights, home blood pressure readings, blood sugar

Fig. 14.1 Example of a pill card

Name: Ana Martinez **Date Created: 11/9/2016**

Pharmacy phone number: 111-222-3344

Name	Used For	Instructions	Morning	Noon	Evening	Bedtime
Crestor 20 mg tablet 	Heart Disease 	Take 1 pill at bedtime				
Metformin 500 mg tablet 	Diabetes 	Take 2 pills in the morning and 2 pills in the evening				
Chlorthalidone 25 mg tablet 	High Blood Pressure 	Take ½ (half) pill in the morning				
Amlodipine 10 mg tablet 	High Blood Pressure 	Take 1 pill in the morning				
Novolin 70/30 	Diabetes 	Inject 22 units in the morning and 18 units in the evening	 22 units		 18 units	
Symbicort 	Asthma (Breathing) 	Inhale 2 puffs in the morning and 2 puffs in the evening	 		 	

readings, and responding to the information; reaching out to patients who do not return to clinic; inquiring about adherence; and encounters with allied health professionals (e.g., pharmacists, nurses, and case managers) improve adherence [19, 50].

Targeted patient education initiatives can significantly improve medication use and subsequently chronic disease outcomes [2]. For example, a nurse-led intervention that included medical detailing to patients about gout and its treatment options, as well as individualized lifestyle advice

and pharmacotherapy modification, led to 91% adherence to allopurinol and 85% attainment of the goal uric acid to reduce gout flares [51, 52]. Information-grounded interventions such as disease state education, including the goal and anticipated outcomes of treatment, self-monitoring guidance, lifestyle modifications and counseling, and drug education and counseling have been found to promote adherence for patients [2, 19, 50].

Prescribers should be mindful of medication costs. Reducing medication copays through prescribing of generic brands, preferred low-cost drugs on insurance plans, and combination drugs is one of the most effective strategies to improve adherence [19, 50]. Other approaches include ordering specific surveillance labs (e.g., serum potassium rather than chemistry profile); obtaining and recording home readings, such as blood glucose and blood pressure data; emphasizing non-pharmacologic therapies (e.g., exercise); and using daily versus multiple daily dosing. Standardizing workflows (e.g., lab draws at specific intervals) for drug monitoring and appropriate dose adjustments and optimizing therapies in order to resolve adverse drug reactions, drug-drug interactions, and food-drug interactions are also important strategies [19, 50].

Case management is another strategy that seeks to create connectivity, alignment, and collaboration within and between the patient and the care providers, as well as healthcare system. The goal is to improve quality of care, reduce barriers to care, and enhance patient experience. Case management often comprises prospective systematic monitoring of patients for nonadherence and clinical status, facilitation of guideline recommendations to providers, patient support for decisions, self-management and treatment, as well as appropriate follow-up [49, 53]. Multidisciplinary case management has been found to improve patient outcomes across a spectrum of chronic diseases, including but not limited to asthma, COPD, hypertension, congestive heart failure, coronary artery disease, gout, depression, and HIV.

Individuals such as nurses, care managers, and pharmacists can serve as case managers, providing a crucial link between primary care providers and patients to promote adherence [19]. For example, a nurse-administered phone intervention increased patient confidence in managing hypertension, and a nurse-led face-to-face self-management program increased inhaler adherence in patients with asthma [54, 55]. A 2011 meta-analysis showed that pharmacist face-to-face interventions can significantly improve adherence and blood pressure control in patients with hypertension [50]. In patients receiving multiple medications, periodic telephone counseling by a pharmacist improved compliance and reduced mortality [20]. Although the majority of the literature highlights the significant impact of pharmacist involvement, healthcare assistants can also promote adherence to medications. Case management provided by primary care practice-based healthcare assistants conducting a structured phone interview to support adherence demonstrated a decrease in depression symptoms in patients with major depression [49].

Multidisciplinary chronic disease management program may especially benefit patients with low literacy. A prospective randomized clinical trial reported that diabetic patients with low literacy, who received a comprehensive disease management intervention, were more likely than control patients (i.e., usual care) to have better control of their diabetes [56]. Patients with higher literacy had a similar likelihood of achieving the goal levels regardless of intervention participation [56]. Multifaceted interventions – those that included reduced copayments, case management, and patient education with behavioral support – have shown to be effective strategies for enhancing adherence in patients with chronic conditions. In any intervention, efforts should be made to improve medication management and treatment adherence by meaningfully connecting with patients [19, 50].

Summary

Medication-related problems (MRPs) commonly occur in patients with chronic diseases, and effective medication management consists of medication reconciliation, comprehensive medication review, and patient counseling. Direct integration of literacy and adherence assessment data from computer-based self-report measures into EMR should be developed further since this will allow information to be readily available for use by providers to improve care [27]. Finally, clinicians and healthcare settings should provide a patient-centered approach to medication-related care with the purpose of improving patient outcomes.

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Patient-Provider Communication and Interactions

15

Jennifer Martini

Introduction

In a letter to his new primary care physician that he penned as part of his patient intake questionnaire in 1964, author John Steinbeck mused "What do I want in a doctor? Perhaps more than anything else—a friend with special knowledge" [1]. With this statement, he alluded not only to the importance of the relationships that develop between healthcare providers and their patients but also to the key role that the communication of medical knowledge and other concepts plays in fostering those relationships and facilitating care over time. Indeed, communication between healthcare providers and their patients, particularly during the provision of chronic care, in many ways defines patients' healthcare experiences. It influences information that is gathered from patients, shapes patients' understanding and conceptualization of their illnesses, and sets the stage for the manner in which patients and providers will collaborate on enacting important management plans over time.

In its 2001 report *Crossing the Quality Chasm*, the Institute of Medicine highlighted six aims for improving healthcare, and among these was the need for care to be "patient-centered," namely, "respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions" [2]. The report further highlighted the essential role that patient-provider communication plays in achieving this aim, recommending that care be based on continuous healing relationships, that knowledge and information flow freely between providers and patients, and that "clinicians and patients should communicate effectively and share information" [2]. There is a substantial body of evidence that supports this approach, demonstrating an association between effective patient-provider communication and numerous health outcomes [3–6]. In addition, quality communication between patients and providers has been linked to patient satisfaction, which is important not only for good health but also as an increasingly prominent outcome measure for value-based care [3, 4, 7]. Finally, providers themselves may achieve enhanced fulfillment and career satisfaction through the provision of care that involves effective communication; this solidifies the role of quality communication as a foundational aspect of care that satisfies the "quadruple aim" of enhancing patient experience, improving population health, reducing costs, and improving the work life of healthcare providers [8].

One potential mechanism for the relationship between effective communication and health outcomes is that the elements of good communication (information exchange, emotional response, relationship building, decision-making, etc.) lead to proximal and intermediate outcomes, which ultimately mediate the endpoints of patient cure, survival, emotional well-being, functionality, and vitality [9]. Effective communication results in the proximal outcomes of patient understanding, satisfaction, trust, motivation, and clinician-patient rapport and agreement. These factors then facilitate the intermediate outcomes of access to care, quality medical decision-making, commitment to treatment, trust in the healthcare system, self-care skill development, and emotional self-management which, in turn, are directly facilitative of the healthcare endpoints described above [9]. Through this mechanism, effective communication strategies serve as the fundamental building blocks upon which all aspects of successful, effective, patient-oriented chronic care management are founded.

Communication occurs in numerous manners during chronic illness and is evolving as models of care and provider-patient expectations and resources change. The communication that occurs in discrete encounters involving the provider-patient dyad has historically been at the core of patient-provider communication, and mastering communication in this forum remains a key element of the successful provision of chronic care. Modern healthcare communication, however, must also incorporate emerging trends in the manner, settings, and context

J. Martini (✉)
Department of Family Medicine, University of North Carolina, Chapel Hill, NC, USA
e-mail: jennifer_martini@med.unc.edu

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in which care is delivered. Team-based models, expanding technology, shared decision-making, and group care are among these trends, and successful communication across these realms is integral to effective chronic care. Finally, recognizing and developing strategies for specific patient populations and communication challenges that arise within chronic care such as conflict management, giving bad news, bridging cultural and language gaps, and communicating with patient companions/advocates further enhance patient-provider communication and interaction.

Communication in the Provider-Patient Dyad

Improved provider-patient communication increases patient involvement in and adherence to recommended therapy, influences patient satisfaction and healthcare utilization, and improves quality of care and health outcomes [3, 4]. Perhaps nowhere is this communication more easily observed, and more crucial, than in the direct interaction between patients and providers that occurs in face-to-face encounters. Both provider and patient personalities and communication styles influence the information that is exchanged in face-to-face encounters, as well as the manner in which that exchange occurs and the aspects of it that are prioritized [5, 6]. In considering the manner in which communication can be optimized in this setting, it is helpful to focus first on the overall goals of patient-provider dyad interaction, followed by specific techniques and skills that can facilitate the achievement of those goals.

Goals of Patient-Provider Interactions

Communication with patients is most effective when it is undertaken with specific goals in mind, and there are several key functions that optimal communication serves in the patient-provider relationship. The patient-centered medical interview is one which "approaches the patient as a unique human being with his own story to tell, promotes trust and confidence, clarifies and characterizes the patient's symptoms and concerns, generates and tests many hypotheses that may include biological and psychosocial dimensions of illness, and creates the basis for an ongoing relationship" [10]. Another popular model for conceptualizing the fundamental goals of patient-provider communication similarly emphasizes the importance of striving to achieve both traditional biologic goals and more nuanced emotional ones, suggesting that providers interacting with patients are charged with achieving the "2 F's" (*F*ind it and *F*ix it) as well as the "4 E's" (*E*ngage patients via an interpersonal connection, *E*mpathize with patients' illnesses and situation, *E*ducate patients by effectively delivering information, and *E*nlist patients to actively participate in decision-making and disease management) [11, 12].

In general, the goals of patient-centered care may be organized along six key dimensions: (1) exploring the illness experience, (2) understanding the whole person, (3) finding common ground regarding management, (4) incorporating prevention and health promotion, (5) enhancing the doctor-patient relationship, and (6) being realistic about personal limitations [13]. This patient-centered *care* can be accomplished through attending to several goals that are specific to patient-centered *communication* within encounters, namely, using a biopsychosocial model, viewing the patient as a person, sharing power and responsibility, building effective relationships, maintaining and conveying positive regard for patients, and remaining aware of the doctor as person [14]. As they strategize nuts-and-bolts methods for communicating with patients in various settings, providers should ensure that the techniques employed are directly facilitative of the communication goals that they hope to achieve.

Communication Models and Techniques

Several techniques and approaches to communication are available to providers and may help to actualize the goal of conducting truly patient-centered interviews and achieving the endpoints outlined above. Practitioners of patient-centered communication use specific knowledge (e.g., define countertransference, identify types of interview questions), attitudes (e.g., unconditional positive patient regard, willingness to join with patients as partners), and skills (e.g., elicit patients' "stories" of illness, overcome barriers to communication) [10]. These sets of attitudes, skills, and knowledge can be studied and practiced by providers who wish to maximize the information exchange and trust that are cultivated during patient interactions.

The Kalamazoo consensus statement, which was developed at an invitational conference that convened leaders and representatives from major medical and professional organizations to focus on essential elements of patient-provider communication, offers another model through which providers may facilitate effective patient interactions. Starting from the foundational assertion that "a strong, therapeutic relationship is the sine qua non of physician-patient communication," and that building this relationship is the fundamental communication task with which providers are charged, the statement delineates specific steps for effective communication in patient encounters [15]. First, providers should open the discussion with patients by eliciting patients' full concerns while establishing/maintaining personal connections. This should be followed by gathering information using open- and closed-ended questions as indicated, actively listening, and structuring, clarifying, and summarizing information that has been exchanged. Next, providers should seek to understand

patients' perspectives by exploring contextual factors (family, culture, socioeconomic status, and spirituality) as well as patients' beliefs, concerns, and expectations about health and illness. This involves active acknowledgement of, and response to, patients' ideas, feelings, and values. Once these tasks have been accomplished, providers may share information with patients using understandable language and incorporate questions to check for comprehension. This enables patients and providers to identify and enlist resources/supports while confirming patients' ability and willingness to follow agreed-upon plans. Lastly, providers should seek to provide closure by soliciting any additional issues or concerns from patients, summarizing and affirming agreement with plans, and creating plans for expected follow-up as well as contingency plans for unexpected outcomes [15].

In addition to the traditional stepwise approach for patient-provider communication are two subtypes of skills that providers can employ to foster effective, efficient relationship building and communication during their patient interactions [16]. One set of techniques is comprised of those which underlie all patient communication and thereby exert their influence on an ongoing basis during face-to-face encounters and during patient-provider relationships over time. The first of these is rapport building and relationship maintenance, which can be accomplished through warm greetings, eye contact, brief non-medical conversation during visits, acknowledging patient cues with empathetic responses, and remembering to check in on important life events. Additionally, maintaining a mindful approach to practice by remaining attentive to patient and provider thought processes and by focusing on being "present and critically curious" during patient interactions is essential to effective communication. Lastly, practicing "topic tracking" during and across patient encounters by maintaining focus on mutually agreed-upon topics, and discussing them in an organized fashion, can greatly facilitate productive interactions [16]. The second set of techniques can be enacted sequentially during face-to-face interactions with patients in order to optimize communication and efficiency. Establishing focus before, and at the commencement of, patient visits by understanding patient expectations and planning the use of time provides a foundation upon which to build productive interaction. This can be accomplished by up-front, collaborative agenda setting, which enables providers and patients to explore and prioritize the concerns that need to be addressed. This should be followed by exploration of patients' perspectives on their concerns and medical conditions using open-ended questions and "curious listening" to ensure that patients feel understood, cared for, and invested. Providers and patients should collaborate to create a plan that incorporates patients' goals of care, readiness to change, and the explicit roles that the provider, patient, and family members or other supports will play [16].

In considering the key features of effective communication models such as those described above, several themes emerge which may help providers to contextualize the specific concepts and skills that are suggested. One such theme is the importance of a fundamental effort to "enter the patient's world, see the world through the patient's eyes" [17]. Performing the "emotional labor" that this requires is a central aspect of patient-centered communication [17, 18]. Verbal interactions with patients that focus on an exploration of illness experience and patient perspective have been independently associated with increased patient trust [7]. Additionally, the concepts of provider introspection, provider self-awareness, and mindfulness in communication play a central role in all effective patient-provider communication strategies. Both provider and patient personalities and beliefs strongly influence the communication styles that evolve between them, as well as the nature and content of information that is exchanged [3, 6, 7, 19, 20]. As such, it is imperative that providers reflect on, and maintain a deep and nuanced awareness of, the manner in which their own personalities, biases, beliefs, mannerisms, reactions, and overall approaches to patient care influence their interactions. As providers carry out the various communication strategies outlined above, they should be guided by a consistent focus on achieving a deeper understanding of their patients and of themselves. It is not surprising that self-knowledge and understanding of patient perspective play such integral roles, as communication is most effective when all involved parties operate from a deep and shared understanding.

Communication Within Evolving Chronic Illness Models

While effective direct communication in the provider-patient dyad plays a critical role in fostering relationships and improving patients' experiences and outcomes, it represents only one element of communication in the modern healthcare experience. Chronic care has increasingly come to include the voices of many contributing team members, as well as significant interactions outside the context of a traditional face-to-face office visit. The participation of multiple providers in complex healthcare teams that incorporate shared decision-making practices, group care models, and expanded communication channels via health information technology has added breadth and complexity to the character of modern chronic care communication.

Communication Within and via Healthcare Teams

One significant evolution in the modern healthcare landscape is the incorporation of non-physician team members into chronic illness management. These additional team members

lend unique and valuable perspectives to the chronic illness conversation, and the successful provision of chronic care involves coordination among those voices within teams, as well as unifying them into one harmonious resource with which patients can interact.

Communication Within Healthcare Teams

Communication among members of patients' healthcare teams is essential to providing efficient, comprehensive, chronic care that is satisfying for both patients and providers [21–24]. While the incorporation of individuals with various areas of expertise into healthcare teams enhances care by providing comprehensive resources to patients, it also increases the complexity of those teams. Modern healthcare teams may include physicians, nurse practitioners, physician assistants, nurses, care managers, dieticians, pharmacists, social workers, office staff, health coaches, and home health aides, who may work in different locations. An Agency for Healthcare Research and Quality (AHRQ) report on creating patient-centered team-based care states "good relationships among provider team members create the foundation for good relationships with patients" [25]. Cohesion among care team members is thus a prerequisite for creating a cohesive relationship between care teams and the patients they serve.

Creating a culture of egalitarianism, unity, and collective responsibility provides an essential foundation for effective communication among teams. While traditional care models have usually placed the physician at the helm of all decision-making, modern models emphasize the value in incorporating the full range of skills and resources provided by each team member into individual decisions as they arise. Modern teams function best via a collaborative approach in which each team member feels empowered to guide aspects of the treatment plan, and relationships among team members are viewed as equal, open partnerships. While it is essential that each team member has a clear understanding of his or her role in the team's overall function, this must be balanced by an overarching sense of responsibility to the patient and a culture of flexibility to temporarily expand or alter that role in accordance with patients' individual needs over time.

Communication within the collaborative culture described may occur through several different channels, and it is essential that providers develop effective tools for intra-team sharing of information, which allows for continuity in patients' interaction with the team and maximizes the efficiency and satisfaction of team members. Strategies for optimizing written communication include establishing record systems that are easily accessed and updated by all team members and creating shared care plans that are founded on patients' goals and needs and which can be reviewed and updated by all care team members. This enables all providers involved in care to track and project the status of patients over time, while also staying focused on individual patients' preferences and unique needs. Additionally, using direct inter-provider written communication, such as secure text messaging or emails, allows for real-time updates on patient status and can streamline the process by which the care plan is adapted and advanced.

Similarly, optimal verbal communication is essential for effective team functioning. This can be facilitated by colocating team members as often as possible so that they can develop rapport and share insights, holding regular team huddles or meetings for care coordination, and intentionally scheduling team members to maximize their overlap in time and location [25–27]. Successful work relationships require that team members consider the goals of their interactions when deciding on which communication channels to employ for different needs. For example, because it potentially allows for more nuanced information exchange, verbal communication may be preferred for unclear or emotional content, while written communication may be more optimal for routine messages or those with a large amount of data to be assimilated [28].

Communication Between Healthcare Teams and Patients

A successful chronic care team must not only achieve effective internal communication but must also consistently and compassionately interact with the patients it serves. Once a care team has achieved internal cohesion and effective internal communication, there are several strategies by which that cohesion can be translated to patient interaction and care. In mobilizing a team to care for patients, it is essential to communicate patient care goals to all team members. Additionally, training team members in motivational interviewing, active listening, and shared decision-making provides them with tools to effectively achieve communication goals; this has been shown to increase providers' ability to facilitate input-seeking conversations and build strong, patient-centered relationships [25, 27]. Considering the specific skills, personality, and resources of individual team members, and attempting to match those traits with the characteristics and needs of individual patients (both initially and as they change over time), sets the stage for meaningful communication as well. Developing more creative environments for the provision of patient care, such as dedicated chronic care clinics with multiple colocated providers and resources, may help to improve patient communication and satisfaction [29].

It is essential that patients are included as the central members of care teams and understand how the team functions. Introducing team members to patients facilitates cohesion and continuity, as can the provision of reinforcements such as team bio sheets, formal naming of teams, and visual cues (e.g., color coding) among clinic structures [25]. There is some data to support the practice of involving patients in interprofessional rounds, meetings, and checklists to improve

the use of healthcare resources and adherence to recommended practices [26]. Eliciting patients' input on how, where, and when they would prefer to communicate with the team is crucial to effective patient-team interaction, as patients often have preferences on which specific providers they would like to interface with most frequently and in what manner [25, 29]. Overtly describing and demonstrating teams' inter-provider information sharing to patients provides them with a sense of teams' overall functions and continuity. Utilizing warm hand-offs between providers, referencing information provided by other team members during patient interactions, and highlighting the talents and roles of other team members can all help to provide a unified message from the care team to the patient [25].

Shared Decision-Making

An increasingly essential aspect of communication in chronic care settings is that of shared decision-making, which involves "a good conversation in which clinicians share information about the benefits, harms, and burden of alternative diagnostic and therapeutic options and patients explain what matters to them and their views on the choices they face" [30, 31]. As chronic care patients' illnesses, circumstances, and individual needs evolve over the course of their lives, they and their providers are often faced with complicated decisions that must incorporate not only medical knowledge but also a complex interplay of personal priorities, changing risk/benefit ratios, and the overall contexts of their lives and diseases. While more traditional models of care involved a relatively paternalistic provider approach to these decisions, modern chronic care hinges on recognition of the importance and value of engaging patients in shared decision-making practices in order to carry out care that is truly patient-centered [27, 32]. Effective shared decision-making has been associated not only with improved patient satisfaction but also with reduced interventions and improved patient functional status [27, 31, 32]. In addition, surveys of provider attitudes about medical decision-making have suggested a preference among providers to ensure patients' full understanding of the risks and benefits of interventions [33]. While relatively straightforward in concept, the actual practice of shared decision-making is often hindered by various logistical, emotional, and knowledge barriers that arise in patient-provider interactions [30, 33, 34]. These barriers may be mitigated by communication strategies within patient-provider conversations, as well as by the use of facilitative decision aids and tools [27, 30, 35].

Several techniques can be used to facilitate a productive discussion of the pros and cons of proposed interventions in the context of individual patients' goals and priorities. One approach which unifies these techniques is the SHARE approach developed by AHRQ (Table 15.1) [36].

The complex information exchange that is required to effectively carry out shared decision-making can be facilitated by the use of decision aids and tools. Patients' knowledge and risk perceptions about proposed interventions are more accurate when they use decision aids, and patients exposed to decision aids feel more knowledgeable, better informed, and clearer about their values than those who receive usual care alone [35]. Decision aids can take several forms, and there is no clear evidence regarding the superiority of one form over another. More traditional aids consist primarily of printed educational materials reviewed by patients prior to, or following, face-to-face visits with their providers, while more modern aids take on a more facilitative character, guiding providers and patients through discussions [21, 30, 31, 35]. Technology plays an increasing role in decision aids; there are numerous interactive online tools for patients, some of which convey information about patient preferences and concerns to providers via the generation of reports and/or integration into electronic medical records [35, 37].

Table 15.1 The SHARE approach to facilitate a productive discussion of the pros and cons of proposed interventions in the context of an individual patient's goals and priorities

*S*eek patient's participation in decision-making	Highlight the importance of patient engagement in decisions
	Summarize the health problems to be addressed
*H*elp patient explore and compare treatment options	Communicate risks and benefits in patient-oriented terms
	Assess patient's pre-existing knowledge
	Use the "teach-back" technique to ensure understanding
*A*ssess patient values and preferences	Ask open-ended questions
	Demonstrate empathy and interest in how treatments might impact patient's life
	Encourage a discussion of patient's goals and priorities
	Obtain agreement and shared understanding of the aspects of interventions that are most important to the patient
*R*each decisions	Confirm that patient has had ample time and information to make a decision
*E*valuate decisions and interventions	Ongoing assessment of barriers to implementation, impact of the decisions on patient's life, and evolving patient priorities
	This is particularly important in chronic care as intervention risks/benefits and patient status may change significantly during the disease process

Developed by the Agency for Healthcare Research and Quality [36]

Group Care Models

The provision of chronic care in focused clinics and through group care models adds another dynamic to modern healthcare communication. Group care allows providers to reenvision the manner in which resources are used to provide chronic care and to capitalize on the value that is added to the chronic care conversation when patients become empowered to educate themselves, and one another, about their illnesses. The Future of Family Medicine Project identified group visits as key elements of new care models aimed at providing patient-centered care in a manner that optimizes quality and outcomes while decreasing access barriers for patients [38]. Within the context of chronic care, group visits generally occur either as drop-in appointments in which a small group of patients meets with the help of a provider facilitator or as part of cooperative healthcare clinics where patients engage in interactive discussions related to self-management while also meeting with several different sets of providers to manage their chronic illnesses [39].

During group visits, providers should adopt an empathetic, open communication approach similar to that which is employed in individual visits [40, 41]. Rather than assuming a didactic role when clinical questions arise, they should refer clinical questions to the group for discussion and feedback in order to maximize the benefits of gathering numerous patients and their perspectives together [41]. Expanding the realm and methods of communication to include recruitment of local speakers or educational materials to reinforce providers' messages, development of reading lists for ongoing patient education, and organization of demonstrative learning environments such as cooking classes or grocery store trips can allow providers to capitalize on the communication opportunities provided by the group visit format [40].

Technology and Chronic Care Communication

Advances in technology permeate all aspects of chronic care and have particularly begun to change the way patient-provider communication occurs. Telemedicine and electronic communication via patient portals provide new avenues for patients and providers to engage with one another beyond traditional office visits, and the increasing provision of health education information via websites and apps has interjected new voices into the chronic illness conversation.

Before considering the manner in which communication should be navigated across various settings, it is essential to recognize the variation among patient preferences regarding willingness and ability to engage with chronic care providers through novel technological mechanisms. There are numerous factors, including age, socioeconomic status, access to resources, and nature of illnesses, that influence the manner in which patients feel most comfortable interacting with their healthcare providers. While some of these factors are static, others can vary with time and with the specific diseases being addressed [22, 42]. For example, younger patients with inflammatory bowel disease who were offered electronic communication with their healthcare providers preferred email over other communication modalities, while older patients with the same disease tended to prefer receiving the majority of their provider communication during traditional office visits [42]. There is variation in the willingness of children and adolescents to utilize a web-based application to support personal management of long-term conditions; factors such as Internet access and a desire to feel "normal" by minimizing engagement with healthcare providers outside of the office or hospital setting exerted substantial influence over patient communication preferences in this group [22]. Given the various forms of technology that are available, and the variety of patient preferences regarding the best utilization of these resources, providers should discuss communication strategies with their patients and strive to reach a shared understanding of the manner in which technology can best augment and facilitate their individual communication and achievement of chronic care goals.

Telemedicine and secure electronic messaging are two relatively new forums for communication. While there is substantial variability among the means in which they are employed, these communication methods are widely utilized and have played key roles in evidence-based chronic care interventions. A 2015 Cochrane Review that examined the impact of interactive telemedicine on professional practice and healthcare outcomes found similar health outcomes in the management of heart failure using telemedicine compared to face-to-face or telephone delivery of care and noted a potential improvement in the blood glucose control of diabetic patients who had telemedicine integrated into their care [43]. Factors such as patient demographics, condition severity, disease trajectory, the general function of telemedicine interventions (e.g., monitoring vs diagnosis), and characteristics of healthcare systems and individual providers all influence the effectiveness of telemedicine.

Secure electronic messaging is often utilized by patients and providers to extend and/or augment the communication that occurs during office visits and is viewed by many organizations as a key element of providing access to care that is truly patient-centered [38]. As is the case with communication among healthcare team members, communication between patients and providers via different modalities should account for the variation in complexity and emotionality of information being conveyed, with a goal of matching the content of the communication with the method best suited to transmit it [38]. In addition, providers should seek to understand the characteristics that their individual patients use to define "good communication," being mindful of the

interpersonal variability that will likely exist among members of their patient populations. For example, some patients may place great value on easy, direct access to providers, frequent communication, and the flexibility provided by asynchronous communication through messaging, while others may prioritize longer face-to-face encounters of greater depth.

In addition to offering new avenues for direct patient-provider communication, technology can be used to augment the education and disease management communication strategies that patients receive from their chronic care providers. There are numerous evidence-based computer and Internet programs and websites that contain educational materials, peer support, and tactics for promoting disease management and prevention, many of which positively affect patient knowledge, self-efficacy, social support, and behavioral and clinical outcomes [44, 45]. Providers should be aware of these technological resources that are available to patients and can engage with patients to determine which resources best match their learning styles, educational needs, and motivation to manage their illnesses. Developing a working knowledge and inventory of vetted Internet and other technological sources can enable providers to direct patients to reputable sources of health information, thereby minimizing the interjection of inaccurate or unclear voices into patients' chronic illness conversations.

Specific Challenges and Special Situations Within Chronic Care Communication

There are situations that arise during the course of chronic care that require special attention to communication strategies to ensure optimal interaction, relationship building, and disease management. Recognizing these situations, and employing tactics to communicate effectively as they arise, allows for the ongoing development of relationships and productive information exchange that is crucial to successful chronic care and satisfying patient-provider outcomes.

Care Involving Family Members, Advocates, and Proxies

Just as providers arrive at patient encounters with the support of various members of the healthcare team, patients enter into these engagements with their own team of advocates and close contacts. While the levels of responsibility that these members of the patients' teams may take over communicating with providers varies based on the mental capacity, self-efficacy, and attitudes of patients, the communication principles that involve working successfully with them are fairly universal.

The involvement of patient companions in healthcare visits often facilitates communication, as companions can assist in building rapport with providers, advocating for patients, and ensuring accurate and thorough information exchange [46–48]. The majority of companion communication during visits is directly aimed at improving providers' understanding of patients' lives, symptoms, and conditions. Facilitative communication techniques employed by companions are "autonomy enhancing" in that they enable patients to take more ownership over their conditions and have more productive visits with providers. Companions can facilitate patient understanding by repeating providers' explanations and asking questions, can prompt patients to discuss topics, can introduce topics for discussion, and can clarify medical information and personal histories.

While companion involvement in patient-provider communication often exerts a positive influence, it can also introduce challenges. Competing visit agendas among patients and companions, variations and contradictions in information provided by patients and their companions, and issues of privacy and role ambiguity often complicate information exchange and rapport building [46]. In addition, there is significant variation among patients in the extent to which they would like family members and companions to be involved in their care, which can lead to confusion and frustration among all parties involved in communication. There are "autonomy-detracting" behaviors that create difficulties in communication [47, 48]. Companions may interrupt patients, include irrelevant information about their personal health or that of a third party, correct or blame patients in front of providers, attempt to take on an expert role that conflicts with that of the provider, or answer questions for patients without allowing them to respond. Companions may engage in inappropriate alliance building, intentionally or unintentionally attempting to persuade patients and/or providers to agree to agendas that are primarily based on the companions' opinions or preferences [47, 48].

As chronic care providers partner with their patients and patients' families to manage illness and promote well-being over time, they should be aware of, and actively manage, the complexity introduced into communication by the inclusion of companions in their patient interactions. There are several techniques providers can employ to capitalize on the positive impacts companions have while troubleshooting potential pitfalls. Helpful strategies include encouraging and welcoming companion involvement in consultations, ascertaining reasons why companions are involved from both patients' and companions' perspectives, and clarifying the roles of patients and companions at the commencement of consultations [23]. It is critical to respect patients' autonomy and preferences, with particular attention to the manner in which they would prefer sensitive information to be discussed and delivered. Highlighting helpful companion behaviors and

explaining methods by which companions can provide effective emotional, informational, and logistical support as part of the overall chronic care plan can ensure an effective team-based approach among providers, patients, and companions.

The use of tools before and during patient-companion-provider interactions may help to foster effective communication [23, 24]. A patient-companion pre-visit checklist to elicit and align perspectives prior to meeting with providers enhances patient-centered medical visit communication and improves the experiences of patients and their providers [24]. This checklist prompts patients and companions to separately identify medical concerns that they feel are priorities for visits and prompts patients to more specifically delineate the extent to which they expect their companions to be involved in visits and the roles they hope companions will play. Eliciting this information prior to visits, and updating it throughout the course of care for chronic conditions, allows providers to maximize the positive influence of patient companions on communication.

Bridging Differences in Language and Culture

While the topics of cultural humility and the provision of culturally competent care are broad and complex, they are associated with several key features of patient-provider communication in chronic care settings that are important to highlight. One situation in which cultural differences exert an overt influence over patient-provider communication is that in which the patient and provider are not fluent in the same language. Data from the US Census Bureau's 2011 American Community Survey Report demonstrated that, of the 292 million people age 5 and over, 61 million (21%) spoke a language other than English at home, and of these individuals, only 58% spoke English "very well" [49]. While providers often practice in communities with language patterns similar to their own and while conducting visits in the same language is optimal for ensuring that patients' communication needs are fully met, the prevalence and diversity of languages other than English create the common scenario in which providers and patients must bridge language gaps in order to communicate [50]. In these situations, utilizing professional interpreters either in person or by telephone is essential to ensuring effective communication [51–53]. The use of professional interpreters is associated with positive effects on communication, care plan comprehension, health resource utilization, clinical outcomes, mental illness management, and satisfaction with care [51–54]. Patients who receive care via interpreters do not differ significantly from those who meet with language concordant providers in their propensity to rate the care they receive as "excellent" or "very good" but are more likely to have questions about their care after their visits [50]. Even when using interpreters, providers should be mindful of the nuances of communication that can be lost in translation and take extra steps to ensure patients' needs have been met.

In addition to their direct effects on the languages used by patients and providers to communicate, cultural differences can exert other influences on the manner in which patients and providers interact [20, 55, 56]. The acknowledgement of, and willingness to embrace, those influences is essential to establishing the trust and effective communication that underlies successful chronic care relationships. Medical cultural competence, which is "the effective communication of diagnosis and treatment plans in a manner that is acceptable to patients from different cultural backgrounds," is associated with improved care and patient-provider satisfaction [57, 58]. The development of cultural humility or "an interpersonal stance that is other-oriented rather than self-focused, characterized by respect and lack of superiority toward an individual's cultural background and experience" is positively associated with the establishment of strong working alliances between patients and providers [58].

There are several culturally competent techniques that improve interpersonal interactions and communication [14]. Providers can explore and respect patient beliefs, values, meaning of illness, preferences, and needs, which helps bridge cultural differences and build relationships. They can work to build rapport and trust, find common ground with patients, remain aware of their own biases and assumptions, and become knowledgeable about different cultures and about health disparities and discrimination affecting minority groups [14]. While gaining awareness of the beliefs and values of different cultures is essential, it is also important that providers avoid cultural generalizations and communicate with each patient as an individual whose interaction with the healthcare system is shaped by a complex set of personal, cultural, socioeconomic, and situational factors [59].

Giving Bad News

Delivering chronic care is associated with the privilege of being involved in the lives of patients over time and thereby bearing witness to moments of joy, sorrow, adjustment, and change. Chronic care providers are often intimately involved with both positive and negative health changes in their patients and frequently are charged with delivering news that is disappointing, upsetting, or devastating to patients and their families. While the delivery of bad news is an area where careful communication is perhaps most crucial, it is also one in which effective communication is often difficult and in which many providers feel uncomfortable [19]. "Bad news" as it applies to the healthcare setting is "any information which adversely and seriously affects an individual's view of his or her future," and the disclosure of bad news to patients

is required of chronic care providers many times during their careers [60, 61]. In addition to the actual verbal task of informing patients of new distressing facts, the complex communication around bad news involves responding to patients' emotional reactions, involving them in ensuing decision-making, and remaining available for concerns that arise as patients and their family members come to terms with the implications of information that has been conveyed [61].

There are two sets of factors that influence the communication around breaking bad news [62]. One set involves issues that arise internally during the patient-provider encounter in which bad news is delivered. Within this setting, providers must evaluate patients' attitudes, wishes, and needs around illness and the news that is to be given. They must strike a balance between accurately disclosing news and sustaining hope, bearing in mind that both patient and provider emotions play a significant role in where that balance lies and the manner in which information is delivered in order to achieve it. The second set of factors involves those which are external to the patient-provider dyad but which shape the manner in which information will be given and received. These include family relationships (in particular, ascertaining the extent to which patients would like family and other support system members involved in, and potentially present for, the delivery of bad news) and systematic and institutional factors such as the amount of time available for conversations, locations and physical settings in which news is delivered, and the cultural and socioeconomic contexts in which patients and their providers are operating. Each of these factors should be carefully considered as providers determine the times, locations, and methods of communication that will most successfully facilitate compassionate and effective bad news delivery.

The SPIKES algorithm is an effective model for the delivery of bad news (Table15.2) [61].

Table 15.2 The SPIKES algorithm for the delivery of bad news [61]

*S*et up	Focus on encounter location and privacy
	Minimize disturbances or interruptions
	Gather appropriate medical team and family members
	Sit down and establish connection with patient
*P*erceptions	Ask open-ended questions to elicit what the patient knows
*I*nvitation	Assess how and to what extent patient would like to be informed about the facts at hand
*K*nowledge	Begin with a "warning shot" that there is distressing information to deliver
	Share the news using nontechnical words
	Provide information in small increments with periodic checks on patient understanding
*E*motions	Offer empathetic statements
	Use exploratory and validating responses
	Help patient connect and process thoughts
*S*ummarize and **s**trategize	Discuss next steps
	Take the information and context elicited in the first five SPIKES steps into consideration

Crucial Conversations and Conflict Management

During the course of chronic care, patients and providers may encounter conversations whose contents, outcomes, or contexts involve divergent viewpoints, uncomfortable topics, or heated emotions. A "crucial conversation" is defined as one in which stakes are high, emotions are high, and/or opinions differ [63]. The intimate relationships that often develop between chronic care providers and their patients, combined with the emotionally charged situations that can arise in healthcare, set the stage for the development of such conversations at various times during the provision of chronic care. Managing the conflicts that underlie these conversations requires specialized, intentional communication techniques in order to facilitate ongoing rapport and desirable outcomes for patients and providers.

While the development of conflict or "high stakes" communication is often fairly overt or easily anticipated in given situations, providers should be aware of cues within themselves and their patients that signal involvement in these types of conversation. Providers may notice their own emotions of anger, fear, or hurt and may feel physical cues of arousal, louder speech, or clenched muscles. In other conversation participants, they may observe behaviors consistent with "silence" (sarcasm, topic avoidance, withdrawing from the conversation, shortening answers to questions) or "violence" (interruption, hyperbolic or threatening statements, aggressive posture) [63]. Recognizing these cues allows providers to step back and meaningfully employ techniques to address arising conflict while managing their own emotions.

Several techniques can be used to diffuse emotionally charged patient-provider conversations and manage arising conflict. Pausing to reflect on the end goal of a conversation and then thinking through the best next thing to say in order to advance toward that goal can facilitate a more intentional, less emotionally charged dialog [63]. Sincerely apologizing when appropriate creates an atmosphere of mutual respect. Partnering with those in conversation to identify a mutual purpose can create a safe environment for negotiation and exchange. Specific techniques such as reflecting observed emotions (e.g., "You seem angry to me. Did I misread you?"), paraphrasing what has been said (e.g., "Let me make sure I'm understanding this correctly…"), and actively soliciting others' viewpoints (e.g., "How do you see it? I'd really like to know your opinions about this.") can be of great utility in diffusing and advancing difficult conversations in an open, respectful manner [63].

The communication around medical errors and unanticipated poor outcomes often generates crucial conversations with patients that are particularly difficult for many providers to navigate [11, 64, 65]. Patients may have powerful and complex reactions to these situations, as the trust that they have previously implicitly placed in their medical providers creates a unique and somewhat vulnerable relationship [65]. Direct, clear communication, preparing for and openly receiving patients' emotional reactions, and summarizing an explicit proactive plan for follow-up and ongoing evaluation are helpful features in the communication of medical errors to patients [11]. Patients who are communicated with fully and clearly regarding medical errors are less likely to change physicians and have greater overall satisfaction [64]. Apology, open communication, and a commitment to continue to work on patients' behalves if this is desired mitigate the fear, loss of trust, and isolation that patients may feel following these situations [65].

Conclusion

As chronic care providers foster meaningful relationships with patients and seek to effectively impart the "special knowledge" to which Steinbeck alluded in his letter, they are faced with a complex and nuanced task that continues to evolve in the ever-changing healthcare landscape. They must work to optimize interactions and exchange information across several forums, ranging from the intimate conversations of patient-provider dyad encounters to the more complicated choruses that characterize group and team-based care. While the goal of effective patient-provider communication is a daunting one, it is also one wherein much of the satisfaction of relationships between patients and providers lies, and its successful achievement enhances the lives of providers and the patients they serve.

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Ambulatory Care

16

Nicholas P. Shungu

Background and Overview

Chronic Disease in the Outpatient Setting

Chronic diseases are generally defined as conditions with clear etiologies that last more than 3 months, have a protracted clinical course, evolve over time, and do not self-resolve. The development of a chronic disease is impacted by genetic susceptibility as well as behaviors and environmental factors. The progression of chronic disease is highly variable and influenced by socioeconomic status, education, employment, and environment [1]. The most common chronic diseases seen in the outpatient setting include hypertension, hyperlipidemia, depression, ischemic heart disease, diabetes mellitus, obesity, osteoarthritis, and asthma [2, 3].

This chapter provides an overview of outpatient practices and models regarding chronic disease, some of which are elaborated upon in other chapters in the book.

Demographics of Chronically Ill Patients

As of 2012, about half of all adults—117 million people—had one or more chronic health conditions, with one in four adults having two or more chronic health conditions requiring concurrent management [4]. Older patients are more likely to have an increasing number of medical problems with three-quarters of individuals aged 65 years and older having multiple chronic conditions. Seven of the top ten causes of death in 2010 were due to chronic diseases with heart disease and cancer accounting for nearly half of all deaths [5]. African-Americans and Latinos are more likely than Whites to develop chronic diseases such as hypertension, hyperlipidemia, diabetes, and asthma [6, 7]. This is due to a complex interplay of factors including genetics, socioeconomic status, access to healthcare, literacy levels, implicit bias, and discrimination. Military studies demonstrate that despite equal access to free healthcare, African-Americans maintained significantly higher prevalence rates of chronic disease [8]. Regardless of race, low socioeconomic status is a predictor of worse functional status in those living with chronic disease [9].

Cost of Chronic Disease

Eighty-six percent of all US healthcare spending in 2010 was for people with one or more chronic medical conditions [10]. Approximately $1.7 trillion was spent in 2012 on chronic diseases [11]. The total cost of heart disease and stroke alone in 2010 was $315 billion [12]. The total cost of diabetes in 2012 was $245 billion, including $176 billion in direct medical costs and $69 billion in decreased productivity. Decreased productivity includes costs associated with people being absent from work, being less productive while at work, or not being able to work at all because of chronic illness [13]. Despite these exorbitant costs, care and care coordination are often suboptimal for the chronically ill, contributing to frequent hospitalizations and emergency room visits and poor outcomes [14].

Settings for Providing Chronic Disease Care

Most chronic illness care is provided in the primary care setting [15]. Sixty percent of outpatient visits are to primary care physicians, and most of these visits involve management of chronic disease. By comparison, 20% of outpatient visits are made to nonsurgical specialists [16]. Some evidence suggests that patients have better outcomes if specialists manage their myocardial infarction, stroke, and asthma but not necessarily for hypertension, diabetes, chronic obstructive pulmonary

N.P. Shungu (✉)
Department of Family Medicine, Medical University of South Carolina, Charleston, SC, United States
e-mail: shungu@musc.edu

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disease, unstable angina, and low back pain [17]. Chronic disease outcomes for patients managed by generalists are similar to those managed by specialists as long as the practice settings are comparable [18, 19].

Almost 90% of outpatient visits are made to physician or group practices with the remaining 10% to healthcare corporations, hospital outpatient clinics, and HMOs. Two percent of visits are to academic health centers. Ninety-six percent of outpatient visits are with a physician. Advanced practice providers, such as physician assistants, nurse practitioners, and midwives, are involved in 6% of office visits, either independently or with a physician [16].

Outpatient Care Team Members

Primary Care Provider

Each patient has an ongoing relationship with a primary care provider who provides continuous and comprehensive care. This provider is usually a physician but can also be an advanced practice provider. The provider leads a team of caregivers who collectively take responsibility for patient care.

Clinical Support Staff

Clinical support staff are critical to optimal provision of chronic disease management and include medical assistants, nurses, clerks, referral specialists, communications team members, nutritionists, phlebotomists, and radiology technicians. Medical assistants room patients, measure vital signs, review medications, take an interim history, and play an increasingly important role in addressing quality metrics and health maintenance. Standing orders that empower non-physician team members to address chronic disease health maintenance issues such as immunizations or blood work are correlated with more effective care [20]. Medical assistants may also assist patients with adherence to chronic disease self-management, both during office visits and through non-office communication. Support staff also includes a communications team who schedule appointments and triage patient messages. A team clerk helps to coordinate specialist referrals and the sending and receiving of faxes and mail.

Care Manager

Care management is a crucial aspect of high-quality chronic illness care. Care managers are usually social workers or nurses who help patients to access and navigate the healthcare system. They coordinate clinical and nonclinical services for the patient which are rendered in the primary clinic, home, community, or by outside practitioners. They teach self-management skills, coordinate care transitions, address barriers to care, and provide psychological support [21]. Care managers improve outcomes, reduce emergency department visits and hospitalizations, and decrease spending for patients with chronic disease [22, 23]. Registries are often used to identify patients who need care management such as those with multiple emergency department visits, a high number of medication claims, or certain chronic illnesses.

Administrative Staff

Practice managers and other administrators oversee finances, quality improvement, and continuous practice transformation in the outpatient setting. These individuals balance the resources needed to achieve the mission of the practice with the financial bottom line that keeps the practice running.

Clinical Pharmacists

Clinical pharmacists are underutilized in the primary care setting despite evidence showing they improve medication use and overall care in patients with chronic disease [24, 25]. Pharmacists can assume primary management of medications such as those used for anticoagulation, hypertension, and diabetes. Collaborative practice agreements (CPAs) allow providers to refer patients to pharmacists who are guided by established care protocols [26]. CPAs are a strategy to manage chronic disease in areas with limited access to healthcare, as well as a tool to improve care in better-resourced areas. Pharmacists also play a key role in post-hospitalization transitions visits, when medication errors are common. They review mediation lists for interactions and strategize solutions for patients who have allergies to or cannot afford prescribed medications.

Outpatient Chronic Care Models

Patient-Centered Medical Home (PCMH)

The term “medical home” was introduced in 1967 by the American Academy of Pediatrics to describe a single centralized source of care and medical record for children with special healthcare needs [27]. The American College of Physicians embraced the term and issued a PCMH report in 2006 [28]. The PCMH is a model of primary care that is patient-centered, comprehensive, team-based, coordinated, accessible, and focused on quality and safety. Practices go through a voluntary recognition process by a private

nongovernmental entity called the National Committee for Quality Assurance (NCQA) to determine whether they have the capabilities to provide patient-centered services consistent with the medical home model. PCMHs increase quality of care and improve the experience of patients and staff. The Veterans Administration implementation of the PCMH model increased patient satisfaction, improved clinical quality, and had less staff burnout and less utilization of emergency departments [29]. Reduced cost and improved quality with implementation of the PCMH model have been repeated in other settings [30]. The PCMH is based on five core principles, as described below [31].

Comprehensive Care

The American Academy of Family Physicians defines comprehensive care as "The concurrent prevention and management of multiple physical and emotional health problems of a patient over a period of time in relationship to family, life events and environment [32]." Providing comprehensive care requires a team of care providers including physicians, advanced practice providers, nurses, pharmacists, nutritionists, social workers, educators, and care managers. Larger practices assemble large and diverse teams, while smaller practices build virtual teams by linking to providers and services in their communities [33]. Each patient has an ongoing relationship with a personal physician who provides the patient's healthcare needs and coordinates care with other appropriate professionals. Physicians serve as leaders of the team who collectively take responsibility for the ongoing care of patients. Non-physician personnel are involved in patient self-management strategies and coordinating routine maintenance tasks such as blood work or foot exams.

Patient-Centered Care

In contrast to traditional disease-oriented care, patient-centered care is oriented around the patient's goals. It is based on the premise that patients are their own principal caregivers for chronic illnesses [34]. A focus is placed on maximizing the health goals of individual patients who have unique sets of risks, conditions, and priorities [35]. This is accomplished by ascertaining a patient's health outcome priorities, identifying diseases and other modifiable factors impeding these goals, communicating the likely effect of treatments, and guiding shared decision-making informed by this information [36]. Patient-centered care involves a balance of applying evidence-based guidelines in a manner that integrates a patient's cultural, economic, and biopsychosocial background. By including the patient's priorities into personalized care plans, providers and patients work collaboratively to increase self-management capacity [37]. Patients and families can even participate in quality improvement activities at the practice level. Community-based participatory research engages and seeks input from community members, organizations, and other stakeholders on important health issues that affect patients.

Coordinated Care

Effective care requires integration across the complex healthcare system which includes primary care providers, specialists, hospitals, home health, nursing homes, community-based services, and the patient's family. Patient registries, information technology, and health information exchanges help facilitate coordination so that patients get the appropriate care at the appropriate time. The role of a PCMH provider is both to direct appropriate specialist consultation and to help patients interpret and comprehend care recommendations from multiple specialists [38]. The PCMH care team is also charged with understanding that community factors such as homes, schools, work sites, health departments, access to healthy foods, accessibility of exercise, and the legal environment may impact health. As such, care coordination involves linking patients with community-based resources such as exercise programs, senior centers, self-help groups, food pantries, and mental health resources [39].

Accessible Services

Enhanced access to care is central to the PCMH model, and practices must provide timely appointments and expanded hours to serve patients including 24-h access to care at least by telephone or electronic communication, including for those with special communication needs. PCMHs also provide convenient on-site services such as phlebotomy, radiology, physical therapy, and behavioral therapy.

Quality and Safety

PCMHs are dedicated to quality improvement and optimizing patient safety. Practitioners are expected to use evidence-based medicine and clinical decision support tools to guide decision-making and are held accountable to quality performance measures and continuous improvement. Information technology is central to this quality improvement process. Electronic medical records (EMRs) can remind practitioners to apply evidence-based guidelines, and patient education materials and care plans can be accessed electronically. EMRs provide data on performance metrics for individuals or teams and allow for targeted interventions. Physician champions or quality improvement coaches can lead practice-wide quality improvement efforts targeting specific measures, a role that involves gathering input from all members of the team while motivating everyone to remain interested in quality chronic disease management [40]. Clinical champions do not have to be physicians, but physicians have the most success in driving sustainable change in chronic disease management [41]. PCMHs are encouraged to share their data publically both to demonstrate quality and to encourage population health management with other

stakeholders. Another core component of quality and safety is to measure and respond to patient satisfaction measures.

Extensivist Care Centers

Extensivist care centers seek to reduce hospitalizations in high-risk populations by focusing on patients recently discharged from the hospital or those with chronic conditions who are perpetually at high risk for hospitalization. Extensivist physicians lead a team that manages 100–200 high-risk patients. They generally split time between the outpatient setting, seeing inpatients as a hospitalist and guiding subacute care in skilled nursing facilities. The intent is that the same physician cares for the patient through all of these care settings. This model saves money, decreases length of stay, and reduces readmission rates [42]. It works well in systems like Medicare Advantage that use capitated payments, meaning that providers are paid a lump sum per patient which incentivizes the practice to reduce the costly complications of chronic disease.

Complex Care Centers

Complex care centers are similar to extensivist care centers in that they serve high-risk populations with multiple chronic diseases and frequent emergency room visits or hospitalizations. They differ in that complex care teams generally follow patients only in the outpatient setting. Complex care centers have existed previously for children and adults with complex childhood-onset conditions such as cystic fibrosis, sickle cell disease, and developmental disabilities. Adapted to adults with chronic disease, complex care centers improve quality and reduce costs. Virginia Commonwealth University demonstrated a 44% decline in inpatient admissions, a 38% decrease in emergency room visits, and annual cost savings of $10,769 per patient in its first year of creating a complex care center. Teams include physicians, nurse practitioners, behavioral health specialists, pharmacists, and social workers who emphasize continuity, accessibility, and trust as a way to reduce emergency department visits.

Direct Primary Care

In the direct primary care model, patients pay a monthly or annual fee directly to a medical practice and are provided with unlimited clinical, lab, specialist, care coordination, and case management services. This exchange does not involve insurance companies which significantly reduces practice overhead [43]. The direct primary care model reduces hospitalizations, emergency room visits, and specialist visits, which reduces healthcare costs [44]. A criticism of this model is that it does not provide patients with coverage for emergency room visits or hospitalizations. In addition, clinics are dependent on charitable contributions or higher fees from wealthier patients in order to provide services to patients with limited finances.

Outpatient Chronic Care Payment Models

Fee-for-Service

The fee-for-service (FFS) model has been the traditional model of payment in this country since the 1960s. In 2013, an estimated 95% of office visits were reimbursed using the FFS modmoniel [45]. In this model, healthcare providers are paid for services like office visits, labs, and procedures based on predetermined fees. Payers assume most of the financial risk, as the providers generally determine what services are provided and payers must reimburse, though payers may deny treatments or tests they deem unnecessary or too expensive. Practitioners may be asked to justify a treatment or test before payers will cover it in a process called prior authorization. Providers are paid based on services provided without regard to patient outcomes.

Capitation/Bundled Payments

The capitation model is one in which a managed care organization such as a health maintenance organization (HMO) or preferred provider organization (PPO) pays providers a fixed lump sum per patient. If physicians render care to patients for less than the lump sum, they make a profit. If the cost of patient care is more expensive than the lump sum, the physician loses money. The theory behind capitation is that it can control costs and eliminate waste by incentivizing physicians to provide only medically necessary care at the cheapest possible cost. Capitation offers providers more freedom to determine the appropriate care for patients without the need for checkpoints such as prior authorizations. It is also beneficial for payers in that setting budgets are significantly simplified. For patients, these plans limit provider choices to only those who are in the HMO or PPO network. Critiques of the capitation model include the concern that the provider assumes the financial risk for patients whose care costs more than the lump sum and the possibility that there is incentive to provide substandard care in order to maximize revenue. The 1990s saw first a rise in the implementation of the capitation model, and then a subsequent abandonment as costs could not be contained. Healthcare economists agree that there is a sweet spot for capitation but where that spot lies has yet to be determined (Fig. 16.1).

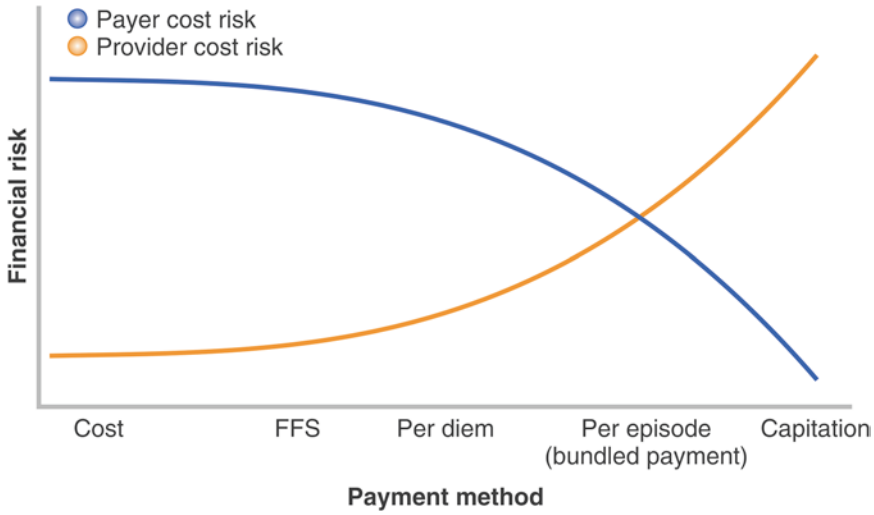

Fig. 16.1 Financial risk of care for provider and payer, by payment method (Adapted from: Frakt and Mayes [102])

Under bundled payments, payers provide a payment for the combined services for an episode of care, rather than paying for each service individually. For example, a bundled payment for an acute myocardial infarction might incorporate cost of hospitalization, procedures, post-discharge transition visit, and cardiac rehabilitation. Providers are again incentivized to avoid unnecessary treatments since they assume the financial risk of each episode of care. Bundled payments differ from capitation in that providers assume the financial risk of cost of each episode of care, but the payer assumes the risk for the number of episodes.

Accountable Care Organizations

Accountable Care Organizations (ACOs) are networks of providers who are responsible for the quality and cost of care of a defined group of patients. Multiple provider organizations unite to share accountability and rewards with a focus on coordinating inpatient and outpatient care. Services are provided in a FFS model, but providers are eligible to receive shared savings based on meeting quality and risk adjustment standards. Providers assume financial risk, but unlike the capitation model, they are incentivized by quality bonuses to provide high-quality, low-cost care. They receive bonuses or penalties if their spending is below or above the benchmark, respectively. The ACO model grew in popularity in the early 2010s. Early data suggest moderate cost reductions, especially in areas with high baseline spending such as in some geographic parts of the country [46]. The Medicare Shared Savings Program (MSSP) allows traditional fee-for-service organizations to enter into an ACO model where savings will be shared between Medicare and the ACO members. As of 2015, there were over 400 MSSP ACOs covering seven million beneficiaries, with a combined savings of $338 million over the previous year [47].

Performance and Quality

The Department of Health and Human Services has a goal that 50% of Medicare payments will be tied to quality or value through non-FFS payments by the end of 2018 [48]. The Healthcare Effectiveness Data and Information Set (HEDIS) is a widely used set of measures that determines quality of care, including in chronic disease. The NCQA develops HEDIS criteria, used by over 90 percent of the nation's health plans as a barometer of quality [49]. HEDIS data is used by insurers to rate practices and determine reimbursement. In addition, the Centers for Medicare and Medicaid Services (CMS) developed the Physician Quality Reporting System (PQRS) which uses individual data similar to HEDIS measures applied to 22 PQRS conditions including diabetes, heart failure, and coronary artery disease (Table 16.1). Practices can receive bonus payments for meeting these measures or financial penalties for not reporting them. The Medicare Access and CHIP Reauthorization Act (MACRA) passed in 2015 incorporated the PQRS measures into a new Merit-based Incentive Payment System (MIPS), which uses performance scores that consider quality, the use of technology in patient care, clinical practice improvement activities, and resource use. Practices are required to report quality data on at least six clinical measures. By 2022, MIPS incentive payments are forecasted to provide high-performing practices with a bonus equaling 9% of their CMS reimbursements with poorly performing clinics penalized a sum amounting to 9% of reimbursements.

Table 16.1 Examples of chronic care Physician Quality Reporting System (PQRS) quality measures

Measure	Measure description
Diabetes: hemoglobin A1c poor control	Percentage of patients 18–75 years of age with diabetes who had hemoglobin A1c > 9.0% during the measurement period
Diabetes: eye exam	Percentage of patients 18–75 years of age with diabetes who had a retinal or dilated eye exam by an eye care professional during the measurement period or a negative retinal or dilated eye exam (no evidence of retinopathy) in the 12 months prior to the measurement period
Diabetes: medical attention for nephropathy	The percentage of patients 18–75 years of age with diabetes who had a nephropathy screening test or evidence of nephropathy during the measurement period
Diabetes: foot exam	Percentage of patients aged 18–75 years of age with diabetes who had a foot exam during the measurement period
Chronic obstructive pulmonary disease (COPD): inhaled bronchodilator therapy	Percentage of patients aged 18 years and older with a diagnosis of COPD who have an FEV1 less than 60% predicted and have symptoms who were prescribed an inhaled bronchodilator
Asthma: pharmacologic therapy for persistent asthma—ambulatory care setting	Percentage of patients aged 5 years and older with a diagnosis of persistent asthma who were prescribed long-term control medication
Heart failure (HF): angiotensin-converting enzyme (ACE) inhibitor or angiotensin receptor blocker (ARB) therapy for left ventricular systolic dysfunction (LVSD)	Percentage of patients aged 18 years and older with a diagnosis of heart failure (HF) with a current or prior left ventricular ejection fraction (LVEF) <40% who were prescribed ACE inhibitor or ARB therapy either within a 12-month period when seen in the outpatient setting or at each hospital discharge
HIV/AIDS: sexually transmitted disease screening for chlamydia, gonorrhea, and syphilis	Percentage of patients aged 13 years and older with a diagnosis of HIV/AIDS for whom chlamydia, gonorrhea, and syphilis screenings were performed at least once since the diagnosis of HIV infection
Coronary artery disease (CAD): antiplatelet therapy	Percentage of patients aged 18 years and older with a diagnosis of coronary artery disease (CAD) seen within a 12-month period who were prescribed aspirin or clopidogrel
Adult kidney disease: blood pressure management	Percentage of patient visits for those patients aged 18 years and older with a diagnosis of chronic kidney disease (CKD) (stage 3, 4, or 5, not receiving renal replacement therapy [RRT]) with a blood pressure <140/90 mmHg OR ≥140/90 mmHg with a documented plan of care

Adapted from 2016 PQRS Measure List. Baltimore (MD). Copyright 1995–2015 American Medical Association. 2016 [cited 10/21/16]. Available from: https://www.cms.gov/apps/ama/license.asp?file=/PQRS/downloads/PQRS_2016_Measure_List_01072016.xls

Evaluation and Management of the Chronically Ill Patient in the Outpatient Setting

The assessment and treatment of a chronically ill patient in the outpatient setting where time is limited can be overwhelming to many providers. Skilled outpatient providers learn the art of providing good patient care by being attentive and efficient without seeming to be rushed or rude.

Prioritizing Multiple Complaints

Many patients have multiple chronic issues that need long-term management as well as frequent acute concerns. It is not possible to address everything during an office visit. One analysis found that applying guideline recommendations for ten common chronic diseases would take 10.6 h a day [50]. A pragmatic approach is to set realistic expectations at the beginning of the visit by letting the patient know how much time is allotted for the visit, negotiating an agenda, and addressing the most important issues first. Providers can help focus a visit by asking the patient with multiple complaints to prioritize his or her concerns. Providers should establish a follow-up plan that sets the agenda for the next visit which is scheduled before the patient leaves [51].

Physical Exam

Physical examinations for patients with chronic stable disease may be limited to a targeted exam focusing on organ systems involved by their disease processes or directed toward new concerns. Clinics should be outfitted with equipment such as blood pressure cuffs, scales, and examination tables that accommodate patients of all body sizes and

mobility levels. The Americans with Disabilities Act of 1990 requires that individuals with mobility disability are provided full and equal access to medical services, so rooms should accommodate wheelchairs or scooters with at least one adjustable exam table that can be lowered to wheelchair level to facilitate transfer. Staff must be available to assist and transfer patients in an ergonomically optimal manner. A full list of necessary accommodations for disabled patients in the medical setting, including those with hearing and visual impairment, has been published by the US Department of Health and Human Services [52].

Functional Assessment

Comprehensive care of the chronically ill patient in the outpatient setting includes assessing his or her functional abilities, usually using the activities of daily living (ADL) and independent activities of daily living (IADL) scales. ADLs are considered the essential elements of self-care and include bathing, dressing, toileting, transferring, grooming, and feeding [53]. Difficulty with any of these activities can increase the likelihood that the patient may need long-term care. IADLs are necessary to live independently and include self-administering medication, grocery shopping, preparing meals, using the telephone, driving or transportation, handling finances, housekeeping, and laundry [54]. Individuals who cannot perform IADLs may need in-home support services from family members or professional service providers. Both the ADL and IADL assessment can be done by a medical assistant in the office within a matter of minutes.

Medication Reconciliation

Medication reconciliation should be completed at each outpatient visit involving patients with chronic disease, who are often on multiple medications and are at an increased risk of medication side effects, drug interactions, and incorrect use due to complicated regimens. They also may not be able to fill prescriptions because of financial or transportation barriers. Others may stop taking prescribed medications because they do not perceive them to be effective or because adhering to multiple dosing schedules is tedious. Only 50% of prescribed medications are taken as directed and up to 30% are never filled [55]. Suboptimal adherence is a significant contributor to hospitalizations as well as morbidity and mortality. Additionally, practitioners prescribing multiple medications are more likely to prescribe medication inappropriately. A Veterans Affairs study found that 85% of patients over the age of 65 were receiving at least one potentially inappropriate prescription [56]. Inappropriate prescriptions cost billions of dollars and can cause increased morbidity, adverse drug events, hospitalizations, and mortality [57].

Care that involves a pharmacist reduces the prescription of inappropriate medications, especially among the elderly [58]. Such care can also improve glycemic, blood pressure, and cholesterol control [59] and improve medication adherence [60]. While medication reconciliation done by a pharmacist provides an additional level of expertise, most clinics cannot provide this service and depend on medical assistants or nurses for this role.

Management Issues in Chronic Disease

Care in the outpatient setting should be patient-centered which includes understanding where the patient is coming from and what is important in his or her life.

Cultural Awareness

Cultural humility is defined as "A lifelong commitment to self-evaluation and self-critique, to redressing the power imbalances in the patient-physician dynamic, and to developing mutually beneficial and non-paternalistic clinical and advocacy partnerships with communities on behalf of individuals and defined populations" [61]. Working with patients in a respectful way that promotes understanding of religious, cultural, and family belief systems can increase their capacity for self-management.

Assessing Motivation

Motivational interviewing involves assessing barriers to change and goals that are proposed by the patient rather than the clinician and is a proven method for promoting behavioral change in persons with chronic disease [62].

Health Literacy

A patient's literacy level including health literacy significantly impacts chronic disease management and should be assessed in the outpatient setting. Poor health literacy is a stronger predictor of a person's health than age, income, employment status, education level, and race [63]. Fourteen percent of US adults cannot read, and 35% have a basic or below basic health literacy level [64]. Literacy should never be assumed, and literacy levels can be assessed in a nonjudgmental way such as asking patients to fill out a form or read the print on a medication bottle. The teach-back method is a strategy to confirm comprehension of instructions in a patient

with limited health literacy and can also be used with patients who are deaf or do not share a common language with the provider.

Urgencies in the Office

As outpatient medical homes manage more sick patients with chronic disease, it is essential that practices are able to handle acute problems. A trained staff should be able to assess and stabilize a patient with a serious acute problem while arranging for transport to a higher level of care. The staff need to be familiar with the location and function of emergency equipment and can benefit from periodic emergency drills.

Mental Health Emergencies

One in four American adults lives with a chronic psychiatric illness which places them at increased risk of chronic disease, and individuals who do have chronic medical illnesses are more likely to develop depression. An estimated 5% of ambulatory care visits and 10% of emergency department visits involve a primary psychiatric disorder [65]. Outpatient clinics need to be equipped to handle mental health emergencies, and can implement behavioral response teams of nurses or social workers who are trained to assess patients in a mental health crisis and de-escalate volatile situations with transfer to a higher level of psychiatric care if indicated.

The PCMH model has been shown to decreased costs and emergency room visits in patients with comorbid chronic medical and psychiatric illness [66].

Care of Patients with Intellectual Disabilities

People with intellectual and developmental disabilities (IDD) are at higher risk of developing chronic diseases and have decreased life expectancy. They receive most of their medical care in the outpatient primary care setting, and the PCMH has been shown to decrease their hospital utilization [67]. Care managers coordinate home- and community-based services for such individuals [68]. A similar approach works for individuals with cognitive deficits such as those suffering from dementia.

Health Information Technology in the Office

Documentation

The proportion of US physicians using electronic health records (EHRs) increased from 18% to 78% between 2001 and 2013, and 94% of hospitals now use certified EHRs [69]. While EHRs improve legibility, broaden chart access, serve as reminders for health maintenance, provide a safeguard for allergies, and generate quality reports, they also can impair the connection between patient and provider, increase documentation time, and decrease revenue for those who are unable to optimize their function [70]. Several strategies make documentation less of a burden including using templates, dropdowns, order lists, and training from document improvement specialists or proficient colleagues. There is an art to using the computer in the outpatient setting. Triangulating the computer between the provider and patient facilitates better connection and allows literate patients to be involved in the documentation process. Voice recognition technology may be a cost-saving measure for documentation, although studies in the outpatient setting show mixed results [71–74]. Medical scribes are used in outpatient offices but have not been studied in the primary care setting [75].

Billing and Coding

Physicians must be familiar with the Current Procedural Terminology (CPT) coding and documentation requirements to bill appropriately for the work they do in outpatient chronic care management [76]. When compared to expert coders, family physicians undercode a third of their return visits, with the majority being qualifying 99,214 visits that were billed as a 99,213 [77]. Wellness visits can be billed with a −25 modifier if two or more chronic conditions require medication refills and either blood work or imaging [78]. People with chronic disease require a significant amount of counseling, and these visits can be billed at higher levels based on time spent with the patient. Post-hospitalization transition visits can be reimbursed at higher levels with the appropriate documentation [79].

In 2015, Medicare began paying for chronic care management services outside of office visits using the CPT code 99490. This program, available for beneficiaries with two or more serious chronic conditions, pays for 20 min of care coordination, including telephone calls, electronic communication, and chart review per month per beneficiary. Either the physician or any other staff who are part of the patient's care team can assume this role. Care coordination requires an evolving care plan that is available electronically, 24/7 communication access, and management of care transitions [80].

Correct billing and coding are imperative for the financial survival of an outpatient practice, and periodic educational sessions with compliance officers or coding specialists or internal auditing with feedback to providers can optimize this aspect of practice.

Communication

EMRs improved the capacity for clinicians and patients to securely communicate health information. Electronic portals allow patients to view test results, schedule appointments, request refills, and send messages between appointments and allow physicians to communicate easily in coordinating care for shared patients. Patients and physicians generally view electronic communication favorably because of the ease of exchanging information. Patients report improved self-reported efficacy in chronic disease management with electronic communication [81]. However electronic patient portals show mixed results regarding their impact on chronic disease management quality metrics [82, 83]. Patients with low literacy levels, lack of Internet access, or language barriers are at risk for further health disparities as EMRs become widespread. For some patients, communication by letter or by telephone may be preferred.

Improving Quality of Care

Quality metrics are a growing part of outpatient care, and reimbursement will be increasingly linked to quality of care and be available to the public. Advances in information technology have led to an exponential increase in quality measures related to patient care, and practices are challenged to use this abundance of data in a meaningful way. Clinical analytics can evaluate the effectiveness of interventions, assess rates of preventive practices and screening, identify individuals who are most likely to benefit from care management, and detect patients at risk for disease complications [84]. Clinical performance dashboards display performance metrics and provide timely feedback to physicians. Quality improvement coaches are increasingly being integrated into PCMHs.

Healthcare systems are implementing organizational transformational models to promote a culture of change and continuous improvement. Three examples used in the primary care outpatient setting are Six Sigma, Lean, and Total Quality Management (TQM). Other models such as ISO 9000, Zero Defects, and the Baldrige Model have been implemented in healthcare but have limited data in outpatient chronic disease management.

Six Sigma

Six Sigma is a strategy that minimizes waste, improves satisfaction, and maximizes profits [85]. Six Sigma observes a process to estimate process variation, defines acceptable limits for variation, and predicts performance. Processes are continuously improved, designed, and monitored using a five-stepped approach: define, measure, analyze, improve, and control. For a given improvement project, historical data are reviewed, the scope of the problem is defined, quality performance targets are agreed upon, interventions are implemented, data are collected to measure process improvement, and validated measures are developed as successful interventions are integrated into standard processes. Six Sigma processes decrease wait times, increase efficiency during office visits, reduce time between hospitalization and follow-up visits, and improve transmission of hospital discharge summaries to primary care practices [86–88].

Lean

Adapted from the Japanese automobile manufacturing industry, Lean principles are used to improve quality of care in the healthcare setting [89]. Lean has significant overlap with Six Sigma but differs in its emphasis on customer satisfaction and elimination of waste and includes input from all workers in the organization with leaders showing humility and openness in learning from others. There is constant evaluation of process and a belief that systems can always be improved with emphasis placed on identifying root causes of a problem by mapping a process from start to finish, identifying imperfections and waste, and then asking why these happen. Rapid experiments are planned and implemented, data is collected and analyzed, and changes are implemented if experiments are found to be successful and add value. Lean methodology has been successfully used in the primary care setting to implement transformation of clinics into PCMHs [90], to improve care in people with diabetes and blood pressure, and to reduce emergency room visits [91].

Total Quality Management

Total Quality Management (TQM) gained attention in the 1980s and is based on the mind-set that improvement is dependent on forward effort from all members of the organization. TQM is based on the concept that success is based on customer care and my focus on issues like patient satisfaction, length of stay, and cost of care. TQM is achieved through continuous improvement, teamwork, and feedback to all members of the organization regarding desirable outcomes. TQM initiatives have been shown to reduce hospital admissions for adults with chronic disease and depression [92].

Creating a Culture of Change

Practice transformation depends on creating a culture of change with all employees comfortable with and appreciated for their contributions to continuous quality improvement. Creating a culture of change involves training all employees, not just physicians and managers, in the lexicon and rationale of a transformational care model. All office staff members are involved in the identification of projects and their design, implementation, and analysis. The plan-do-study-act (PDSA) approach is integrated into most transformation models and can be adopted by practices that lack the ability to train all staff in transformation methodology [93]. PDSA interventions are generally designed and implemented by a subset of individuals rather than on a practice-wide level and involve identifying a problem, planning how it will be addressed and measured, doing (carrying out) the intervention, studying the results, and acting by either modifying and repeating the PDSA cycle, adopting the changes throughout the practice, or abandoning the idea and starting afresh. Once best practices are established through PDSA cycles, friendly competitions among care teams can remind and motivate team members to integrate the new changes until they become standard practice. In this and all quality improvement projects, the culture of change is built on mutual respect and the welcoming of perspectives and ideas from all office staff members, and fostering a shared belief that changes will positively impact the lives of patients and improve the workplace.

Transitional Care

Transitional care seeks to avoid rehospitalization of chronically ill patients as they move from one site of care to another, especially in the vulnerable period of time right after hospital discharge [94]. In 2009, approximately 20% of Medicare beneficiaries discharged from hospitals were readmitted within 30 days with 34% readmitted within 90 days [95]. Nearly 13% of Medicare beneficiaries discharged from hospitals experience three or more provider transfers during a 30-day period [96]. These potentially unavoidable hospitalizations cost Medicare $15 billion annually [97, 98].

The Coleman Model offers an evidence-based approach to transitional care with impressive outcomes and focuses on four key pillars: medication self-management, a patient-centered record, primary care and specialist follow-up, and knowledge of warning signs and symptoms indicative of worsening condition [99]. Patients or their caregivers are provided with detailed instructions before hospital discharge, which accompanies them to follow-up visits and facilitates communication with the follow-up physician. A transition coach who is often an advanced practice provider with training in chronic disease management meets the patient before discharge and reviews medications, the discharge checklist, unmet needs, and self-management strategies including signs of worsening of their health condition. Transition coaches call the patient at least three times in the 24 days after discharge to make sure the patient has received prescribed medications and services, understands the treatment plan, and feels empowered to address questions or preferences in care. This model reduces hospitalizations by 20–50% during the 6 months after discharge, improves functional status and quality of life in over 50% patients, and significantly reduces healthcare costs [100, 101].

Summary

Effective and cost-efficient care of patients with chronic disease requires robust and effective outpatient management. The outpatient setting affords the opportunity to innovate with new models of how care is delivered including team-based care and the patient-centered medical home and will be the centerpiece of Accountable Care Organizations and other initiatives to provide low-cost, high-quality care. Quality metrics and efficiency measures will be key to continued innovation in this most important theater of care delivery.

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Emergency Care

17

Mary R. Mulcare

Introduction

Emergency care is defined as "any healthcare service provided to evaluate and/or treat any medical condition such that a prudent layperson possessing an average level of knowledge of medicine and health, believes that immediate unscheduled medical care is required" [1]. Emergencies can happen to anyone at any time, and people with chronic conditions may be especially prone to acute changes in health status. Emergency medicine is the medical practice of handling such events. This care may be provided in the field by emergency medical services (EMS) or in an emergency facility. Larger hospitals are staffed by physicians trained in emergency medicine, while smaller hospitals, rural facilities, and urgent care centers may be staffed by general internists, family physicians, or advanced practice providers (APPs).

The scope of emergency medicine practice has broadened over the years, mostly due to the increased medical complexity of patients seeking care in emergency departments (EDs) and an increase in ED utilization across the population, irrespective of insurance status or age [2, 3]. As the population ages, the number of older adults with chronic medical diseases and multiple comorbidities will increase. Between 2012 and 2060, the population of adults 65 years of age and older is expected to more than double to 92 million [4]. This aging of the population, along with increasing diversity of the people and growing international migration [4], will likely increase the need for emergency care [5].

Emergency facilities across the country are already overcrowded relative to the resources available, and there is significant interest in managing the populations most likely to come for emergency care. People with chronic illnesses are often high utilizers of the healthcare system, including emergency care for exacerbations of illness [6], which is a significant driver of healthcare costs [5].

The Emergency Medicine Treatment & Labor Act (EMTALA) [7] was enacted in 1986 as part of the Social Security Act, to ensure that anyone seeking emergency medical treatment in the United States is assessed, regardless of socioeconomic background or ability to pay. This act requires hospitals to provide a medical screening examination to determine whether a medically emergent condition exists in any person who presents for care in the ED. This legislation was created to ensure that an expectation of service is met at a minimum uniform standard at institutions receiving public support.

Patients have an expectation of care when activating 911 or presenting to an emergency care center. The specifics of that expectation vary considerably and are based on an understanding of their illness (both acute and chronic), cultural background, health beliefs, and ability to comprehend the current situation [8]. When a person with an underlying chronic illness presents for an exacerbation of the disease or a new complaint, he or she should anticipate an evaluation for an unforeseen complication of the chronic illness or an uncovering of a potentially new condition affecting their health. The patient should not expect a cure to their underlying chronic condition or a definitive diagnosis of a problem that is in the process of being worked-up in the outpatient setting.

Emergency care use by patients with chronic illness deserves additional research and process improvement given how costly and resource intensive it is and how it often represents a failure of preventative or primary care. Interventions to reduce emergency department utilization have typically focused on patients with specific chronic diseases such as congestive heart failure or chronic obstructive pulmonary disease, but few studies have demonstrated success in reducing emergency department usage by patients with chronic illness [9].

M.R. Mulcare (✉)
NewYork-Presbyterian Hospital/Weill Cornell Medicine, Division of Emergency Medicine, New York, NY, USA
e-mail: mrm9006@med.cornell.edu

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Organization of Emergency Services

Emergency Facilities

Different models for emergency care exist internationally and involve varying levels of infrastructure. In the United States, emergency medicine is provided through a complex network of services, both public and private, designed to get a patient from the location of occurrence to the appropriate facility for definitive care. After initial evaluation and treatment in the emergency setting, the need for ongoing evaluation and treatment may require an inpatient stay in the hospital which may be followed by a stay in a long-term care facility before returning to home. In other cases, the patient may be sent home directly from the emergency facility.

Emergency care is provided in an array of settings that have varying capabilities and designations, which are usually regulated by state law. The traditional and most comprehensive type of facility is an emergency department affiliated with and located in a medical center or hospital and open 24 h a day. These EDs are subject to the rules and regulations of the Centers for Medicare & Medicaid Services (CMS), as well as other state-based rules and regulations that apply to the facility within which they are located. EDs usually have access to a broad range of resources, including procedural interventions such as a cardiac catheterization, operating rooms, subspecialty consultation, and pharmacologic therapy. In addition, and pertinent to caring for patients with chronic illness, larger EDs have access to case management and social workers who can facilitate care plans, including home services or placement in a skilled nursing facility.

Though the ED has a broad range of capabilities for assessment and treatment, providing care in this setting is expensive. Overutilization of emergency care strains already limited resources and leads to long wait times for care. Almost 30% of care rendered in the ED could more appropriately be provided at an alternative clinical setting, based on the chief complaint, diagnostic studies completed, and medications prescribed [10]. This has led to the growth of alternative settings and facilities for the provision of emergency care.

Freestanding emergency departments are structurally separate and distinct from a hospital, though ideally should be subject to the same regulatory standards [11]. Some freestanding EDs are owned and operated by a hospital or hospital system and are bound by the same regulatory rules as the primary institution. Others are independent freestanding emergency centers, owned by individuals or independent groups. The available resources vary at these sites, as do the applicable rules and regulations from the state and CMS. These types of facilities are fairly new and have grown in popularity in response to the growing demand for emergency or "convenience" care. There is a lack of standardization among these facilities, and many are not recognized or reimbursed by CMS. The consumer should be aware of the limited regulatory oversight, variation in staff training, and limited access [12].

Urgent care centers (UCCs), also known as walk-in care, immediate care, or convenient care, are designed to care for patients with an urgent medical condition that is not life-threatening [11]. UCCs typically have limited hours of operation and a fee-for-service payment structure. There is limited regulatory oversight and they do not have to comply with EMTALA. Some states require that UCCs have physician owners. UCCs are typically more convenient, faster, and less hectic than EDs, which might be advantageous to patients with chronic illness. However, these patients may go to an UCC only to find that they are too medically complex to be cared for there, which then requires their transfer to the ED where a higher level of medical care and services are available.

Telemedicine is another form of emergency care that is evolving. Telemedicine uses video technology that allows communication between a patient and healthcare provider who are not in the same place, allowing for face-to-face interaction but no physical contact. Telemedicine may improve access especially in rural settings, though this option remains limited at this time [13]. State reimbursement policies for telemedicine significantly impact the practical viability of this type of care [14].

Emergency Providers

The first providers a patient will encounter after activating the 911 system are those who work in emergency medical services (EMS). EMS units (ambulances) are staffed by a combination of Emergency Medical Technicians (EMTs), who are trained in basic life support and have a limited scope of practice, and paramedics, who are trained to approach patients in a clear and organized approach and have a larger scope of practice and skills. All EMS providers are trained in basic resuscitation and have the ability to take a comprehensive history, including gathering information from bystanders at the scene, which helps to convey as complete a picture as possible to the receiving providers in the ED. This is the first step in the triage system, which is designed to determine the acuity of illness and the appropriate order for intervention and transportation, especially if multiple patients are involved.

In the United States, emergency medicine was originally the domain of surgeons and general practitioners who typically worked in these departments in addition to their practices. No additional emergency-specific training was

required. In recent decades, emergency medicine has become a specialty unto itself and has established over 200 emergency medicine residency training programs for medical school graduates across the country [15]. The American Board of Emergency Medicine hosts a certifying exam for eligible practitioners from credentialed training programs. There are still many physicians practicing in the ED setting who are not board certified in emergency medicine, especially in rural areas [16]. Broad training in medicine as well as in behavioral and social issues, and the shortage of providers in rural areas, will ensure that family physicians will continue to fill the health workforce gap addressing urgent and emergent care in isolated and under-resourced communities [17, 18].

Physicians who work in emergency rooms are trained to assess a patient and determine the severity of illness and initiate appropriate evaluation and treatment, which can include resuscitation and stabilization. For patients with acute trauma or a medical emergency, the approach to care is often grounded in algorithms, such as those established by the advanced cardiac life support (ACLS) or advanced trauma life support (ATLS) courses [19, 20]. The goal of the emergency physician is to identify the issue, rapidly stabilize the patient, perform necessary interventions, and then direct the patient to the appropriate setting in a timely manner. An emergency physician does not assume the role of being a primary care provider for a patient.

In addition to physicians, advanced practice providers (APPs) commonly work in emergency care settings. These physician assistants and nurse practitioners usually have additional training in emergency medicine or years of experience in emergency settings. While they may be the primary provider interacting with a patient, they usually work in concert with and under the supervision of a physician.

Additional Resources

Every emergency department has its own set of resources, usually reflecting those of the hospital to which it is affiliated. These can include, but are not limited to, social work, case managers, home services, physical therapy, and occupational therapy. Supportive follow-up resources can sometimes be arranged by the ED such as visiting nursing services and referral to local senior centers.

Transitions of Care

Transitional care is defined as the set of actions used to establish uninterrupted care for a patient switching from one healthcare environment to another [21]. As a patient moves from their permanent dwelling through the emergency medical system to definitive care, there will be a sequence of emergency care providers that they will encounter.

Prehospital Care: Emergency Medical Services

Emergency medical services (EMS) provide out-of-hospital acute care and transportation to emergency departments for sudden illness and injury related to a medical problem or trauma. EMS systems are both regionally and locally based, funded both publically and privately, and regulated by both federal and state governments. Depending on location, EMS systems may have ambulances as well as other forms of emergency transportation including helicopters or fixed wing planes.

The type of unit deployed to a given situation is determined by a dispatch center if 911 is called or there are private ambulances that may be dispatched through a call center for that fleet. The hospital to which EMS transports the patient depends on the location, type of illness, and capabilities of the receiving facility. Patients with significant trauma are transported to an appropriate regional trauma center, bypassing other EDs that have less capability. Patients presenting with a concern for stroke may be transported to the nearest stroke center. Still, care received in the field or at an intermediate facility is critical to improved outcomes. For example, the implementation of a prehospital stroke triage policy in Chicago led to an increase in the number of patients eligible for and receiving intravenous tissue plasminogen activator (tPA) for thrombolysis once they reached the comprehensive primary stroke centers [22].

EMS has access to medical control, which allows for real-time consultation with a physician who can advise on medications and other urgent decisions. For critically ill patients, EMS will call ahead to the ED to relay information so that the receiving facility is ready for patient resuscitation and other critical treatments.

EMS will transport patients from any place they are called to within a given radius of care, including private dwellings, skilled nursing facilities, ambulatory care centers, and outpatient doctors' offices. EMS will also transport patients from hospitals to other facilities, including other hospitals, skilled nursing homes, or private homes. Long-distance transports are typically managed by private ambulance groups. EMS can transfer important medical information and instructions between these facilities and can provide a safety assessment at the arriving destination.

Importantly for patient with chronic illnesses, there are key pieces of data that EMS providers are trained to look for when transporting a patient. This includes documents that address a patient's advanced directives, such as a Medical Order for Life-Sustaining Treatment (MOLST), Physician Orders for Life-Sustaining Treatment (POLST), Medical

Orders for Scope of Treatment (MOST), and other similar forms that express a patient's previously stated wishes for care. Information on the patient's designated healthcare power of attorney as well as any wishes regarding resuscitation, such as a do not resuscitate (DNR) form, also provides important information in an emergency situation.

Arrival at the Emergency Department

Upon arrival at the receiving hospital, EMS usually hands off the care of the patient to a nurse or team of providers who triage the patient to the appropriate area in the emergency department. Many EDs are trying to improve this step with models that allow the patient to go directly to a bed without front door triage [23].

The Emergency Severity Index (ESI) system is a validated tool that rates patient acuity and resource needs and helps direct the patient to the appropriate area of the ED [24–26]. ESI is rooted in military and mass-casualty incidents and is conducted on a five-point scale, with a score of 1 reflecting a patient who most acutely needs care to a score of 5, which represents a patient who is the least sick with limited need for urgent resources. While the ESI system has been proven useful, its utility in older adults and those who are chronically ill is unclear. The ESI triage score has been shown to under-identify older adults who need life-saving care [27]. This may mean that in older adults, chronic illness may mask an acute serious problem. Providers need to have a high level of suspicion for significant illness when treating patients with chronic diseases.

Additional components of the intake or triage process upon arrival at the ED that may be particularly helpful in patients who have chronic disease include screening for advance directives, level of pain, falls risk assessment, home situation, and access to a primary care provider. The visit to the ED may be one of the few times the patient encounters the healthcare system and may be a rare opportunity to evaluate and screen for important health considerations. If the patient is unable to provide this information, EMS may have documentation that is helpful, including the name of the patient's healthcare decision-making proxy.

Patient Care in the Emergency Department

Initial Assessment

The first providers encountered by a patient upon arrival in the ED usually include a nurse and a trained provider, such as a physician, physician assistant, or nurse practitioner. For patients with chronic disease, the provider must assume the possibility of an exacerbation of the chronic illness as part of or in addition to an acute concern.

A thorough history, physical exam, and review of any available records will help in the assessment. For chronically ill and older patients, ascertaining the patient's baseline health status is critical. For example, if the patient has slurred speech, it is helpful to know if this is a new finding. In addition to the medical and surgical history, medical records can also provide family history, which may help risk stratify if, for example, a patient with chest pain has a family history of heart disease.

The provider will review medications and allergies, which underscores the importance of having an accurate and up-to-date list of medications either in the medical record or provided by the patient. A major system issue in the United States is that many outpatient providers do not use the same electronic medical record (EMR) as the hospital, and many hospitals in the same geographic region do not share an EMR. This significantly hampers care for patients with chronic illnesses who see a variety of providers.

Obtaining a thorough social history is also important for patients with chronic illnesses including where and with whom the patient lives, how much support the patient has at home, and what additional services might be needed. This is important for a safe disposition from the ED should the patient be medically cleared to go home. Sometimes this information is important in understanding why the patient with chronic illness is in the ED in the first place. For instance, a worsening of a chronic condition may be exacerbated by a social situation such as not having enough money for medications or a problem with family dynamics. In such cases, the patient's ultimate disposition may have less to do with medical care than with social needs, such as placement in a skilled nursing facility.

Algorithms of Care

Experienced emergency providers have a well-established approach to acute problems. Clinical algorithms are particularly important in emergency care where a fast and appropriate response to a complicated problem presenting in a stressful environment is needed [28]. For every presenting complaint that the provider may encounter in the ED, there are certain interventions and diagnostic tests that will assist the heuristic approach. As the provider receives results of these tests, the differential will narrow until the most likely diagnosis is reached. Depending on that diagnosis and the severity of symptoms after treatment, the patient will either be admitted to the hospital for ongoing care or deemed safe for discharge to their usual residence with appropriate follow-up.

Goals of Care

After arrival in the ED, it is often important to have end of life and goals of care discussions before care is initiated, especially in the chronically ill patient who has an acute problem. If a patient arrives with advanced directives, such as a MOLST, POLST, or MOST form, the wishes of the patient are known and should be honored. In acute, unanticipated situations, the patient's wishes may change, and thus it is always important to discuss goals of care for this specific emergency department visit with the patient or the healthcare proxy. Each state has its own laws as to how the appropriate healthcare proxy is identified.

Disposition

After a patient is evaluated, diagnosed, and stabilized, the ED must determine the disposition of the patient which may include admission to a hospital observation or inpatient unit; transfer to a different healthcare facility, such as a nursing home or psychiatric facility; or discharge to home. Staying in the hospital unnecessarily is both expensive and potentially dangerous to the patient's health. Older or chronically ill patients are particularly susceptible to unintended deleterious consequences of hospitalization, including delirium, falls, and hospital-acquired infections [29]. The ED provider must be confident that the patient has a compelling need for hospitalization before arranging for admission. Some EDs are affiliated with observation units, which allow short-term stays that are not considered inpatient admissions. This is an option for some patients when a decision about disposition cannot be made within 6 h of presentation to the ED [30]. Medicare beneficiaries are often surprised to later learn that a stay in an observation unit is not covered the way hospitalization is, leading to greater out-of-pocket expenses. This is an unintended consequence of Medicare payment policies that are designed to reduce hospital admissions and an area of policy debate [31].

Some chronically ill or elderly patients are brought to the ED from home when family members are no longer able to care for them. The patient may need admission to a nursing home, but EDs are not usually in a position to negotiate the complex process of admitting patients to long-term care. In many cases, the patient is admitted to the hospital by default, but if there is no true acute medical reason for admission, the patient will not have the 3-day qualifying stay that would allow for even short-term Medicare coverage in a skilled nursing home. Placement in such circumstances can be challenging and requires the involvement of hospital care managers. For patients who only need additional assistance at home, this can often be arranged directly from the ED through social workers.

New CMS guidelines aim to reduce readmission to the hospital within 30 days, which happens in approximately 20% of Medicare beneficiaries and costs the American public billions of dollars per year [32]. Hospitals that have high readmission rates can lose part of their Medicare reimbursement. This focus on avoidable hospitalizations has increased the effort put forth by ED providers in arranging outpatient disposition rather than readmitting a returning patient. This involves ensuring that a follow-up appointment with an outpatient provider is secured in a timely manner. This involves contacting primary care or specialty provider offices or finding a provider for patients who do not have one. Most EDs have patient navigators or social workers to help with these sometimes challenging dispositions.

Quality of Care

Many emergency departments have specific protocols that help the physicians in the heuristic process and ensure quality control. For instance, an ED may have a protocol for when to place an indwelling urinary catheter in an older adult. This can reduce overutilization and prevent unintended consequences such as catheter-associated urinary tract infections, falls, and urethral trauma [33]. State and federal agencies are promoting high-quality care by using measurable metrics in various clinical settings that encourage transparency and value-driven healthcare [34]. ED care is evaluated by CMS through the Hospital Outpatient Quality Reporting Program. The goal of this program is to create a streamlined, systematic format for reporting data specific to the functioning of hospital outpatient settings, including the ED. This effort is intended to uphold a standard of care, and the resultant data is used to educate consumers. Emergency departments are incentivized to perform well since both accreditation and payments from CMS are linked to this quality data. Similar systems exist for inpatient settings.

Figure 17.1 shows examples of quality measures that are monitored in EDs. Measures are based in a specific field of evaluation for improvement such as Process, Outcome, Structural, and Web-Based. Such measures are not applicable to urgent care center and are use inconsistently in freestanding emergency departments. It is important for healthcare consumers to be aware of this difference. The Hospital Outpatient Quality Reporting Specifications Manual [Version 10.0, accessed 10/9/16 and shown below] is periodically updated by the Centers for Medicare & Medicaid Services.

Outpatient Delivery Settings

Acute Myocardial Infarction (AMI)		
Measures:	OP-1	Median Time to Fibrinolysis
	OP-2	Fibrinolytic Therapy Received Within 30 Minutes of ED Arrival
	OP-3	Median Time to Transfer to Another Facility for Acute Coronary Intervention
	OP-4*	Aspirin at Arrival
	OP-5*	Median Time to ECG

Chest Pain (CP)		
Measures:	OP-4*	Aspirin at Arrival
	OP-5*	Median Time to ECG

ED-Throughput		
Measures:	OP-18	Median Time from ED Arrival to ED Departure for Discharged ED Patients
	OP-20	Door to Diagnostic Evaluation by a Qualified Medical Professional
	OP-22	Left Without Being Seen

Pain Management		
Measure:	OP-21	Median Time to Pain Management for Long Bone Fracture

Stroke		
Measure:	OP-23	Head CT or MRI Scan Results for Acute Ischemic Stroke or Hemorrhagic Stroke Patients who Received Head CT or MRI Scan Interpretation Within 45 Minutes of ED Arrival

Imaging Efficiency		
Measures:	OP-8	MRI Lumbar Spine for Low Back Pain
	OP-9	Mammography Follow-up Rates
	OP-10	Abdomen CT – Use of Contrast Material
	OP-11	Thorax CT – Use of Contrast Material
	OP-13	Cardiac Imaging for Preoperative Risk Assessment for Non-Cardiac Low-Risk Surgery
	OP-14	Simultaneous Use of Brain Computed Tomography (CT) and Sinus Computed Tomography (CT)

*OP-4 and OP-5 are used for both AMI and Chest Pain.

Fig. 17.1 Outpatient delivery settings (Reprinted with permission from American Medical Association)

Older Adults in the Emergency Department

Older adults with chronic illness frequently utilize emergency care. An increasing number of ED visits by adults aged 65 and older require many resources and are a growing burden to the healthcare system [35, 36]. Visits by older patients to the ED have increased by 25% from 2001 to 2009 [37]. By 2030, the older patients are expected to account for one in four ED visits in the United States [38]. Compared to younger patients, older adults stay in the ED 20% longer, use 50% more imaging studies, and require 400% more social services [39].

Older adults usually present to the ED from either a community-dwelling or a skilled nursing facility (SNF). Older patients who live in a SNF represent 14% of all ED visits by older adults [40], with a 12.8% increase from the preceding decade [40]. More than 25% of SNF residents present to the ED at least once annually [41]. These patients often have unique and complex needs, are on multiple medications, may be cognitively impaired, and are at greater risk of falls compared to their community-dwelling counterparts [42]. It is essential that communication between the SNF and the ED is thorough, accurate, and timely during transitions of care between these two settings. This can be challenging which can result in the provision of unneeded services in the

ED to the admission of patients to the hospital unnecessarily [43]. Patients who reside in a SNF and are hospitalized are at greater risk of iatrogenic complications than their community-dwelling counterparts [42]. Significant barriers to caring for SNF patients in the ED include lack of access to important and relevant medical information [44] and ineffective communication between the ED providers, emergency medical services (EMS), and care team at the SNF [43]. SNF patients often arrive at the ED without records from the SNF, and even when they do present with this documentation, it is often incomplete and missing the information necessary for proper patient care [45, 46]. One study found that 94% of patient transfers from SNFs had information gaps including code status, the reason for transfer, and current medications [45]. As the population ages, these communication challenges must be addressed.

Summary

For patients with chronic illness, emergency care is available 24 h a day, 7 days a week, 365 days a year. Emergency medicine providers are well equipped and trained to handle life-threatening emergencies and any other unforeseen circumstances surrounding an illness, whether it is an acute problem or an exacerbation of a chronic disease. Care in the emergency department is greatly enhanced when medical records are readily available. Expectations of the visit to the emergency department should be set early after arrival to the ED. Quality measures and training oversight are intended to assure a standard of care across facilities. The emergency department team strives to ensure medical stability and safety in disposition planning for the patient with chronic illness.

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Acute Hospital Care

18

Amir H. Barzin

Introduction

Patients with chronic conditions contribute to a large portion of healthcare services and costs that are attributed to acute hospitalization. In 2009, the Centers for Disease Control and Prevention (CDC) reported that 39% of all hospital admissions were linked to people with two to three chronic conditions, while 33% of admissions were tied to those who had four or more chronic conditions [1]. The aggregate number of chronic illnesses is associated with overall mortality, cost, and length of stay for hospitalized patients (1, Table 18.1). Common chronic illnesses that are treated in acute hospital settings can broadly be classified into four categories: circulatory disorders (e.g., hypertension, congestive heart failure, stroke, coronary artery disease), respiratory disorders (e.g., asthma, chronic obstructive pulmonary disease), endocrine disorders (e.g., diabetes mellitus), and mental health disorders (e.g., depression, anxiety, substance abuse, schizophrenia) [1]. Chronic diseases such as congestive heart failure (CHF) or chronic obstructive pulmonary disease (COPD) account for greater than 35% of admissions not related to surgery, obstetric care, newborn care, or psychiatric admission [2].

Each acute hospitalization is an opportunity to improve chronic disease management. This vision of care starts with a structured, patient-centered approach at admission and ends with successful posthospital planning. If hospital and transition care – from the inpatient to the outpatient setting – is well executed, there is great potential to improve outcomes and decrease inappropriate healthcare utilization and reduce costs. This chapter addresses the unique challenges of providing hospital-based care for chronically ill patients. The first section directs attention to assessment and evaluation strategies, as well as admission workflows, for patients who may require hospital care. The next part of the chapter addresses both system-level (e.g., antibiotic stewardship) and patient-level (e.g., advance care planning) care principles for chronically ill patients who are hospitalized. The chapter closes with a review of discharge planning principles that is inclusive of transitional care.

A.H. Barzin (✉)
Department of Family Medicine, University of North Carolina School of Medicine, Chapel Hill, NC, USA
e-mail: amir_barzin@med.unc.edu

Preadmission Evaluation and Assessment

When evaluating a chronically ill patient for possible admission, it is important to address the patient's presenting complaints and gather collateral subjective and objective information regarding both the acute problem and underlying chronic medical conditions.

History and Physical Examination

In an era of multiple information sources, a clear understanding of the patient's chief complaint and associated signs and symptoms is essential. This process begins with a detailed history of the events that led to a new or unexplained presenting symptom or to an acute exacerbation of the chronic illness. While gathering the history and developing a differential diagnosis, it is important to note the patient's main complaint and the linkage of signs and symptoms with the underlying chronic disease. Understanding patient self-management and monitoring of chronic conditions (e.g., glycemic control, home/clinic blood pressure readings); use or repeated use of medications, such as rescue inhalers or insulin; and acute changes allows the provider to gauge insight into the patient's understanding of their chronic disease or the lack of understanding of current medical management. Communication techniques such as active listening, rapport building, targeted open-ended and closed-ended questions, and nonverbal communication should be adapted to facilitate information gathering from the patient [3].

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Table 18.1 Number of chronic diseases and mortality, inpatient service use, and cost in hospitalized patients

	0–1 Chronic conditions	2–3 Chronic conditions	>4 Chronic conditions
Percent of discharges	28.81	38.56	32.64
Mortality rate	0.02	0.03	0.03
Mean length of stay in days	4.46	5.21	5.42
Mean cost in dollars	10,544.91	11,180.93	11,095.01

Reproduced with permission from Steiner and Friedman [1]

After the initial history taking and information gathering has been completed, a thorough physical examination can refine the differential diagnoses and guide next steps in ordering laboratory and other diagnostic testing. The physical examination should include a comprehensive inventory, as well as focused organ systems (e.g., heart and cardiovascular) that are informed by the history. Collateral information from family members or prior medical records can help distinguish physical findings (e.g., dependent edema, cardiac murmurs) that are stable and chronic, versus those that are acute and decompensating. Biometric data, such as dry weight, blood pressure, and other vital signs, should be confirmed during the initial evaluation.

Collateral Information

As part of the American Recovery and Reinvestment Act, all public and private healthcare providers are required to adopt electronic medical records (EMRs) in order maintain participation in Medicaid and Medicare [4], a regulation that has promoted more widespread use of EMRs. The patient's primary care physician (PCP) can be a key information source since most chronic disease management is maintained in the outpatient setting. In recent years, hospitalists have increased, and fewer primary care physicians include hospital care in their scope of practice [5]. With this growing trend, many patients that have a long-established relationship with an outpatient provider are encountering unfamiliar physicians in the hospital who have little familiarity with their medical history. Effective and timely communication with the PCP and family members can improve the quality of care by gauging potential barriers to care, prior medication and therapeutic regimens that have been ineffective, and comorbid problems that may have led to hospitalization.

Medication Reconciliation

Medication reconciliation is a valuable component to the initial assessment since medication errors occur in 3.8 million inpatient admissions and 3.3 million outpatient visits a year, accounting for 7000 deaths annually [6–8]. Several medication-related triggers can contribute to a hospitalization, including patient misunderstanding of medication instructions or misadministration by the patient. Ideally, medication reconciliation should be performed via direct visualization of pharmacy bottles or containers with the patient. However, this may not always be an option, and reconciliation via an EMR report, a patient medication list, or verbally with the patient are alternative approaches. Other strategies include conversations with family members that have access to the patient's medications or confirmation with a patient's identified pharmacy.

Advance Care Planning

In chronically ill patients, advance care planning and discussions of resuscitation status and surrogate decision-making should ideally occur prior to admission. Studies have demonstrated that as much as 70% of Medicare costs per patient are accrued in the last year of life [9], and this has been associated with often unwanted and aggressive acute care management of chronic conditions with no defined end point. Emergent interventions such as intubation and other resuscitation measures may not meaningfully contribute to the overall quality of life or functional status in the chronically ill patient, a reality that may not be understood by patients and family caregivers in the setting of an acute illness. Initiating discussions that are patient-centered and informed by evidence can guide goals of care discussions in order to identify the preferred level of care for the hospitalized patient and parameters around escalating medical management (e.g., intensive care) should the clinical condition worsen. These discussions and decisions should be clearly documented in the patient's chart and be available to all members of the care team.

Admission

After the preadmission assessment has been completed and the decision for hospitalization has been reached, there are several areas to consider when admitting the chronically ill patient. These domains include determining the appropriate level of care (e.g., intensive care, step-down, observation bed) and a thoughtful process for admitting orders that ensure a care plan that addresses the current medical problems and limits the risk for iatrogenic error. At the time of admission, a rational approach to diagnostic testing and planned therapeutics should also consider discharge planning to facilitate a smooth transition once discharge goals have been met.

Level of Care

Patients who are admitted to the hospital in a nonsurgical setting are generally designated as either inpatient or observation status. This classification impacts not only the level and intensity of care but also the potential cost of care to the patient. For example, there is variability among third-party payors regarding reimbursement for observation admissions. In some cases, the cost can fall to the patient (e.g., copayment, deductible); in others it is absorbed by the hospital. The admitting physician should use best clinical judgment to decide on the level of care that is the most appropriate for the patient. A discussion with the primary care physician may play a key role at the time of admission, since early and reliable outpatient follow-up can often contribute to a shorter length of stay.

Admitting Orders

Admitting orders should be placed in a structured fashion that is responsive to the total care needs of the patient and with attention to limiting unnecessary testing and prevention of nosocomial infections and iatrogenic errors. Many electronic health records also include the capacity for provider order entry (POE), which is an electronic interface that allows clinicians to directly place care orders. POE programs were originally designed to identify and mitigate medication errors, and they have evolved with capacities to order laboratory tests, imaging, and hospital and outpatient consultations [10]. In addition, they often have functionalities for clinical decision support and evidence-based order sets that help to standardize workflows.

Patient mapping is an emerging practice that seeks to match and aggregate patients in specific hospital locations, based on the clinical needs of the patient, and the nursing and associated resources of the hospital. The process begins at admission when individual patient needs are identified, such as complicated medication regimens, frequent nursing assessments, or intensive biomonitoring (e.g., telemetry), which are matched to the hospital location that can provide this level of care. Ideally, patient mapping has the potential to facilitate throughput from the emergency room to the hospital wards; however bed availability is a rate-limiting step [11].

Preventing Iatrogenic Errors and Nosocomial Infections

As many as 60% of hospitalized patients are at risk for developing venous thromboembolism (VTE), and nearly 275,000 new cases of (VTE) occur each year [12]. Appropriate VTE prophylaxis can decrease the rate of VTE events by up to 63% [12], and there are many modes of prophylaxis, including both mechanical and pharmacologic prophylaxis. The assessment of VTE risk at admission should be undertaken with consideration of existing chronic diseases to mitigate the potential risk for kidney damage or bleeding events. The mode for prophylaxis is based on an assessment of functional status, estimated length of stay, and risk of bleeding during the admission. For those with limited mobility and longer lengths of stay, or those at increased risk of VTE, pharmacologic prophylaxis such as subcutaneous heparin or low-molecular-weight heparin is preferred [13]. Attention should be directed to patients with chronic kidney disease in dosing and medication selection. For those patients who are already on anticoagulation such as warfarin or direct oral anticoagulants (DOACs), continuation of these therapies is preferable if there are no contraindications. Patients with anticipated shorter hospital stays may benefit from early ambulation or sequential compression devices (SCDs) if ambulation is not a limiting factor.

In addition to VTE prophylaxis, gastrointestinal (GI) prophylaxis should be considered in certain situations. The American Society of Health-System Pharmacists recommends prophylaxis with a proton pump inhibitor (PPI) for patients with the following conditions in the intensive care unit (ICU): coagulopathy, mechanical ventilation longer than 48 h, GI ulcer or bleeding within the past year, sepsis, a stay longer than 1 week in the ICU, GI bleeding for 6 or more days, and steroid therapy with more than 250 mg of hydrocortisone daily [14]. Patients admitted to a general medical unit who are not hemodynamically unstable, or are not showing signs of an active GI bleed, do not require GI prophylaxis since this intervention does not significantly decrease the risk of GI bleeding [15]. However, the risks of continued or unnecessarily prolonged PPI use may lead to infections and complications, such as *Clostridium difficile* and community-acquired pneumonia, bone fracture, and reduced efficacy of medication absorption [16].

Nosocomial infections account for approximately 7 infections per 100 admissions [17]. Patients with chronic conditions are at increased risk for these infections, and hospital-wide protocols can limit the spread of existing infections and prevent outbreaks of new infections. At the time of admission, providers should be aware of isolation/contact precaution guidelines, such as requirements for contact precautions in patients with a known history of resistant infection or respiratory precautions. Frequent handwashing or use of a sanitizing agent and the use of sterile gowns and gloves or masks in identified patients are hallmarks of such precautions. These measures have been shown to significantly reduce the risk of spreading nosocomial infections in healthcare settings [18, 19].

Patients who are at risk for developing pressure ulcers (e.g., limited mobility, cognitive impairment) should be identified at admission, and a prevention and treatment plan should be in place to reduce further progression. A thorough initial skin examination can target specific body locations (e.g., buttocks, heels) in patients who have decreased mobility or those with neuropathic conditions that limit their perception of pain. Risk factors for these patients include non-blanchable erythema, lymphopenia, immobility, dry skin, and decreased body weight [20]. Some current interventions to reduce the risk of skin ulcers and breakdown include the use of support surfaces, frequent repositioning by nursing or ancillary staff, and the use of nutritional support. The evidence around repositioning and nutritional support for mitigating skin breakdown is variable, while some studies support the use of technology-based support surfaces in the management and prevention of pressure ulcerations [21].

Laboratory and Diagnostic Testing

Laboratory and diagnostic testing can greatly inform disease management during hospitalization. In patients with chronic conditions, laboratory values and radiographic studies can be flagged as abnormal when they may represent a true baseline state for patients. An elevated creatinine in a patient with chronic kidney disease, for example, may not reflect an acute event and needs to be interpreted within the context of a larger disease trajectory. Abnormal diagnostic values, when interpreted by providers who are not familiar with the patient, may trigger a cascade of unnecessary testing or duplicate testing that was performed in a relatively recent time period. To limit unnecessary testing, collateral information from the EHR and primary care physician, as well as the clinical history and physical exam findings, can reduce unnecessary phlebotomy draws and decrease hospital costs [22]. Less frequent testing can also be patient-centered via fewer patient interruptions and improvement in overall patient satisfaction.

Medication Management

Ongoing medication management is a foundation to quality hospital care. Providers should be attentive to the indication and selection of medications and the potential interactions of new medications with existing chronic medications. For example, acute infections can require initial empiric antibiotic coverage which may have interactions with long-standing medications (e.g., fluoroquinolones and warfarin) or may predispose to iatrogenic complications (e.g., clindamycin and *C. diff* colitis). To mitigate this risk, a growing number of EMRs have the capacity to identify drug-drug interactions and reconcile medications.

Patients with chronic illness are generally maintained on long-term medications that reduce progression of their disease or improve their overall health status. During admission, these medications may need to be titrated depending on the clinical situation, a task that requires an understanding of attempted and failed therapies, and the therapeutic goals for treatment. Comprehensive changes to the medication regimen must weigh indications and benefits related to initiating a new drug and potential adverse effects, versus the proven track record of the long-term medication. It is also important to evaluate the efficacy and indications for new therapeutics after the acute phase of treatment.

Antihypertensive medications and heart failure regimens are frequently modified during the acute hospitalization. A patient with hypertensive crisis in the hospital, for example, may need to have an increased dose of their home medications to maximize therapy. When considering a medication change, the provider should consider how the presenting signs and symptoms – and the preliminary diagnosis – may impact the decision to increase or alter therapy. In a patient admitted with a COPD exacerbation, increasing the frequency of home medications (e.g., inhaled beta agonist) must be considered in the context of perceived side effects for prolonged use. The 2016 Global Initiative for Chronic Obstructive Lung Disease (GOLD) update recommends limiting the use of long-acting inhaled corticosteroids when possible, and recommends against the use as a monotherapy, given the risks of pneumonia and fractures and lack of efficacy when compared to combination inhaled corticosteroids and long-acting beta$_2$ agonists [23].

The management of fluids and electrolytes is another clinical consideration at admission. Maintaining overall fluid balance is important to prevent electrolyte abnormalities and to treat possible volume depletion states that can occur with acute illnesses. In some clinical settings, (e.g., septic shock) initial fluid resuscitation is required, and the immediate post-resuscitation period requires close monitoring of the patient. Fluid and electrolyte management requires the appropriate selection of maintenance fluids and infusion rates. For hospitalized patients who require intravenous fluids, a combination of 5% dextrose in isotonic saline solutions (e.g., D5NS) is commonly used [24]. The infusion rates should be guided by the underlying disease process and associated laboratory values; however a commonly accepted rate in a euvolemic patient with no underlying illness is 100–120 cc/hr [24].

Glucose management needs to be delineated in patients with diabetes mellitus. An informed understanding of the patient's medication regimen, current disease state, and nutritional status (e.g., NPO) leads to a structured approach to glucose management. Diabetic patients may require coverage with sliding scale insulin or a higher dose of

Table 18.2 Sliding scale insulin regimen for hospitalized patients

Blood glucose level	51–70 mg/dl	71–150 mg/dl	151–200 mg/dl	201–250 mg/dl	251–300 mg/dl	301–350 mg/dl	351–400 mg/dl	>400 mg/dl
Units of aspart	Give juice	0	1	2	3	4	5	6
Insulin sensitive								
Units of aspart	Give juice	0	2	4	6	8	10	12
Standard								
Units of aspart	Give juice	0	4	8	12	16	20	24
Insulin resistant								

insulin to treat hyperglycemic states that are present in infection or acute illness. Table 18.2 presents a sliding scale insulin regimen for hospitalized patients. There is, however, an increased risk of hypoglycemia in patients with acute illness with tight glycemic control [25]. Patients who have limited or no oral intake will need an adjustment in their home insulin dosing regimen, which is achieved by a reduction in the basal insulin requirement by approximately 50% and by limiting bolus dosing and covering elevated glucose readings with a sliding scale parameter for testing and insulin administration. Metformin has the potential to cause renal injury, particularly in patients with volume-depleted states and those undergoing intravenous contrast studies.

Anticipated Length of Stay and Discharge Needs

The final component of the admission process is an estimation of the length of stay and the anticipated needs at hospital discharge. By identifying potential barriers to discharge at the time of admission, care teams can begin to assess needs, such as occupational or physical therapy or nursing care via home health or other community-based services. The early identification of discharge care needs has the potential to reduce length of stay and subsequently decrease inhospital mortality and 30-day mortality in chronic conditions such as congestive heart failure [26]. Although the anticipated length of stay may change due to progression of the index disease or new medical problems, the consideration of discharge planning at the time of admission can help optimize resource planning.

Acute Hospital Management

After the admission, attention must be turned to hospital management of the patient. There are greater healthcare costs and increased morbidity associated with chronically ill patients who are hospitalized, and a structured daily management plan must be utilized and adapted to maximize care.

Antibiotic and Medication Stewardship

With a rise in antibiotic resistance in the United States, the Center for Disease Control and Prevention (CDC) has identified antibiotic stewardship as a public health issue [27]. In acute hospital settings, 20–50% of the antibiotics prescribed are either not needed or inappropriate for patient care [28, 29], which contributes to resistance or an increase in nosocomial infections such as *Clostridium difficile,* as well as patient death. Hospital care of the chronically ill patient should include measures to limit unnecessary or prolonged medication use through antibiotic stewardship programs.

According to the CDC, successful stewardship programs should contain the following elements: leadership commitment, accountability, drug expertise, action, tracking, reporting, and education [30]. Leadership commitment includes buy-in from administrative and clinical champions, as well as securing institutional resources and removing barriers that impact the unnecessary use of antibiotics. Accountability and drug expertise require identifying and recruiting physician and pharmacy content experts who have the knowledge base and skills to work with their colleagues in this area. Implementation strategies encompass planning and execution approaches, as well as information technology (IT) systems that can provide tracking and reporting mechanisms for the provider and greater care team. IT approaches that have been embedded in POE systems have included required documentation of the antibiotic indication with clear start and stop dates and prompts and flowcharts to inform antibiotic coverage.

Both IT processes and academic detailing by pharmacy specialists have been found to be effective strategies. For example, Doctor of Pharmacy (PharmD) accreditation now includes a component of health improvement and outreach [31], a development that has increased the role of hospital pharmacists with this level of training in improving antibiotic management [32] and the diabetes care [33]. The responsible and evidence-based use of medications can provide an approach to reduce the over 20,000 deaths that are attributed to antibiotic-resistant infections [34].

These system-level principles of active medication management can be applied to other hospital care strategies. For example, the use of a fixed order sets (e.g., bundles) for

sepsis often includes rapid laboratory and other diagnostic tests and targeted antibiotics that are based on a presumed source of infection. In addition, a patient at risk for VTE would have a bundle that includes laboratory and radiographic testing, nursing interventions, and a heparin nomogram based on whether treatment is indicated for a pulmonary embolism or deep vein thrombosis.

Changes in Patient Status

The clinical course of the hospitalized patient changes, which informs the level of required surveillance, nursing, and ancillary care, such as a medical unit bed or higher level of care (e.g., ICU or intermediate care unit). Medical unit beds are generally indicated for stable hospitalized patients who require structured surveillance (e.g., vital signs, biometrics) and a standardized level of nursing and ancillary care (e.g., intravenous medication administration, wound care, respiratory therapy).

The resources and staffing model for medical beds can vary by hospital; however there are common guidelines which include the nursing-to-patient ratio and frequency of patient assessments [35]. Intensive care units (ICU) typically have a more individualized nurse-to-patient ratio and greater resources and supports to care for critically ill patients, such as the capacity for patients requiring mechanical ventilation. This level of care is typically managed by a team of specialists, led by an intensivist, and is usually limited to a finite number of patients. Many hospitals have an intermediate care or step-down unit, which is a hybrid between the medical floor and ICU. These units have a reduced nursing staff model when compared to an ICU setting, but they provide a more closely monitored environment than a medical floor. For example, patients who are transitioning out of the ICU are often transferred to a step-down unit for closer monitoring. Other patient subgroups who are candidates for step-down units include those who require closer monitoring for conditions such as alcohol withdrawal or patients that are not critically ill but are unstable and require advanced therapies such as continuous respiratory support with bilevel positive airway pressure (BIPAP).

Chronically ill patients may acutely decompensate in hospital settings, and these situations require a timely assessment, expedited treatment, and possible escalation in their care. Prompt evaluation of such patients can be achieved through a rapid response or code team. The rapid response or code can be initiated by any member of the hospital staff and activation results in a structured and timely evaluation of the patient and mobilization of resources to promote care. These teams can be composed of a physician, a senior nurse, and, if available, a pharmacist, a security officer, and a patient transport technician. Common conditions for evaluation of such patients include low blood pressure, rapid heart rate, respiratory distress, and altered mental status [36]. After the arrival of the team, stabilization of the patient is performed, and a rapid assessment process allows for administration of medications and bedside testing. Once the patient is stabilized, the care team decides on the subsequent level of care.

Care Teams

Hospital medicine programs have greatly expanded through the establishment of care teams. Multidisciplinary teams have shown to improve patient education and quality of care while decreasing length of stay [37]. These teams are generally composed of physicians or advanced practice providers (APPs), nurses, therapists (speech, occupational, and physical), pharmacists, and care managers. Within this structure, each provider works at the top of his or her license in order to complement the skill set of each team member. Physicians and APPs are often looked to as leaders of the team and are directly accountable for the overall care provided to the patient. However, information about the patient and care duties, such as daily care plans, medication management, and assessment for discharge, can be delegated to respective members of the care team.

Input from all care team members is vital to effective patient management. Activities and tasks include ongoing nursing discussions regarding changes in patient status, vital signs, or overall medical condition. Nurses also have the ability to engage in patient education at the bedside. Allied health therapists (e.g., OT, PT) provide vital functional assessments and treatments that inform discharge planning. As noted earlier, pharmacists can provide evidence-based recommendations in medication management, champion antibiotic stewardship, and be key resources for patient education.

Care managers are a relatively recent addition to the hospital care team. These individuals are traditionally either social work or nursing trained and are available to patients and their families for facilitating discharge planning and coordinating care across healthcare settings, as well as in the home or long-term care setting. Care management functions may include identifying resources to help with chronic disease management, assisting families in outreach to community-based organizations, or by serving as a line of communication between the patient and the physician. Care managers can also provide patients with resources regarding government and private agencies in areas such as housing, legal aid, and securing health insurance in programs such as Medicaid.

Multidisciplinary rounding (MDR) is a process that involves a discussion among all members of the patient care

team about patient care, including progress, barriers, and disposition. Physicians, nurses, and other clinical members of the care team may address the hospital course of the patient, while nonclinical personnel may take on social and other resource needs that impact discharge, such as durable medical equipment, transitional care to a skilled nursing facility, or referral to other providers if indicated. The overall goal of MDR is to maximize hospital care by promoting communication and patient care information in real time. When MDR is done effectively, quality of care improves, and utilization is maximized.

Advance Care Planning

Advance care planning should ideally be undertaken during every hospital admission for chronically ill patients. Advance care planning (ACP) has shown to improve the quality of end-of-life care and decrease unnecessary hospitalizations [38], although there is variability in the number and types of frequently hospitalized patients with chronic disease who have considered ACP [39, 40]. Several principles can help guide effective ACP: (a) there is an overall intent to improve communication with patients, caregivers, and providers, (b) the process seeks to identify and clarify goals of care, (c) care teams and providers should prepare patient and family caregivers for the functional limitations and overall health declines that may occur at the end of life, and (d) the ACP process should seek to mitigate family member or surrogate burden [41].

Among chronically ill patients with end-stage disease, providers should engage in ACP discussions when patients are clinically stable and have decisional capacity. Family members and other stakeholders should also be involved in the discussion and ongoing decision-making process. In cases where there is a lack of decisional capacity by the patient, the provider and care team should seek to facilitate the appointment of a surrogate.

There are many resources to help with ACP processes. Some organizations have trained and certified staff workers to assist in locating documents (e.g., living wills) and in the process of appointing decision-makers and healthcare powers of attorney [42]. In some states, a Medical Orders for Scope of Treatment (MOST) form is available to help tailor specific care plans, such as the initiation or withholding of antibiotic therapy. Do-no-resuscitate (DNR) orders and information placards that specify no further hospitalizations provide a visual reminder to medical providers of patient goals of care. ACP should be viewed as an ongoing, iterative process, and it is important to review prior discussions and documents to promote an active dialogue with the patient and surrogate decision-makers.

Family members and patient surrogate decision-makers may request a meeting with the care team to clarify ACP. Standardized documentation of the meeting's outcome in the medical record is recommended to communicate the care plan to all members of the hospital team. Elements of the meeting should include notation of the meeting's date, the stakeholders who were involved and their role in the patient's care, documentation of the disease process and patient and stakeholder understanding of the disease trajectory, treatment options, and prior discussions and current decisions regarding care planning. Closed-loop communication between providers and both inpatient and outpatient care team members (e.g., nurses, therapists, primary care physician) should occur in order to ensure that all members understand the plan of care.

Discharge

Discharge planning should not wait until the day of discharge but should be part of the ongoing workflow in daily inpatient care to facilitate a timely and effective transition after acute hospitalization.

Post-discharge Location

Table 18.3 displays posthospitalization care sites and associated services which include home healthcare, skilled nursing facility care, and hospice care. Many chronically ill patients are stable after an acute hospitalization can safely be discharged to home with early follow-up with their primary care physician. Other patients may have nursing or other needs at discharge that require subacute care.

Home healthcare services are resources for patients who may require a basic level of nursing care, such as wound care or intravenous antibiotic therapy, or allied healthcare services such as physical, occupational, or speech therapy. Home health agencies provide patient education around medication management and self-monitoring of chronic diseases, such as congestive heart failure. Family and other caregivers are generally required to be available to assist patients in their care [43]. In general, to be eligible for home health services by Medicare, the patient must be confined to the home, under the care of a physician, have a prescribed plan of care, and be in need of skilled nursing on an intermittent (e.g., approximately three times a week) basis or require physical, speech, or continued occupational therapy [44]. Information regarding the patient's progress and care plan is reported to the patient's PCP.

Skilled nursing facilities (SNFs) may be considered in posthospitalized patients who require more intense or pro-

Table 18.3 Posthospitalization care sites and associated services

	Home with no home health	Home with home health	Skilled nursing facility	Home hospice
Nursing services	None	Medication reconciliation and management	Provided on site at facility for oversight of care of the patient	Provided on intake and an on-call basis
		Wound care		
		IV therapy		
		Chronic disease teaching		
Medication management	Patient administers own medications	Patient administers own medications	Administered by facility staff	Review of medications with family and emphasis on pain and symptom control
Physical therapy	Not provided	Provided at a maximum of three times a week	Provided up to five times a week	Provided as needed
Occupational therapy	Not provided	Provided at a maximum of three times a week	Provided up to five times a week	Provided as needed
Speech therapy	Not provided	Provided at a maximum of three times a week	Provided up to five times a week	Provided as needed
Responsible physician	Primary care physician	Initial orders usually signed by hospital physician with subsequent orders by primary care physician	Facility medical director	Hospice medical director or primary care physician

longed therapy that cannot be provided in the home. SNFs are licensed facilities that provide on-site nursing and allied health services with medical oversight, and the average length of stay is about 26 days [45]. If a patient is a candidate for a SNF, the hospital physician will work with ancillary team members (e.g., care manager or discharge planner) to identify a facility that will accept the patient for admission. Once identified, the discharging physician prepares a discharge summary with an accurate medication list and care plan to the facility. Upon transfer to the SNF, the receiving physician (e.g., the medical director) reviews the orders and assumes care of the patient while they are in the SNF. The Centers for Medicare and Medicaid Services (CMS) has developed a five-star quality rating system for nursing homes that is indexed to quality of care.

Hospice care, either at home or in a nursing facility, is an option for chronically ill patients with limited life expectancy. Patients may be eligible for hospice if they have a life expectancy of less than 6 months. The hospice model offers patients and families a more patient-centered approach to care where a family member serves as the primary caregiver. The hospice care team develops an individualized plan to meet the needs of the patient based on managing symptoms and provides on-call staff to manage acute symptoms or other problems. Over 75% of those entering hospice care has the primary diagnosis of cancer, dementia, heart disease, or lung disease [46]. Inpatient hospice is generally considered for patients with ongoing nursing care needs, such as pain and symptom management, which cannot be managed in other settings. The quality of life for patients who are in hospice remains relatively stable throughout their terminal illness course and at the end of life [47].

Medication Reconciliation

Medication reconciliation is a vital part of the discharge process since medications often change during hospitalization. The patient's medication list should be reviewed and updated to account for what will be prescribed during posthospital care. This list should also identify medications that the patient is no longer taking, as well as the duration of medicines that have a defined timeframe, such as antibiotic therapy. Medication adherence and compliance can be enhanced after discharge with the use of a pillbox [48].

Patient Education

Patient education should include information about the underlying disease processes, treatment instructions, an inventory of warning signs and symptoms, and guidelines and locations for seeking emergency care for worsening conditions. Unfortunately, patient discharge information is generally provided at a level that is higher than the reading level of the average patient [49]. The provider or health educator should identify any functional, cognitive, or educational limitations to how patients process information and consider strategies to mitigate these challenges.

Patient education can be facilitated by several members of the hospital care team, and nursing or pharmacy staff can complement and enhance patient understanding. Teach back is one strategy in which the patient educator provides the patient with specific information items, such as how to limit future exacerbations, and then asks the patient to instruct the provider in their own words. This method of education requires processing and comprehension from the patient.

Multidisciplinary approaches and strategies that use detailed information sources can improve outcomes as much as 50–80% [50].

Discharge Summary

After a hospitalization, communication with the PCP or other care providers is best achieved through a structured and well-organized discharge summary. There is no standard format for information components in the discharge summary in the United States; however other countries have required specific elements. In the United Kingdom (UK), for example, discharge summaries include complete patient details (e.g., name, date of birth, admission date, discharge date), admitting diagnosis and any comorbidities and procedures, prescribed medications and dosing and frequency of all medications, description of why a medication was started or stopped, length of course for medications (e.g., antibiotics), allergies, and health and treatment information that was provided to the patient [51].

The hospital course should accurately describe the patient's clinical problems and associated treatment plan. A clear and succinct narrative allows the PCP or follow-up physician to grasp the differential diagnosis for nonspecific presenting symptoms (e.g., chest pain) and follow the clinical logic flow of a patient's hospitalization. The discharge summary should also include relevant laboratory values that informed treatment, as well as those that are still pending at the time of discharge and require follow-up. Any diagnostic tests or therapeutic procedures or operations should also be included to limit duplicate testing.

Finally, the discharge summary should include any clinical complications that occurred or new diagnoses that will require follow-up items after discharge. Documentation of advanced care planning should also be included. Social determinants that were identified during the hospitalization, such as poverty, should be included since these factors may impact the capacity of the patient to receive medications or follow-up care.

Transitional Care

Transitional care is an emerging principle that focuses on the care processes that occur when a patient moves between healthcare settings, such as from hospital to home. The Coleman Model is well recognized and seeks to engage patients with multiple care needs and improve the quality of the care they receive at the time they are being discharged from hospitalization [52]. There are four pillars in the model: assistance with medication self-management, a patient-centered record owned and maintained by the patient, timely follow-up with primary or specialty care, and a list of "red flags" indicative of a worsening condition and instructions on how to respond to them [52]. The model has demonstrated that engaging chronically ill patients with a transition coach helps reduce hospital readmissions and has associated cost savings [52]. In this approach, patients take ownership in their disease process, and the coaches provide the capacity for ongoing assessments in the critical timeframe immediately after discharge [52].

Future Directions

There is an ongoing movement to value-based healthcare, and the Center for Medicare and Medicaid Services (CMS) has set reimbursement and penalty guidelines around hospital readmission. In fiscal 2017, for example, CMS will reduce $500 million of payments to 2597 hospitals [53]. In consequence, hospitals and healthcare systems will be looking at ways to decrease inappropriate readmissions and improve the care of those with chronic disease. Many hospital systems are looking at extensivist model. In general, extensivists are physicians or care providers that provide comprehensive, coordinated care to a limited number of high-risk chronically ill patients [54]. The small panel size facilitates a focus on managing complex medical conditions and coordinating care. This recent innovation seeks to place patients at the center of a complex medical system and work with them to improve care. Many variations of extensivist models are beginning to appear across the country, and the impact of this staffing approach on chronic disease management is uncertain.

Another development will be in the area of transition clinic models. In these settings, high-risk and medically complex patients receive care in outpatient primary and specialty care settings by a team that includes a physician, a pharmacist, and a care manager [55]. This model has shown benefit, especially when performed within 7 days of discharge and can lead to a 20% reduction in readmission for patients with multiple chronic conditions [55].

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Acute Rehabilitation Care

19

Karen D. Halpert

Introduction

Rehabilitation is a multidisciplinary approach to helping patients overcome disability. The Agency for Healthcare Quality and Research describes rehabilitation as a way to help the person with disabilities to achieve the highest possible degree of performance. This involves training and practice with graduated withdrawal of support as a patient progresses. Comprehensive rehabilitation involves selecting the right setting that takes into account the care needs of the patient. For older patients, frailty and comorbidities must be considered. Geriatric rehabilitation is a multidisciplinary set of evaluative, diagnostic, and therapeutic interventions whose purpose is to restore functional ability or enhance residual functional capability in elderly people with disabling impairments [1].

Rehabilitation can start during a patient's hospital stay or when deficits are noted at an outpatient appointment. Needs are identified and a plan to help the patient regain function is arranged. Given the high incidence of disabling conditions associated with aging, rehabilitation generally involves older adults. Hospitalization often triggers the need for rehabilitation, which is usually covered by Medicare.

Rehabilitation is multidisciplinary, and a coordinated team that communicates well is more effective than fragmented care for patients with chronic illness [2]. Treatment plans are created by team members with input from the patient and his or her support network. The plan organizes the team, estimates the duration of therapy, and is dynamic and modified as indicated. Physicians generally lead the interdisciplinary team. However, the traditional model with the physician in the authoritarian role with limited time to coordinate the efforts of others can lead to redundant work by other team members [3]. A better model is the multidisciplinary team approach which allows the various health-care professionals to interact frequently to coordinate their efforts [4]. The physician still leads the team, but there is free communication between team members who share responsibility for the patient's progress. Care-coordinating conferences can be led by any team member. Descriptions of the team members and their roles are listed in Table 19.1.

K.D. Halpert (✉)
Department of Family Medicine, University of North Carolina, Chapel Hill, NC, USA
e-mail: Karen_halpert@med.unc.edu

Rehabilitation Settings

Rehabilitation can be offered through inpatient or outpatient services depending on the patient's illness and rehabilitative needs. Inpatient services include hospital rehabilitation units, long-term care hospitals, and skilled nursing facilities. To qualify for inpatient services under Medicare, a patient must have a hospital stay of at least 3 consecutive days for a related illness or injury, known as a "qualifying stay." Private insurance plans or Medicare Advantage programs may not require a qualifying stay. Outpatient rehabilitation is conducted at home or in an ambulatory care setting.

Acute Inpatient Rehabilitation

Acute inpatient rehabilitation (AIR) is the most aggressive rehabilitation option available. To qualify for AIR, a patient must have complex needs requiring multiple therapies managed by an interprofessional team. The patient must be able to tolerate at least 3 h of rehabilitation therapy per day for at least 5 days per week (15 h per week). To evaluate appropriateness for this level of care, patients are screened to evaluate their condition, need for services, prior level of function, and physical and mental ability to participate in aggressive therapy. The rehabilitation team will assess if 3 h a day of therapy is needed to meet the patient's goals, which include returning the patient to the community setting in a realistic time frame.

Medicare part A covers this form of intense rehabilitation as these patients usually have complex needs. A

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Table 19.1 Roles of team members in effective and comprehensive rehabilitation, which depends on multiple professionals who communicate well and work cohesively

Role	Responsibilities
Medical director (physician)	Lead the multidisciplinary team, working collegially with other team members
	Ensure the rehabilitation program is safe, appropriate, comprehensive, and cost-effective
	Certify the need for rehabilitation
	Evaluate and treat medical comorbidities
	Direct program evaluation, ongoing quality improvement
Administrator	Proficient in both business management and health care
	Oversee operation of the facilities including supervision of staff and personnel management
	Financial planning and budgeting
	Ensure compliance with state and federal regulations
	Handle grievances of employees, patients, and families
Physical therapist	Assess the patient's pain, ability to move, and function, and develop a treatment plan
	Instruct physical exercise to improve and restore range of motion, strength, endurance, balance, coordination, and gait
	Provide appropriate assistive devices
Occupational therapist	Evaluate self-care skills and ability to conduct activities of daily living (ADLs)
	Provide training that helps the patients return to participation in activities that they need and want to do
	Make recommendation and train in use of assistive technology
	Fabricate splints
Speech therapist	Evaluate and treat patients regarding communication ability such as language comprehension, verbal expression, and auditory comprehension
	Address cognitive function such as attention, memory, thought organization, reasoning, and problem solving
	Assess swallowing disorders and recommend dietary or positioning changes to treat dysphagia
Recreation therapist	Individual therapy to meet patients' interests to help them reach their physical, cognitive, emotional, social, and leisure needs
	Assist in developing skills, knowledge, and behaviors for daily living and community involvement
	Use of recreational modalities to improve function
Social worker	Advocate for the patients and promotes their dignity and intrinsic worth
	Assess psychosocial factors and address uncertainty, anxiety, depression
	Help patients adjust to changes such as increased dependency, loss, grief
	Support patient and family in adapting to changed roles or relationships
	Address financial and social stressors related to disability, help with medical expenses
	Find resources needed in home environment or transportation
Nurse	Monitor for signs and symptoms of medical conditions
	Administer medications
	Care for wounds
	Assist patient with tasks of bathing, dressing, and other ADLs
Nutritionist	Assess nutritional status, eating patterns, and dietary issues associated with medical conditions
	Nutrition education and individual plans for sustained healthy eating

Medicare-certified inpatient rehabilitation program must show that at least 60% of the patients have at least 1 of 13 conditions: stroke, spinal cord injury, congenital deformity, amputation, multiple major trauma, hip fracture, brain injury, neurologic disorder (e.g., multiple sclerosis, Parkinson disease), burns, three arthritic conditions for which appropriate aggressive and sustained outpatient therapy has failed, joint replacement of both knees or hips when surgery immediately precedes admission, a BMI > 50 kg/m^2, or age > 85 years old [5]. Medicare covers via a prospective payment system that is based on case-mix groups using various functional status measures such as Functional Independence Measure, Barthel ADL Index, or Stroke Impact Scale. Medicare part A fully covers the first 20 days, partially covers day 21 through 100, after which there is no further coverage. Private insurance coverage depends on the patient's status and improvement during rehabilitation.

Beyond being able to participate in 15 h of rehabilitation a week, patients must have medical supervision by a physician with specialized training or experience in rehabilitation,

24-h nursing care, and be managed by an interdisciplinary team of skilled nurses and therapists. The team usually includes a physician trained in physical medicine and rehabilitation, physical therapist, occupational therapist, recreational therapist, respiratory therapist, psychologist, social worker, and dietician. Weekly team meetings review and update the patient's goals, progress, and discharge plans. Families are involved in these discussions.

Intense rehabilitative services provided in AIR can help even the most debilitated patients have the best chance of returning to their home or community. The relatively strict admission criteria limit the number of patients who qualify for this type of aggressive rehabilitation. Given the limited number of AIR beds, patients with cognitive limitations or low potential for rehabilitation are not usually deemed appropriate candidates for AIR.

Long-Term Care Hospitals

Long-term care hospitals (LTCHs) provide extended medical and rehabilitative care for patients who are clinically complex or have multiple acute or chronic conditions [6]. Patients who are admitted to these facilities have medical needs such as dialysis or mechanical ventilation and have an average stay of 27 days. Most of the patients are transferred from intensive or critical care units and require at least 8 h of direct skilled nursing care per day. This can include ventilator management, care for chronic wounds, or provision of services for conditions such as chronic renal failure requiring dialysis. Patients may also qualify if they require at least 4 h per day of complicated respiratory care such as ventilator weaning, tracheostomy maintenance, or complex airway management. In all LTCHs, patients are seen nearly daily by a physician with specialty consultation available if needed. The goal of this kind of rehabilitation is to get the patient home or reduce care needs to the level where the patient can transfer to a skilled nursing facility.

LTCHs are exempt from Medicare's acute care hospital prospective payment system, but rather are paid based on the average cost per discharge [7]. Payments are based on long-term care diagnosis-related groups (LTC-DRGs). These patients tend to be sicker and have higher costs in these facilities than patients in acute care hospitals [8]. The patient must pay their Medicare part A deductible and 20% of Medicare part B charges.

In most parts of the country, LTCHs serve patients who require ventilators, are medically complex, and may not be able to participate in aggressive rehabilitation. LTCHs are unevenly distributed across the nation and have strict qualification standards. Still, they are the appropriate option for medically complex patients who need their care optimized while attempting rehabilitation.

Skilled Nursing Facilities

Patients who have a qualifying hospital stay or an insurance approval may be candidates for a skilled nursing facility (SNF) if they require skilled nursing care and physical or occupational therapy. The skilled care must be necessary to improve or maintain the patient's condition or at least prevent or slow further deterioration [8]. The patient must transfer to the facility within 30 days of discharge from the hospital. Patients must be medically stable allowing for the focus to be on rehabilitation needs. For Medicare to cover care in a SNF, the Centers for Medicare & Medicaid Services (CMS) requires that the care is ordered by a physician and requires the skills of professional personnel, such as registered nurses, physical therapists, occupational therapists, or speech pathologists, and is furnished by, or under the supervision of, these skilled personnel. The skilled care must be provided on a daily basis and rendered for a condition for which the patient received inpatient hospital services, or for a condition that arose during the hospitalization, or for a new condition that started during the SNF care [9, 10].

Skilled nursing needs include injectable medications, tube feeding for gastrostomy tubes, and wound care that may include wound vacuums or management of pressure ulcers. Skilled physical therapy can address loss of function where significant improvement is not expected to occur spontaneously. Occupational therapists teach compensatory techniques that improve the ability to independently perform activities of daily living (ADLs) by designing, fabricating, and fitting orthotic and self-help devices. Speech therapy addresses voice production and improves the patient's ability to communicate.

Nursing care in SNFs is less intensive than in acute care hospitals. In a SNF, a nurse may care for 12–20 patients at a time. Patients in this type of subacute rehabilitation tend to be younger than those in the long-term care part of a SNF (average age 70s versus 80s). Most patients are admitted from acute care hospitals and return home after discharge from the SNF.

Medicare part A fully covers the first 20 days of rehabilitation in a SNF. Days 21 through 100 are partially covered, requiring a co-payment from the patient. Medicare does not cover a SNF stay past 100 days. Private insurance may pay, depending on the patient's status and improvement during rehabilitation.

SNFs are highly regulated facilities and require 24-h nursing with clinicians on call 24 h a day for needed consultation or emergencies. A physician must complete a comprehensive history and physical examination in a timely manner after the patient's arrival, then every 30 days for the first 90 days and then every 60 days thereafter, along with any as-needed visits. SNFs are licensed and regulated by the Omnibus Budget Reconciliation Act (OBRA) of 1987 [11].

These regulations require the medical regimen to be comprehensive and part of an interdisciplinary care plan. Decline in the physical or mental well-being of the patient should be demonstrably unavoidable. Any physical restraint is strongly discouraged and requires individual clinical assessment and appropriate drug regimen to be justifiable.

Rehabilitation at a SNF provides a stepping stone from hospital level care to home. It is a good alternative for patients who need skilled care when home services are not sufficient. It is also an appropriate location for patients who need rehabilitation but are not able to tolerate 3 h a day of therapy such as in an inpatient program. They are intended to be for lower acuity medical care, and providers are not always on-site, nor is therapy always available 7 days a week. Some patients and families may feel underwhelmed by SNF level care if they feel that the amount of therapy is not as intense as expected.

Home Health Rehabilitation

Patients who have a need for skilled nursing, or physical, occupational, or speech therapy and have an appropriate support system in their dwelling may have their rehabilitation at home. Home health can be arranged at a home or in an assisted living facility. Services are provided by Medicare-certified, state-licensed home health agencies. Medicare covers 60-day episodes which can be extended with recertification for another 60 days. Medicare has no limit to the number of 60-day episodes for which a patient can qualify [12]. Beyond the need for skilled care, the patient must be considered homebound with inability to attend therapy in an ambulatory facility. CMS requires that the care is ordered by a physician, who approves and periodically reviews the care plan. The care provided by home health is intermittent meaning fewer than 7 days a week with less than 8 h of each day. The required criteria to designate a patient as homebound are listed in Table 19.2 [12].

Medicare part A will pay for services if a patient is a Medicare beneficiary and homebound and has intermittent skilled nursing or therapy needs. Medicaid will cover services if a patient qualifies for Medicaid and has no other insurance coverage. CMS coverage for each 60-day episode covers all indicated home health services, such as skilled nursing, home health aides, physical and occupational therapy, speech and language therapy, and social work. It also covers necessary medical supplies. Physicians bill for certification and recertification under Medicare part B using the Healthcare Common Procedure Coding System (HCPCS) codes G0180 (certification) or G0179 (recertification) [12].

The home health agency is required to provide medical supplies, while the patient is under a home health plan of care. Durable medical equipment is covered separately from the home health services. Coverage of the skilled care is not dependent on the patient's ability to improve, rather depends on the patient's need for skilled care, the goal of which may be to improve a patient's condition, maintain the current condition, or prevent or slow further deterioration [12]. The home health team is required to maintain the plan of care and certify that the patient remains homebound and requires the skilled needs. Physicians must sign orders at least every 60 days or when there is a change in the frequency or nature of the services. A written or oral order is acceptable regarding increased or additional services. As part of the Medicare certification, a physician or non-physician practitioner must complete a face-to-face encounter with the patient which can be done by the provider who cared for the patient in the hospital or in a rehabilitation facility. The face-to-face encounter must occur no more than 90 days prior to the start of home health services or within 30 days after the start of care. Home health aide services may be appropriate but require that the patient also receive skilled nursing or therapy care.

Home health has many appropriate indications. Patients who benefit from home health rehabilitation are those who are transitioning from a higher level of care such as a hospital or SNF who would benefit from ongoing skilled nursing or therapy at the level that can be provided in the home setting. Home health services are also available to patients identified in outpatient clinics who may be frail or have other significant health problems and would benefit from rehabilitation, though are unable to regularly travel to outpatient therapy. For example, a patient with a significant risk for falling may benefit from physical therapy conducted in the home which includes a home safety evaluation which can help with strategies that reduce the risk of falls.

Table 19.2 Medicare criteria for considering a patient to be considered "confined to the home" (homebound) and therefore eligible for home health services. CMS Guidelines [12]

1. Criteria-one:
The patient must either:
Because of illness or injury, need the aid of supportive devices such as crutches, canes, wheelchairs, and walkers; the use of special transportation; or the assistance of another person in order to leave their place of residence
Or
Have a condition such that leaving his or her home is medically contraindicated
If the patient meets one of the criteria-one conditions, then the patient must ALSO meet two additional requirements defined in criteria-two below
2. Criteria-two:
There must exist a normal inability to leave home
And
Leaving home must require a considerable and taxing effort

Ambulatory Rehabilitation Facilities

Patients who have a skilled physical, occupational, or speech therapy need may receive this care in the outpatient setting. These services are covered by Medicare part B when they are referred for such by a provider who has seen them recently and is willing to certify that the care is needed [13]. Patients must have a safe home and the ability to travel to attend the intermittent outpatient therapy appointments. The patient's physician must review the plan periodically with the therapist. There should be reasonable expectations of improvement with treatment. A patient may be treated for more than one condition including any new condition that may arise, such as the development of low back pain during physical therapy for a hip fracture, which allows the physical therapist to modify the initial treatment plan.

Management of Care

Admissions and Transfers

Admissions and transfers from one setting to another are critical points in care, and errors or omissions that happen during these transitions can cause setbacks or even require readmission to a higher level of care. Medication reconciliation is a particularly important step and should be carefully reviewed, including doses and frequency, with the patient and caregivers to ensure key medications are continued and home medications are not forgotten. Medications for management of chronic disease or treatment for an acute problem are important, but background medications, such as eye drops, may improve quality of life and engagement during rehabilitation.

A thorough history and physical exam should be performed with each admission or transfer to ensure that the patient's symptoms are well controlled and that no new problems have developed. Documentation of the condition of the patient's skin is vital as skin breakdown and ulcers are closely monitored parameters by CMS and the Joint Commission, which accredits and certifies health-care organizations. Functional status should be assessed to reestablish appropriate rehabilitative goals for the new care team. Functional level at admission is the most reliable predictor of functional outcome [14]. Assessing cognition may identify barriers to successful rehabilitation [15]. Evaluating the overall status of the patient who may have multiple complex conditions is important and helps establish goals of care and prognosis. It is important to be realistic with the patient and family regarding the likelihood of recovery and return to prior level of function and the expected time frame for improvement.

Advance Care Planning

During any admission or transition, it is important to clarify with the patient and his or her family the goals of care and advance directives. While the default may be to continue the advance directives from the last source of care, it is important to readdress goals of care, review written directives, and clarify who is the health-care power of attorney. Most states have documents that allow for expression of wishes regarding hospitalization, resuscitation, antibiotics, hydration, and feeding tubes.

Quality Improvement

CMS collects quality measures during short (≤100 days) and long (>100 days) stays in skilled nursing facilities, the purpose of which is to provide consumers with information about the quality of the nursing home and to provide facilities with feedback that helps improve care [16]. Short-stay quality measures include self-reported moderate to severe pain, pressure ulcers that have developed or have worsened, influenza and pneumococcal vaccine rates, and new orders for antipsychotic medication. These data are routinely collected at nursing homes and reflect how well the facility cares for the physical and behavioral needs of the patients. It is the role of the medical director to help the facility develop and manage quality and safety initiatives [17].

Discharge Planning and Transitional Care

The goal of rehabilitation is to return the patient to prior functional status in the most appropriate setting, the planning for which begins as soon as the patient is admitted. The multidisciplinary team is continually planning for eventual discharge and anticipating the care needs involved in the next transition which could include continuation of services in another facility or at home. Physical therapy may work on car transfers, occupational therapy will assess the home, social work will identify social or family barriers, and the clinician will make sure the patient's symptoms are well-managed and that only necessary medications are continued. To reduce the risk of unforeseen problems during a transition of care, close follow-up is arranged, usually with the patient's primary care provider plus any appropriate specialists.

Common Conditions in Rehabilitation

Stroke

Strokes are the fifth leading cause of death in the USA and cost $33 billion annually [18, 19]. It is a major cause of disability and reduces mobility in more than half of stroke

survivors who are older than age 65 [19]. Improvements in acute stroke care have increased survival with rehabilitation then playing a major role in helping the patient regain function and independence. Rehabilitation also includes compensating or adapting to functional losses and preventing secondary complications.

Multidisciplinary evaluation after a stroke is critical in addressing rehabilitation needs and developing an appropriate care plan. Early evaluation and initiation of therapy decreases medical complications and improves functional outcomes [20]. By the time a patient is transferred to a rehabilitation program, the goal is to have him or her fully engage in therapy, which requires stabilization of comorbid illnesses, facilitation of the patient's and family's coping skills, and addressing psychosocial factors that could affect participation.

Guidelines for rehabilitation after a stroke have been developed by the Department of Veteran Affairs and the Department of Defense and by the American Heart Association/American Stroke Association [21, 22]. These guidelines highlight the importance of team-based coordinated care which reduces complications and mortality rates and improves functional independence. Medical complications often occur during the post-acute phase of the stroke during early rehabilitation and can affect as many as 60% of patients, with the highest incidence in those with significant brain injury [23]. Some of the more common medical complications include:

Aspiration and Aspiration Pneumonia Dysphagia is a common and serious complication of stroke. Aspiration can be visually apparent due to coughing or can be unrecognized. The patient's swallowing ability should be assessed by a speech pathologist who will monitor feeding and advance as appropriate. If the patient develops fevers, difficulty breathing, or a worsening cough, evaluation for aspiration pneumonia and possible treatment should be considered.

Malnutrition A patient's diet may be adjusted to decrease aspiration risk which may limit caloric intake, which can compound any weight loss and deconditioning that may have occurred during the hospitalization [24]. Caloric intake may be reduced due to reliance on others for oral or tube feedings, lack of interest in food, depression, or difficulty with communication. Food intake and weight should be monitored with a nutritionist consulted for recommendations regarding caloric needs, dietary adjustments, or supplements, taking into account the patient's food preferences.

Deep Venous Thrombosis (DVT) Prophylaxis DVT prophylaxis should be considered as long as the patient remains relatively immobile. For patients who do not have a medical indication for long-term anticoagulation, short-term low-molecular-weight heparin can prevent thromboembolic disease in patients with ischemic or hemorrhagic stroke. Compression stockings or intermittent pneumatic compression devices may also be used. DVT prophylaxis may be discontinued when the patient is walking although the optimal duration of therapy is not clear [25].

Bowel and Bladder Dysfunction Following a stroke, the patient may develop bladder dysfunction causing intermittent incontinence or urinary retention. An ultrasound-based bladder scans can determine the volume of urine retained. Catheterization should be avoided if possible, with attempts to improve voiding made by appropriate positioning of the patient and timed bladder training. If urinary retention over 150 cc remains, intermittent catheterization is preferred over indwelling Foley catheter. Anticholinergic medications may be needed for incontinence but should be monitored closely due to significant side effects, especially in older patients. An appropriate bowel regimen should be ordered to prevent constipation.

Pain Patients recovering from stroke may develop pain in the upper extremities due to rehabilitation efforts, which should be assessed and treated so therapy can continue. Spasticity after stroke can contribute to musculoskeletal pain. Medications should be started at low doses and titrated up slowly to avoid confusion and sleepiness that might interfere with participation in rehabilitation.

Depression Depression after a stroke is common and occurs in almost a third of patients [26]. Simply asking "Do you often feel sad or depressed?" was compared to a more involved depression assessment tool and found to have a sensitivity of 86% and specificity of 78% in screening for poststroke depression [27]. Treatment of depression improves functional outcome at 3 and 6 months [28]. There is no definitive evidence to guide treatment for poststroke depression. Use of pharmacotherapy and psychotherapy is based on patient and provider preferences.

Hip Fracture

More than 300,000 Americans age 65 and older are hospitalized for hip fractures every year [29]. Most of these patients receive post-acute hospital care either in acute inpatient rehabilitation or, more commonly, in skilled nursing facilities, especially with the emphasis on shortening hospital stays. Rehabilitation reduces complications and helps patients regain function. Most patients over the age of 65, especially those who have cognitive impairment, remain functionally dependent 3 months after a hip fracture [30]. Ongoing dependence is increased in those with advancing

age, multiple comorbidities, hip pain, previous employment in a prestigious occupation (management, professional), and poorer self-rated health. The risk of death is increased during the first year after the fracture. Approximately one in four women and one in three men who sustain a hip fracture from a low-impact injury will die within 1 year. Many people will be unable to return to their pre-fracture level of function, and 25–50% of individuals will not have returned home 1 year after a fracture [31].

For patients with severe dementia or end-stage heart or lung disease who break their hip, the risks and benefits of surgical repair must be weighed [32]. If deemed not appropriate, the focus is on comfort. These patients are essentially wheelchair bound, need support for transfers, and usually cannot live independently. They are at risk for skin breakdown, malnutrition, and sarcopenia, all of which can be addressed with a limited plan for rehabilitation. For those patients who do have surgery, rehabilitation is tailored to the type of surgical repair undertaken. A percutaneous nail can be done under local anesthesia with minimal limitations to weight-bearing status after the procedure. A hemiarthroplasty is a more involved procedure and requires weight-bearing restrictions for a while postoperatively. Patients should be mobilized as soon as deemed safe by the surgeon and the physical therapist. Early mobilization reduces postoperative complications from bedrest or relative inactivity [33, 34].

The decision for outpatient versus inpatient rehabilitation is determined by a patient's functional status, comorbidities, and support at home. Factors associated with discharge directly to home after hip fracture (which occurs in only 20% of patients) include prior status of residing in the community, age younger than 85 years old, absence of postoperative complications, achieving bed mobility, ambulation with a walker, and a greater number of physical therapy sessions [35]. If the patient has comorbid medical conditions, she or he may benefit from a short stay at a SNF with transition to home when appropriate. Factors associated with permanent institutionalization after hip fracture include the need for assistance with ADLs, age greater than 80 years, lack of family involvement, and insufficient physical therapy at the SNF [36].

Venous thromboembolism is a leading cause of postoperative morbidity and mortality in patients after a hip fracture, as it is with many orthopedic surgeries, the prevention of which usually surpasses the risk of bleeding complications from treatment. Rehabilitation includes choosing an anticoagulation treatment such as low-molecular-weight heparin, fondaparinux, low-dose unfractionated heparin, adjusted-dose warfarin, aspirin, a newer anticoagulation agent, or an intermittent pneumatic compression device for a *minimum* of 10 days after surgery [37]. Anticoagulation should start 12 or more hours after the surgical repair and continue up to 35 days postoperatively. Shorter treatment may be indicated for people who successfully ambulate early in their rehabilitation.

Control of pain is necessary if patients are to work with physical therapy. Sufficient pain control can decrease length of stay, enhance recovery, and improve long-term functional outcomes [38]. An approach to pain that employs multiple modalities works best. Narcotic (opioid) pain medications are associated with delirium and constipation, but can be used judiciously even in the geriatric population. Undertreated pain, especially in patients with dementia, contributes to delirium, sleep disturbance, and decreased response to treatments [39–41]. No particular regimen for pain control is proven to be superior for pain associated with a hip fracture [31, 42].

Total Hip and Knee Arthroplasty

Half a million new cases of symptomatic osteoarthritis of the knee and hip arise annually in the USA [43]. Total joint arthroplasty (joint replacement) has revolutionized the care of patients with end-stage joint disease, offering pain relief and functional improvement [44]. In 2010, over 600,000 total knee replacements were performed annually in the USA with the number expected to grow to 3.5 million procedures by 2030 [45, 46]. Over 300,000 total hip arthroplasties are performed every year in the USA [45]. Early postoperative rehabilitation restores mobility, strength, and flexibility while preventing thromboembolic disease and other medical complications [47]. The surgeon recommends a physical therapy plan and postoperative care preferences, while the medical physician manages pain and other medical problems.

The appropriate setting for rehabilitation is determined by the functional status of the patient and the resources available. Patients with hip replacement generally can go home when they meet these milestones: adherence to hip precautions, ability to ambulate 100 ft with an assistive device, independence with a home exercise program, and only requiring supervision with toilet use, transfers, and activities of daily living [48]. For those patients requiring skilled nursing care, the rehabilitation stays are generally less than 2 weeks.

Pain from joint replacement is generally adequately managed with scheduled acetaminophen with narcotics available as needed. Nonsteroidal anti-inflammatory drugs should be used with caution due to potential side effects of gastrointestinal track bleeding and kidney dysfunction. COX-2 anti-inflammatory medication after knee replacement was associated with less pain and improved knee motion [49].

The American Academy of Orthopaedic Surgeons (AAOS) and the American College of Chest Physicians (ACCP) have developed evidence-based guidelines to reduce

the risk of deep venous thrombotic disease (DVT) after joint replacement [37, 50]. The recommendations balance the reduction in the risk of fatal and symptomatic pulmonary embolism and symptomatic DVT with the increased risk of bleeding from preventative treatment. Low-molecular-weight heparin, fondaparinux, apixaban, dabigatran, rivaroxaban, low-dose unfractionated heparin, adjusted-dose vitamin K antagonist, aspirin, or an intermittent pneumatic compression device (IPCD) are all options and should be given for a minimum of 10–14 days after a total hip or knee arthroplasty starting 12 h after surgery [51]. Low-molecular-weight heparin is the preferred treatment. The use of both medication and IPCD is recommended during the hospital stay. The AAOS recommends monotherapy with high-dose aspirin (325 mg) twice a day for 6 weeks as an acceptable option for DVT prophylaxis in low-risk patients [50]. This regimen is favored by many orthopedic surgeons [52]. Discrepancies between guidelines are likely due to differences in perspective and focus. While the AACP focuses on DVT prevention, the AAOS is also concerned with surgical wound complications and bleeding problems worsened by anticoagulation [53]. Another difference is the AAOS focuses on the outcome of symptomatic or fatal pulmonary embolism while the AACP looks at symptomatic DVT in addition to those outcomes. A meta-analysis found that aspirin for DVT prophylaxis in hip and knee arthroplasty resulted in a low rate of thromboembolic disease and few bleeding complications [54]. Aspirin is not considered adequate prophylaxis in high-risk patients such as those with medical problems that place them at significant risk for DVT. Future studies may provide consensus on the best treatment to prevent postsurgical DVT in patients with joint replacement surgery.

Common Acute Medical Problems in Rehabilitation

Skin Breakdown and Pressure Ulcers

Patients at high risk for skin breakdown during rehabilitation include those with end-stage disease, poor nutritional status, cognitive impairment, immobility, incontinence of urine and stool, and sensory impairment. Pressure ulcers can result in infections, prolonged rehabilitation, immobility, malnutrition, pain, and hospital admission. The rehabilitation care team should routinely examine the skin and treat with scheduled turning, optimized nutrition, avoidance of prolonged sitting, and use of pressure-relieving devices such as pillows and mattresses. Moisture from urine and stool incontinence should be minimized with regular toileting.

Acute Infectious Illness

Patients in rehabilitation often have medical comorbidities and frailty and are at increased risk of developing infections, sometimes requiring transfer back to the hospital. Common infections include pneumonia, urinary tract infection, or cellulitis, which should be appropriately evaluated and treated. Advance directives and the appropriateness of the setting in managing the situation are factors taken into account regarding possible transfer back to a hospital.

Incontinence

Many patients in rehabilitation are discharged from the hospital with an indwelling urinary catheter. Unless there is a medical reason to continue use, catheters should be removed as they are a potential source of infection and can interfere with physical therapy. For patients with urinary incontinence or retention, medication lists should be reviewed for any medications that might be contributing. Delirium, immobility, fecal impaction, and deconditioning can also contribute to problems with urinary function and should be addressed if present.

Durable Medical Equipment

Nearly seven million Americans use a device to assist with mobility [55]. Many older adults would likely benefit from a mobility aid but prefer not to due to concerns that it makes them feel old or they have a preference for human assistance. Durable medical equipment (DME) is defined by CMS as equipment that can withstand repeated use, is primarily used to serve a medical purpose, is not useful to a person in the absence of illness or injury, and is appropriate for use in a home [13]. During rehabilitation, a physical therapist will evaluate the need for a mobility aid and then determine the most appropriate type for the patient. Table 19.3 describes commonly used mobility aids [56]. All of these devices require fitting based on the patient's height, weight, and disability.

Physical therapy will work with the physician or other clinician to properly document the need for the device and complete the necessary paperwork which includes documenting the diagnosis, indication, and length of need. Medical equipment is covered by Medicare and other insurers if the equipment meets the definition of DME and the documentation requirements are met [57]. In addition to mobility aids, DME can include hospital beds, intermittent positive pressure breathing machines, nebulizers, and commodes.

Table 19.3 Commonly prescribed mobility aids

Assistive device	Characteristics and features	Common indications
Straight cane	Provides unilateral support	Osteoarthritis
	Assists with balance and proprioception	Peripheral neuropathy
	Reduces weight bearing on opposite leg	
	Supports 15–20% of body weight	
	Used in hand contralateral to affected knee or hip	
	Sensation of cane in hand can improve proprioception in feet and legs due to peripheral neuropathy	
Quad cane	Provides unilateral support	Stroke with hemiparesis
	More stable platform than straight cane	
	Allows more weight to be borne by device	
Stationary Walker	Provides bilateral support	Unilateral amputation before prosthesis
	Must be lifted to advance	Hip fracture with non-weight-bearing status
	Very stable and reduces weight bearing on legs	
	Cannot fully support body weight	
	Requires upper extremity strength	
Two-wheeled walker	Less stable than stationary walker but easier to move	Deconditioning
	Allows for smoother gait	Parkinson disease
	Brakes automatically with downward pressure	
Four-wheeled walker with seat and brakes (rollator)	Less stable but allows for faster gait	Cardiopulmonary disease
	Requires ability to coordinate braking	
	Has seat for resting	
	Easier for outdoor use given larger wheels	
	Appropriate for patients who easily fatigue	
Manual wheelchair	Requires use of arms and some endurance	Non-ambulatory patient with cognitive impairment
	Easier for caregivers to assist with mobility	Low-level spinal cord injury
Power wheelchair	Allows community mobility for those with limited ambulatory ability	Neurologic disease
	Controls do not require upper extremity strength	Stroke
	Need preserved cognitive ability to operate safely	
Scooter	Similar to power wheelchair but must have intact upper extremity strength and coordination to operate	Cardiopulmonary disease
		Osteoarthritis

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Nursing Home Care

20

Maureen C. Dale and Margaret R. Helton

Introduction

Residential care has evolved from the almshouses for the poor and elderly of medieval England to the modern nursing home that employs healthcare professionals who provide care to patients with increasingly complex needs. In the USA, the number of nursing homes increased in the 1950s after Congress approved the construction of hospitals and related healthcare facilities in response to President Harry Truman's call to improve the health and healthcare of Americans [1]. The creation of Medicare and Medicaid in 1965 expanded funding for healthcare for older Americans, including nursing home care. Growth has continued, and in 2014 the USA had 1.6 million certified nursing facility beds (averaging 109 beds per facility) at 82% capacity [2].

Nursing home residents generally are classified as short stay or long stay (Fig. 20.1) [3]. Short-stay care has grown significantly over the past decade and provides subacute (or "post-acute") care, usually after hospitalization and for the purpose of rehabilitation or reconditioning. Long-stay residents have care needs that can no longer be met independently or by family members. Nearly half of these residents have dementia, and nearly a third have psychiatric conditions such as schizophrenia or other mental health problems [2]. Nearly 65% of residents depend on a wheelchair for mobility or are unable to walk without constant support from others. Four percent are bed-bound. A large number have bladder or bowel incontinence. Behavior problems such as yelling, hitting, wandering, and disinhibition are common, making this a challenging population for caregivers.

M.C. Dale
Division of Geriatric Medicine, Department of Medicine, University of North Carolina, Chapel Hill, NC, USA

M.R. Helton (✉)
Department of Family Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA
e-mail: Margaret_helton@med.unc.edu

Regulations for Quality

Nursing homes have been viewed negatively by the public in the past, with many people claiming they would "rather die" than live in a nursing home. Alarmed by ongoing reports of fraud, neglect, abuse, fires, and "shockingly deficient" care in nursing homes, the Institute of Medicine in 1986 released a report proposing regulation to improve care [4]. In 1987 the US General Accountability Office (GAO) proposed federal regulation to address the low standards of care in nursing homes [5]. In response to these reports, federal nursing home legislation was passed in the Omnibus Budget Reconciliation Act (OBRA) of 1987 with the goal of significantly improving the physical and mental well-being and functioning of residents in nursing homes [6]. Efforts to improve care included yearly inspections, interviews with residents, record reviews, sanctions, financial penalties, and denial of payments.

As part of the federal Nursing Home Reform Act of OBRA-87, a resident assessment instrument known as the Minimum Data Set (MDS) was developed, and it remains the foundation of clinical assessment and care planning for individual residents. The 230-item MDS collects information on each resident of the nursing home and is used for quality, payment, and research purposes.

State Government Oversight

States are responsible for ensuring that nursing homes meet federal and state regulations. State surveyors visit nursing homes at least every 15 months and review patient care and overall functioning of the facility and assess both process and outcome measures for almost 200 individual requirements across 8 areas (Table 20.1) [2]. Each specific requirement has a measurement and an identifying number known as an F-tag. Failure to meet a requirement results in a citation. In 2014, the most common deficiencies were in infection control, accidents, food sanitation, quality of care, and

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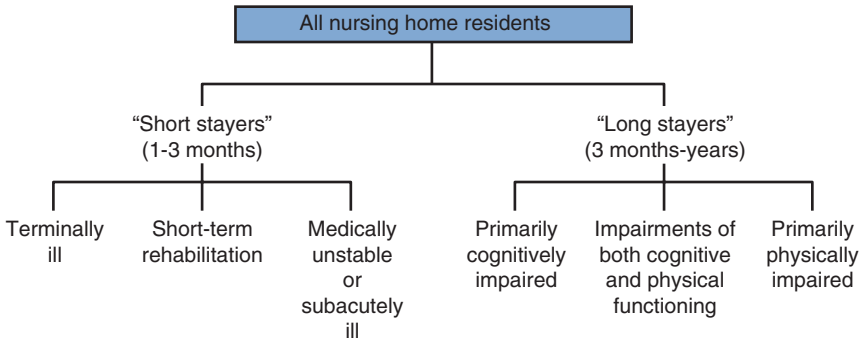

Source: J.B. Halter, J.G. Ouslander, S. Studenski, K.P. High, S. Asthana, M.A. Supiano, C. Ritchie, W.R. Hazzard, N.F. Woolard: Hazzard's Geriatric Medicine and Gerontology, Seventh Edition, www.accessmedicine.com

Fig. 20.1 Types of patients residing in nursing homes (Modified from Nursing Home Care, *Hazzard's Geriatric Medicine and Gerontology, 7e*)

Table 20.1 State surveyors assess and measure both the process and outcomes of nursing home care in eight categories. Each category includes numerous federal regulations known as "F-tags"

Administration
Environment
Mistreatment
Nutrition
Pharmacy
Quality of care
Resident assessment
Resident rights

unnecessary drugs [2]. Nursing homes vary widely in the number of cited deficiencies.

The Centers for Medicare and Medicaid Services (CMS) uses survey data for its quality reporting database including the Online Survey, Certification, and Reporting (OSCAR) system, the results of which are made available to the public through CMS's *Nursing Home Compare* website. This website was created in 1998 and has been updated several times including the addition of a Five-Star Quality Rating System which provides individual and composite ratings for nursing facilities based on health inspections, nurse staffing hours, and selected quality measures [2]. Another database is the Certification and Survey Provider Enhanced Reports (CASPER) which is additional quality data that is available to the nursing homes themselves.

The 2010 Affordable Care Act (ACA) furthered quality of care efforts for nursing facilities that participate in Medicare and Medicaid by requiring nursing homes to be transparent in disclosing financial relationships and costs and imposing monetary penalties for lack of compliance with federal regulations [7]. This was due to the growth in for-profit nursing homes and the concern that profit is prioritized over quality [8, 9]. In 2014, 69% of nursing homes were for-profit, 24% were nonprofit, and about 6% were government-owned [2]. The ACA also incorporated the Elder Justice Act and the Patient Safety and Abuse Prevention Act, which protect nursing facility residents from abuse and other crimes and require that staff undergo background checks. The law also has reporting requirements for nurse staffing, ethics rules, notification requirements when a facility closes, and additional staff training on dementia care.

Financing

Nursing home care accounts for 22% of healthcare spending by those aged 65 years and older (about $175 billion per year) [10]. A year's worth of care in a nursing home for an individual typically costs $80,000 [11]. This is clearly out of reach for most individuals and their families which is why Medicaid, the jointly funded federal and state health insurance program for low-income and needy people, is the primary payer source for 63% of all nursing home residents [2]. Individuals must first exhaust or spend down all their personal assets before they qualify for Medicaid, which serves as the long-term safety net for millions of people in long-term care. The significant cost of Medicaid makes it a significant issue of concern for federal and state policy makers and citizens. Government's role as the primary payer enables it to enforce quality and accountability in nursing homes.

Medicare, the federal health insurance program for people who are 65 or older, only covers short stays in nursing facilities, under Medicare Part A, and only after a 3-day qualifying stay in the hospital after which a physician orders ongoing care that required the skills of a professional staff nurse and therapist for a condition for which the patient was hospitalized or for a new condition that started during the stay in the nursing home. Medicare fully covers the first 20 days in the nursing home and partially covers days 21 through 100. Medicare does not cover a nursing home stay beyond 100 days [12]. Medicare was the primary payer for 14% of the total residents in nursing homes in 2014. Private payers (mostly families or individuals paying out of pocket) are the primary payer for the remainder of residents (23% in 2014) [2].

Licensed nursing facilities must be certified for participation in the Medicare and/or Medicaid program. In 2014, the vast majority (96%) of beds were dually certified though most were filled with residents covered by Medicaid. Medicare classifies facilities as skilled nursing facilities (SNFs), while Medicaid uses the term "nursing facilities" (NFs).

The Nursing Home Care Team

Physician

Although the physician role in long-term care is important, physicians are not always the most present members of the patient care team. In the USA, physicians who care for patients in long-term care settings usually do not work exclusively in nursing homes and spend a limited amount of time there as they maintain office and hospital-based practices [13, 14]. Despite this, physicians have important roles including developing and directing the care plan for each patient and communicating the plan to the interprofessional care team. They must address acute issues and manage chronic conditions, many of which are geriatric syndromes like frailty, urinary incontinence, and cognitive impairment. While much of the care plan is implemented by other members of the care team, the physician is responsible for developing the plan, periodically reassessing its appropriateness, and following up on any diagnostic data [15]. The physician is responsible for communicating with and reviewing the recommendations of any consulted specialists. Federal regulations dictate the frequency with which physicians must see patients in long-term care. They must also be available for acute issues which must include a coverage system so that there is always a provider available by phone when needed. Physicians should also be actively involved with quality assurance and quality improvement initiatives at the facility including working with the medical director and director of nursing to identify problems and work in a systematic way toward solutions.

Advance Practice Providers

Many physicians partner with advanced practice providers to deliver care in nursing facilities [15]. Nurse practitioners have been authorized to provide Medicare services to residents in long-term care facilities for 30 years and serve as an important and growing foundation of skilled nursing home care. Their presence is associated with improvements in several measures of health status and behaviors of older adults in long-term care settings, increased family satisfaction, and a reduction in the utilization of emergency medical services [16–18]. They are reimbursed at 85% of the Medicare physician rate for performing the same service and must defer the admission physical and first monthly visit to the physician with whom they may then alternate monthly visits, practices that are challenged by their professional organization as their importance and competence are established [19].

Medical Director

It is a legal requirement that all nursing homes have a physician who serves as the medical director which entails multiple responsibilities (Table 20.2) [20]. The American Medical Directors Association (AMDA) has a certification program for physicians, although this is not a requirement to be a medical director. The presence of a certified medical director, along with increased physician presence and enhanced nurse-physician communication, has been shown to improve the quality of care in nursing homes [21–23].

Nursing

Registered nurses (RN), who are trained at an associate's degree or higher, often hold leadership, supervisory, and administrative positions at nursing homes. The only federal requirement to hold the director of nursing position is to be an RN, although additional training and education are encouraged, given the role's administrative and quality assurance duties [24, 25]. The core responsibilities of a director of nursing are listed in Table 20.3 [26].

Most direct clinical nursing in the nursing home is performed by licensed practical nurses (LPNs), who have had 12–18 months of post-secondary education. About half of LPNs work in long-term care, three out of four of whom are employed in skilled nursing facilities [27]. Their patient care tasks include taking vital signs and administering medications, as well as implementing much of the care plan as prescribed by the physician or nurse practitioner [28]. Certified nursing assistants (CNAs), who are required to have 75 h of training and pass a certification exam, provide additional personal care to patients in nursing homes and are often the first to answer a patient's call. Nursing assistants often have

Table 20.2 Roles and responsibilities of the medical director in the nursing home [20]

Quality assurance
Performance improvement initiatives
Staff education
Community relations
Assurance of resident rights
Support of person-directed care
Collaboration with the administrator and director of nursing

Table 20.3 Roles and responsibilities of the director of nursing in the nursing home [26]

Coordination of nursing services
Monitoring and evaluating the outcomes of nursing care
Nursing oversight
Defining the scope of nursing services
Ensuring nursing accountability
Quality assessment and improvement
Overseeing care plans
Management of nursing staff
Administrative duties

limited education in working with residents with extensive behavioral and physical needs and benefit from training and experience in learning how best to manage them.

Nursing homes face high staff turnover rates, which can be as high as 38% for Directors of Nursing, 50% for LPNs, and 66% for CNAs and other unlicensed caregivers [24, 29]. This poses many challenges, including maintaining staff morale and quality care and delivering necessary education to staff regarding the special needs of patients in long-term care, particularly as curricula on these competencies are often lacking during their training.

Physical Therapy and Occupational Therapy

Physical therapists and occupational therapists are important members of the interdisciplinary care team in nursing homes, particularly for patients who have recently been discharged from a hospital or have had a change in status such as an acute illness, injury, or fall. Physical therapists help patients improve mobility, reduce pain, and work to prevent or reverse debility. Occupational therapists help patients regain, build, or modify skills that are needed to function in daily living including the ability to perform self-care. The two specialties work together to improve patient independence particularly in the case of patients in a nursing home for subacute rehabilitation where the goal is to improve function so the patient can safely return home [28].

Social Workers

In nursing homes with more than 120 beds, federal regulations require a social worker on staff. The role of the social worker varies among facilities, but care planning and case management, particularly around the time of admission and discharge, are two mainstays. Social workers may also offer counseling services to patients to help promote physical and emotional wellness [28].

Pharmacists

Along with a physician, pharmacists are responsible for the Medicare-required monthly medication review which includes reassessing the indication, appropriateness, and dosing of the medications prescribed to the patients. They advise physicians regarding medications and work with the nursing staff to determine the patients' medication requirements, such as those for pain and constipation, and identify possible side effects of the medications [30]. A pharmacist's involvement can help prevent a prescribing cascade, where new symptoms, which are often side effects of current medications, lead to new prescriptions for additional medications. Pharmacists also educate nursing home staff, including physicians, on the evidence related to frequently used medications, help establish best practices, and make recommendations about tapering or discontinuing medications [26]. There are many F-tags related to the role of the pharmacist, for example, F431 which requires a pharmacist to develop and oversee a system for tracking and disposing of controlled drugs and F329 which indicates that residents should be free from unnecessary drugs.

Because many patients are admitted to nursing homes after hospitalization, with new medications that address the acute illness, the role of the pharmacist is increasingly important. Nursing home residents often stay on medications long after they are indicated and, conversely, often experience complications when necessary medications are held in the acute care setting and never restarted. Pharmacists assist by performing home and hospital medication reviews and determining the indication for each medication.

Dieticians

Registered dieticians oversee the nutritional needs of individuals in nursing homes. This is particularly important as there are several F-tags related to maintaining nutrition and prescription of appropriate therapeutic diets based on each patient's needs. Dieticians screen nursing home residents to identify those at risk for malnutrition or other dietary issues and are then responsible for planning and monitoring an appropriate intervention. This can be difficult, as nursing home residents often have multiple chronic medical problems that require dietary considerations, such as chronic kidney disease, heart failure, and diabetes, leading to complex and restrictive diets. Dieticians work with nursing home residents, their families, and the interprofessional staff to balance nutritional needs with individual wishes of the patient [31, 32].

Administration

Nursing home administrators oversee the supervision and management of staff and are responsible for ensuring that the nursing home is compliant with federal and state regulations. Administrators are licensed by individual states, and requirements may vary among states, but generally their role spans several domains involving resident care, human resources, financial stewardship, maintaining the physical environment, and leadership and management (Table 20.4) [26].

Family Caregivers

Family caregivers should be considered members of the nursing home care team, although their involvement varies among residents. Nursing home staff must maintain an effective relationship with a resident's family, the manner and needs of which vary including the extent to which they want to be engaged regarding the care plan [33]. Open communication starting at admission helps establish trust, confidence, and a sense of involvement in the care of the resident [34]. The nursing home care team must remember that a resident's admission to the facility is also a time of transition for the family who is adjusting to a new routine of caregiving which is often due to an acute decline in functional or cognitive status or a recent illness and may involve financial concerns about the need for care. Spouses and partners who remain at home may face the loss of companionship and adjustments to what caregiver responsibilities they still have [35]. These times of transition can bring feelings of loss, guilt, and anxiety and can strain relationships, especially if the resident was reluctant to move to a nursing home. The nursing home care team should be mindful of these possibilities and provide support and information to the family.

Table 20.4 Roles and responsibilities of nursing home administrator [67]

Resident care and quality of life	Planning, ensuring quality, and evaluation of nursing, medical, social, and food services
Human resources	Recruit staff
	Ensure communication between staff and management
Finance	Manage operating budget
	Ensure adequate revenue
	Negotiate contracts with vendors and consultative services
Physical environment	Ensure maintenance and upkeep of facility
	Comply with health and safety regulations
Leadership and management	Policies and procedures
	Ensure compliance with federal and state regulations
	Strategic planning
	Communicate with residents and families
	Risk management

Daily Care of the Nursing Home Patient

Admission

A physician must perform a timely history and physical exam for each admission to a long-term care facility, especially for patients who are coming from a hospital where they may still have acute issues that need assessment, monitoring, and follow-up of pending studies or laboratory results. This visit should include a careful medication reconciliation, an assessment of cognitive and functional status and decision-making capacity, the development of a care plan, and documentation of advanced directives. Admission also prompts the entry of information into the Minimum Data Set [15].

The transition from an acute care hospital to a skilled nursing facility is a particularly high-risk period for patients, and about 23% of patients admitted to a skilled nursing facility after hospitalization have at least one hospital readmission [36]. Because Medicare now penalizes hospitals and, starting in 2018, skilled nursing facilities for these readmissions, there is increasing focus on this time of transitional care [37]. Hospitals are working to ensure continuity of care in the transition by ensuring post-acute care visits and follow-up phone calls, improving discharge summaries and electronic communication with nursing homes, and reconciling medications [38–42]. Physicians and other members of the care team should review hospital discharge paperwork, clarify any discrepancies with the hospital providers, and ensure that recommended follow-up is performed.

Rounding

Rounds in long-term care consist of periodic regulatory visits and acute visits for incidents or a change in status. Regulatory visits to a patient in skilled nursing care occur every 30 days for the first 90 days after admission and subsequently every 60 days, the latter of which can alternate between an advanced practice provider and a physician. Visits include a review and update of the current plan of care, with particular attention to any concerns from the care team, advice from consultants, laboratory or diagnostic testing, and medications [15]. Acute care visits that address a change in clinical status may be performed by a physician or an advanced practice provider and should address the issue of concern with a history and physical exam and diagnostic testing as indicated, followed by communication to the rest of the care team regarding the next steps. Acute care visits should also occur after an incident or accident, such as a fall,

and must include a physical exam and a review of the nursing notes and incident report followed by an assessment of possible causes and contributors, including environmental factors and medications. The provider then documents the circumstances and possible cause of the accident, as well as the plan of care and safety measures that will be put into place to prevent further incidents [15, 43].

Discharge

Physicians are required to complete a discharge summary in a timely fashion, which includes diagnoses, a summary of the care at the facility, an updated medication list, relevant test results, and a post-discharge plan of care. Discharge from a skilled nursing facility to home is another high-risk transition for patients who often have multiple morbidities and limited social support, increasing the risk of poor outcomes after leaving the facility [44]. Care plans should be multidisciplinary and comprehensive and address geriatric syndromes such as incontinence, falls, weight loss, and mobility impairment that are often still present upon discharge, despite rehabilitation care [45]. Older patients who received post-acute care in a nursing facility have a 22% rate of presenting for an acute care visit to the emergency room or rehospitalization within 30 days of discharge and a 38% rate of doing so in the first 90 days after leaving the nursing home [46]. Improved care coordination during this transition period is increasingly important as Medicare begins penalizing skilled nursing facilities for hospital readmissions in 2018 [37].

Managing Common Conditions in the Nursing Home

Behavior

Behavioral issues, particularly in patients with dementia, are common and difficult problems in nursing homes and may have been the reason for long-term care placement in the first place [47]. Up to 90% of patients with dementia demonstrate behavioral problems, particularly as their dementia advances. These behavioral problems range from anxiety and depression to psychosis, agitation, aggression, and wandering, which can be dangerous to the patient as well as other residents and staff, for whom they significantly affect job satisfaction and turnover [48]. Although historically behavioral problems in dementia were treated with antipsychotics, recent studies have shown that while there may be a modest reduction of problematic behaviors, there is also a significant increase in adverse events for the patient, including extrapyramidal symptoms, worsened cognitive function, and, most concerning, an increase in cerebrovascular events and overall mortality [49]. Overuse of antipsychotic medications is an issue for regulation and quality metrics, and their use is included in quality data including the Five-Star Quality Rating System that is available to the public. Their use should be minimized and limited to a set period of time with clear indications for administration and well-delineated plans for discontinuation. Another past approach used to address behavior problems was physical restraints, which is now a subject to federal law and ongoing education about the negative effects of this practice, which has reduced the share of residents in physical restraints to 2% in 2014 [2]. An F-tag (F221) requires residents to be free of physical restraints imposed for purposes of discipline or convenience and not required to treat medical symptoms.

Non-pharmaceutical interventions are now the first-line therapy for behavior issues and include person-centered care, which fosters positive relationships with others, Dementia Care Mapping, which identifies and responds to causes of agitation and aggression, and emotion-oriented care, which trains staff to acknowledge the resident's perception of his or her surroundings and then attempt to communicate with that perspective [48]. Music therapy, exercise, standard daily activities, and other methods show promise but have limited proven effectiveness [50].

Urinary Incontinence and Infections

Nearly two-thirds of nursing home residents have urinary incontinence, which is one of the leading causes of long-term care placement. Because of the risk associated with indwelling Foley catheters and poor perineal care and hygiene, CMS has an F-tag (F315) directly addressing urinary incontinence [51, 52]. Patients must be evaluated for urinary incontinence at admission and whenever there is a change in functional or cognitive status and, if present, must have a care plan that addresses causes or contributors including medications, mobility issues, and urinary tract infection [43]. Post-void residuals should be measured to ensure that there is not a component of retention with overflow incontinence. The care plan must prevent skin breakdown and urinary tract infection (UTI) and maintain as much continence and urinary function as possible [53]. Toileting should consider resident mobility, cognitive status, and ability to communicate. Timed toileting and prompted voiding are effective strategies but require caregiver support and reinforcement [54]. Staff must ensure that residents receive appropriate hygiene, including timely changing of soiled or wet pads and linens, cleaning, and application of barrier creams to protect skin from breakdown.

Indwelling urinary catheter use is historically high in nursing home residents, and an F-tag (F315) requires that

staff ensure such use is justified. Chronic indwelling catheters put patients at increased risk of UTI and are associated with higher morbidity and mortality. If a catheter must be used, staff must monitor for catheter leakage, change in urine characteristics, and systemic signs or symptoms of a bladder infection [55].

One challenge is that UTIs, while common, are overdiagnosed in the nursing home population, and bacteriuria is often treated without evidence of clinically significant infection. Overuse of antibiotics can lead to side effects, resistant bacteria, and other infections such as candidiasis and *Clostridium difficile* colitis. A patient without an indwelling catheter must have three of the following to support diagnosis and treatment of a UTI: fever (above 38.0 °C) or chills, new or increased dysuria, frequency or urgency, new flank or suprapubic pain, change in urine character or urinalysis with pyuria or hematuria, and worsening of mental or functional status. In residents with an indwelling catheter, only two of these need be present to make the diagnosis, with fever plus hematuria or a catheter obstruction being especially predictive of UTI [52].

Preventive measures that prevent UTIs include ensuring adequate hydration, promoting complete bladder emptying, performing daily perineal skin care, and using incontinence products that keep urine away from the skin. Recurrent UTIs in a patient should lead to an investigation into possible predisposing factors such as inadequate bladder emptying or poor hygiene, along with consideration of structural abnormalities of the urinary tract, including kidney stones, bladder prolapse, and abscesses or fistulae that could be seeding the urinary tract [52].

Falls

Approximately 40% of nursing home residents fall every year, many more than once [56]. Up to 25% of these falls lead to a fracture or a hospitalization, much higher than the morbidity of falls in the community [57]. This is likely attributable to the frailty and cognitive and functional impairment that is characteristic of nursing home residents which are often the factors that led to nursing home admission in the first place.

Nursing homes must reduce factors that lead to falls. Extrinsic risk factors include poor lighting and lack of proper assistive devices, lines or cords, and restraints. Intrinsic risk factors include cognitive impairment, polypharmacy, female gender, and low body mass index (BMI) [57, 58]. Interventions that address environmental factors, ambulation safety, and polypharmacy can reduce fall rates in nursing home residents and include staff education, exercise programs for residents, and reductions in the use of psychoactive medications [59].

Nursing home staff are legally obligated to report falls with notification to the medical director or clinician on call, as well as the resident's family. They must perform an assessment to identify any injuries, particularly when a fall is unwitnessed or when a head injury is suspected [56]. After a resident fall, the interdisciplinary team should develop an individualized care plan to help prevent further falls and consider any contributing factors, such as an exacerbation of chronic condition medications. Physical therapy can address weakness or balance issues or adjust assistive mobility devices. Treatment or prevention of osteoporosis should be considered given its high prevalence in nursing home residents, including the provision of vitamin D. For residents at high risk of falling, hip protectors may be considered. Even though falls cannot be completely prevented, serious injury and fracture risk can be reduced with some of these modifications [57].

Pressure Ulcers

Eleven percent of nursing home residents have a pressure ulcer with 35% of these patients requiring costly specialized care because of it [60]. The rate of pressure ulcers in residents is a published quality indicator for long-term care facilities. Medicare considers pressure ulcers preventable and does not pay hospitals for hospital-acquired stage III and IV ulcers. Similar regulations may be imposed on nursing homes.

The prevention of pressure ulcers requires a multipronged, interdisciplinary approach that is individualized for each patient [61, 62]. Like falls, the risk factors for the development of ulcers are both intrinsic and extrinsic, and both must be addressed. Intrinsic risk factors include immobility, protein malnutrition, age, and comorbidities. Extrinsic factors include moisture, pressure, shear forces, and friction. For immobile patients, repositioning every 2 h while in bed and every hour while in a wheelchair reduces the risk. Inactive but able patients should be prompted to reposition themselves every 15 min. Pressure-relieving cushions and mattresses can be helpful as can nutritional supplements given to malnourished patients. Toileting strategies in patients with incontinence should attempt to reduce excess moisture. Higher staffing levels of registered nurses and nurse's aides are associated with lower levels of resident pressure ulcer development, indicating that prevention requires a hands-on approach [60].

Nursing home staff must document and describe new wounds and then monitor the healing process including size, staging, exudate, anatomic location, and appearance of the wound. A care plan for the wound must address predisposing factors, nutrition needs, dressings, antibacterial treatments, pain management, and debridement, if necessary.

Polypharmacy

In the USA, half of nursing home residents are on nine or more medications [63]. The cause of these long medication lists is multifactorial and includes having multiple prescribers, changes made during hospitalizations, and the cascade of treating symptoms that are due to medication side effects with other medications [64, 65]. Polypharmacy is associated with an increased risk of adverse drug reactions and interactions, functional decline, as well as geriatric syndromes such as incontinence, falls, and delirium. The use of five or more medications increases the odds of an adverse drug-related visit to a clinic or emergency provider by 88% [66, 67]. Nursing home providers should review the medication list at admission and discharge, at each regulatory visit, and at the time of illness or other events, paying careful attention to medication dose and indication, and take into consideration whether the medication is truly indicated or, in fact, is causing unintended problems. Medications that have been prescribed for long periods of time, particularly for sleep, depression, and pain, should be critically reviewed with consideration of tapering and discontinuation. Providers should also consider whether preventative medications (e.g., statins) are still beneficial in the setting of old age or changes in the goals of care. It may be prudent to discontinue one medication at a time, particularly if there is potential for withdrawal symptoms, with staff educated on any necessary monitoring after medication discontinuation [63].

Infection Control

Respiratory and gastrointestinal infections like influenza and norovirus are the most common types of outbreaks in nursing homes and lead to higher rates of hospitalization and death than in the community [68]. CMS requires nursing homes to have a comprehensive infection control program that includes surveillance of infections, implementation of preventative measures and isolation measures when needed, and employee health guidelines. The facility vaccination rate for influenza is publicly reported. Protocols allow for rapid identification of communicable diseases, the prevention of spreading through isolation of affected residents and limitation of visitors, and prophylaxis to other residents when necessary. Infection control programs also educate staff members on the identification of communicable illnesses, hand hygiene practices, employee health protocols, and the importance of staff vaccinations, which is usually at a lower rate than that of the nursing home residents themselves [55].

Emerging as another vital role for infection control programs is antibiotic stewardship. With the increase in antibiotic-resistant bacteria, it is more important than ever to weigh the necessity and duration of antibiotic therapy. Educational initiatives that distinguish between bacterial colonization (in chronic wounds and urine) and infection and collaborations with pharmacy on appropriate duration of therapy may decrease complications such as *Clostridium difficile* colitis and the development and spread of multidrug-resistant organisms, although whether these interventions have a lasting effect on prescribing practices is uncertain [55, 69].

Pain Management

An estimated 45–80% of nursing home patients suffer from chronic pain, which is likely underrecognized due to communication barriers caused by cognitive impairment and delirium and undertreated due to a reluctance to prescribe medications that may cause dependency or confusion [70, 71]. Untreated pain in the nursing home population can cause or worsen delirium, depression, immobility, and sleep disturbances, so systematic, structured pain assessment at regular intervals is both a compassionate and good medical practice. Patients with cognitive impairment are able to use pain scales, and staff can be taught to recognize nonverbal signs of pain in less communicative patients including tachycardia, tachypnea or noisy breathing, restlessness, and sad or frightened facial expressions [43].

Treatment of pain should be a multimodal approach and include physical therapy (stretching and exercise), warm or cold compresses, music therapy, and counseling in addition to judicious use of medications. Medication use should involve counseling the patient and family on adverse effects, with consideration given to whether the patient is able to request medications if needed or if scheduled medications are necessary. If opioids are prescribed, proactive measures should be undertaken to prevent adverse effects such as constipation and gait instability. Clinicians should continuously assess the need for ongoing pharmacotherapy and consider tapering if pain is diminishing over time.

Weight Loss, Poor Nutrition, and Tube Feeding

Poor nutrition and unintentional weight loss are common in nursing home patients and contribute to poor functional status, pressure ulcers, and frailty. Although there are many reasons why residents of nursing homes have unintended weight loss, there are a few contributing factors that should always be considered. Well-intentioned dietary restrictions due to diabetes or heart failure can lead to weight loss and should be liberalized if the patient is losing weight to the point of undernutrition [32]. Oral health issues such as poor dentition, inadequate oral hygiene, dental pain, xerostomia, and chewing problems can limit a resident's ability to take in adequate nutrition and can be addressed by a dentist or

speech therapist [72]. Residents with stroke or dementia may have apraxia that limits their ability to feed themselves and required one-on-one assistance at mealtimes [43]. In patients who continue to have unintended weight loss, additional work-up for a cause should be guided by the goals of care. Supplement drinks or puddings are often given to improve caloric intake though they should not replace meals.

In residents who continue to lose weight or have difficulty eating, the subject of artificial feeding through a tube often arises. In patients with dementia or stroke, tube feeds do not improve nutritional status, quality of life, and mortality or decrease the risk of aspiration [73–77]. In addition, tubes for feeding can lead to agitation, discomfort, and the increased use of chemical or physical restraints. The American Geriatric Society (AGS) has recommended offering careful hand-feeding in patients with advanced dementia and recommends against tube feeding in such patients [78, 79]. These messages seem effective as the proportion of US nursing home residents with advanced dementia and inability to eat who received feeding tubes decreased by 50% between 2000 and 2014 [80].

Palliative Care in the Nursing Home

Many people, whether healthy or chronically ill, indicate that they would prefer to die at home and find nursing homes the least preferred place of death [81, 82]. Many nursing homes are working to change this perception and improve end-of-life care. One way is by bringing hospice agencies into the nursing home, a practice which more than doubled in frequency between 1999 and 2006 [83]. This increase is due to the growing trend of using hospice for noncancer diagnoses and to an increase in hospice providers. There is good evidence that the provision of hospice care to nursing home residents improves pain management, reduces hospitalizations, and improves family satisfaction with end-of-life care [84–86]. However, the increasingly long stays of nursing home patients in hospice care reduce the well-documented cost savings in the last months before death that hospice brings as the costs of prolonged care exceed the potential savings from reduced hospitalizations. Estimating life expectancy in people with dementia is challenging [87, 88]. Patients with dementia who are reasonably functional and patients with strokes are especially likely to survive more than 6 months after enrollment in hospice [89]. These cases contribute to the significant minority of patients (10–15%) referred to hospice who survive for more than 6 months. In 2011, the US Center for Medicare and Medicaid Services (CMS) required that patients who have been enrolled long term in hospice have a face-to-face visit by a physician or nurse practitioner to ensure that they continue to meet the eligibility criteria before they receive the 180-day recertification. This requirement for more scrutiny has not increased hospice discharges, including for hospice enrollees at nursing homes [90].

Due to the concern that the flat per diem payment structure of hospice incentivized the recruitment of more stable patients, the CMS changed the reimbursement model effective on January 1, 2016, to a two-tiered per diem payment practice where hospice services are paid at a higher rate for the first 60 days of care with a lower rate for subsequent days as patients are potentially relatively stable, with an allowance for increased payments in the last week of life as acuity of symptoms and need for care increases [91]. Another important change since January 1, 2016, is the provision of payment for advanced care planning discussions between physicians, patients, and families.

Another model is to train the physicians and staff who work in nursing homes to effectively provide comfort to dying patients without outside hospice care. In its report *Dying in America*, the Institute of Medicine stresses that "all clinicians across disciplines and specialties who care for people with advanced serious illness should be competent in basic palliative care, including communication skills, interprofessional collaboration, and symptom management" [92]. New models that increase physician presence in nursing homes would likely increase physician engagement and expertise in end-of-life care. Training the nursing staff in comfort care may increase their professional satisfaction and engagement as such care has a profound and beneficial impact on the lives of their patients who are terminally ill and deeply affects staff themselves [93, 94]. Providing comfort care with internal staff alone could address some of the negative feelings that can occur between staff and outside hospice services due to poor communication and unclear expectations and roles [95].

Future Directions

Workforce

Meeting the demand for healthcare in an aging society will require a significant expansion of the healthcare workforce, which presently receives very little geriatric training [96]. The demand for nurses and nursing assistants will increase, and innovation in training can include Internet-based education and community colleges. More social workers will be needed, especially geriatric case managers, including those who work in nursing homes.

The looming shortage in physicians trained in geriatrics is a source of great concern. The number of geriatricians in active practice in the USA increased to 22% between 2010 and 2015, but this growth rate is deceiving because the total number of geriatricians is small. In 2015, there were

5227 geriatricians in practice, representing just 5% of the total number of internal medicine and family physicians [97]. About two-thirds of board-certified geriatricians are internists, and the remaining third are family physicians. Given the significant shortage of formally trained geriatricians, family physicians and internists will continue to play a critical role in caring for elderly patients including those in nursing homes. Despite increased demand and potential shortages, family medicine, general internal medicine, and geriatrics have not been popular career choices due to perceived low prestige and low remuneration compared to other specialties [98–100]. Even residents who have chosen family medicine have a limited interest in nursing home care [101].

One solution to the lower compensation of working in geriatrics in general and in long term specifically is to move toward salaried positions, similar to the hospitalist model which has been so successful over the past decade. This could change the nursing home physician role from that of an occasional visitor to that of a committed employee, which would likely improve the quality of care [102–104]. Presently, the Netherlands is the only country where nursing home medicine is a recognized specialty for which physicians are trained in nursing homes and then employed there as their site of practice [105]. The Society for Post-Acute and Long-Term Care Medicine has initiated efforts to work with CMS to seek full recognition of nursing home care as a medical specialty [106]. Nursing home medicine may meet the lifestyle expectations and overall job satisfaction for physicians and other healthcare providers, which is proposed as part of the quadruple aim for improving healthcare [107]. Some such practices already exist such as Extended Care Physicians [http://www.ecpmd.com/] and Physicians Eldercare [http://peltc.com/].

Nurse practitioners can help fill the physician gap, and many nursing graduate school programs are allowing nurse practitioners who are planning to enter geriatric care to follow a flexible model of training that has fewer requirements and is of shorter duration compared with the training model for geriatricians. Whether the care provided by nurse practitioners is comparable to the care provided by physicians remains a subject of debate, but the perception is that the skill level of an experienced nurse practitioner is close to that of a geriatrician in the long-term care setting. In fact, some have proposed that geriatricians have too many educational and certification requirements, and the medical profession could consider adopting a similarly innovative model that decreases the length of training (medical school and graduate medical education) for those intending to practice as geriatricians. This, along with the provision of educational debt repayment, could incentivize career interest in geriatric medicine [98].

Innovative Models

The desire to make nursing homes less institutional and more homelike has driven the “culture change” movement. The Eden Alternative® was pioneered in 1991 and is an international nonprofit organization that promotes a person-centered approach that seeks to deinstitutionalize the nursing home and enliven it with a homelike environment that includes children, animals, plants, and other warm and caring aspects of home [108]. The Green House Project® creates long-term care homes with no more than 12 residents in the home, meals cooked in a central open kitchen, and patient-centered life such as allowing personal control over eating and sleeping patterns, all of which are intended to deinstitutionalize the nursing home [109, 110]. As of May 2015, 174 Green House homes were in operation. They have shown promise in improving quality of life as well as lowering hospital readmissions and Medicare expenditures while alleviating the problem of high staff turnover, though the impact on most clinical quality measures is not significant and comparable to traditional nursing homes [111]. The principles of transforming the feel of the nursing home are laudable, and many larger homes are making efforts to adopt them, but at this time these efforts of person-centered care constitute a small fraction of long-term care.

Another growing model of care is the Continuing Care Retirement Community (CCRC), which offers a tiered approach to living that accommodates the changing needs of the individuals who live there. Upon moving into such a community, healthy older adults can live independently in small homes or apartments. When their care needs increase, they can move into the assisted living or nursing home part of the community. This model allows older adults to live in one community for the duration of their life, which is a source of security and comfort for older adults and their families. These communities are popular and often have long waiting lists. The limitation to this being a solution to the growing need for long-term care is their expense. CCRCs require a hefty entrance fee and ongoing monthly charges, making this living option available only to people with means.

New Payment Models

The fee-for-service system that is the basis for payment in the US healthcare system is a poor fit for professional reimbursement for caring for people with chronic diseases, including those in a nursing home. While alternative payment models have been introduced into some healthcare systems and are likely to grow in the future, nursing home care has been slow to adopt new models of payment. Medicare

has Accountable Care Organization (ACO) initiatives that seek to improve population health while containing healthcare costs. CMS has defined several measures to help gauge the performance of ACOs, one of which is the 30-day readmission rate from skilled nursing facilities (see chapter on Value-Based Payment Models). Given the aging of the population and the growth in need for long-term care and the billions of dollars that this will cost, innovative models will address the quadruple aim of improving the quality of care, improving the health of the population, reducing costs, and providing professional health and satisfaction to the professionals who work in the system. If these goals are met, nursing homes will transform from being dreaded institutions to places where chronically ill people with significant care needs can be treated with quality care in a dignified manner by staff who are compassionate and competent.

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Community Care Alternatives for Older Adults

21

Amy C. Denham

Introduction

Adults with chronic conditions have complex care needs. While providing care for non-disabled younger adults with chronic disease can be complex and includes acute care, preventive services, and management of one or more chronic illnesses, caring for chronically sick older adults has additional layers of complexity. In contrast to younger patients, in older adults multi-morbidity is the rule rather than the exception: over half of patients over age 65 seen in primary care practices in the USA have three or more chronic diseases [1]. In addition, older adults often have cognitive and functional impairments. Approximately one in ten community-dwelling adults age 65 and older has dementia, with higher prevalence in older age groups [2]. Older adults have high rates of functional limitations, including visual and hearing impairment, mobility limitations, challenges with communication, and inability to perform activities of daily living (ADLs) or instrumental activities of daily living (IADLs) independently. Care models for older adults therefore need to address not only acute care and chronic disease management but also the custodial care needs of this population.

The USA faces a number of challenges regarding its preparedness to meet the health and long-term care needs of its population. The proportion of the population aged 65 and older is projected to continue to increase in the coming decades with proportionally fewer younger adults to meet the care needs of an aging population [3]. Institutional settings such as nursing homes are able to manage the care of medically complex older adults with functional and cognitive impairments. However, nursing home care is costly, and many nursing homes in the USA have deficiencies in quality of care [4, 5]. The vast majority of Americans prefer to receive care in community-based settings, with most expressing a preference to remain in their own home [6]. There is therefore a need for high-quality, cost-effective, community-based models to meet the health and long-term care needs of an aging population.

Much of the care provided to older adults in the community is provided by family and friends, most commonly adult children and spouses [2]. About 80% of older adults living at home who need some assistance with ADLs or IADLs receive that assistance solely from these unpaid caregivers, and another 10% receive assistance from a combination of paid aides and unpaid informal caregivers. Older adults generally express a high level of satisfaction with the care they receive from family members, perceiving them to provide high-quality care and to be more responsive than paid caregivers [7]. Family caregivers, however, report high levels of emotional and physical stress related to their caregiving responsibilities [8]. For older adults to continue to receive the community-based care they prefer, these caregivers need assistance and support.

A number of models have emerged that provide long-term care supports for older adults and their family caregivers that meet their preference to remain in the community. Long-term care services exist on a continuum, and there are not always sharp lines between home-based care, other community-based settings, and institutional care. Nursing home care and home-based care are addressed elsewhere in this textbook. This chapter will address models that exist along the continuum between home and institutional care.

Community-Based Care Financing Models

Community-based care for older adults is financed through a patchwork of out-of-pocket payments and in-kind contributions by the individuals and their informal caregivers, Medicaid, Medicare, other public sources (e.g., the Department of Veterans Affairs or state and local government), and private long-term care insurance. Private health insurance generally does not pay for institutional or

A.C. Denham (✉)
Department of Family Medicine, University of North Carolina School of Medicine, Chapel Hill, NC, USA
e-mail: amy_denham@med.unc.edu

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community-based long-term care services. Although private long-term care insurance is available, it is relatively expensive, and only a small proportion of the population has this kind of coverage [9]. Long-term care insurance policies vary in whether they pay for community-based long-term care services or institutional care only.

Although Medicare is the main payer for *medical* services for older adults in the USA, it has a limited role in paying for either community-based or institutional *custodial* care. Medicare pays for short-term skilled care in home or institutional settings, for example, covering nursing, physical therapy, or occupational therapy following discharge from the hospital for acute illness, and provides limited personal care assistance at the end of life for patients enrolled in hospice services. Medicare also pays in part for enrollment in Programs of All-Inclusive Care for the Elderly (PACE), an alternative care model described below. Outside of these limited contexts, however, Medicare does not pay for long-term custodial care.

Unlike Medicare and private health insurance, Medicaid does cover long-term care services. Nationally, it is the largest payer for long-term care, accounting for just over half of national spending on long-term care [10]. Medicaid is funded jointly by the federal government and states but is administered at the state level. Coverage of certain services is mandated by federal law, and coverage of other services is optional and at the discretion of states. While nursing home care is a mandated service, home- and community-based personal care services are optional [11]. States vary considerably in the proportion of Medicaid-covered long-term care that is institutional versus community-based and in how home- and community-based services (HCBS) are organized. Overall, about half of seniors who receive long-term care services through Medicaid receive those services in the community rather than in institutions [9, 10]. In the recent decades, the proportion of Medicaid spending on HCBS has been increasing relative to spending on institutional long-term care. Although the original Medicaid legislation had an inherent bias toward institutional care, by requiring coverage for nursing home care but making HCBS optional at the discretion of states, Medicaid legislation has been amended multiple times to expand states' options for covering HCBS. States can apply for waivers that allow them to increase Medicaid eligibility standards to provide HCBS for individuals who might otherwise need institutional care and to develop experimental or pilot projects that explore new models for delivering HCBS [10]. States' options for funding HCBS have expanded since 2010 under the Affordable Care Act [9].

After Medicaid, the second largest source of funding for long-term care services is out-of-pocket payments. Medicaid only covers individuals with low incomes, so a large segment of the population is not Medicaid eligible. Families that do not have Medicaid or private long-term care insurance that covers community-based long-term care can pay out of pocket for home health aides or for adult day care services. The median cost of these services in 2015 was $20 per hour for home health aides or $69 per day for adult day care [12]. Although the cost of community-based services is generally less than that of nursing home care, it is still expensive for families of average means. Families that initially pay for long-term care services out of pocket may eventually deplete their resources, so-called spending down, until they are Medicaid eligible. Medicaid therefore remains the payer of last resort.

When considering the out-of-pocket costs of community-based care alternatives, one must also consider the in-kind contributions of unpaid informal caregivers. The large majority of older adults living at home who need assistance with personal care receive at least some of that assistance from unpaid caregivers, usually spouses or adult children [2]. If these informal caregivers were paid at a rate similar to that of paid caregivers, the cost of care provided by informal caregivers would far exceed that provided by paid caregivers [7]. In addition, there is an opportunity cost when unpaid caregivers reduce their work hours or leave paid employment. One of the reasons that community-based care alternatives are generally less expensive than nursing home care is that they rely on unpaid caregivers filling in the gaps not covered by paid caregivers.

Models of Community-Based Care Services

Community-based care services for adults who are chronically ill and usually older can be provided in a variety of settings, including in individuals' homes, in facilities that provide care during the day only, or in residential facilities. There is some overlap between these models, and individuals may receive care from more than one model simultaneously.

Home-Based Care

Most individuals who have paid assistance for personal care receive that service from aides who provide one-on-one care in the home [13]. This service may be provided through licensed home care agencies or through direct arrangements between families and independent caregivers. Home-based care might include assistance with IADLs, such as housekeeping or meal preparation, hands-on assistance with personal care such as bathing and dressing, or supervision for individuals with cognitive impairment. Licensing for home care agencies occurs at the state level, so there is state-to-state variability in how home care services are organized and

what training is required for aides to be licensed to provide personal care in the home. This is covered in more detail in the chapter "Community-Based Home Care."

Nonresidential Options for Community-Based Care

Area Agencies on Aging and Senior Centers

Although they are generally not providers of long-term care services, senior centers and Area Agencies on Aging are important parts of the network of community-based supports available to older adults. Established by the Older Americans Act of 1965, Area Agencies on Aging coordinate services for older adults at the local level. They serve as clearinghouses of information on community-based supports for older adults, and they may provide case management and counseling services to help connect older adults and their families with long-term care services. Area Agencies on Aging may operate as branches of state, county, or local government, or states may contract with nonprofit organizations to fulfill these services.

Senior centers, often the focal point of services provided by Area Agencies on aging, are community centers financed through a combination of federal, state, local, and private funds. Senior centers typically provide social and recreational activities for older adults, as well as congregate meals and transportation services. They may provide health and wellness activities such as exercise programs or health screenings. Although they are not set up to provide personal care, they are an appropriate setting for daytime activities and meals for older adults who have mild functional or cognitive impairments but do not need significant supervision or assistance with personal care.

Adult Day Service Centers

Adult day service (ADS) centers, also referred to as adult day care or adult day health programs, provide care during daytime hours for community-dwelling older and disabled individuals. The ADS model allows older adults to continue to reside in their own homes or with caregivers but receive supports during the day, thus providing respite or allowing caregivers to remain in the workforce. Adult day programs serve both older adults and younger adults with disabilities, but the majority of participants are age 65 and older. About half have dementia, about half have physical disabilities, and about a quarter have chronic mental health conditions [14]. Although there is considerable heterogeneity in the services provided at ADS centers, typically programs include recreation and social engagement, supervision, assistance with personal care, and meals. In the past, there was a distinction between ADS centers that provided primarily social engagement and recreation and centers that provided for medical needs, but now most ADS programs fulfill a combination of psychosocial and medical needs. Although it is not typical for ADS centers to have physician services on-site, the majority have nurses on staff, with about half providing complex nursing services such as wound, ostomy, or catheter care. Other common health-related services include health education, blood pressure or blood sugar monitoring, medication management, and foot care. About half of adult day care centers provide social work services, and a similar proportion provide skilled therapy services such as physical or occupational therapy [13]. Many ADS programs provide education, counseling, and support groups for caregivers.

There are currently approximately 4800 ADS centers across the country, serving more than 250,000 participants [15], and as interest in home- and community-based options for long-term care increases, enrollment in ADS is increasing [14]. Although ADS have historically been provided by nonprofit organizations, sometimes in association with larger organizations such as hospitals and nursing homes, the proportion of for-profit businesses providing ADS is increasing, currently accounting for about 44% of adult day services. The average size of ADS facilities is also increasing, with about half of the centers serving greater than 25 participants. Most ADS centers are in metropolitan areas [13]. The majority of funding for ADS comes from participant fees paid by public sources such as Medicaid or the Department of Veterans Affairs, with a smaller portion coming from privately paid participant fees, although individual centers vary in the proportion of public versus private funding.

Adult day service programs provide a variety of benefits to older adults and their caregivers. Participants in ADS programs and their caregivers perceive positive effects on participant well-being and caregiver stress. Enrollment in ADS programs appears to lower caregivers' levels of stress and burden, reduce the amount of time caregivers spend addressing behavior problems, and reduce the level of hostility caregivers feel from their loved ones [16–19]. Participants may also experience benefits, including decreased agitation and improved sleep patterns, perhaps related to increased stimulation and wakefulness during the day [17, 20].

The evidence is mixed regarding whether ADS attendance reduces or delays nursing home placement. Although some research has suggested that ADS programs are able to delay institutionalization [21], other research suggests that ADS attendance has no effect or even increases nursing home placement [22–24]. It is difficult to control for all of the markers of severity of illness or caregiver stress that might result in both increased ADS attendance and increased risk for nursing home placement, so one need not infer from this research that ADS attendance *causes* nursing home placement, but in some cases ADS may serve as a stepping stone toward nursing home care, as caregivers transition from providing all care in the home to a greater

level of reliance on institutional care. Evidence is still preliminary regarding whether ADS enrollment has an impact on other healthcare utilization, for example, hospitalizations or emergency department visits, but there is some evidence that ADS may prevent readmissions in the post-acute setting [16].

Programs of All-Inclusive Care for the Elderly (PACE)

Programs of All-inclusive Care for the Elderly (PACE) represent an innovative model for community-based care, designed to be an alternative to nursing home care for frail, functionally, and/or cognitively impaired older adults. The PACE model originated in San Francisco in 1971 and has evolved and spread nationally in the subsequent decades. PACE services are typically based at an adult day service center, with a primary care clinic and rehabilitation services on-site, but PACE organizations coordinate all medical care and long-term services across settings, including home, hospital, medical subspecialty clinics, and nursing homes. Care is managed by an interdisciplinary team of professionals. To be eligible for PACE services, individuals must be 55 years old or older, must have significant enough impairments to be nursing home eligible in their state of residence, and must be able to be safely supported in the community at the time of enrollment. Nationally, the average PACE participant is 77 years old, is dependent in three activities of daily living, and has eight acute and chronic medical conditions. About half of PACE participants have dementia [25].

The first PACE program, On Lok Senior Health Services, was created in the San Francisco Chinatown district in 1971, as a culturally acceptable alternative to nursing home care in the Chinese immigrant community. On Lok is Cantonese for "peaceful, happy abode." When On Lok demonstrated success in providing coordinated support services for individuals with long-term care needs, the organization was provided Medicare and Medicaid waivers to allow it to receive a monthly fixed payment for each enrolled individual to deliver full medical services while assuming full risk for the cost of that individual's medical care. In 1986, ten additional waivers were provided by the federal government, to replicate and disseminate the On Lok model to other areas of the country, and in 1997 PACE was recognized as a permanent provider type to receive Medicare and Medicaid funding. In 2005, further grants were awarded to expand the PACE model to rural areas of the USA [26]. Since that time, the PACE model has expanded nationally: in 2016 there were 121 PACE programs in 31 states, serving over 38,000 participants [27]. PACE organizations are typically operated by nonprofit organizations, although legislation recently passed to allow for-profit companies to operate PACE centers [28].

The vast majority of PACE participants are dually eligible for both Medicare and Medicaid. PACE organizations are financed through capitated payments from Medicare and Medicaid, although some PACE organizations also enroll participants who do not have Medicaid and who pay privately for a portion of PACE fees. Medicaid pays PACE organizations a fixed per-member-per-month fee that is set at the state level. Medicare pays a risk-adjusted per-member-per-month fee that varies at the individual participant level, based on demographics, frailty, and medical diagnoses [26]. In exchange for these capitated payments, PACE organizations assume full risk for the cost of medical and custodial care for their participants. The PACE organization assumes the cost not only for the services provided at the PACE center but also for subspecialty medical care, hospitalizations and emergency care, short- and long-term nursing home placement, home care, and durable medical equipment.

The PACE financing model allows individual PACE organizations flexibility in what services to deliver, allowing coverage for some services that might not be typically covered under fee-for-service Medicare or Medicaid. This flexibility results in variability in services from one PACE organization to the next, but there are several common features to the care provided at all PACE organizations. Care is coordinated by an interdisciplinary team, consisting at a minimum of a primary care provider, nurse, social worker, physical therapist, occupational therapist, dietician, recreational therapist, home care coordinator, aide, driver, and PACE center supervisor. This team assesses the medical, functional, nutritional, and psychosocial needs of each participant on enrollment and at least every 6 months thereafter, to create an interdisciplinary plan of care.

Participants attend an adult day health center, generally from 1 to 5 days a week, that provides socialization, recreational activities, exercise, meals, and personal care services as needed. Primary care and rehabilitation services are provided on-site. Typically, the PACE team provides all primary care services, although some PACE organizations have piloted partnering with primary care physicians in the community to provide this care. Transportation to and from the center and to outside medical appointments is provided. Personal care assistance in the home may also be provided outside the hours of PACE attendance, either by PACE staff or on a contract basis with home care agencies in the community. The PACE team follows each participant across sites of care, even if the individual is ultimately placed in a nursing home, through the end of life.

Outcomes for PACE participants appear to be generally positive, as measured by participant and caregiver satisfaction, quality of care, functional status, mortality, and health service utilization. Understanding the effectiveness of the PACE model, however, is limited by the lack of research using randomized trials or study designs that adequately control for potential confounders [29–31]. Because individuals who enroll in PACE services are likely different from individuals who are admitted to nursing homes or who enroll

in other home- and community- based services (HCBS), it is difficult to find an equivalent comparison population, so our current evidence base does not fully capture how outcomes for PACE participants compare to other similar patient populations not enrolled in PACE.

Satisfaction with PACE services tends to be high, as evidenced by low disenrollment rates [32] and self-report by participants and caregivers [25]. Participants in PACE services tend to fare better on a number of outcomes, including decreased mortality, better control of pain, and higher rates of completion of advance directives [31, 33].

PACE enrollment also appears to have a positive impact on rates of hospitalizations and nursing home placements. Rates of hospitalization, preventable hospitalization, and readmission are lower than for other individuals dually eligible for Medicare and Medicaid [31, 34]. All PACE enrollees are nursing home eligible at the time of enrollment, reflecting a high risk for nursing home placement. Although early research suggested higher rates of nursing home admissions among PACE participants as compared to other community-based populations, these studies did not distinguish between short- and long-term nursing home placements [31]. More recent research has suggested lower rates of long-term nursing home placements compared with participants in other Medicaid HCBS waiver programs [35]. These data may reflect that PACE programs make use of short-term nursing home placements for respite or to avoid unnecessary hospitalizations for unmet custodial care needs but still minimize long-term nursing home placements.

Further research is needed to address the important question of whether PACE services are more cost-effective than other models of HCBS for dually eligible Medicare and Medicaid beneficiaries. The dually eligible population accounts for a disproportionate share of both Medicare and Medicaid spending: although dually eligible individuals account for 20% or fewer of Medicare and Medicaid beneficiaries, they account for about a third of Medicare and Medicaid spending [36, 37]. There is active interest in finding models for cost-effective care for this population. Studies on cost of PACE services have produced mixed results. Although PACE does appear to decrease utilization of some costly services, the cost of PACE services overall may be greater than other HCBS. Medicare costs are similar between PACE participants and individuals enrolled in other HCBS models. Although Medicaid costs are similar to comparison populations living in nursing homes, they are higher than those of individuals enrolled in other HCBS funding models [31, 38]. Further research is needed that takes into account ways in which the payment model has evolved and that adequately controls for differences between PACE participants and comparison populations.

Residential Options for Community-Based Care

For individuals who do not have sufficient caregiver support to allow them to continue living in a private residence in the community, there are a variety of options for residential care that exist along a continuum between independence and assistance with ADLs and IADLs. There may be considerable overlap between categories of residential options, and the distinctions between the care models described below are not always clear.

Approximately 3% of US individuals age 65 and older live in community housing in which at least one service is available, such as meal preparation, housekeeping, or assistance with medication management [2]. In the USA, there are approximately 30,200 licensed residential care communities that provide room and board, meals, and help with personal care and/or medication management. The majority of these facilities are run by for-profit companies, and less than half participate in Medicaid [13]. Depending on the level of service that they provide, not all residential facilities for older adults are licensed at the state level, so the true number of residential facilities for community-based care is unknown.

What distinguishes these residential options from nursing home care is the lack of clinical, skilled nursing, or rehabilitative services on-site. These congregate settings are designed to meet social and custodial, but not medical, needs. Clinicians must therefore be aware of the level of care provided at residential care settings in which their patients live, so that they do not overestimate the amount of medical oversight or monitoring that is available.

Independent Living Senior Housing

Independent living refers to a variety of housing arrangements geared toward older adults who do not need round-the-clock supervision or assistance with personal care. Independent living communities might include freestanding homes or apartments and are generally set up to be accessible for older adults who are beginning to experience mobility limitations. They might provide some supports, such as congregate meals, activities, transportation, or housekeeping, but they are not set up to provide personal care for individuals with functional impairments or to provide supervision for individuals with significant cognitive impairments.

The cost of independent living varies widely, depending on the type of housing and amenities that are provided, and might include both an initial investment and monthly fees. The cost of independent living is not paid by Medicaid or long-term care insurance. Senior housing subsidized by the US Department of Housing and Urban Development (HUD) is an option for low-income seniors, although waiting lists for subsidized senior housing are often long.

Assisted Living

"Assisted living" is a term that emerged in the mid-1980s to describe a residential model that provided care in a homelike setting, emphasizing the privacy, dignity, and autonomy of residents. Assisted living facilities typically had private sleeping quarters, bathrooms, and kitchens that were furnished with residents' personal belongings. Features that emphasized privacy, such as locks on doors, and autonomy, such as individual temperature controls, were often present [39]. Since that time, the term "assisted living" has come to be used more generally to refer to residential facilities that provide some assistance with ADLs or IADLs but not skilled nursing care. Because there is no clear definition, there is a wide variation in what types of facilities are marketed under the designation of assisted living [39–41].

Assisted living facilities create an environment that is more homelike than a nursing home, although some assisted living facilities are large and have a more institutional feel. Residents generally live in private units that include a bathroom and limited cooking or food storage facilities, with common dining and living areas. Assisted living facilities typically offer medication reminders or administration but otherwise have limited health-related services. They are generally staffed by aides trained to provide personal care assistance but may not have nurses on-site or may only have nursing staff for limited hours. Many assisted living facilities offer a care unit specifically for individuals with dementia [13], usually including restricted entrance and exit to assist with management of residents who are prone to wandering. Dementia care units may also offer specialized programming targeted toward residents with cognitive impairment.

The assisted living model grew rapidly in the 1990s, and by 2007 there were 838,746 units in 11,276 facilities nationally [42]. There is no uniform regulatory structure nationally, so how assisted living is defined and regulated varies from state to state. Unlike nursing homes and home health agencies, which have clear national quality standards and measures, uniform quality standards on which to measure outcomes for assisted living residents are lacking, making it harder for families to compare different facilities. The lack of consensus on what assisted living is and how to measure its quality of care limits the ability to interpret research comparing assisted living to other community-based models of care [40, 42, 43].

Payment for assisted living is generally out of pocket by residents or their family members. In some states Medicaid pays for the personal care services received in assisted living facilities but not room and board. Assisted living is therefore out of reach for many low-income older adults. The availability of assisted living is generally highest in areas with greater educational attainment, income, and wealth, with lower access in rural areas, geographic areas with lower incomes, and minority communities [42].

Adult Foster Care

Adult foster care is another residential option for meeting the care needs of older adults who have some functional impairments but do not need skilled nursing care. Adult foster care may be referred to by a variety of names, including family care homes, adult family homes, or elder group homes, but the common feature of this arrangement is a private home or homelike residence that serves a small number of individuals, usually no more than six residents.

Licensing and regulation of adult foster care vary by state. In some states, adult foster care is licensed and regulated in the same manner as assisted living, but in other states these smaller care settings are a separate category, with their own regulatory structure. Requirements for staffing ratios, staff training, and provision of services vary by state [44]. Individuals usually pay privately for adult foster care services, but in some states Medicaid pays for the personal care services, but not room and board, provided in adult foster care homes in the context of HCBS waiver programs [45].

Although early research on adult foster care suggested that these individuals experienced greater improvements in self-care skills and mobility at a lower cost than nursing home residents, [46] and experienced greater levels of social activity [47], there is a paucity of recent research on adult foster care, and it is unclear whether prior research findings apply to models of adult foster care prevalent in the current era.

Medical Foster Home Care

A specific setting in which an adult foster care model has been employed is in the US Department of Veterans Affairs (VA) Medical Foster Home (MFH) program. Veterans who have disabilities significant enough to be eligible to live in nursing homes and who do not have caregivers who can meet their needs at home can live in medical foster homes, in which individual caregivers provide round-the-clock care in their own homes for up to three veterans. Caregivers are usually individuals who have prior caregiving experience in nursing homes or other institutional settings or experience caring for disabled family members. Caregivers and homes are screened for suitability by a social worker and occupational therapist associated with the MFH program, and home safety is monitored through monthly unannounced visits by program staff. Caregivers provide for personal care needs, supervision, meals, and medication administration in a manner similar to what a family member caregiver would provide. Veterans or their family members pay the caregiver out of pocket, at a rate individually negotiated between the caregiver and the veteran. The arrangement is intended to be long term and often lasts through the end of life [48–50].

The MFH program works collaboratively with the VA's home-based primary care (HBPC), in which medical care for homebound veterans is provided by a team of physicians, nurses, social workers, dieticians, pharmacists, and rehabili-

tation professionals. The HBPC program coordinates the medical care of veterans living in medical foster homes and works together with providers of MFH care.

The MFH program was established in 2008, and as of 2016, there were 117 MFH programs nationally, with a total of 693 homes serving 992 veterans [48]. Residents of medical foster homes have a similar level of frailty and comorbidity as veterans living in VA nursing homes. Cost of care is lower for veterans using MFH care than veterans in the VA's institutional long-term care settings [49]. Residents of medical foster homes have lower rates of hospitalization for COPD and CHF exacerbations, diabetic crises, dehydration [51], pressure ulcers, skin infections, and mental health conditions [50].

Homelike Models of Nursing Home Care: The Green House Model

Models of long-term care are typically divided into nursing home care and home- and community-based care, but the divisions between these settings of care are not always distinct. While most of the models described in this chapter are considered community-based, independent living and assisted living facilities are sometimes large and have an institutional feel not dissimilar to nursing homes. On the other hand, some nursing homes, although technically institutional care, try to replicate homelike environments, thereby meeting the public's desire to have the option of living in home- or community-based settings while still receiving nursing home level care.

The Green House model has gained attention in recent years and attempts to make nursing homes feel more homelike and person-centered. Green House homes have small units, housing 10–12 residents in private rooms with their own bathrooms, with a shared a living and dining area. A consistent staff of universal caregivers is responsible for filling all caregiving roles, including hands-on personal care, clinical tasks, meal preparation, and housekeeping. Residents are able to set their own meal and activity schedules, rather than adhering to a predetermined daily schedule, and they are encouraged to participate in household tasks. The Green House model is trademarked, but some other nursing homes attempt to incorporate some of the principles of the Green House model. Most Green House homes are licensed as nursing homes and certified by Medicare and Medicaid to provide skilled nursing care, although a few are licensed as assisted living facilities [52]. The Green House model and other alternative models of organizing nursing home care are addressed in more detail in the Chap. 20.

Continuing Care Retirement Communities (CCRCs)

Continuing care retirement communities (CCRCs) provide progressive levels of care, including independent living, assisted living, nursing home care, and sometimes specialized dementia care. They are designed with the intention that individuals can remain in the same community through the end of life, regardless of the level of care needed. Usually, CCRCs require that individuals are healthy and functional enough to live at the independent living level when they first join the community, so CCRCs are not an option for older adults who already have significant functional or cognitive impairments at the time that they are interested in entering a community. CCRCs also often have waiting lists, so older adults who are interested in CCRCs must plan for their care needs well in advance. CCRCs vary widely in size, cost, and services offered. They often offer a range of independent living options, from freestanding homes or cottages to small apartments. There are generally dining and recreational facilities within the community, and many CCRCs also have medical clinics on-site. Some CCRCs now offer a "CCRC at home" or "CCRC without walls" option, so that individuals can pay an entrance fee and/or monthly fees to a community and receive some of services of a CCRC while remaining in their own homes, with an option to enter at a higher level of care if needed in the future.

The high cost of CCRCs puts them out of reach to low- and many moderate-income individuals. Entry fees of tens to hundreds of thousands of dollars are required, in addition to monthly fees that may increase as the level of care increases. Prior to joining a community, applicants generally have to demonstrate that they have assets sufficient to be able to pay the community's fees over a period of many years.

Because there is no single licensing or regulatory agency that oversees care provided at CCRCs, it is difficult to determine how many CCRCs exist or how many older adults live in them nationally. The assisted living and nursing home portions of CCRCs are regulated according to state and federal regulations for that level of care. CCRCs may be run by nonprofit or for-profit organizations, and some are affiliated with faith-based organizations.

Principles of Care of the Community-Dwelling Older Patient

Selecting an Appropriate Setting of Care

Although research has been done on many of the models of community-based long-term care outlined above, there is still limited high-quality evidence that any one model is superior to another or to nursing home care with regard to quality of care, patient outcomes, or cost [43]. In this context, there is no clear right or wrong answer when a family is seeking long-term care services for their loved one, and choosing a setting of care is therefore an opportunity for shared decision-making. Primary care providers who have an understanding of the options in their communities can help patients and their caregivers choose the most appropriate setting of care.

Primary care providers should explore several key questions when helping patients and their caregivers select an option for long-term care. Several practical matters must be considered. What is the patient's functional and mobility status? What ADLs and IADLs does he or she need assistance with? What is the patient's cognitive status? Can he or she manage medications independently? Does he or she need 24-h supervision? Do aggressive behaviors or wandering point toward a need for specialized dementia care? Does the patient have complex nursing care needs, such as wound, catheter, or ostomy care? Does he or she have fluctuating medical conditions that would benefit from monitoring or oversight by a nurse? The answer to these questions will help determine whether the patient needs independent, assisted living, or nursing home level care.

Additionally, primary care providers should explore goals of care with patients and their caregivers. What does the family hope to accomplish for their loved one? When choosing a setting for long-term care, there are often trade-offs between safety and independence, and although healthcare providers often have a bias toward settings that offer the greatest safety, patients or their caregivers might place a higher value on autonomy and independence. It is important to explore how a patient and family prioritize longevity, quality of life, maintenance of physical function, and comfort. Not all settings of care will be the same in their ability to support each of these goals. Sharing information about prognosis and life expectancy can help clarify goals of care. A patient might prioritize goals and choose a setting of care differently with the knowledge that he or she is facing a shorter versus a longer life expectancy.

For patients who wish to remain in home- and community-based settings, it is also important to explore the patient's home and family environment. Are there barriers to mobility in the home? Is there any special equipment that is needed to help the patient successfully navigate the home? Who are the patient's primary caregivers? How close do they live? What is their ability and commitment level for providing and coordinating care? An interdisciplinary team, including physical and occupational therapists and social workers or care managers, can be invaluable in helping answer questions necessary to address when making a plan for long-term care.

Once a setting of care has been chosen, primary care providers need to understand what care transitions are necessary and how handoffs in communication will occur. Who will be taking responsibility for managing the patient's healthcare needs? Some settings, for example, PACE or nursing homes, may necessitate a transfer of care between treating physicians. The primary care provider should ensure that relevant clinical information is shared with the new provider. If the primary care provider will continue to follow the patient, he or she must ensure understanding of mechanisms for communication regarding medication changes, changes in clinical status or emergencies, test results, appointments, or other concerns.

Coordinating Care Across Different Settings

Caring for medically complex, functionally, and/or cognitively impaired older adults living in the community can feel overwhelming to the primary care provider. Medical education does not always include training in balancing the competing demands of managing multiple acute and chronic illnesses simultaneously while at the same time addressing cognitive and functional limitations and navigating a complex web of community-based agencies and programs.

Several models of primary care have emerged that show promise in managing the complex care needs of older patients with multiple chronic conditions and functional impairments. For example, the Geriatric Resources for Assessment and Care of Elders (GRACE) model pairs primary care physicians practicing in community health centers with off-site geriatrics interdisciplinary teams to provide quarterly reviews and input on patient management. The Guided Care model partners primary care physicians with registered nurses who provide care management and support for older patients who are at high risk for excessive healthcare utilization. Models that have shown success in managing the care needs of these medically and functionally complex older patients have several features in common. They make use of an interdisciplinary team that carries out medical and functional assessment and develops a comprehensive, evidence-based plan of care. They proactively monitor the patient's clinical status and adherence to the plan of care. They coordinate care across settings and facilitate transitions between settings, and they facilitate access to community-based resources [53].

Although implementing a comprehensive assessment and care planning process coordinated by an interdisciplinary team may not be realistic for all primary care providers, employing elements of these models may help clinicians tackle the challenge of caring for community-dwelling older patients with long-term care needs. Practices that have implemented patient-centered medical home principles likely have or are developing the infrastructure needed to carry out care coordination functions that take place outside of the individual face-to-face encounter. The Center for Medicare and Medicaid Innovation (CMMI) is funding primary care transformation demonstration projects which are piloting practice and payment models that emphasize care management and coordination across disciplines [54]. Practices participating in these demonstration projects may be able to implement key features of models such as GRACE and Guided Care in ways that facilitate interdisciplinary assessment of both medical

and functional needs, collaboration with community-based care providers, and coordination of care across healthcare and long-term care settings, with the potential for more widespread dissemination in the future.

Administrative and Regulatory Issues

When a patient is entering a new long-term care arrangement, there are usually administrative requirements for physicians to complete to attest to the patient's level of functional impairment and the level of care needed. Because eligibility requirements for HCBS or nursing home care are determined at the state level, the process for certifying necessity for long-term care varies from state to state. Physicians will generally need to complete a form attesting to the patient's medical problems, medications, functional status, dietary, and nursing care needs.

For skilled home healthcare such as nursing or physical therapy, the Centers for Medicare and Medicaid Services (CMS) mandates that physicians (or treating nonphysician providers such as nurse practitioners, certified nurse midwives, or physicians' assistants) attest to the fact that they have evaluated the patient face-to-face within 90 days before or 30 days after the initiation of services. Documentation must include the date of the face-to-face encounter, the clinical status of the patient, the patient's homebound status, and the conditions present necessitating skilled services. The initial plan of care must be reviewed and signed, and if home health services are still needed at the end of the initial 60 days of services, the physician or nonphysician provider must review the plan of care, attest to the need for ongoing services, and provide an estimate of the length of time that services will be needed [55]. Medicare pays for certifying and recertifying home health plans of care, to help cover the care coordination function of overseeing home healthcare, if providers submit the requisite codes for reimbursement.

Future Directions in Community-Based Care Services

As the US population ages, models for community-based long-term care services will continue to evolve, but several potential future directions are currently emerging which represent novel ways of organizing assistance and/or financing the care that older adults need.

Aging in Place and the Village Movement

Aging-in-place villages are an emerging model that organizes neighborhoods to support older adults living in their own homes. With increasing geographic mobility, extended families have become more widely dispersed. The informal support networks that may have once provided support for older adults living at home in neighborhoods and small towns often no longer exist. Aging-in-place villages attempt to recreate some of that informal support in preexisting mixed-generation neighborhoods. The village model originated in the Beacon Hill neighborhood of Boston in 2002 and has disseminated nationally since that time [56]. When a neighborhood organizes to become a village, individuals who wish to participate join and pay an annual fee. The village may have one or two paid staff who do not provide direct services to members of the community, but instead organize community members or community-based organizations to provide assistance on a voluntary basis when needed. Village staff also maintain lists of resources for paid assistance, in some cases at a reduced fee negotiated on behalf of the village.

This sort of village model can help members who need assistance with minor tasks such as shopping, transportation, or household maintenance stay in their own homes longer than they might have otherwise been able to. The model, however, is typically not adequate to meet the needs of older adults with more significant cognitive and functional impairments, who need supervision or daily assistance with their ADLs.

Technologies to Facilitate Aging in Place

As the use of smart home and robotic technologies increases, there is an opportunity to make use of these technologies to assist older adults to age in place in their own homes, without the physical presence of another person to provide assistance. Simple call buttons that can be used to summon help in the event of a fall have been in long-standing use. With further advancement in wireless technology, more sophisticated devices are becoming available. For example, remote sensors can monitor blood sugar or vital signs and transmit information to healthcare providers. Pillboxes can provide medication reminders and notify caregivers if doses of medications are missed. Other devices can sense and call for help when someone has fallen. Although not yet widely available in the USA, robotic technologies have been developed to assist with tasks such as toileting or transfers. Although none of these technologies are able to substitute for hands-on care or supervision from another person for the most cognitively or functionally impaired older adults, they may be part of the solution to help older individuals remain in their homes.

Emerging Payment Models

In recent years, a number of innovations in healthcare financing have emerged that have the potential to alter how both institutional and community-based long-term care are organized and

delivered. Although healthcare and long-term care are still largely paid for on a fee-for-service basis, CMS is increasingly emphasizing value-based payment models and capitation, a trend that was accelerated with the passage of the Affordable Care Act in 2010 and the establishment of the Center for Medicare and Medicaid Innovation (CMMI) [57].

Arrangements such as Accountable Care Organizations (ACOs) or clinically integrated networks (CINs) encourage physicians and healthcare organizations to build collaborative relationships in which they share responsibility for cost and quality of care. With these arrangements, incentives are aligned between primary care, specialty care, hospitals, and long-term care, potentially creating opportunities to bring long-term care programs under the same umbrella as medical care. In older patients, medical illness and functional impairments are intimately intertwined, with exacerbations in one domain leading to exacerbations in the other. Treating these domains separately can lead to inefficiencies and increased cost; for example, acute hospitalizations may be necessitated due to unmet custodial care needs rather than medical illness. If ACOs or CINs bring community-based providers of long-term care into their organization, they will have both the incentive and the mechanism to provide the right care in the right setting.

Capitated payment models that focus on overall cost rather than on payment for specific services by specific providers can provide healthcare systems the flexibility to deliver care in a way that is most efficient and effective for the patient, without silos between medical and custodial care and between different disciplines. Programs of All-Inclusive Care for the Elderly (PACE) have demonstrated on a small scale how capitated payments can transform the way that medical and long-term care are delivered in an integrated way. Growth in capitated payment models may provide an opportunity to replicate similar models on a larger scale.

Conclusion

Much of the complexity of caring for older patients relates to managing the intersection of medical illness, functional impairments, and cognitive deficits. Healthcare providers must attend to not only the medical needs but also the personal care needs of their older patients. Although institutional care sometimes seems to be the most straightforward way to meet functionally impaired older adults' care needs, most older adults prefer to remain in the community. There are a variety of community-based options that allow older patients to remain in their homes or in homelike settings, spanning the continuum from independence to greater functional dependency. The primary care clinician can be a key resource in helping older patients anticipate their care needs and select the most appropriate setting of care.

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Home Care

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Christine E. Kistler and Margaret A. Drickamer

Introduction

The practice of home visits by medical professionals is as old as the profession itself. Most medical care was delivered in the home prior to the twentieth century, and even through the 1950s, almost half of care was rendered in the home [1]. With the advent of emergency rooms and the shift to wellness and prevention services as well as the growing complexity of care, medical care changed and became overwhelmingly provided in health-care facilities. By the end of the twentieth century, less than 1% of medical care was given in the home [2]. Since 2000 this trend is slowly reversing with the number of physician home visits growing from about 1.5 million in 1998 to over 2.6 million in 2015. The number of domiciliary calls to physically or mentally disabled patients who live in supervised but home-like living arrangements has more than doubled between 2006 and 2015, from 1.5 to 3.3 million [3].

Home health care by nursing services increased over the latter half of the twentieth century. Long done on an ad hoc basis, formal provision of nursing care through professional organizations began around 1890 [4] and by 2017 included over 12,000 organizations nationwide [5]. As an outgrowth of the inpatient hospital prospective payment system of 1983 and court actions in 1988, home care payment practices were standardized and liberalized, primarily in regard to post-acute care. This led to a doubling of rehabilitation services in the home and an increase in home care costs from 2 billion dollars in 1988 to 17 billion dollars in 1997, where it has generally remained [6].

In 1972 the Veterans Association established what was initially called hospital-based home care which in 1996 was renamed home-based primary care (HBPC). HBPC utilizes an interprofessional team that includes physicians, nurse practitioners or physician assistants, nurses, social workers, pharmacists, psychiatric staff (psychologist, psychiatric nurse practitioner, or geriatric psychiatrist), dieticians, and rehabilitation staff. The HBPC program differed not only in having physicians on the team but by its focus on longitudinal, comprehensive care of patients who have on average eight chronic diseases and who are best treated in their home. Unlike the Medicare benefit, this program does not require improvement of the patients' condition for the continued provision of care in the home but remains involved as long as the program is helping to maintain the person in the home environment. The HBPC model decreases hospitalization, nursing home placement, and costs while increasing satisfaction [7].

As part of the Affordable Care Act of 2010 [8], 15 sites were selected to participate in the Independence At Home project [9, 10]. These were physician- or nurse practitioner-led teams whose purpose was to provide home-based primary care to individuals with multiple chronic illnesses who met these inclusion criteria:

- Two or more chronic conditions
- Coverage from original, fee-for-service (FFS) Medicare
- Need assistance with two or more functional dependencies (e.g., walking or feeding)
- Had a non-elective hospital admission within the last 12 months
- Received acute or subacute rehabilitation services in the last 12 months

At the end of year 2 of this 3-year project, overall savings compared to a control group was 7.8 million dollars for 10,000 beneficiaries. There were reductions in the rates of hospitalization, nursing home placement, and emergency

C.E. Kistler (✉)
UNC School of Medicine, Department of Family Medicine, Chapel Hill, NC, USA

University of North Carolina at Chapel Hill, University of North Carolina Hospitals, Department of Medicine, Division of Geriatrics, Chapel Hill, NC, USA
e-mail: christine_kistler@med.unc.edu

M.A. Drickamer
University of North Carolina at Chapel Hill, University of North Carolina Hospitals, Department of Medicine, Division of Geriatrics, Chapel Hill, NC, USA

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department visits as well as increases in documentation of patient preferences, clinician contact with patient within 48 h of a hospitalization, and medication reconciliation. This demonstrates that home care for complex chronically ill individuals can both save money and provide quality care.

Although there have been small increases in the fee-for-service payment for home visits, the practice remains financially nonviable, due to the amount of time and travel involved. Accountable Care Organizations (ACO), which consider the overall financial costs to patient care, will likely change this calculation. Under an ACO, where a health-care entity is given a predetermined amount of money to pay for all the care of a specified population of patients, home visits may make more financial sense. If home visits are shown to reduce costs for the most expensive, frail complex patients while maintaining high standards of care, they will have a role in the medical care and management of chronic disease. This has been shown to be the case for patients receiving palliative care at home [11].

Home visits to patients who reside in domiciliary care have greatly increased. As of 2015 there are over 30,000 residential care facilities in the USA, almost twice the number of nursing homes, serving over 1,000,000 residents. The medical care of residents in these homelike facilities is often complex since there is limited support staff and the absence of skilled nurses, such as one finds in nursing homes. Home visits by health-care providers to domiciliary care and assisted living facilities can better serve the residents, who may have complex medical needs and limited professional staff available, though this varies between facilities.

Organization of Home Health Services

Most daily care for chronically ill patients is provided by family and friends. Home care services can augment this care. Home health care is a large umbrella term that can include many different health-care providers. Caregiver aid agencies, home health agencies, hospice, and home-based medical care groups, including specialty groups such as palliative care, dentistry, and podiatry, provide health care in homes. Less commonly, chronically ill patients with ongoing complex medical needs may be cared for with a hospital-at-home model. Home care provider groups provide both distinct services and those that overlap with other groups. Home care may be time-limited, as in post-acute needs that remediate, or long-term. Some home care agencies are for profit entities. Many provide services that are covered by most traditional health insurances.

Personal Care Services

Personal care services include assisting patients with bathing, dressing, light meal preparation, and basic household tasks. Providers of these services may assist with shopping, transportation, medication management, or other instrumental activities of daily living. The scope of personal care services is regulated by individual states and includes both private pay and Medicaid-funded services. Depending on the state, these services may be referred to as personal attendant services or attendant care services. States also control what types of services are provided through Medicaid and whether services may be provided inside or outside of the home [12]. Workers who provide hands-on assistance for homebound adults are described as home care aides or personal care attendants, most of whom have limited education and training in home care. Recruitment and retention of these workers are problematic due to low wages and poor training and supervision [12].

Some states have programs that pay for direct assistance to homebound patients that can then be used to pay a family member or an independent personal care service agency [13]. While economically disadvantaged families are likely to receive Medicaid assistance to cover personal care services, almost all of these services received by those with family incomes over $75,000 annually are privately paid [14]. The Patient Protection and Affordable Care Act (ACA) of 2010 [8] offered six new or enhanced options for states to provide personal care services through Medicaid [15, 16]. A popular option is the Balancing Incentive Program, which provides matching federal funds to states that spend less than 50% of their Medicaid dollars on home- or community-based care services (HCBS) [17]. The goal of this program is to increase the proportion of Centers for Medicare and Medicaid Services (CMS) long-term care spending on HCBS as opposed to skilled nursing or assisted living facilities, with the goal to expand the provision of these services to homebound adults. The Personal and Home Care Aide State Training (PHCAST) Program is a six-state ACA-funded demonstration project to develop career ladders for workforce training and development [18]. The programs vary by state but may improve the quality of aides in home care.

Home Services by Allied Health Professionals

Home health agencies (HHA) provide a wide scope of services that enable persons with disabilities, chronic conditions, and functional impairments to continue to live in their homes safely. These services are usually time-limited, provided as discrete episodes of care, and are reimbursed by CMS. HHA only provide direct health care during limited visits over a period that typically does not exceed 4–6 weeks. They do not provide 24-h care or homemaker services. They focus on reversible conditions and require demonstrable improvement to continue service.

An episode of care may include home visits by several allied health professionals including nurses, physical therapists, occupational therapists, speech therapists, nutritionists,

medical social workers, and home aides. Most nurses in home health are registered nurses with 2–4 years of training. Some home health agencies employ licensed practical nurses (LPNs) who typically have about 1 year of training. While LPNs cannot do physical assessments or perform triage, they can provide education, medication reconciliation, wound care, and dressing changes [19]. Registered nurses are qualified to do these skills as well as higher-order nursing such as the provision of medical assessments and the administration of medications, including those given intramuscularly or intravenously.

Home-based physical therapy focuses on improving ambulatory functions and attaining independence in mobility, usually in patients with a recent fall-related injury, joint replacement, or who have gait problems. Physical therapy is often complimented by occupational therapy, which addresses a broad range of activities of daily living, including self-care tasks such as feeding, dressing, toileting, and bathing, and can include the provision of adaptive equipment. Speech therapists address feeding and swallowing issues as well as speech and cognition limitations. They often work with nutritionists for patients with weight loss or uncontrolled diabetes or hypertension. Social workers provide a range of social, financial, and emotional support for patients, including accessing resources in the community for transportation, meal providers, or aide needs, as well as crisis intervention and direct counseling [20].

Home health agencies individualize care plans and coordinate medication and durable medical equipment (DME) delivery. To be eligible for a HHA, a chronically ill patient must be under the care of a physician who will guide the treatment plan. The care plan must include either a nursing or physical therapy component, and the patient must be homebound and unable to leave the home unaided [21]. CMS requires that patients be strictly homebound and cannot leave their homes for anything other than medical appointments or religious services. Patients benefit from continuity of care from a small team of consistent providers, which decreases the risk of hospitalization and emergency department visits and increases the chances of improved functioning in activities of daily living between admission and discharge from home health care [22].

Home-Based Medical Care by Physicians and Advance Practice Providers

Home-based medical care (HBMC) is defined as the provision of care from physicians or advance practice providers and includes both primary and specialty care. One of the first HBMC programs was the Veterans Affairs home-based primary care (HBPC) program which was authorized for six sites in 1972 [23]. It targets frail, chronically ill older veterans who need an interdisciplinary health-care team and have difficulty traveling to outpatient appointments, though may otherwise not be strictly homebound. The program is interdisciplinary and typically includes a physician medical director, advance practice providers such as nurse practitioners and physician assistants, nurses, social workers, dieticians, pharmacist, and physical or rehabilitation therapists. The largest home-based medical practice in the USA is the Mount Sinai Visiting Doctors Program, which cares for more than 1000 patients annually and employs eight full-time equivalent physicians, two nurse practitioners, two nurses, four social workers, and a staff of administrative assistants [24].

Other Home Care

Home care services can include telehealth, podiatry, dental services, and other types of care. Telehealth is an increasingly popular way to manage complex adults in their home. The Veterans Administration telehealth program reduces medical hospitalizations for veterans with schizophrenia and other psychiatric conditions [25]. Telehealth home care methods are developing and include both active and passive technologies. Active technologies require participation of patients and caregivers [16]. These technologies include devices that monitor weight, blood pressure, pulse, glucose, and oxygen and then send this information to a medical clinician or home health agency. Security technologies for falls or wandering can be installed and may trigger action from a monitor. New technologies include remote medical visits with video conferencing. Passive technologies are sensors or cameras or other devices that allow for monitoring without the involvement of the patient or caregiver, such as oximetry readings or bed sensors [26]. Both active and passive technologies improve outcomes for patients with complex illnesses [27, 28].

The home provision of podiatry and dental services is growing in the USA. This care is not covered by insurers, requires private payment, and is of variable quality. Podiatrists may manage wounds and perform simple toenail hygiene with limited debridement. Dentists who provide home care should coordinate care with the medical clinicians to address possible anticoagulation and diabetic, antibiotic, and other medical concerns [29].

Care management or case management refers to social workers, nurses, and other individuals who oversee and organize the homebound patient's medical care, allowing them to remain in independent home living. These managers can be affiliated with a health system or part of a growing private sector. The National Association of Professional Geriatric Care Managers maintains a list of all accredited members (http://www.aginglifecare.org/). These services

usually include an assessment of the patient's living situation with interventions as indicated. They can monitor in-home aides and provide "eyes on the ground" for out-of-town relatives. Costs of these services vary based on the level and frequency of the services provided.

Program for All-Inclusive Care for the Elderly

The first Program for All-Inclusive Care for the Elderly (PACE) was the On Lok Senior Health Services in San Francisco, California, created in the 1970s by a social worker in response to the exclusion of minority populations, particularly individuals of Chinese, Italian, and Filipino descent, from local white-only nursing homes [30]. It was discovered though several CMS demonstration projects that the PACE program was associated with decreased hospitalization and nursing home days [31]. In response to these impressive results, PACE became part of Medicare in 1997. The PACE model allows older adults who would otherwise need nursing home care to stay in their homes by addressing both social and medical needs in a day care setting, with the patient returned to home at night. Adults in the PACE program go daily to a site that provides adult day health services such as assistance in activities of daily living, medication management, activities, and meals, under the directorship of a physician or advance practice provider, who is on site. The care team conducts interdisciplinary rounds and can supplement the day care with home services if needed. PACE programs provide daily transportation for the participants, who are at the site anywhere from 1 to 5 days a week. Enrollees must be dually eligible for Medicaid and Medicare or a sliding scale fee applies.

Community Resources

Community resources and programs for aging adults can provide needed support for patients who are still in their homes. These programs are generally county-based in the USA and vary widely. Some of these programs are associated with the local department of social services, such as adult protective services, and others are independent, such as agencies or departments that address aging. County health departments may provide services to the homebound patients via social workers and other care coordinators. Other community resources include disease-specific resources for patients with conditions ranging from neurologic conditions such as dementia (Alzheimer's Association) and multiple sclerosis (National Multiple Sclerosis Society) to cancer (American Cancer Society) and many other conditions. Faith-based groups often have a benevolent arm that supports local good works including those for homebound adults such as ramp-building, home renovation, and the provision of food. These groups may also provide much-needed socialization in the home. Other organizations such as Meals on Wheels and the Boy Scouts of America also provide services. Meals on Wheels and other meal delivery groups help homebound patients continue to live in their homes and increase their nutritional content and quality, though more work is needed to rigorously assess their benefits [32, 33].

Types of Patient Evaluation by Clinicians

Home-based medical care provides professional clinical services that include single consultative assessments, disease-specific care, primary care, and palliative care.

Consultative Visits

The most discrete form of HBMC is time-limited involvement that addresses safety or other medical care needs and usually involves one or two visits after which recommendations are sent to the patient's primary care provider. This often happens after a hospitalization and is part of transitions of care initiatives. The Community-Based Care Transitions Program, created under Section 3026 of the ACA, devotes up to $500 million to pilot transitional care models at more than 100 participating sites [34]. These programs not only provide short-term assistance for patients; they reorient people's thinking in the community and involve them in the process of improving health care [16]. Early evaluation of these programs suggests they improve care and decrease costs.

Disease-Specific Care

Diabetes, heart failure, and atrial fibrillation are examples of specific conditions where home assessment, telemedicine, and ongoing input from providers can positively impact the health of the patient. For example, telehealth improves the management of patients with heart failure and reduces emergency department utilization [28]. Home monitors with weekly telephone follow-up can help with anticoagulation management that involves warfarin.

The provision of home medical care for adults with persistent and severe cognitive or mental illness, such as dementia or schizophrenia, is challenging but may effectively manage behaviors and address safety concerns. Home-based mental health care that also mobilizes community and county resources may allow these individuals to remain independent rather than living in a facility. Clinicians who provide home visits are familiar with the staff providing the care in

domiciliary settings and can thereby provide more effective medical recommendations.

A growing number of complex treatments can be provided in the home but require coordination and communication between the home care clinician and specialists, such as peritoneal dialysis, home ventilator care, left ventricular assist devices, total parenteral nutrition, and continuous inotrope infusions. This list will grow, and systems of communication that clarify responsibility and coordination between providers will be necessary for this type of technological care to be transferred to the home setting.

Primary Care

Home-based primary care (HBPC) is the provision of continuity of care to homebound adults. This type of care reduces costs and improves the quality of care when provided to frail patients who have multi-morbidities [35]. Independence at Home, funded by Section 3024 of the ACA, is home-based primary care that is targeted to post-acute care patients who have several serious chronic conditions and disabilities [36]. Participating sites, which vary in their organizational model, may be able to share in cost savings, which is intended to create incentives for clinicians to provide longitudinal home-based care for a high-cost population. Models will be studied for efficacy. Successful features include access, affordability, coordinated care, and patient-oriented goal alignment [37].

Home-based medical care, including both primary care and palliative care, meets the health-care needs of homebound patients with serious medical illness [7, 9, 11, 38].

Palliative Care

Home-based palliative care providers focus on symptom control to homebound patients with serious illnesses. The care prioritizes the relief of suffering, either physical or emotional, with the goal of maximizing the quality of life of the patients and their families, many of whom want to avoid hospitalization but may still find some treatments appropriate, such as palliative chemotherapy. Palliative care is multidisciplinary, and team members focus on patients who are seriously ill and functionally limited but not yet ready or eligible for hospice [39]. This care is covered under traditional Medicare services, not the Medicare hospice benefit.

Evaluation and Assessment

Home care clinicians have training and expertise in the principles of geriatric medicine including palliative care, dementia, delirium, urinary incontinence, constipation, weight loss, hearing and vision impairment, pressure ulcers, and fall management [40]. They are skilled in symptom management and understand rehabilitation modalities. In addition to assessing for medical conditions and safety, clinicians must be able to address symptoms to improve the quality of life for patients with complex illness. They understand how to reduce unnecessary treatments and individualize care plans to address what is important to patients and their families. They can explain prognosis, assess decisional capacity, identify a surrogate, help patients and surrogates clarify goals of care, and review advance directives.

Patient and Family Communication

The cornerstone of home visits is the communication and trust that is built between the provider, patient, family, and caregivers. While a clinic or hospital is the domain of doctors and nurses, the home is the patient's environment. The act of coming to the home tells the caregivers and patients that they can trust that the provider sees them as individuals and is willing to put forth effort on their behalf. Communication is enhanced by the authenticity of the home setting, and the clinician learns a great deal by seeing the patient in his or her home where the patient can demonstrate both the strengths and challenges of the home situation with solutions discussed in a pragmatic manner.

Home Safety

Home safety assessments include interventions to reduce falls and other injuries. Discussions include strategies to manage safety and autonomy in the face of worsening cognitive impairment and functional decline. A home safety evaluation assesses for neglect, elder abuse, and caregiver fatigue. Elder abuse is evaluated with the aid of instruments such as the Elder Abuse Suspicion Index (EASI) [41]. These tools use self-report which the home visiting clinician can verify with firsthand observation. Medication safety is assessed by not only reviewing the medication list but by learning how they are administered, where they are stored, and how often they are dispensed. The American Geriatrics Society has a Portal of Geriatrics Online Education (POGOe) that can help home care clinicians with educational needs, the web-based application of which can be assessed at http://www.pogoe.org [42].

Home safety evaluations can be expertly done by an occupational therapist, but any home visiting provider can look for safety concerns such as low lighting, clutter, throw rugs, electrical cords, stairs, and poor bathroom accessibility, with appropriate suggestions for improvement. Efforts to improve safety might include the installation of an alert

system, appropriate locks on doors, and removing conditions that increase the risk for falls.

Functional Status

A functional evaluation of the patient in the home includes an assessment of the patient's ability to perform the instrumental and basic activities of daily living (IADLs and ADLs, respectively) [43, 44]. Gait and balance assessments with tools such as the Timed Get-Up-and-Go test can assess the risk for falls [45, 46] Assistive devices, medication changes, and physical therapy are recommended as indicated to improve functional status. Durable medical equipment includes walkers or wheelchairs which should be carefully selected; CMS will only cover one walker every 5 years. CMS will only pay 20% of the Medicare-approved amount, and the Medicare Part B deductible applies. Prior authorization of durable medical equipment is usually required, given concerns about overutilization [47]. There are specific requirements for power wheelchairs and scooters.

Medication

Home care clinicians will review medications and recommend practices that maximize adherence and limit the use of medications that increase the risk of adverse effects such as falls, confusion, drug interactions, and other common geriatric syndromes. Practices that maximize adherence include minimizing the number of times a day the patient takes medications and using a weekly or daily pillbox to organize medications. Clinicians can help the patient find pharmacies that provide home delivery and other services, such as prepackaged weekly pill packs. The American Geriatrics Society publishes the Beers Criteria, which is a list of potentially inappropriate medications in older adults [48].

Nutrition Management

Homebound adults are at risk for malnutrition and limited access to food. Malnutrition can lead to the frailty cascade of weight loss, muscle atrophy, exhaustion, and inactivity, which increases mortality [49]. The Short Nutritional Assessment Questionnaire (SNAQ©) is a simple questionnaire to determine a patient's risk of weight loss and includes four self-reported measures about appetite, food taste, feelings of satiety, and meal frequency [50]. Home care clinicians can address food access problems by contacting Meals on Wheels or other local agencies that supply food to patients at home. Liberalization of the patient's diet to include high-fat foods, whey, protein powder, or oils or the purchase of breakfast drinks provides additional calories, protein, and fat without significant expense [51]. Patients with dementia and other neurologic conditions may need assistance with meal preparation and eating.

Social Support

Providers who visit the home must assess the patient's social support, which is vital to a homebound patient's overall health and well-being and can be provided by family members, friends, paid aides and attendants, drivers, and volunteers from local community organizations. These individuals provide companionship, conversation, and transportation. Social workers help homebound patients complete applications for benefits such as pharmacy assistance, food stamps, or housing vouchers and contact adult protective services agencies if indicated.

Physical Examination

A thorough home visit by a clinician includes a comprehensive physical examination of the patient including often overlooked components such as physical and oral hygiene, which reflect the ability for self-care and nutritional status. The provider will assess hearing aids and glasses and whether they are in working order and properly used by the patient. Mobility and falls risks are evaluated by the sit-to-stand test [52], Timed Up and Go test [46], or the 6-min walk [45]. Proper and safe use of assistive devices such as canes or walkers is assessed.

Home visits are a good opportunity to assess memory and cognition with screening tools such as the Veterans Affairs St. Louis University Mental Status (VA-SLUMS) test or the Montreal Cognitive Assessment (MoCA) [53, 54]. The VA-SLUMS and the MoCA include 11 items and 9 items, respectively, with a scoring system that ranges from 0 to 30 points and can be completed in less than 10 min. They both measure multiple domains of cognition including visuospatial abilities, executive function, memory, numeracy, delayed recall, and orientation [55]. Scores below 20 indicate dementia and possibly a lack of decisional capacity. Patients with conditions such as frontotemporal dementia may score well on these assessments yet lack capacity given deficits in certain cognitive domains.

Tests and Procedures

Home care clinicians perform basic in-home medical tests and procedures that involve instruments such as a sphygmomanometer, otoscope, thermometer, and pulse

oximeter. Phlebotomy skills are needed, including correctly understanding which blood test corresponds to which tube. Tubes must be kept up to date and delivered in a timely manner to the processing laboratory, in a refrigerated cooler if indicated. Providers should clean equipment at regular intervals, use gloves as indicated, and use hand sanitizer or thorough hand-washing before and after every home visit. Clinicians can perform basic in-home procedures such as joint injections, nail care, wound debridement, incision and drainage of abscesses, minor skin procedures, suture/staple removal, and ear cleaning, all of which require equipment and supplies.

Advance Care Planning and Prognostication

Homebound patients usually have serious medical problems for which advance care planning is appropriate. Home visits provide the opportunity to discuss goals of care and personal priorities, all in the comfort of the home where preferences to forgo burdensome interventions and avoid trips to emergency rooms and hospitals are understood. Home visiting clinicians elicit patient and family values and goals, understand fears and worries, explore trade-offs in quantity and quality of life, determine a health-care proxy, and discuss prognosis [56]. Home visits from clinicians reassure patients that they can be supported in the home, which is where most patients want to stay, even until death.

Proper paperwork is completed during home visits, including forms that designate the health-care power of attorney. Living wills and documents such as the Physician Orders for Life-Sustaining Treatment (POLST) provide a framework for medical preferences at the end of life [57]. Clinicians should sign do-not-resuscitate (DNR) forms for those patients who express this preference. These forms should be readily available and, in the case of a DNR form, displayed in the home.

Continuous assessment of the patient's prognosis helps with decisions. Providers are familiar with the criteria for enrollment in hospice [58, 59] and are aided by tools which help with prognosis such as ePrognosis (https://eprognosis.ucsf.edu). Judging the patient's decisional capacity and utilizing surrogates require skill and compassion and often have subtleties and nuisances when patients retain capacity to state wishes but not necessarily to weigh options. Finally, the provision of support to the family and caregivers throughout the home care process and, if death should occur, through a bereavement period is an important focus for the home care team.

Quality of Care

Experts in the field launched a national project in 2013 to develop standards for home-based primary and palliative care [60]. They involved exemplary home-based medical practices, professional societies, and advocacy groups in an iterative process that developed quality-of-care standards with the aim of fulfilling the home care goal of reducing unnecessary hospitalizations and emergency department visits while providing high patient and family satisfaction. These standards include ten domains which are listed in Table 22.1 [60].

In addition to the basic requirement for competent medical assessment, the home care team must provide the important and expansive task of coordinating care. Care coordination involves communication between the patient, the family, and clinicians and other providers and across health-care settings such as between the hospital or rehabilitation center and home. It includes both the communication of medical knowledge and of the patient's treatment goals

Table 22.1 Quality standards for home-based primary and palliative care [60]

Medical assessment	Ability to perform a comprehensive assessment of physical, emotional, social, spiritual symptoms and cognitive function
Care coordination	Coordinated care when patient changes setting, including communicating patient goals and other key information to all members of the care team and family
Safety	Performance of medication reconciliation, falls prevention, home safety for patients with dementia, and assessment for abuse and/or neglect
Quality of life	Optimization of comfort in the home, symptom management, reducing treatment burden, and the use of assistive devices to optimize function
Clinician competency	Ability to manage medical problems in the home and effectively communicate those problems and care plans to the patient and others
Goal attainment	Alignment of patient's and family's goals with the care plan and facilitating realistic goals of care
Education	Use of knowledge of patient's goals to educate patients and promote understanding, including the support of self-management and the development of a contingency plan
Access	Provision of timely care including access to specialty care and allied health services, as well as 24/7 access to urgent care
Patient and family experience	Management of patient wait times, patient and family stressors, and facilitation of trust with the patient and family
Cost or affordable care	Measurements of health-care use, appropriateness of patient for home-based care, and concern for patient and family financial constraints

and preferences. Quality home care coordination utilizes interdisciplinary team meetings, electronic medical records (EMR), secure e-messaging, and standardized patient assessments [61]. Interdisciplinary meetings include clinicians, social workers, pharmacists, and therapists, all of whom review and discuss the patient's situation and offer their own expertise in formulating the care plan [62]. A nurse practitioner model of home visits after discharge from the hospital has been shown to improve communication, though does not necessarily decrease repeat hospitalizations [63].

The EMR can enhance quality by providing effective communication if it stores vital information and notes and is easily accessible by the interdisciplinary team, specialty clinicians, hospitalists, and other home care providers. Secure e-messaging is concise and expeditious and leads to better communication, improved access to patient information, and reduced errors [64]. The EMR and e-messaging can also be used for timely communication with family caregivers, enhancing the trust that responsiveness helps build between patients and their caregivers and their home care team, which is an important component of quality care.

Quality medical care depends on clinicians who are competent in geriatric principles, palliative medicine, advance directives, and bereavement support. This competence can be gained through experience or through additional training such as completion of a geriatrics or palliative care fellowship or coursework through the American Academy of Home Care Medicine (http://www.aahcm.org/).

A hallmark of high-quality home-based medical programs is the ability of patients to enroll in care in a timely manner and then have reliable access to that care including the ability to contact a provider 24 h a day for urgent medical advice.

Quality home care is focused on the patient and the family with respect for their priorities. Plans are grounded in those values with the care team providing ongoing education about the expected health trajectory. Clinicians work to meet hopes and expectations while not unduly burdening the patient with treatments and interventions that are not likely to be of benefit.

Several organizations have proposed measures for the ten quality-of-care domains listed in Table 22.1, including outcomes such as emergency room visits, hospitalization, readmissions, and family financial concerns. Table 22.2 lists the many organizations that have established quality measures for home-based medical care [60].

Table 22.2 Organizations and entities that establish quality metrics for home care [60]

National Quality Forum
National Committee for Quality Assurance (NCQA)
Healthcare Effectiveness Data and Information Set (HEDIS)
Consumer Assessment of Healthcare Providers and Systems (CAHPS)
Outcomes and Assessment Information Set (OASIS)
Program for All-Inclusive Care for the Elderly (PACE)
Assessing Care of Vulnerable Elders (ACOVE)
Minimum Data Set for Home Care (MDSHC)
Patient Assessment of Chronic Illness Care (PACIC)
CMS Meaningful Use 2014 Standards

Challenges for Clinicians in the Home

The dynamics of a home visit are different from those of an office visit given that care is provided in a private space where the patient and the family are in charge and the clinician is the visitor. The clinician works with limited support staff and equipment. The first visits require flexibility, assessment, and adjustment to the reality of the patient's home. A skilled clinician can adapt to whatever circumstances the home visits present and develop the ability to feel comfortable in many different types of home environments.

Safety concerns may arise during home visits. Families should be told to remove dogs from the environment where the patient and clinician will interact. Even friendly dogs may misinterpret the clinician's actions and move to protect their owner. Clinicians with allergies may not wish to be in a home where tobacco smoke, cats, or other allergens are prevalent. Clinicians may ask that guns be locked and ammunition stored separately from the weapon. Home care providers may opt not to visit a home if there are concerns for safety, whether it be because the neighborhood is threatening in some way or there are individuals in the home who are problematic. Many providers find it wise to visit with at least two team members. Clinicians may feel ambivalence about supporting certain home situations in which patients seem neglected. The presence of bed bugs, vermin, or other unsanitary circumstances may lead the clinician to forgo future visits until the infestations or other problems are addressed, either by the family or by social services. These situations merit mentioning but are usually a very small proportion of what is usually a friendly, supportive way of rendering patient care.

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End-of-Life Care

23

Margaret R. Helton and Jenny T. van der Steen

Chronic Disease and the Change in How People Die

Throughout human history, death was an unpredictable and often random event that could strike anyone at any time at any age. People were used to being around death, which was usually due to infection, injury, starvation, or childbirth. In the last century, with the dramatic increase in life expectancy, the experience and expectations around death have changed. Advances in science have medicalized death to the point where it is seen as a failure of the system and something to be fought all the way to intensive care, if needed, and with aggressive therapies such as chemotherapy and life support, even if these interventions provide little if any chance of restoring meaningful life. The experience of death has been taken out of the home and placed in hospitals.

As the population ages and medical technology continues to develop, people question the utility and morality of prolonging life at all cost, especially when their loved one is not restored to health and has poor quality of life. Along with these concerns comes the advent of new attitudes such as increased intolerance of pain and suffering and the right to personal autonomy and self-determination. These demographic and cultural trends have brought awareness and preferences for a "good death" to the forefront, and the experience and circumstances of how people die is seen as a significant issue in health care for society and a crucial aspect of population health [1].

Most people now die from chronic diseases such as heart disease, stroke, cancer, and diabetes, all of which are treatable at some stage. It is often not clear when it is time to stop treatment and the default has been to keep going. Death from chronic disease is rarely sudden and tends to follow one of three trajectories [1]. Those with cancer tend to be relatively stable and then enter a period of rapid decline. Those with organ failure tend to have ups and downs against a background of steadily declining function, while people with frailty and dementia tend to slowly dwindle (Fig. 23.1). These trajectories occur in the background of emotional, physical, and spiritual changes for the patient and his or her family. Addressing these issues through compassionate palliative care is considered by many governing, legal, and religious organizations to be a human right [2].

Birth of Modern Hospice and Palliative Care Movement

The modern hospice movement began with three women who brought public and professional attention to the plight of dying people and their families [3]. Cicely Saunders, considered the founder of the modern hospice movement, promoted teaching and research on the dying based on her clinical work at St. Christopher's Hospice in London, which she established in 1967. One of her protégés was Florence Wald, then dean of Yale's School of Nursing, who studied with Saunders and launched the American hospice movement, establishing Connecticut Hospice in 1974. Elisabeth Kübler-Ross brought the concept of death with dignity and her theory of the five stages of grief to the attention of the public with her international best seller *On Death and Dying*, published in 1965 [4]. Awareness of the tension between what technology is capable of and what is ethical caused further reflection in the American public by highly publicized cases such as that of Karen Ann Quinlan, a young woman in a vegetative state who was granted the right to have life support withdrawn based on evidence of what her personal wishes had been, leading to the widespread use of advance care planning. In 1990, the US Supreme Court affirmed the

M.R. Helton (✉)
Department of Family Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA
e-mail: Margaret_helton@med.unc.edu

J.T. van der Steen
Leiden University Medical Center, Public Health and Primary Care, Leiden, The Netherlands

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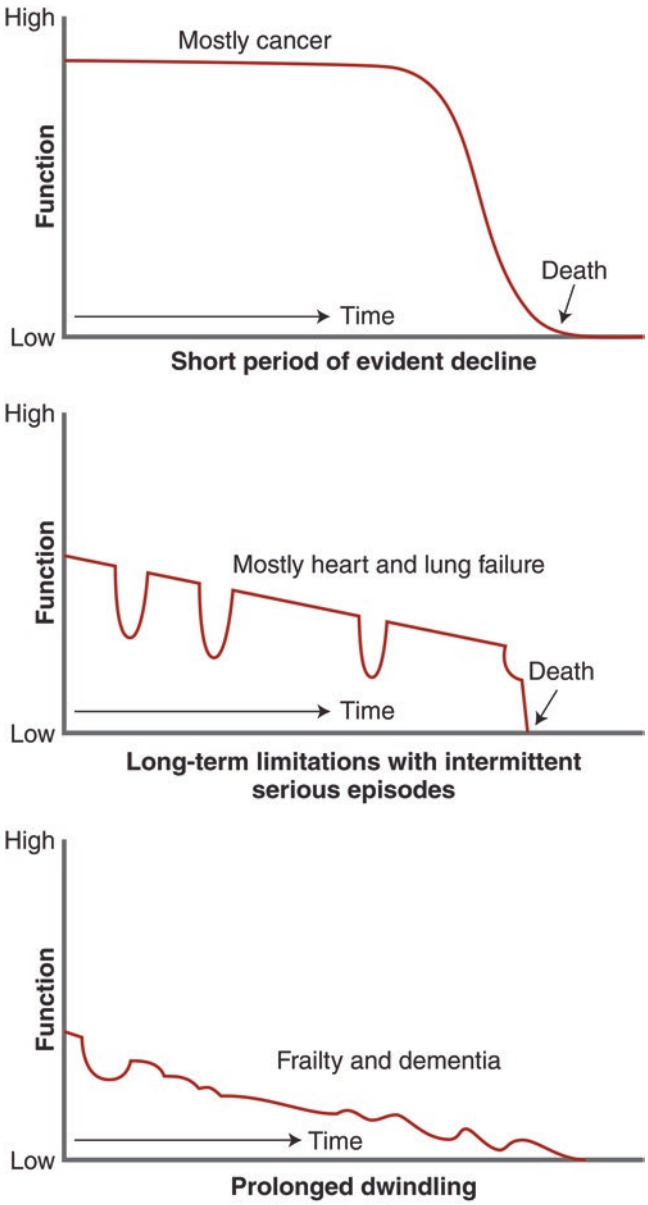

Fig. 23.1 Trajectories of death (Modified from Lynn and Adamson [1])

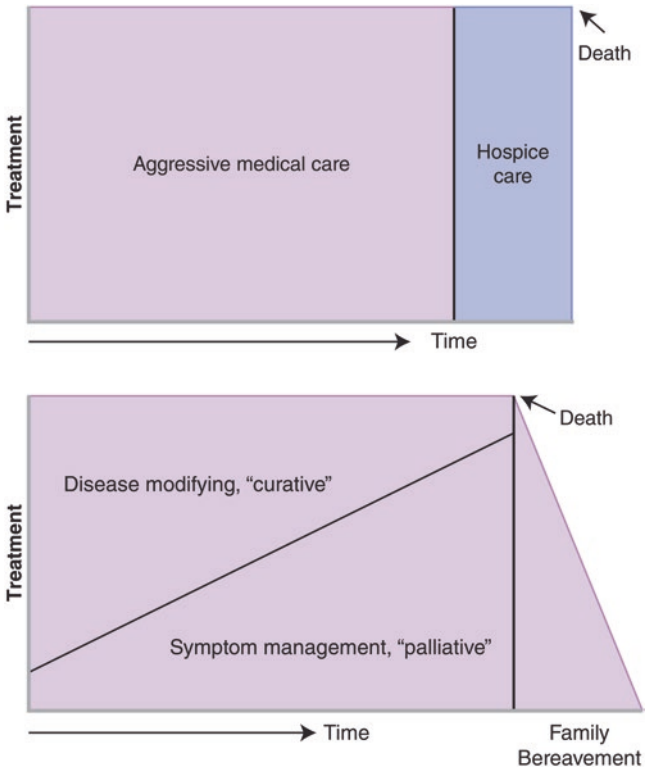

Fig. 23.2 An older model (*top*) drew a sharp distinction between curative care and hospice, a line that patients and families were often reluctant to cross. A newer model (*bottom*) allows the integration of palliative care into the care continuum earlier in the disease process (Modified from Lynn and Adamson [1])

right of a patient to refuse unwanted treatment in the case of Nancy Cruzan, another young woman in a persistent vegetative state. This led to a federal law, the Patient Self-Determination Act, which requires medical institutions to counsel patients about their right to state their wishes regarding end-of-life care, should they become unable to do so themselves. Congress further advanced the discipline with the passage of a Medicare hospice benefit in 1982, made permanent in 1986. While well-intended, this provision drew a sharp distinction between curative care and comfort care, as patients crossed from one payment program to the other. Patients and their families were reluctant to cross that line and usually did so late in the course of the illness. This lead to growth in palliative care which attends to patient suffering across the disease spectrum and allows for the integration of care that manages distressing symptoms while curative care efforts are still ongoing, whether the patient is expected to live days or years (Fig. 23.2) [1].

In 2006, the American Board of Medical Specialties approved hospice and palliative medicine as a subspecialty with the first board certification examination offered in 2008. The Accreditation Council for Graduate Medical Education (ACGME) standardized the program requirements for fellowship training with an emphasis on compassion, guidance in decision-making, and competence in reducing the burden of serious illness and supporting the best quality of life possible for the patient and the family through the course of the disease [5].

Palliative care and hospice have evolved into distinct roles (Table 23.1). Palliative care focuses on improving quality of life for people who are living with any serious illness, using a multidisciplinary approach that addresses pain, other symptoms, and psychological and spiritual distress [6]. It is provided in addition to any ongoing curative treatments. Hospice is more specific in that it provides palliative care to dying patients in the last months of life. Patients are eligible

Table 23.1 Distinction between palliative care and hospice

	Palliative care	Hospice
Providers	Multidisciplinary team of physicians, nurses, social workers, chaplains	Multidisciplinary team of physicians, nurses, social workers, chaplains, volunteers
Goal	Improve quality of life	Improve quality of life, relieve suffering, address emotional and spiritual issues of dying
Eligibility	Patients of all ages with any chronic illness; life-prolonging and disease-related treatments may continue	Patients of all ages who are expected to live less than 6 months; curative treatments are foregone
Place of care	Hospitals, outpatient, nursing homes, home	Home, assisted-living facilities, nursing homes, residential hospice facilities, inpatient hospice units
Payment	Provider fees covered by Medicare Part B; hospital care covered by Medicare Part A or commercial insurance; flexible bundled payments under Medicare advantage, managed Medicaid, Accountable Care Organizations, and other commercial payers	Medicare hospice benefit; standard hospice benefit from commercial payers is usually modeled after Medicare; Medicaid (varies by state); medications and supplies are covered for illnesses related to the terminal illness

Adapted from Kelley and Morrison [6]

and appropriate for hospice care if their prognosis of survival is 6 months or less and no further curative treatments will be sought. When hospice care was established in the USA in the 1970s, most of the enrolled patients had cancer. Today, cancer diagnoses account for 36% of hospice admissions with the majority now due to other diseases, with the top four non-cancer diagnoses being dementia (15%), heart disease (15%), lung disease (9%), and stroke or coma (6%) [7].

Decisions and Communication

Health-care providers must determine which patients are suitable for palliative care or hospice and then support patients and families with an approach that allows for management of difficult symptoms, limitation of futile medical procedures and practices, psychosocial support, and assistance with decision-making. Timely transition to palliative care optimizes the likelihood of appropriate care but often does not occur until late in the disease process without time to allow for the full provision of supportive services [8]. Almost a third of patients referred to hospice use those services for 3 days or less, and nearly half of these short hospice stays come from acute care hospitals after a mean hospital stay of almost 8 days [9]. Another indicator of the challenges involved in deciding to transition to hospice care is the finding that 12% of people who died in hospice care had three or more hospitalizations in the last 90 days of life, including time in an intensive care unit. While even 1 day of hospice services may be viewed as beneficial by the family of a dying patient, it is not certain that this is consistent with patient preference, improved quality of life, or a reduction in resource utilization. While some late referrals to hospice occur because physicians did not communicate this option or prognostication is difficult, a third of patients who were referred for short stays in hospice had a sudden change in their medical condition or had previously refused hospice so were not able to be referred to hospice at an earlier point in time [10]. The health-care system should be prepared and able to provide short-term hospice care.

Timely referral to end-of-life care is dependent on the establishment of a prognosis, which will always be an inexact science. Identifying who is suitable for palliative care can be challenging even for physicians with years of clinical experience. Though disease trajectories are better understood, there is uncertainty in predicting what will happen to an individual patient. Some have proposed that providers ask themselves "Would I be surprised if my patient were to die in the next 12 months?" as a guidepost as to whether a discussion of palliative care should be initiated [11]. The introduction of palliative care should not be seen as an abrupt cessation of curative treatment, rather it is an approach that is gradually adopted as the disease progresses [12]. Given the challenge of predicting life expectancy, palliative care should be offered based on a desire for comfort care, rather than on prognostication. Estimating life expectancy in people with advanced dementia is particularly challenging [13, 14]. Patients with dementia who are reasonably functional and patients with strokes are especially likely to survive more than 6 months after enrollment in hospice [15]. These cases contribute to the significant minority of patients (10–15%) referred to hospice who survive for more than 6 months [7, 15]. In 2011, the US Centers for Medicare and Medicaid Services (CMS) required that patients who have been enrolled long-term in hospice have a face-to-face visit by a physician or nurse practitioner to ensure that they continue to meet eligibility criteria. These visits must occur to determine the continued eligibility of that patient prior to the 180-day recertification. This requirement for more scrutiny has not increased hospice discharges [16].

Physicians should not feel like they are abandoning patients when they consider palliative care, rather they are fulfilling their responsibility to provide compassionate, sensitive, and timely care for patients who are hopelessly ill or dying [17]. It can also be reassuring for physicians to realize that patients and their families benefit from earlier initiation of palliative care which can improve quality of life, allow for the patient's wishes to be followed, reduce family stress, and

even prolong survival [18, 19]. Provision of end-of-life care that is consistent with a patient's goals and values is an important part of high-quality care and a priority for the health-care system [20].

Once a physician identifies the patient who is likely to benefit from palliative care, the next step is to effectively communicate with patients and families. While this may be uncomfortable for physicians, it is a skill that can be taught [21]. A structured approach may be helpful, with clinicians trained to identify patients with serious illnesses who are appropriate for palliative care and taught to use a guide for advance care planning conversations with the patient and family that can then be documented [22].

There is a range of styles in decision-making, from paternalism, where the doctor knows best and makes the decisions, to a merely informative model, where the physician objectively provides information but otherwise plays a relatively passive role, leaving the decisions to the patient and family [23]. Neither of these styles is ideal. The medical evolution away from a physician-centered style toward patient-centered care, where the patient's perspective is considered, is applicable [24]. The best approach is usually a shared decision-making process using "enhanced autonomy," where deliberation and negotiation occurs and includes the physician's expertise and experience while also considering patient and family preferences and perspectives [25]. Still, there are times when a physician may override expressed values and use reasonable medical judgment when an intervention such as cardiopulmonary resuscitation is futile [26].

Decision Aids and Documentation

Explaining complicated medical information and dealing with the emotions involved in contemplating death, all in the setting of uncertainty, are challenging for clinicians, families, and patients. Discussions regarding palliation, hospice, and goals of care can be assisted by decision support tools [27]. Decision aids provide a framework for discussion that leads to informed decisions consistent with the patient's values, needs, and wishes [28]. In advance care planning, they can encourage truthful discussions with physicians, improve patient knowledge and awareness of choices, increase ease of decision-making, reduce decisional conflict, reduce futile care, increase comfort care, and improve documentation [29]. Video decision aids that are complimented by discussions with the nursing home staff improve communication regarding the disease process, comfort measures, and goals of care and reduce hospital transfers without an adverse effect on survival [30].

Most states have Internet sites that provide forms that are variably known as Medical Orders indicating Scope of Treatment or Physician Orders for Life-Sustaining Treatment (MOST or POLST) and do not resuscitate (DNR) forms which increase the documentation of treatment preferences and reduce the likelihood of medical interventions and hospitalization [31, 32]. The state of Oregon reduced hospitalization rates and intensive care use in the last 30 days of life and increased the likelihood of death at home since initiating its POLST program, though this is attributable not only to the form but also to educational efforts, a statewide registry, regulation that allows EMS providers to honor the POLST form, and readily available home hospice services [33]. Other established materials are available online at www.agingwithdignity.org/five-wishes and www.acpdecisions.org.

Patients should be encouraged to name a health-care proxy and ensure that person is aware of care preferences. These wishes can be conveyed through a living will which spells out a person's directives regarding medical treatment should he or she become incapacitated. Public interest in such documents is high and forms are readily available on the Internet. Still, patients cannot accurately predict the circumstances around the closing days of their lives and what medical interventions might be available, and the effect of written directives is limited by inattention to them and by consideration of other priorities over the patient's autonomy [34]. Living wills should thus be complimented by the designation of another person to interpret the patient's preferences and make decisions for them. Known variably as a surrogate, proxy, or health-care power of attorney, this person should consider the patient's written or oral advance directives and then choose treatment options that align with those preferences [35]. When the directives are not clear for the situation at hand, the proxy will use substituted judgment according to what they think the patient would want or make a decision on what they perceive as being in the patient's best interest.

Ethical Issues

The right of an individual to refuse care is well established and based on the principle of autonomy and the right of self-governance. Many landmark cases in the legal system have confirmed this based on ethics and constitutional law.

Withdrawing, Withholding, and Refusing Care

Withdrawal of life-sustaining medical support is a common event in the intensive care unit, and guidelines have been developed that address the medical, legal, cultural, and ethical considerations that are involved [36, 37]. This can be morally justified as omission rather than an act meaning that the practice lets someone die and is not an active act of killing [38]. There is general legal and ethical consensus that withdrawal is equivalent to withholding treatment. In practice, they are different in that doctors may withhold

information about interventions they judge to be futile while withdrawal of care requires a discussion with patients and families [39].

Physician-Assisted Death

Though a majority of Americans believe individuals have a right to end their own lives in the face of suffering and pain with no hope of improvement, the public is closely divided on the issue of physician-assisted suicide, which is the practice where a doctor is aware of the patient's desire to end his or her life and provides that patient with the means (usually a medication) to do so [40]. Euthanasia is the act of ending the life of a hopelessly sick and suffering individual at the patient's request. Currently, euthanasia or physician-assisted suicide is legal in the Netherlands, Belgium, Luxembourg, Colombia, and Canada [41]. Physician-assisted suicide, excluding euthanasia, is legal in five US states (Oregon, Washington, Montana, Vermont, and California) and Switzerland. In these jurisdictions, between 0.3% and 4.6% of all deaths are reported as euthanasia or physician-assisted suicide. In no jurisdiction is there evidence that vulnerable patients are more likely to die in this manner compared to the general population.

Palliative Sedation

The concept of terminal sedation was first described in 1991 and is the practice of drug-induced sedation for painful symptoms that are difficult to control [42]. Many expressed concern that this practice was "slow euthanasia" or mercy killing [43, 44]. To clarify that the intent is not to end the life of the patient but to provide medications for the express purpose of limiting awareness of intractable and intolerable suffering in a patient who is dying, the term palliative sedation is now widely accepted. Multiple organizations have issued guidelines that state that palliative sedation is different from euthanasia [45–48]. This has not resolved the ongoing controversy about the practice. While it is acknowledged that the intent is sedation, there may be "mission creep" based on beliefs regarding aging, dependence, suffering, and dying [49]. Palliative sedation is seen by some as a diminishment of the hospice philosophy of a holistic and caring approach to human suffering and a turn toward the medicalization of end-of-life care.

Quality of Care

Public health and modern medicine provide the opportunity for many people to live longer lives than probably ever in human history, whether the person is productive and functional or afflicted by significant chronic illness. In the latter case, supporting the survival of people who have advanced illness can be viewed as prolonging the dying process with unnecessary physical and emotional suffering [50–53]. Families, patients, and society may worry about prolonged emotional and financial costs and a medicalized, impersonal, and painful dying process with loss of control and the use of unnecessary and futile interventions [54, 55]. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) documented many shortcomings in end-of-life care, including poor communication and misunderstanding between physicians and patients regarding resuscitation preferences, which led to increased consumption of hospital resources [56, 57]. These findings have fostered efforts to improve care of seriously ill and dying patients including in the public arena where written advance directives are widely accepted and most people are aware of the right-to-die movement. The medical community has responded in kind and the maturation of palliative care as a medical specialty has created a growing evidence base for practices that improve care. The National Consensus Project (NCP) for Quality Palliative Care espouses the value of high-quality palliative care and the importance of delivering it in an organized manner [58]. The NCP consists of multidisciplinary organizations with professional roles in hospice and palliative care and uses consensus to address policy and quality issues for end-of-life providers, caregivers, consumers, and payers. Their guidelines are available at www.nationalconsensusproject.org. Other collaboratives such as the Global Palliative Care Quality Alliance, Palliative Care Quality Network, and the project Educate, Nurture, Advise, Before Life Ends (ENABLE) enhance and standardize the quality of palliative care for persons with serious illness [59].

The PEACE project is a CMS-initiated effort to develop hospice and palliative care quality measures including measurements of physical, psychological, and social aspects of palliative care [60–62]. The Measuring What Matters (MWM) project convened a panel of experts who recommended the most important, valid, and clinically relevant indicators for measuring the quality of hospice and palliative care [63]. The final ten indicators are listed in Table 23.2. Designing workable ways to collect, report, and respond to these quality measures within the complex and busy environment of palliative care delivery is challenging but will need to become routine [64]. Other countries including Australia [65], Belgium [66], and the Netherlands [67] are developing quality measurement projects and will contribute to ongoing quality improvement efforts.

Table 23.2 Top-ranked quality indicators for hospice and palliative care

	Quality indicator
National Consensus Project domain	Each indicator has an established measure or one in development
Structure and process of care	*Comprehensive assessment* including documentation of prognosis; functional assessment; screening for physical, emotional, and psychological symptoms; assessment of social and spiritual concerns
Physical aspects of care	*Screening for physical symptoms* (pain, dyspnea, nausea, and constipation)
	Pain screening and management with medication or nonmedication treatment
	Dyspnea screening and management with a documented plan of care
Psychological and psychiatric aspects of care	*Discussion of emotional or psychological needs*
	Documentation of emotional or psychological needs with a documented plan of care
Social aspects of care	Deemed important, but appropriate indicators lacking
Spiritual, religious, and existential aspects of care	*Discussion of spiritual/religious concerns* or documentation that the patient/caregiver/family did not want to discuss
Cultural aspects of care	Deemed important, but appropriate indicators lacking
Care of the patient at the end of life	Deemed important, but appropriate indicators lacking
Ethical and legal aspects of care	*Documentation of surrogate* or documentation that there is none
	Treatment preferences with chart documentation of preferences for life-sustaining treatments
	Care consistency with documented care preferences such as a DNR order, no tube feeding, or no hospital transfer
Global measure	*Patient and/or family assessments* of the quality of care provided by palliative or hospice providers

Adapted from Dy et al. [63]

Relief of Suffering

Physical Suffering

Regardless of whether the disease is heart, lung, or kidney failure, cancer, or dementia, terminally ill patients can experience breathlessness, fatigue, anorexia, nausea and vomiting, constipation, dry mouth, oropharyngeal secretions, poor sleep, confusion, anxiety, or depression, in addition to pain, which is usually the condition that most concerns patients, families, and providers [6, 68]. Despite national guidelines in addressing these symptoms, they often remain insufficiently addressed [69]. Primary care physicians, specialists, and other health-care providers should be proficient at managing the common symptoms of dying patients, and references are widely available to help them do so [70–72].

Psychological Suffering

The emotional suffering experienced by patients and families as the end of life approaches varies among individuals and is a complex interplay of cognitive, behavioral, social, cultural, and spiritual factors. There are efforts in palliative medicine to better conceptualize psychological distress to aid in the provision of effective interventions as well as create measures that may be used to ascertain quality of care [73].

Even if people can find meaning in the death of a chronically ill loved one, family caregivers may be anxious or depressed, feel exhausted, or even develop an existential crisis [74]. Emotional support of family caregivers can lower levels of grief, improve psychological and physical health, and increase the chance that the patients may die at home [75]. The US National Consensus Project (2013) recommends and the Medicare hospice benefit covers grief services to patients and families prior to and for at least 13 months after the death of the patient. The European Association for Palliative Care recommends assessing bereavement support needs with referral as indicated [76]. Bereavement support can include memorial services, therapy, education, and emotional support [77–79]. Such support may alleviate or even prevent complicated grief disorder or prolonged grief, which is characterized by intense grief that lasts longer than would be expected and causes impairment in daily functioning and feelings of disbelief and preoccupation with the deceased love one, sometimes requiring professional support [80]. Depression, high pre-loss grief levels, and low preparedness for the patient's death are predictors of complicated grief [81, 82]. Larger hospice organizations are more likely to provide screening for depression and complicated grief and access to bereavement therapy [83].

Places for End-of-Life Care

Chronic illness that is progressive and does not involve cognitive impairment provides opportunities to consider preferences at the end of life including place of death. Many people, whether healthy or chronically ill, indicate that they would prefer to die at home and find nursing homes the least preferred place of death [84, 85]. However, there is limited evidence about how often patients change their mind, whether they actually have a preference, or how strongly they feel about the preference [86].

Hospitals

Although many people express a wish to die at home, it cannot be assumed that *most* patients have this preference. Some prefer the hospital for safety and effective symptom control or do not want to be a burden for their family. Family members may not be comfortable with medicalizing the home environment with equipment and outside staff or may worry about exchanging the good memories associated with home with the legacy of a death at home. Given these feelings, it is likely that hospitals will continue to be the place of death for many and should be prepared to support dying patients and their families [87].

For patients with chronic diseases such as dementia, hospitalizations in the last weeks of life are burdensome, may be medically unnecessary, or are discordant with the patients' preferences [88]. Such hospitalizations occur in up to 20% of nursing home patients with advanced dementia, a rate that can be lowered with advance care planning in the form of a do-not-hospitalize order [88, 89].

Home

In the USA, more people are dying at home and hospice use has increased [9]. People who die of chronic diseases with organ failure or neurological deterioration are less likely to die at home than people with cancer [90]. Home death with palliative care is more likely in women, older people, married people, and when fewer hospital beds are available in the region. Patterns and predictors of home death vary between countries likely due to policy and cultural differences.

Nursing Homes

Rates of nursing home hospice use more than doubled between 1999 and 2006 [91]. This increase is related to the growing trend of using hospice for non-cancer diagnoses as well as to an increase in hospice providers. There is good evidence that the provision of hospice care to nursing home residents improves pain management, reduces hospitalizations, and improves family satisfaction with end-of-life care [92–94]. However, the increasingly long stays of nursing home patients in hospice care have raised concern about higher Medicare hospice expenditures. The challenge is how to reign in the costs of long hospice stays without removing the accessibility of a comfort care approach to dying patients in nursing homes. This can be addressed by varying payments based on length of enrollment in hospice (see financial section below). Experienced physicians who work in nursing homes can effectively provide comfort to dying patients without outside hospice care, and most patients who die there are perceived to do so quietly and without suffering [95]. Patients whose deaths are unexpected or caused by pneumonia appear to suffer more during the final hours of life.

Hospice patients in nursing homes or assisted living facilities receive more nurse's aid care than those who are at home, likely appropriate for patients in the final stages of dementia, which are patterns that may eventually affect payment practices [96]. Nursing home staff have a profound and beneficial impact on the lives of their patients who are terminally ill, are themselves deeply affected by their encounters when caring for dying patients, and have a favorable view of hospice services [97, 98]. Still, there can be negative feelings between staff and outside hospice services due to poor communication and unclear expectations and roles [99]. There may be opportunities in the future to ensure that nursing home staff are trained in comfort care. Similarly, new models that increase physician presence in nursing homes would likely increase physician engagement and expertise in end-of-life care [100]. Whether committed and trained staffing at both the nursing and provider level can provide the same level of quality end-of-life care as an outside hospice agency is an area ripe for study.

Outpatient Palliative Care

Community-based care to seriously ill patients has generally only been available through hospice programs and, therefore, only available to patients with a prognosis of survival of 6 months or less [6]. Many patients who are seriously ill at home or in nursing homes are in need of palliative care but are not yet eligible for hospice. Community-based palliative care programs can seamlessly link inpatient and outpatient settings, providing longitudinal care that is consistent, continuous, coordinated, collaborative, and fully integrated into the health-care system [101] (Fig. 23.3). New payment incentives under the Affordable Care Act and the shift from fee-for-service to capitated models of reimbursement support cost-saving quality care innovations for patients who are seriously ill but not eligible for hospice. The expansion of outpatient palliative care improves patient, family, and provider satisfaction, symptom control, and quality of life while reducing intensity of health resource use [102, 103].

Transitions

Palliative care consultation is now widely available in hospitals but has limited effect without meaningful post-acute care. Reduction in cost of care and rates of readmission after discharge are not achieved unless inpatient consultation is followed

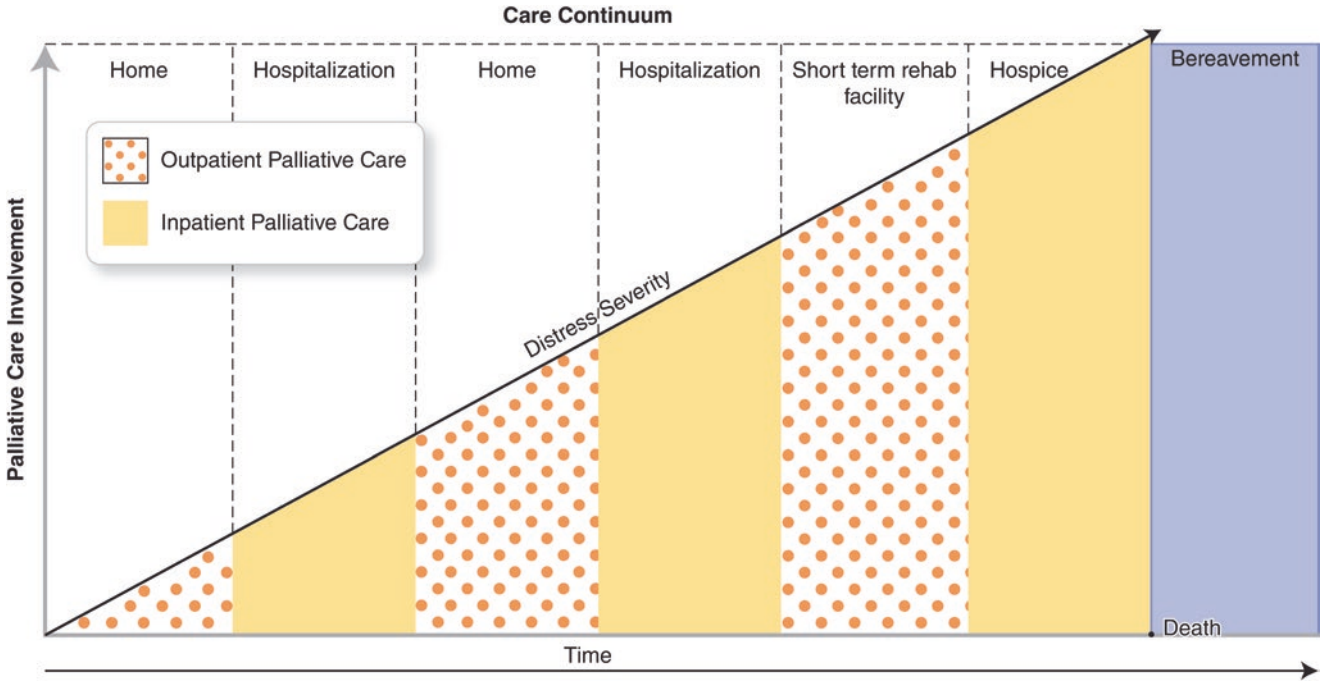

Fig. 23.3 Community-based palliative care creates a continuum of care for a patient, regardless of location, linking home, institutional care, and hospice. Without such a system, gaps may occur in palliative care needs, including during periods of worsening illness and deterioration

by hospice care after discharge [104]. Transitional care planning is an essential part of inpatient palliative care and ensures a continuum of care that effectively provides quality end-of-life care and consistently honors patient care preferences.

Financial Reimbursement and Cost Savings

The Medicare hospice benefit was created in 1983 with the dual intent of providing compassionate and quality end-of-life care while simultaneously reducing costs. Hospice enrollment lowers Medicare expenditures, hospitalization, intensive care unit use, and in-hospital deaths in both short-term (1–30 days) and long-term (53–105 days) hospice use [105]. Palliative care consultation in the hospital reduces direct costs by almost $1700 per admission ($174 per day) for live discharges and of almost $5000 per admission ($374 per day) for patients who died which for an average 400-bed hospital translates into a net savings of $1.3 million per year [106].

The public has accepted that hospice improves the quality of care to both the patient and family at the end of life. In 2012, 47% of Medicare beneficiaries received hospice care prior to death, and in 2013 Medicare spent $15 billion on hospice, representing 420% growth over the past 13 years [107]. Hospice programs are available to almost all Americans, and the number of hospice programs, including those that are for-profit, has risen substantially over the past 20 years [108, 109].

Though hospice improves care at the end of life, the well-documented savings in the last months before death may diminish as hospice stays increase beyond 180 days after which the costs of prolonged care exceed the potential savings from hospitalizations. Due to concern that the flat per diem payment structure incentivized the recruitment of more stable patients, the Centers for Medicare and Medicaid Services (CMS) changed the payment model effective January 1, 2016, to a two-tiered per diem payment practice where hospice services are reimbursed at a higher rate for the first 60 days of care with a lower rate for subsequent days as patients are potentially relatively stable, with an allowance for increased payments in the last week of life as acuity of symptoms and need for care increases [110]. Another important change since January 1, 2016, is the provision of payment for advance care planning discussions between physicians, patients, and families [110]. The Center for Medicare and Medicaid Innovation in CMS is conducting a demonstration that allows hospice-eligible patients to access palliative care without having to forgo curative treatments as had always been required in the Medicare hospice benefit, with providers receiving a monthly payment for providing this care.

Special Populations

Dementia

Dementia is a chronic, progressive, and incurable disease. People with dementia often die from complications such as pneumonia due to swallowing problems or food and fluid intake problems [111]. These problems can begin when peo-

ple have moderate dementia and continue until they are in the advanced stages where they can die from these complications or can continue to live for a surprisingly long time. Prognostication is difficult because it is hard to predict when a fatal infection or intake problem will develop [76, 112].

Caring for people with dementia is often burdensome for families who usually grieve while watching their loved one decline both cognitively and physically and then may have to manage challenging behavior. Admission to a facility is sometimes unavoidable, and in western countries most people with dementia (two-thirds in the USA) spend the last part of their life in a nursing home [113]. People with dementia and their families have variable needs along the disease trajectory and may benefit from palliative care, which is aimed at maintaining or improving quality of life. With advancing dementia, communication and shared decision-making often established comfort as the goal of care rather than life prolongation [76]. Palliative care in dementia is distinct from palliative care in cancer. Because of the inevitable cognitive decline along with an uncertain trajectory, early advance care planning with the patient and the family is important. However, applying palliative care early in the disease is somewhat controversial in dementia care and is still often limited to the terminal stage. This can place people with dementia at risk for overtreatment with burdensome interventions and undertreatment of pain and other symptoms because of their difficulty verbalizing complaints. Palliative care monitoring of symptoms should include observational scales that assess facial expressions and body language to recognize pain, discomfort, or other problems [114].

Nearly 90% of patients with dementia develop eating problems [115]. This can be distressing for family caregivers and providers alike who believe that providing artificial feeding through a percutaneous endoscopic gastrostomy (PEG) feeding tube will prolong life [116]. However, this is not the case regardless of the timing of the placement (early or late after the development of feeding problems) [117]. Feeding tubes neither prolong survival nor prevent aspiration in persons with advanced dementia [118–120]. They do, however, increase health-care costs [121]. By the time chronically ill persons are unable to eat, the quality of their life is so poor that insertion of a feeding tube likely just prolongs the dying process without the addition of days of meaningful life. Several organizations recommend against tube feeding in patients with advanced dementia [122, 123]. These messages seem effective as the proportion of US nursing home residents with advanced dementia and inability to eat who receive feeding tubes decreased by 50% between 2000 and 2014 [124].

Dementia-specific hospice programs that emphasize comfort rather than maximal survival time were first proposed in 1986 [125]. Over time, many western countries have expanded hospice and palliative care programs to include people with dementia. Medicare beneficiaries with dementia who sign up for the Medicare hospice benefit receive less aggressive care at the end of life, such as fewer feeding tubes, and are less likely to die in hospitals [126]. Raising awareness that dementia is a terminal disease to which palliative or hospice care applies is important in the education and training of health-care professionals, families, and the general public [127, 128].

People with Intellectual Disabilities or Mental Illness

An intellectual disability is usually a permanent condition while a mental illness may be temporary, but both bring special challenges in communication and ethics when it comes to end-of-life care.

Intellectual Disability

In the USA, about 3% of people of all ages have an intellectual disability, which affects nearly one in ten families at some point [129]. Life expectancy for people with intellectual disability has increased due to improved health and social care but remains below that of the general population [130]. The difference may be attributed to genetic causes but health inequalities also play a role [131]. Still, the overall increase in life expectancy for people chronically affected by intellectual disability increases their chance of developing a life-limiting condition such as cancer [132, 133]. People with intellectual disabilities are especially at increased risk of developing dementia [134]. People with intellectual disability are at risk of being under-referred including to specialist palliative care or hospice. The American Association on Intellectual and Developmental Disabilities (AAIDD) calls for access to high-quality end-of-life care for people with intellectual disability that includes dignity, respect for autonomy, protection of life, and equality [135]. AAIDD and the European Association for Palliative Care recommend that discussions about the end of life begin before the anticipated last 6 months of life or before the need for palliative care [131].

Some people with intellectual disability may not have a chance to contribute to advance care planning discussions, but others are able to communicate about death and dying and indicate preferences including a desire to be involved in their own care, have friends and family around, stay occupied, and be physically comfortable [136]. Special communication and assessment skills are particularly relevant with these patients [132]. This can also prevent the well-intended but sometimes inappropriate tendency for relatives or others to protect people with intellectual disability from hearing bad news [137]. Unless it is demonstrated otherwise, people with intellectual disabilities should be assumed to have

capacity to make decisions around their care and treatment and provided with support in end-of-life decision-making.

Symptom management in end-of-life care in people with intellectual disability requires special skill as it may not be clear whether a symptom is behavioral or reflects pain. Assessment tools such as the Disability Distress Assessment Tool (DisDAT) use baseline mapping of usual behaviors so that changes to that pattern can be recognized as a sign of distress [138]. Early referral to palliative care services is helpful so that the team can learn about the patient's usual behavior and build familiarity and trust with the patient, the family, and all members of the care team. People with intellectual disabilities have often been at the center of the family and caregivers' lives, and they can be deeply affected by the loss of this beloved person and often need support in grief and bereavement [131].

Mental Illness

In the USA, 18% of adults have some form of mental illness including 4% with serious mental illness [139]. Mental illness increases risk of a life-threatening physical illness for a number of reasons, including not attending cancer screening, unhealthy lifestyles, and physical complaints that are not well examined but ascribed to the mental illness or are self-medicated rather than evaluated by a physician. People with psychiatric illness and palliative conditions often do not receive the care they need [140]. Similar to intellectual disability, psychiatric disease increases the risk of impaired decision-making capacity. Good communication, collaboration, and multidisciplinary teamwork are essential in providing good end-of-life care. This may be facilitated through a liaison who acts as a bridge between mental health and palliative care services [140].

Children

In the USA, unintentional injury is the leading cause of death in children after the first year of life with congenital anomalies the leading cause of death in infants under the age of 1 [141]. Malignant neoplasms are the second most frequent cause of death among those aged 5–9 years and can also cause death in toddlers and preschoolers. Psychosocial suffering and symptom burden are especially high in children with cancer [142, 143]. Heart disease and chronic respiratory disease are other progressive conditions that can affect children. While any of these conditions can cause death, many children with chronic, life-shortening illnesses are now living into adolescence and young adulthood [144].

The American Academy of Pediatrics has advocated an integrated model of palliative care for children with high-risk cancer and other life-threatening conditions [144]. This integration between ongoing curative efforts and palliative care can be facilitated by consultation with a palliative care expert, a collaboration that normalizes the concept and supports continuity of care and a continued focus on quality of life [142]. The focus may change depending on the location in the disease trajectory (whether far from or close to the end of life), but at any point managing and clarifying goals of care are important. Cohesive care transitions should occur between the hospital, ambulatory care, home care, and respite support services [143].

Palliative care in pediatrics potentially involves a broad target population of those involved in the child's social and relational spheres, such as parents, siblings, grandparents, and extended relatives. Parents or guardians need support in living with the prospect of a premature death and in subsequent bereavement, given the general expectation that children outlive their parents. Parents are distressed by seeing their children in pain, and patients may experience complex psychosocial symptoms with exponentiation of these symptoms at the end of life. Parents would like to know if professional caregivers are uncertain about the best treatment or prognosis, although not all wish to be responsible for end-of-life decision-making [145]. Professional caregivers can improve their comfort level regarding their responsibility to have these emotional conversations by preparing ahead of time and providing accurate and honest information while avoiding medical jargon [143–145]. Parents may be ambivalent about advance care planning, and a sensitive and gradual approach with the same trusted professional with whom there is also room to discuss nonmedical concerns may accommodate such ambivalence [146]. Excellent interpersonal and communication skills is one of the six core competencies for all trainees in US residency programs, including those who will practice pediatric hospice and palliative medicine [147]. Different settings and location in the disease trajectory (whether far from or close to the end of life) require different conversations, but typically, patients and families simultaneously pursue disease-modifying therapies and palliative care, and managing and clarifying goals of care is of utmost importance. Specific to pediatric palliative care is also different bereavement after the loss of a child, different physiology in the context of change and growth, and communication with children adapted to their cognitive ability, although the overall approach to symptom management is similar, regardless of age.

Pediatric palliative care is under-resourced and often misunderstood, with little evidence available regarding treatment of symptoms, which means that guidelines are mostly based on expert views [148]. There are efforts to improve and extend the provision of children's palliative care. The International Children's Palliative Care Network (ICPCN) provides a global network of advocacy (www.icpcn.org). There are pediatric networks such as that within the European Association for Palliative Care which provide a platform to

share knowledge and expertise between resource-rich and resource-poor countries in Europe as well as pediatric standards available through the National Hospice and Palliative Care Organization in the USA [149, 150].

Future Directions

Workforce and Access

The National Priorities Partnership identified palliative care as one of six priorities in improving the quality of US health care [151]. Given the significant growth in the number of patients in need of palliative care, a major challenge will be the provision of an adequately trained workforce. There is a significant shortage of physicians specially trained and certified in hospice and palliative care [152]. This means that others will need to help. In its report "Dying in America," the Institute of Medicine stresses that "all clinicians across disciplines and specialties who care for people with advanced serious illness should be competent in basic palliative care, including communication skills, interprofessional collaboration, and symptom management" [50]. While physicians trained in the specialty of palliative care have expertise and comfort in such conversations, there are not nearly enough of them to meet the needs of the population [152]. It is critical that primary care physicians are trained and comfortable with end-of-life care. Graduate medical education should teach palliative medicine to all clinicians who serve patients with serious chronic illness. Practicing physicians should be provided opportunities for professional development in end-of-life care. The ongoing involvement of the patient's primary care physician can reduce the intensity and cost of end-of-life care [153].

Other innovations such as telehealth will increase access. The ENABLE project demonstrated the effectiveness of a telehealth model of palliative care that provided support and expertise to the primary caregivers of a rural-dwelling population of adults with advanced heart failure [154].

Decision Aids

The default to undesired and aggressive nonbeneficial care harms patients and wastes resources. In response to these known risks, the Institute of Medicine publication *Dying in America* emphasizes the need to enhance advance care planning and improve decision-making for patients with serious illness [50]. Patients should be offered an effective and validated decision tool to assist them with advance care planning and treatment decision-making. Ongoing development of such tools, their introduction in a timely manner in the appropriate context, and subsequent monitoring of their quality and impact will be important to develop an evidence base [155].

Electronic Medical Records

In the USA, the public has embraced advance care planning, and most older adults with chronic conditions have made advance care plans. However, these plans are not consistently communicated with providers and are rarely documented in the electronic medical record (EMR) [156]. This is especially problematic in the emergency room (ER) setting, where despite high completion rates of advance directives among older adults in the ER, only 4% had this documented in the EMR [156]. This gap between patient preferences and documentation defeats the whole purpose of advance care planning and often results in the delivery of inappropriate and unwanted care. The EMR can also help identify patients for whom advance care planning is appropriate, taking the onus off physicians and other staffers who may not remember to do this in the course of a busy day [155]. EMR-based reminder systems significantly improve advance care documentation [157]. Ready availability of advance directives is critical in fulfilling the responsibility of delivering appropriate care and honoring the wishes of the patient and his or her caregivers, and furthering the capacity of the EMR to assist in communicating these plans will undoubtedly play a role in this effort.

Racial and Cultural Diversity

As western democracies grow increasingly diverse, an understanding of racial or ethnic variation in end-of-life decision-making will allow for more culturally sensitive approaches to care. In general, studies indicate that African Americans prefer the use of life support while people of Asian and Hispanic heritage place a high value on family-centered decision-making [158]. Among religious people, whites are more likely than blacks or Hispanics to halt medical treatment in the face of an incurable disease with suffering and pain [40]. Muslim patients and families are often reluctant to stop aggressive therapy but may do so if the treatment is deemed futile by physicians [159].

Socioeconomic status is of consequence as well. In the USA, people with more education and higher incomes are more likely than those with less education and lower incomes to have communicated their wishes for end-of-life care. Research and training should continue to better prepare providers who provide end-of-life care to a population that is increasingly racially, culturally, and ethnically diverse.

Value-Based Payment Models

The changes to Medicare payment policies for end-of-life care since January 1, 2016, will be thoroughly evaluated to determine whether the historical expectations that hospice should reduce overall costs can be realized [160]. Will the higher payment in the first 60 days after hospice enrollment lead to earlier use and reduce the practice of late enrollment? Will it decrease long hospice stays? Will the changes impact quality of care? This is particularly important as Medicare moves toward value-based payments based on quality measures. Palliative care and hospice are behind other parts of the health-care system in moving toward new payment models.

Paying physicians to discuss advance care directives will also be studied to determine whether this practice affects decisions or impacts referrals to hospice or palliative care or, for those who do not formally enroll in such programs, increases the practice of comfort care, with fewer medically complex interventions that provide little benefit to the patient.

The CMS demonstration project that allows hospice enrollees to continue curative care will be carefully studied to determine if this flexibility increases hospice enrollment, improves quality of life, and reduces costs. Medicare spending on end-of-life care is significant. The unquestioning offering of expensive life-prolonging technologies regardless of cost and no matter how marginal the benefit is considered by some to be ethically questionable, since it comes at the expense of other publicly-funded social priorities such as universal access to health care, clean air and water, education, and needed infrastructure [161].

Quadruple Aim

In addition to the widely referenced triple aim of enhancing patient experience, improving population health, and reducing costs, a fourth aim that addresses widespread burnout and dissatisfaction among clinicians and staff will enhance the functioning of the health-care system. Improving the work life of health-care providers leads to better care, better health, and lower costs [162]. Providers who work in end-of-life care are vulnerable to burnout due to chronic stress from working with terminally ill patients with the associated frequent exposure to death and loss, physical and emotional suffering, increasing workloads, and competing role demands. Nurses often have the most interaction with patients and may experience family-like grief, especially with more intense and longer relationships [163]. Nurses mature emotionally with experience and find reward in end-of-life care with opportunities for personal and professional growth [164–166]. Exposure to death and dying can lead palliative and hospice care professionals to live in the present and cultivate a spiritual life which can include coping mechanisms that decrease chances of burnt-out, such as clinical variety, transcendental meditation and quiet reflection, realistic expectations, and remembering patients [167, 168]. Innovations that promote resiliency and self-awareness using mindfulness, health education, cognitive strategies, and other coping skills will support the people working in the expanding field of end-of-life care [169–171].

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Special Population: Children and Adolescents

24

Morgan A. McEachern and Cristen Page

Introduction

Chronic illness in childhood is defined as any biological, psychological, or cognitive condition expected to persist for at least 12 months and either necessitates health care and related services or leads to functional or cognitive limitations of the child compared to peers [1, 2]. The diseases are due to genetic conditions, environmental factors, or a combination of both. Common childhood chronic diseases are listed in Table 24.1.

An estimated 25% of children in the United States (US) have at least one chronic illness [3], and the prevalence of chronic disease in childhood has steadily increased over the last decades. This is attributed to several factors. Advances in medical care for many chronic conditions have increased life expectancies. For example, in the 1940s children with cystic fibrosis had a life expectancy of less than 2 years of age but now have an average life expectancy exceeding the age of 40 [4]. While cure may not be achieved, many children with chronic illness are now surviving well into adulthood. Dramatic increases in the incidence of chronic conditions such as obesity, asthma, and attention deficit disorder also contribute to the increasing prevalence of childhood chronic illness. Nearly 20% of children and adolescents in the USA meet clinical criteria for obesity compared with less than 5% of children and adolescents in the 1970s [5, 6]. The prevalence of asthma, now at nearly 10% of children and adolescents in the USA, has nearly doubled since the 1980s [7]. Significant disparities exist in the prevalence rates of childhood chronic illness between racial and ethnic groups. When compared to non-Hispanic whites, asthma rates are 60% higher among blacks and 25% higher among Native Americans [8]. Mortality rates are six times higher for blacks when compared with non-Hispanic whites [9, 10]. Rates of long-term disability, increased health-care spending, and decreased workforce participation will increase as children with chronic illness transition into adulthood. Multidisciplinary interventions will prevent and treat childhood chronic illnesses and allow children to reach their full potential as adults.

M.A. McEachern (✉) • C. Page
Department of Family Medicine, University of North Carolina School of Medicine, Chapel Hill, NC, USA
e-mail: morgan_mceachern@med.unc.edu

Sites of Care for the Child with Chronic Illness

Caring for a child with chronic illness is complex and requires a multidisciplinary approach involving caregivers and providers in a variety of settings. Comprehensive care for these children goes beyond outpatient and inpatient settings into homes, schools, and the community.

Medical Care Settings

Hospitals

In 2012, there were 5.9 million child and adolescent hospitalizations in the USA, 73% of which were related to conditions in the newborn and infant period [11]. Asthma exacerbation was the most common chronic disease requiring admission in children over age one and accounted for nearly 125,000 hospitalizations in 2012. Other chronic diseases that are in the top 10 reasons for hospitalization in children are mood disorders, epilepsy, and cancer.

Prolonged or frequent hospitalizations can negatively affect a child's physical, cognitive, emotional, and psychological development. In addition to the provision of medical care, the hospital environment must support the child's growth and development. Parents must be allowed to stay with their children and trained health professionals must provide programs that use age-appropriate therapeutic play to address the social, emotional, and developmental needs of hospitalized children [12]. Daily discussions regarding the

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Table 24.1 Common chronic diseases in children

Autism spectrum disorders
Asthma
Cancer
Cerebral palsy
Congenital heart disease
Cystic fibrosis
Diabetes
Developmental disabilities
Immune deficiency
Inflammatory bowel disease
Mental illness
Obesity
Seizure disorder
Sickle cell anemia
Consequences of low birth weight and prematurity (chronic lung disease, developmental delays)

plan of care should include the family, other caregivers, and the child, when developmentally appropriate. Expectations regarding behavior should be discussed early in the hospitalization. Efforts should be made to minimize fear and pain during hospitalization, especially in regard to procedures.

The Outpatient Medical Home

Poor communication between the inpatient and outpatient setting leads to fragmentation of care, hospital readmission, and poorer health outcomes in patients with chronic illness [9, 13]. The patient-centered medical home (PCMH) model of care addresses this problem and improves care for the child with chronic illness by providing patient-centered, comprehensive, team-based, coordinated, and accessible care that is focused on quality and safety [14]. In the PCMH model, the primary care physician coordinates the comprehensive care of complex medical conditions while also addressing the patient's biopsychosocial issues. Optimal management of chronic illness through the PCMH includes collaboration with children, families, and the entire care team, commitment to evidence-based therapies, and the individualization of care to meet the needs of the individual [13]. Co-located care management by a social worker is an especially important component of care to children with chronic disease and a cornerstone of the PCMH. Care managers enhance the management of the patient by identifying barriers to care and providing connections to community resources [13, 15]. Using the population health principles of the PCMH, practices create disease registries that organize and track care and make sure evidence-based guidelines are followed. These registries can identify children who have missed appointments or who have had emergency room visits, alerting a care manager who can provide outreach to the patient and his or her family, which can improve outcomes for individuals with chronic illness.

Home and Community Settings

Home

A comprehensive understanding of the home environment allows providers to better care for the child with chronic illness. For example, indoor pollutants and allergens are known triggers for asthma and disproportionately affect urban minority youth [16]. Providers and care managers can identify these problems and seek modifications, which could involve asking a landlord to remove mold, seeking help from legal services when necessary and if available.

Comprehensive medical care and support services can be provided in the home and are most successful when individualized for the child and his or her caregivers [17]. Home is usually a nurturing environment that best allows for ongoing growth and development. Home care is expensive but potentially offsets higher health-care costs by decreasing hospital admission rates and length of hospitalization [18]. Home care increases caregiver satisfaction, decreases parental anxiety, and improves behavior in children with chronic illness [19]. Home-based medical care eases the transition at hospital discharge, which is a particularly vulnerable time for children and families [20].

Family members and caregivers are active participants in a child's care in the inpatient and outpatient setting, but it is at home that family life can provide structure and stability. Empowering families and caregivers with the knowledge and tools to actively participate in the management of the disease improves adherence and outcomes for children with chronic illness [13, 15]. The Yale Bright Bodies Weight Management Program provides a good example. This intensive lifestyle intervention was aimed at reducing obesity in intercity youth by engaging both children and their families [21]. Children and caregivers attended nutrition and behavior modification classes, while the children also engaged in supervised exercise. This family-based program lowered the children's BMI, improved body composition, and increased insulin sensitivity.

Implementations of evidence-based care plans can help families and caregivers become informed partners in care and follow through on recommendations given by healthcare providers. Asthma action plans are another example where family members and caregivers learn to recognize the symptoms and severity of an asthma exacerbation, initiate appropriate treatment, and identify when the child needs care in the clinic or hospital setting [9]. Caregivers and families can benefit from receiving anticipatory guidance about the struggles of caring for a child with chronic illness at various stages in a child's development [12]. Family structure and support systems play a critical role in the health of these children. Disparities or dysfunction within the family structure can interfere with care plans. Children in single-mother households and grandparent-only households have poorer

health outcomes when compared to children living in households with two biological parents [22]. Increased stress levels and decreased resources are likely contributors to this disparity.

Schools

Schools are an important care setting for children with chronic illness as most children spend nearly as much time at school as they do at home. School-based health programs can play an integral part in managing childhood chronic illness, allowing the child to pursue an education. Most publicly funded schools in the USA include some level of nursing services and care management, although services vary widely from system to system based on community needs and financial support [23]. Schools with more generous nurse-to-student ratios are associated with lower absenteeism rates and higher graduation rates [24]. School-based health centers provide primary care and mental health services to schools in high-risk communities [23]. Bringing health care to the school aims to decrease health-care disparities and improve the overall health of communities, including children with chronic disease. Embedded mental health services improve access for high-risk children and adolescents and are correlated with improved attendance, behavior, and test scores [25]. The connection between health and successful education makes school-based interventions strategic in improving health outcomes for children with chronic illness [16, 25, 26]. The Centers for Disease Control and Prevention (CDC) and the Association for Supervision and Curriculum Development (ASCD) have developed a framework for school-based health interventions called the Whole School, Whole Community, Whole Child (WSCC) model [25, 27]. This model of care aims to maximize limited resources to address health-related barriers to learning.

Community

The community in which one lives influences beliefs and attitudes about health, increases or decreases one's risk for certain health conditions, and may determine one's behavior [9, 28]. The condition of the community and its surrounding resources can have a dramatic impact on the health of children and their families. Improving the health of a community and those that live there requires more than simply embedding health services in the neighborhood. The social determinants of health that put individuals at increased risk of poor health outcomes must also be addressed. More than $200 billion is spent yearly in the USA on community development in low-income neighborhoods [28]. Community leaders and public health officials identify needs and decide which interventions are most likely to improve health in a particular community. Community level interventions aimed at improving the health of children with chronic illness are highly varied. Successful interventions that have decreased childhood obesity rates in high-risk communities include improving access to outdoor recreational facilities, installing sidewalks to improve walkability, and embedding community gardens and farmers' markets [29]. Several community level interventions reduce asthma exacerbations by promoting construction that reduces allergens and pollutants in public spaces and by conducting educational campaigns to promote flu vaccination [30]. Care managers provide a link to appropriate community-based resources that can both improve the child's health and provide support to families and caregivers [15]. Community-based youth development programs and support groups that focus on children with chronic illness can not only improve health outcomes now but help children develop strategies to succeed in the future as they transition to adulthood [31].

Medicaid and Financing

Chronic illnesses in childhood and adolescence contribute significantly to overall health-care costs in the USA. In 2007, $56 billion was spent on childhood asthma-related medical costs, lost schools and workdays, and early deaths [9, 32]. Children receive financing for health-care costs through several different avenues. In 2009, 50% of American children under the age of 18 had employer-sponsored insurance, 33% had public insurance, 4% had individual coverage, and 11% were uninsured [33]. Public insurance includes both Medicaid and the State Children's Health Insurance Plan (SCHIP), now known simply as the Children's Health Insurance Program (CHIP). Medicaid was established in 1965 and is jointly funded by the state and federal governments and managed by the states. In 2011, 48% of those enrolled in Medicaid were low and middle-income children. Established in 1997, CHIP is administered by the US Department of Health and Human Services and provides funds to states that cover uninsured children in families with incomes that are just above the level at which they would qualify for Medicaid. More than 80% of children enrolled in public health insurance are enrolled in Medicaid [34]. Public insurance plays an important role in addressing the health needs of the most vulnerable children in the USA. Children enrolled in public insurance are more likely to be economically disadvantaged and are more likely to have special health needs. Health outcomes for children are similar regardless of whether they have public or private insurance, as long as coverage is continuous [34, 35]. Gaps in insurance coverage, whether public or private, can adversely affect a child's access to quality health care. Children with gaps in health insurance coverage are more likely to delay necessary care and less likely to reliably fill prescriptions for recommended medications, compared to children with continuous

health coverage [35]. More than 80% of children with gaps in insurance coverage had working parents at the time of the insurance lapse. Children without insurance or with gaps in insurance are less likely to have a primary care physician and less likely to receive necessary medical care [36]. While these realities are problematic for all children in the USA, those with chronic illness are particularly at risk for poorer health outcomes when appropriate access to care is limited. The Affordable Care Act (ACA), which was implemented in 2010, includes provisions to improve the health of children and families in the USA by increasing access to quality-covered health care. The ACA expands Medicaid to those up to 138% of the federal poverty limit, creates a health insurance marketplace where families shop for plans, and allows young adults to remain on their parent's insurance plan until age 26 [33]. It also bars insurance companies from using pre-existing conditions as a means of denying coverage to individuals. The ACA provides a higher federal match for states that implement patient-centered medical homes for children with chronic illness, although most states have not implemented this provision [33]. While the future of the ACA is uncertain, it has definitely improved access to health care for children in the USA.

Implications for the Child

Chronic illness and frequent or prolonged hospitalizations can have a negative effect on a child's physical, cognitive, emotional, and psychological development. These problems can be mitigated by early recognition and appropriate support and intervention.

Growth and Development

Chronic illness in childhood can affect normal patterns of growth and development. Growth failure and decreased growth velocity have been linked to several chronic illnesses in childhood. For example, delayed skeletal maturation and delayed puberty in inflammatory bowel disease are well documented and may even be the presenting symptom in adolescents [37]. Poor absorption of nutrients and prolonged steroid use can further complicate growth and lead to a reduced adult height in individuals with inflammatory bowel disease. Growth failure is also commonly seen in childhood chronic kidney disease and is associated with increased mortality rates. While the mechanism is not well understood, it is likely due to abnormalities in the growth hormone – insulin-like growth factor axis [38]. Childhood obesity is associated with early pubertal onset and menarche in girls [39] although this same association has not been consistently shown in obese boys [40]. Adolescents with chronic illness often define themselves by their disease and can have difficulty developing their identity and forming a sense of confidence [41]. This can lead to difficulty connecting with healthy peers. Many adolescents with chronic illness report a higher rate of body dissatisfaction as they enter puberty. Health-care providers may not provide age-appropriate anticipatory guidance on puberty and sexuality as they are focused on managing the child's chronic illness, even though adolescents with chronic illness report higher rates of sexual intercourse and unsafe sexual practice compared to healthy peers [42]. It is important that providers normalize sexuality and provide age-appropriate anticipatory guidance about sexual development for all children, including those with chronic illness [43]. This includes counseling on puberty, sexual identity, safe sexual practices, sexually transmitted infections, and contraception.

Education

Chronic illness can negatively impact a child's education. Frequent outpatient visits and hospitalizations can interfere with school and cause children to fall behind compared to their peers. In 2013, there were 14 million missed school days due to asthma alone [10, 32]. Many chronic illnesses reduce academic achievement and hinder learning. Children with chronic illness may be subject to bullying and are more likely to report feeling unsafe at school which is associated with lower grades and increased absenteeism [25, 26]. Obesity is associated with poor academic performance, possibly due to the increased rates of bullying but also to high rates of psychosocial comorbidities such as depression and anxiety [44]. The association between asthma and poor academic achievement is well established [16, 25, 45]. Children with poorly controlled asthma perform worse on cognitive tasks, particularly those that test concentration and memory [16]. Uncontrolled nighttime symptoms likely contribute to this educational gap given the importance of uninterrupted sleep for the cognitive development of children. Mild cognitive delays, decreased academic achievement, and increased rates of absenteeism are also seen in patients with sickle cell disease [46]. Children with sickle cell disease may develop neurocognitive deficits due to both silent and overt cerebral infarcts.

Creating a safe and supportive educational environment as well as promoting healthy behaviors for all children, including those with chronic illness, improves academic achievement [25–27]. This is one of the primary aims of the Whole School, Whole Community, Whole Child (WSCC) educational model developed by the CDC and ASCD.

Family Role and Socialization

Parents and caregivers play a crucial role in the emotional development of children and adolescents with chronic illness [47]. Parents and caregivers can foster the child's independence by giving him or her increasing responsibility in the management of the disease, or they can become overprotective and interfere with the child's ability to develop autonomy. "Vulnerable child syndrome" is a phenomenon where parents and caregivers treat children with chronic illness differently than their other children, as they subconsciously perceive them as being more vulnerable [48]. This can hinder a child's emotional development and delay the ability to independently function. This failure to develop autonomy makes it difficult to transition to self-management and leads to poorer health outcomes. Providers should promote an encouraging family environment, which is associated with better adherence to medical treatment [49].

Psychological Consequences

Mood disorders accounted for over 100,000 child and adolescent hospitalizations in 2012 [11]. About 20% of children and adolescents with chronic illness report comorbid mental health conditions, which is twice that of the general pediatric population [50]. They are at increased risk of developing depression, anxiety, and post-traumatic stress disorder. Conversely, children with chronic illness and their families can be resilient and able to overcome adversity. The family's ability to cope with and manage the chronic illness is an important predictor of psychological outcomes for the child [51]. Factors associated with poor coping and increased risk of psychological comorbidities for the adolescent with chronic illness include dependence on others for daily activities, inability to engage in activities with peers, and social stigma [50]. Peer relationships are particularly important for the health and well-being of adolescents. Those who feel excluded from their peer group or who miss big events, such as prom or graduation, are at increased risk for poorer mental health outcomes. Adolescents with chronic illness have an increased risk of depression, low self-esteem, and suicidal ideation [41, 49, 51]. Obese and overweight children and adolescents are more likely to have low self-esteem and associated mental health conditions including depression and anxiety [44]. Signs of psychological distress include medical symptoms not explained by organic disease, nonadherence, poor educational achievement, or engagement in risky behavior including unsafe sexual practices and substance use [51]. Recognizing psychological distress can lead to interventions such as cognitive behavioral therapy, biofeedback, and guided imagery, all of which effectively improve psychological outcomes. Interventions should be aimed at a child's mental age rather than chronological age as these may not match [52].

Transition to Adulthood

Over 90% of children with chronic illness born in the 1990s are expected to survive into adulthood where they will continue to deal with the effects of the disease [53]. In 2002, the American Academy of Pediatrics, the American Academy of Family Physicians, the American College of Physicians, and the American Society of Internal Medicine developed a consensus statement on the transition to adult care [53, 54]. The statement highlighted the role of health-care professionals trained in transitions of care who are willing to assume responsibility for the patient's health care. For primary care, the patient may continue to see a familiar family physician who is trained to provide care to all ages or may transition from a general pediatrician to an adult primary care provider. For specialty care, the patient is likely to transition from pediatric to adult specialists. Other important components of a successful transition include an up-to-date medical record, a comprehensive transition plan in place by age 14, and continuous health-care coverage [54]. Young adults are at risk of a gap in insurance coverage as they transition to adulthood, a problem addressed by the Affordable Care Act which allows young adults to remain on their parents' health plan until the age of 26 [33].

The steady transition of disease management from the parent to the adolescent is important and lays the groundwork for adulthood and independence, where the patient is likely still dealing with the chronic disease. For example, childhood obesity persists into adulthood the majority of the time and is associated with type II diabetes, hypertension, hyperlipidemia, obstructive sleep apnea, orthopedic complications, nonalcoholic fatty liver disease, and cardiovascular complications [44, 55].

Young adults who had childhood chronic illness do well socially and are just as likely to get married and have children as healthy peers but have lower annual incomes and are less likely to graduate from college [52, 54, 56]. Children with developmental arrest due to the disease may not have the life skills needed to operate independently in a complex medical system and are at higher risk for nonadherence, poor health outcomes, and comorbid mental health conditions [52]. As these individuals transition from the pediatric medical system to the adult medical system, they are sometimes labeled as "difficult patients," which may further impede their care.

Conclusion

Traditional models of medical care were based on the identification and management of acute illness [13, 15, 57]. Over the last decades, there has been a shift in disease burden from acute to chronic illness. As the prevalence of chronic illness continues to increase, new models of care must be developed that meet the challenges of caring for children with chronic

illness and maximize their health potential [13, 58]. The patient-centered medical home switches the focus of care from the provider and health-care system to the individualized needs of the patient and population health. An improved health system will use the chronic care model and develop links between medical care, mental health, and community [58]. The primary goal of health care for children is to maximize their functional abilities and sense of well-being, their health-related quality of life, and their development into healthy and productive adults [50]. A functional health-care system will support this goal.

There is an urgent need for more research into the causes of the increased rate of chronic diseases in children [59]. The epidemiologic shift from childhood disease caused by congenital anomalies and neonatal problems to those increasingly related to obesity, asthma, and behavioral problems is likely related to a change in the social ecology of childhood including a more sedentary lifestyle, high-calorie drinks and foods, stress of modern life, exposure to toxins, and excessive multimedia use. Unless addressed, these factors will predispose these same children to adult diseases [60]. Prevention and treatment of childhood chronic disease will have a major impact on both individuals and the health of the population in the future.

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Special Population: Older Adults

25

Gregg A. Warshaw

Epidemiology of Chronic Disease in Older Adults

The ability of modern medical care to successfully treat acute infections, trauma, and other medical emergencies has allowed many Americans to live into old age, when the focus of medical treatment is now largely on the management of chronic illness. These medical problems are common among older adults and it is not unusual for individuals to simultaneously have several chronic illnesses. When treating older adults with chronic illness, the focus of treatment is seldom on cure but rather on slowing disease progression and limiting the resulting functional limitations.

Chronic conditions are more common in adults aged 65 years and over than in younger adults. Common chronic illnesses in older adults include hypertension, heart disease, dementia, arthritis, hearing and vision disorders, diabetes, stroke disease, and cancer [1]. Eighty-four percent of individuals aged 65 and over have one or more chronic illness and 62% have two or more [2]. For example, among older adults with hypertension, only 17% have hypertension alone, while the other 83% have at least one other chronic condition [2]. The burden of chronic illness is greater among older women due to their relative longevity compared to men. Age-specific rates of chronic illness are otherwise comparable among men and women [2]. Across all age groups, white populations have a slightly higher prevalence (46%) of chronic illness than black (37%) or other racial groups (32%). However, black Americans are 1.5 times as likely as whites to report impairment of activities of daily living. The prevalence of chronic illness is similar across all family income levels [2].

The burden of chronic illness on the individual, families, and society is significant. Chronic illnesses, specifically heart disease, cancer, stroke, chronic lung disease and pneumonia, diabetes, and Alzheimer's disease, are among the leading causes of death in US adults [3]. Living with chronic illness over many years can result in chronic pain, loss of function and independence, and increased reliance on family and friends for support. As the number of chronic conditions increases the prevalence of functional limitations rises. When surveyed, one-third of older adults report being in fair or poor health [4].

The cost of medical care for older adults with chronic illness is financed by Medicare, Medicaid, private insurance, and out-of-pocket expenditures. The impact of chronic illness on medical expenditures is best illustrated by the large portion of Medicare spending directed to adults with multiple chronic illnesses. Twenty-three percent of Medicare beneficiaries with five or more chronic conditions account for 68% of total Medicare spending. An example of a common complex of illnesses is an older adult with diabetes, hypertension, coronary heart disease, congestive heart failure, and kidney failure. Each year, older adults with such complexes of 5 or more chronic illnesses see, on average, 14 different physicians, make 37 physician office visits, and fill 50 prescriptions [5].

Characteristics and Considerations in Older Adults with Chronic Illness

The approach to the assessment and management of chronic illness in older adults requires the clinician to consider several distinctive factors. The key objectives of care for older adults with chronic health problems are (1) to help the individual maintain his or her quality of life, (2) to support relatives and other caregivers, and (3) to arrest or slow down the rate at which functional abilities are lost.

G.A. Warshaw (✉)
Departments of Family Medicine and Internal Medicine, Geriatrics Division, School of Medicine, University of North Carolina, Chapel Hill, NC, USA
e-mail: gregg_warshaw@med.unc.edu

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Function

Maintaining physical function and independence is particularly critical to chronically ill older adults who desire to live in their own homes. The patient's list of diagnoses is not as important as the measure of how illness and treatment affect function and quality of life. Questions such as "Can you reach the toilet in time?" and "Can you get to the grocery store to buy food?" are important in old age. In addition to medical treatments, the clinician needs to look to rehabilitation and social supports to improve function and maintain independence [6].

Standard measures of function (activities of daily living and instrumental activities of daily living) are valuable parts of the ongoing assessment of older adults with chronic illness (Table 25.1). Direct observation of function is best, although reports from family and caregivers are usually necessary unless the older adult is observed in his or her home.

Table 25.1 Activities of daily living

Self-care	
Bathing	Toileting
Dressing	Grooming
Transferring from bed to chair	Feeding oneself
Instrumental	
Using the telephone	Doing laundry
Preparing meals	Doing housework
Managing finances	Transportation independence
Mobility	
Walking from room to room	
Climbing a flight of stairs	
Walking outside	

Life Expectancy

Multiple chronic conditions and old age shorten life expectancy. Older patients by definition have fewer years ahead of them to benefit from aggressive management of chronic illness. The likelihood that a patient will benefit from a particular intervention is dependent on the amount of time available for effect. Estimating a patient's life expectancy can help guide a patient-centered care plan. Older adults' health and function are heterogeneous, and individualization is an essential part of assessment and treatment planning. Actuarial tables that provide mean life expectancy data for older adults can be helpful when considering treatment options (Table 25.2).

Table 25.2 Mean life expectancy

	Mean life expectancy (years)	
Current age	Men	Women
65	18	20
70	14	16
75	11	13
80	8	10
85	6	7
90	4	5

Adapted from Actuarial Life Table [Internet]. Ssa.gov. 2016 [cited 4 October 2016]. Available from: https://www.ssa.gov/oact/STATS/table4c6.html

Prognosis and Diversity

Careful consideration of prognosis is particularly important for clinical decision-making in older patients [7]. Clinical practice guidelines increasingly incorporate life expectancy and function as a central factor in weighing the benefits and the burdens of tests and treatments. For example, the American Geriatrics Society recommends a target goal for glycosylated hemoglobin (HbA1c) in older adults with diabetes of 7.5–8%, which is more relaxed than the goal in younger adults. A HbA1c goal of 7–7.5% may be appropriate in healthy older adults with few comorbidities and good functional status. Higher HbA1c targets of 8–9% are appropriate for older adults with multiple comorbidities, poor health, and limited life expectancy. There is potential harm in lowering HbA1c to less than 6.5% in older adults with type 2 diabetes [8].

Prognostic indices are tools for moving beyond arbitrary age-based cutoffs in clinical decision-making for older adults [9]. For example, *ePrognosis* is a repository of published geriatric prognostic indices where clinicians can find evidence-based information on patients' prognosis (http://eprognosis.ucsf.edu/). *ePrognosis* is also available as a smartphone application to assist with point-of-care decisions regarding colon or breast cancer screening in older patients. The application utilizes the patient's age, gender, weight, height, self-assessment of health, current or previous tobacco use, presence or absence of lung disease, cancer, congestive heart failure, diabetes, cognitive difficulty, hospitalization in the past 12 months, and physical function to provide an estimate of the potential risk/benefit of screening for colon or breast cancer.

Frailty and Geriatric Syndromes

Many older adults are vulnerable to loss of function from the stress of disease as a result of a decrease in physiologic reserve. This susceptibility can be partially attenuated through exercise and fitness, but many older adults, especially after age 80, have some degree of frailty. Frailty is now understood to be clinical syndrome of dysregulation of energetics and

Table 25.3 Geriatric syndromes

Delirium
Dementia
Falls
Gait disturbance
Osteoporosis
Dizziness
Incontinence
Hearing loss
Weight loss
Disturbance of appetite, feeding, swallowing
Sleep disturbance
Frailty
Pressure ulcers

multiple physiologic systems [10]. The frailty syndrome is present when an individual presents with an array of symptoms, including weakness, slowed walking speed, low physical activity, low energy, and weight loss. Frailty is estimated to have a prevalence of 7% in community-living older adults, with a range of 3.2% among those aged 65–70 years to 23% among people aged 90 years or older [10]. Although frailty is less common than many chronic illnesses, frail older adults commonly have one or more chronic illnesses [10]. In addition, poor nutrition, which may be associated with chronic disease, is common in frailty.

The accumulation of multiple chronic diseases, especially in the frail patient, results in additional syndromes that are multifactorial in etiology and occur from a combination of frailty, underlying medical problems, and medical treatments. Common syndromes include falls, incontinence, and confusion, which are conditions that influence function, independence, and the ability to engage in self-care (Table 25.3).

Case finding for common geriatric syndromes can be challenging in a busy primary care office but is an important part of chronic disease management. Primary care physicians may overlook these diagnoses or may not know how to effectively intervene [11]. A symptom review checklist tailored to the care of older adults can be added to the electronic health record to ensure that key case-finding questions are not overlooked (Table 25.4).

Using the patient-centered medical home model, the RAND/UCLA Assessing Care of Vulnerable Elders project documented that office staff case finding combined with focused assessment tools increases the identification and assessment of patients with falls, urinary incontinence, and dementia [11]. Office staff used simple questions to trigger a brief assessment by the clinical provider (Table 25.5).

Table 25.4 Symptom review

Enter **N** for no, **Y** for yes, **C** for chronic		
Informant	Patient	
_____	_____	Anorexia
_____	_____	Fatigue
_____	_____	Weight loss
_____	_____	Headache
_____	_____	Insomnia
_____	_____	Visual impairment
_____	_____	Transient visual disturbance
_____	_____	Hearing impairment
_____	_____	Smelling difficulties
_____	_____	Dental/denture discomfort
_____	_____	Chewing/swallowing difficulties
_____	_____	Chest discomfort with exertion
_____	_____	Orthopnea
_____	_____	Edema
_____	_____	Claudication
_____	_____	Syncope
_____	_____	Abdominal pain
_____	_____	Constipation
_____	_____	Urinary frequency/urgency
_____	_____	Nocturia
_____	_____	Incontinence
_____	_____	Joint pain/swelling
_____	_____	Dizziness/unsteadiness
_____	_____	Falls
_____	_____	Focal weakness/sensory loss
_____	_____	Forgetfulness
_____	_____	Disruptive behavior/wandering
_____	_____	Hallucinations
_____	_____	Delusions

Iatrogenic Illness

Diagnostic and treatment interventions in older adults frequently carry a risk of iatrogenic complications which include geriatric syndromes such as falls from overtreatment of hypertension, delirium precipitated by hospitalization, and acute renal injury from radiologic contrast agents. The risk-benefit ratio of interventions is narrower in an older population, and diagnostic tests and treatments should be carefully evaluated for their potential benefit and risk [12]. Adverse drug effects from prescribed and over-the-counter medications are a common source of complications.

Medications/Polypharmacy

Over the past 20 years, the use of prescription medications to prevent the complications or treat the symptoms of chronic illnesses has expanded rapidly. Many of these pharmacological

Table 25.5 Office case-finding questions for falls, urinary incontinence, dementia, and polypharmacy (positive responses trigger further assessment)

New patient: "During the past 12 months"
Established patient: "Since your last visit here"
Falls
Fallen two or more times?
Fallen and hurt yourself or needed to see a doctor because of the fall?
Been afraid that you would fall because of balance or walking problems?
Urinary incontinence
Had a problem with urinary incontinence or your bladder that is bothersome enough that you like to know more about how it could be treated?
Dementia
Ask the patient to listen and repeat the words "ball, flag, and 'tree." In 1–3 min, ask the patient to recall these words. *Or* ask a surrogate if the patient has recently had more trouble than in the past with memory for day-to-day happenings around the house, such as remembering where he/she put things, recalling recent events, forgetting what you told him/her or what she/he told you, remembering plans, appointments, or phone calls
Polypharmacy
Use more than 12 doses of any medications per day
Used more than nine different medications at one time

Adapted from ACOVE Materials | POGOe – Portal of Geriatrics Online Education [Internet]. Pogoe.org. 2016 [cited 3 October 2016]. Available from: https://www.pogoe.org/search/site/acove

advances have had a measurable positive effect on the progression of chronic illness or reduced associated symptoms. The addition of outpatient prescription medication coverage by Medicare is a direct result of the central role that drugs now play in the management of chronic illnesses.

Although they are only 13% of the population, adults aged 65 years and over utilize a third of all prescription drugs [13]. Effective medication use requires prescribing the correct medication, at the correct dosage, for the appropriate condition, for a patient where the benefits outweigh the risks. Evidence-based chronic disease-specific management guidelines include guidance on use of medications. An excellent site for accessing these guidelines is maintained by the Agency for Healthcare Research and Quality (www.guidelines.gov). These guidelines are usually developed from research in patients under age 65 years without comorbidities so their application to older adults with multiple chronic illnesses requires an individualized approach [14]. The use of multiple prescription medications increases the risk for adverse drug-drug or drug-disease interactions. Adverse drug events (ADEs) are associated with the use of 9 or more prescription medications or the ingestion of 12 or more medication doses per day and are the primary cause of more than 10% of hospital admissions in older adults [13].

Health Literacy

Health literacy is the ability of individuals to understand health information and related skills for successful health communication. It requires providers to use plain language and understand the cultural background of the patient. Older adults, especially those aged 80 or older, are at high risk for limited health literacy which can be compounded by lower income level, limited education, minority population status, and limited English proficiency. This limited health literacy further enhances health risks in an already at-risk fragile population [15].

Older adults may experience cognitive decline related to age-associated memory loss or dementia, which affects their ability to comprehend medical information and follow treatment regimens. Even in a well-educated affluent population of older Americans, 30% have poor comprehension of written health information, and only 50% could accurately answer questions from a Medicaid application [16]. People who have limited or low health literacy are not illiterate, and virtually everyone has limited health literacy at some point, regardless of education or reading level. When confronted with new information about a serious illness, it is difficult for patients to comprehend and retain what they are being told. The health system itself contributes to health illiteracy with the trend toward earlier discharges, more home health, and complex medication regimens. Older adults with low health literacy have more preventable hospital visits and admissions. Limited literacy can affect the health practices of older people including skipping preventive measures such as mammograms and flu shots [17].

Social Support

Family and other caregivers are an important part of the care team for most patients with chronic illness, and this is certainly true for older adults. The health-care system is challenging to navigate, especially if you are chronically ill and have limited mobility, vision or hearing loss, language or cultural barriers, or low health literacy. Marital status and living arrangements among older men and women varies with longevity. Older women are more likely to be widowed or living alone, requiring support from their children, other relatives, or caregivers. In 2014, a larger proportion of men aged 65 years and older (72%) than women (46%) were married and living with a spouse, a gender difference that increases with aging. At age 85 years and older, 57% of men lived with a spouse, whereas only 16% of women did. About 11% of men ≥65 years old were widowed, versus 35% of women in the same age group. At the age of 85 years and older, 30% of male householders and 56% of female

householders lived alone [4]. Family and other caregivers can greatly enhance the ability of older adults to live successfully with chronic illness and in most cases should be considered critical members of the care team (Table 25.6).

Elder Abuse

Elder abuse includes physical, psychological, verbal, or sexual abuse, financial exploitation of money or property, neglect, or the failure of a designated caregiver to meet the needs of a dependent older person. Some form of elder abuse is experienced by 10% of the older population [18]. In the context of managing chronic illness clinicians need to be especially alert for signs of neglect which can be intentional, or unintentional when the caregiver is simply overwhelmed. Assessment includes the patient's hygiene, skin care, evidence of medication adherence, weight, hydration, and family/caregiver understanding of care plan.

If neglect is identified, and the family/caregivers are receptive to improving the care, providers can arrange for in-home assistance, respite care or day care, an alternative living situation, and other community resources, such as the local chapter of the Alzheimer's Association. If intentional neglect or exploitation is identified, or if the caregivers are not responsive to suggestions to improve the care environment, then referral to local Adult Protective Services is indicated (http://www.napsa-now.org/get-help/help-in-your-area/).

Decision Capacity and Advance Directives

Caring for older adults with chronic illness can involve complex treatment regimens and requires patients to understand and follow instructions. It is not uncommon for clinicians to be unaware of their patients' early to mid-stage progressive dementias. Decision-making capacity should be routinely assessed in older adults, particularly in those aged 75 years or older. Decision-making capacity can be assessed by members of the patient's care team. It is not a legal determination, nor does it suggest the need for guardianship or conservatorship, which are legal determinations decided by a court. The capacity to make medical care decisions can vary over time based on the stability of the patient's underlying illness, and patients may be able to make informed decisions about some topics but need assistance with more complex questions. In most cases, decision-making capacity can be accurately assessed by the primary care clinician. Assessment can include exploring the patient's understanding of his/her medical problems, treatment plan and expected outcomes, and consequences of not accepting a treatment [19, 20].

Advance directives include living wills, which provide information about an individual's end-of-life care preferences, and Durable Powers of Attorney for Health Care, which designate someone to be an individual's legal decision-maker should that person lose decisional capacity [21]. Durable Power of Attorney (DPOA) documents can vary by category of decision-making. Some designate a proxy for medical decisions, some identify a surrogate for financial decisions, and some establish a surrogate for both financial and medical decisions. Some DPOA documents give surrogates the power to make medical decisions even if the patient has not lost decisional capacity. Because of these differences, health-care providers should review and understand the intent of their patients' DPOA documents.

Table 25.6 Roles for family caregivers in the care of older adults with chronic illnesses

Support living as long as possible, in a familiar environment, such as the patient's home
Provide substituted support for impaired activities of daily living
Ensure access to appropriate preventive care
Facilitate early diagnosis and treatment of new health problems
Monitor medication use, help coordinate, and ensure adherence
Provide or arrange, when necessary, supervision of finances
With cognitive impairment, learn skills to avoid precipitating behavioral symptoms
Monitor safety of automobile driving
Advocate for safe and appropriate care, especially in the hospital

Adapted from Sloane et al. [6]

Rehabilitation and Exercise

The application of a rehabilitation approach is an essential part of the management of older adults with chronic illnesses. The focus is on the older adult's functional independence, whether it be lost function that may be restored (restorative therapy) or remaining function that needs to be modified and strengthened to accommodate other disability (maintenance therapy). The assessment and goal setting processes need to be individualized, capitalize on the patient's strengths and abilities, and be designed to restore or make adaptive change to foster independence. The family and social network should be involved, and assessment should be ongoing, with goals regularly reassessed [22].

Rehabilitation can occur in a variety of settings and can range from care provided by a single discipline to that offered by many disciplines. The site (acute inpatient rehabilitation hospital, skilled nursing facility, home care, or outpatient) and number of disciplines involved depend upon the needs and resources of the patient. An inter-professional model is preferred in most cases.

Parkinson's disease is an example of the successful application of rehabilitation approaches in the care of chronic illness in older adults. Rehabilitation has not been shown to

retard the progression of Parkinson's disease; however, rehabilitation efforts can lessen the impact of the illness by helping an individual maximize function and remain independent as long as possible [23, 24]. Therapy is usually provided in the outpatient setting by physical, occupational, and speech therapists. The *physical therapist (PT)* will focus on body alignment, gait, and transferring. A program of regular exercises can improve or maintain strength and range of motion as well as prevent contractures. Group exercise programs also help prevent the social isolation common in patients with Parkinson's disease. If needed for stability, the PT can prescribe the appropriate assistive device, usually a front-wheeled walker. The *occupational therapist (OT)* will focus on the patient's independence in performing ADLs. To simplify dressing routines, the OT may recommend Velcro closures or zippers and over-the-head shirts rather than buttons. Environmental aids such as grab rails in the bathtub and near the toilet, a raised toilet seat, and raising the back of chairs by 1–3 in. to facilitate rising from a chair are also useful. The *speech pathologist* can help with communication and swallowing. Hypokinetic dysarthria is common in Parkinson's disease, and therapeutic efforts designed to improve respiration by teaching the patient diaphragmatic breathing exercises can improve the volume of sound and the number of words spoken per breath. Parkinson's disease is associated with swallowing difficultyand individualized swallowing and stimulation techniques taught by a speech pathologist may be beneficial.

Palliative Care

Older adults frequently die of protracted chronic diseases, with multiple coexisting problems, dependency on others, and heavy personal care needs, which are met mostly by family members. Family members and clinicians face difficult decisions about the use or discontinuation of life-prolonging treatments [25]. Quality of life during the dying process is often poor. For many older adults, dying is characterized by inadequately treated physical symptoms and poor communication among clinicians, patients, and families.

Although older adults usually spend most of their final months at home, their deaths frequently occur in the hospital or nursing home. The location of death varies from one part of the country to another. For example in 2011, in Portland, Oregon, 20% of adult deaths occur in hospitals, but in New York City more than 46% occur in acute care hospitals [26]. Availability of community support for the dying may contribute to this variation. Also, availability of social support also accounts for these differing patterns. The need for paid caregivers or institutionalization in the last months of life is higher among poor individuals and women. Similarly, older adults suffering from cognitive impairment and dementia are much more likely than cognitively intact individuals to spend their last days in a nursing home.

In one study of community-living adults aged 80 years and older, the subjects frequently overestimated their chances of survival during their last 6 months of life. Patients who died within 1 year of study enrollment had significant functional impairment in activities of daily living (ADLs) and expressed strong preferences for no resuscitation attempts and for comfort care. The number of patients reporting severe pain increased toward the end of life, with one in three reporting severe pain within 3 months of death [27]. In a study of nursing home residents with advanced dementia, pneumonia, eating problems, and fevers were factors most associated with 6-month mortality. Patients in the study commonly experienced pain and dyspnea, with prevalence of these symptoms comparable to those of dying cancer patients. Patients with advanced dementia were underrecognized to be at high risk of death and received suboptimal palliative care [28].

The ethnic, cultural, and religious heritage of the patient and family can influence their responses to serious illness, desire for aggressive care, death, grief, and mourning. It is important to remember that not all patients and families from a particular background will respond and make choices in a similar manner. A useful way to explore this topic is to ask "Is there anything about your culture or your beliefs that would be helpful for me to know as we plan together for the future?" [25]. Clinicians should talk with their older patients with chronic illnesses early about their preferences and provide better symptom control and palliative measures at the end of life.

Integration of Long-Term Services and Supports

Long-term services and supports (LTSS) include health and personal services provided to adults with chronic illness over an extended period of time. It is estimated that 60% of older adults with functional limitations receive some LTSS, such as personal care or assistance with household chores [29]. Families and friends provide most of this care with less than 20% provided by formal, paid caregivers [30]. The availability of community-based resources to support older adults and their caregivers varies widely throughout the United States. In addition, the local funding to support these services for low-income adults is variable. Table 25.7 lists examples of the array of community resources that may be available to support older adults with chronic illnesses.

Care management integrates LTSS and medical care and is key to achieving effective patient care. It can be challenging to successfully integrate LTSS with medical treatment but when accomplished improves outcomes and reduces

Table 25.7 Examples of community resources for older adults with chronic illness

Adult protective services
Area agencies on aging/county departments of aging
Assisted living facilities
Care management services
Continuing care retirement communities
Dental care clinics
Disease-specific family and patient support groups
Driving evaluations
Family care homes/congregate living
Geriatric assessment centers
Home health-care providers
Home-delivered meals
Home modification/repair programs
Hospice providers
Legal aid
Medicare/Medicaid assistance
Mental health resources
Nursing homes
Ombudsman programs
Personal emergency response systems
Prescription assistance programs
Senior centers
Social service agencies
Tax preparation assistance
Transportation services
Veteran services
Volunteer opportunities
Wellness programs

overall costs. Statutory and regulatory reforms affecting financing and the poorly coordinated nature of the service delivery system are needed to remove barriers that make integration difficult [31].

A growing body of evidence suggests that addressing older adult's functional limitations and need for social services can impact their physical health and health-care costs as much as medical interventions. Lowering costs and improving outcomes for high-need, high-cost individuals requires a combination of strategies that address psychosocial and medical care needs in an integrated manner. Health-care payment and delivery reform and innovation are providing incentives for health plans and other organizations assuming financial risk to target high-value interventions to reduce health-care spending. Integrating medical and LTSS meets several goals, listed in Table 25.8 [31].

Dual-Eligible Beneficiaries

The Affordable Care Act of 2010 (ACA) includes several provisions related to the cost and quality of the care received by dually eligible Medicare and Medicaid beneficiaries. The "dual eligibles" are low-income older adults and younger persons with significant disabilities. More than nine million Medicare beneficiaries are also enrolled in the Medicaid program. Sixty percent are aged 65 years and older and 40% are under age 65 [32]. Among the participants in Medicare and Medicaid, the dual-eligible population includes many recipients who have the lowest incomes and highest chronic disease burden. It is recognized that providing care for the dual-eligible population is an expensive component of both the Medicaid and Medicare budgets. The "duals" comprise only 15% of total Medicaid enrollment yet represent 39% of annual Medicaid expenditures. Similarly for Medicare, duals represent 21% of Medicare enrollees but 36% of Medicare expenditures [33]. In 2007, Medicare, Medicaid, supplemental insurance, and out-of-pocket expenses averaged $28,500 per dual-eligible beneficiary, which is nearly twice as much as for other Medicare beneficiaries [34]. Since the costs of Medicaid are shared between the federal government and the states, Congress and state legislatures are seeking more effective and less costly approaches to caring for the "duals" population.

Table 25.8 Goals of integrating medical and long-term services and supports

Create a seamless experience for the individual
Provide a higher level of support to enable the individual to remain in their home and in the community
Support and build on the care that families already provide
Avoid unnecessary nursing home and hospital admissions
Enable people discharged from the hospital to stabilize in the home and community
Reduce medical costs associated with high-risk individuals
Attain better health and quality of life outcomes

Adapted from Windh et al. [31]

In response to the challenges facing the dual-eligible population, the ACA established the Federal Coordinated Health Care Office (FCHCO or Duals Office). Some of the goals of this small office are [35]:

- Simplifying the processes for dual-eligible beneficiaries to access the items and services they are entitled to under the Medicare and Medicaid programs
- Increasing dual-eligible beneficiaries' understanding of and satisfaction with coverage under the Medicare and Medicaid programs
- Eliminating regulatory conflicts between rules under the Medicare and Medicaid programs
- Improving care continuity and ensuring safe and effective care transitions for dual-eligible beneficiaries
- Eliminating cost shifting between the Medicare and Medicaid program and among related health-care providers

In 2011, the Duals Office began the Medicare-Medicaid financial alignment demonstration. The program allows state Medicaid offices to develop innovative approaches to improve the coordination of care for the dual-eligible population, while adding efficiencies and incentives that will reduce the cost of care. Adults with full Medicaid and Medicare benefits can participate in these demonstration projects, although each state can choose whether to include dual-eligible adults over 65 years old and may limit participation by geographic area. The plans in most states are implemented by contracts with private managed care insurance companies. As of June 2016, over 370,000 beneficiaries who are dually eligible for Medicare and Medicaid were enrolled and receiving services from health plans in nine states with capitated financial alignment demonstrations [36].

Models of Care for Older Adults

Over the past 20 years, a wide range of care models directed at providing improved quality of care at lower cost to older adults with multiple chronic illnesses have been developed and tested in a variety of settings (Table 25.9). Many of these models have a strong evidence base but have not yet been widely disseminated. Although these care models are developed for older adults with chronic illness, most are applicable to adults of any age with multiple chronic illnesses. A few examples are briefly described below and some are more fully discussed in other chapters of this book.

Table 25.9 Examples of evidence-based geriatrics models of care

Hospital based
Acute Care for Elders (ACE) Units
Hospital Elder Life Program (HELP)
The Nurses Improving Care for Hospitalized Elders (NICHE) program
Transitions of care
Project Boost: a comprehensive program to improve discharge coordination
Transitional Care Model (Naylor)
Care Transitions Intervention (Coleman)
Outpatient-based models
The Geriatric Resources for Assessment and Care of Elders (GRACE) model
"Guided Care" for people with complex health needs
Chronic Disease Self-Management
Patient-centered medical home
Hospital at Home
Home-based primary care
Outpatient geriatric evaluation and management
Collaborative care for older adults with Alzheimer's disease
Nursing home models
Optum Care Plus: in place clinical delivery for nursing home residents
Interventions to Reduce Acute Care Transfers (INTERACT)
Community-based models
Program of All-Inclusive Care for the Elderly (PACE)

Inpatient

Two characteristics of acutely ill older adults are diminished physiologic reserve and a decreased capacity to adapt to unfamiliar surroundings. When admitted to the hospital older adults with an acute illness in the context of preexisting chronic illnesses are at high risk for iatrogenic complications and functional decline.

The *Hospital Elder Life Program (HELP)* is a patient-centered, multidisciplinary integrated model of care. Developed in 1993, the HELP program is present in more than 200 hospitals [37]. The program goals include maintenance of cognition (prevent delirium) and function during the hospitalization, assistance with the transition back home, and reduction of unplanned readmissions. Patients aged 70 years and older are screened at the time of admission for program eligibility. Interventions target the older patient's orientation, sleep, function, hydration, nutrition, and susceptibility for iatrogenic problems such as nosocomial infections, hypoxia, and poorly managed pain. The intervention team includes a master's level nurse with geriatrics experience, a program coordinator, a geriatrician, other hospital professional, and lay volunteers. Volunteers with 32 h of training are a unique aspect of this program and extend the efforts of the professional staff by providing patient support at the bedside three times per day, 7 days a week. Although trained not to interfere with the medical treatment plan, volunteers provide socialization, orientation, family support, and assistance with sensory loss, early mobilization, and feeding. HELP has been shown to reduce the development of delirium, reduce falls, and reduce the length of hospitalization, while providing direct savings to hospitals, with more substantial savings in capitated systems across the continuum of care [38].

Acute Care for Elders (ACE) programs were developed in the early 1990s and created hospital units for at-risk older adults with acute illness in the context of preexisting chronic illness. Currently, as many as 200 US hospitals have these units which are designed to be safe for functionally impaired older adults, promote independence, and are staffed by interdisciplinary teams with expertise in the care of frail older adults with chronic illnesses [39]. The ACE programs create an inpatient experience for older adults that is similar to the best aspects of a children's hospital's approach to providing care to young patients. The key components of the ACE unit include nurse-driven geriatric care protocols and a team approach to preventing iatrogenic complications with a spe-

cial emphasis on reducing delirium. A 2009 meta-analysis of the numerous outcome studies measuring the impact of ACE units demonstrated improved functional performance at hospital discharge, reduced hospital length of stay, and an increased likelihood of returning to live at home [40]. Recognizing that a high percentage of hospitalized patients are older adults and not all can be located in one unit, roving ACE consult teams and ACE concepts integrated into the electronic health record are now being implemented and evaluated [41].

Hospital at Home programs are developed to avoid the risks and expenses of hospitalization for older adults with a care model that provides hospital-like patient evaluation and treatment directly in the patient's home. These programs allow early discharge or avoidance of hospitalization in the first place, providing inpatient-level nursing and medical services in a patient's home. This model requires a clear diagnosis and a home environment appropriate for treatment and has been applied successfully for the treatment of community acquired infections, exacerbations of congestive heart failure, deep venous thrombosis, dehydration, and other problems that traditionally have required hospitalization. Hospital at Home has positively impacted functional outcomes, patient and family satisfaction, and overall cost [42–44]. Many of the larger studies were conducted in capitated payment systems which are more suited for such a program than Medicare's traditional fee-for-service payment model.

Care Transitions

Improving the transition of older adults recovering from an acute illness from the hospital to home or other post-acute settings (assisted living, nursing home, inpatient rehabilitation, or long-term acute care) is the focus of a number of geriatrics care models [45–47]. The introduction of Medicare payment penalties for hospitals with excessive recidivism has led to more investment in these models of care. Key components of these models include effective communication between care settings, patient/caregiver education and engagement in the transition, medication reconciliation across settings, and the involvement of nurses and social workers to provide continuity between the hospital and the next care setting. Measures of quality in care transitions include readmission rates and timeliness of follow-up visits with home-health teams and the primary care physician. This subject is addressed in more detail elsewhere in this book.

Nursing Homes

Frequent transfers of older adults with acute and chronic illnesses from the nursing home to the hospital can result in poor care and high costs. Interventions to Reduce Acute Care Transfers (INTERACT) is a quality improvement program widely used in US nursing homes and recognizes the critical role of direct care providers and nursing assistants. Developed with funding from the Centers for Medicare and Medicaid Services [48], INTERACT is disseminated through a tool kit and training materials available online at no cost (http://interact.fau.edu). INTERACT is based on core quality improvement principles with these objectives: (1) early identification of patient symptoms to avoid acute transfer, (2) management protocols for treatment of acute or chronic illness in the nursing home when appropriate, (3) advanced care planning and goal setting, (4) the availability of palliative care, and (5) improved communication within the nursing home staff, with the older adults and their families, and with hospitals. INTERACT has been reported to reduce hospitalization from the nursing home by 17% with an average 6-month implementation cost of $7700 per nursing home and projected savings to Medicare of $125,000 per year per 100-bed nursing home [48].

Optum Care Plus (previously known as Evercare) is a well-established model of care created by UnitedHealthcare that focuses on the provision of enhanced primary care for older adults with multiple chronic problems who live in nursing homes [44]. Funded through a variety of mechanisms, Optum spread as part of the Special Needs Plans (SNPs) authorized in 2003 as part of the Medicare Modernization Act. SNP focused on developing capitated Medicare programs for nursing home residents that reduce the unnecessary hospitalization of nursing home residents for medical problems that could be safely managed in the nursing home setting. The key component of the Optum program is the provision of a dedicated nurse practitioner in the nursing home who collaborates with the nursing home staff and the patient's primary care physician. By reducing transfers to hospitals by 45–64% [49], Optum is able to support the nurse practitioner salaries, enhance payment to nursing homes to care for patients who develop acute or chronic illness, and incentivize physicians to increase the intensity of their medical care. This shift in care from emergency rooms and hospitals to the nursing home has not compromised patient outcomes and is currently providing enhanced primary care to more than 38,000 nursing home residents [50]. There is more to read on nursing homes in other parts of this textbook.

Outpatient

The *Geriatric Resources for Assessment and Care of Elders (GRACE)* model applies the principles of team collaborative care to manage complex older adults in the outpatient setting. Every patient is assigned a support team composed of a nurse practitioner and social worker who work closely with the patient, caregiver, and patient's primary care physician.

The support team performs an in-home geriatric assessment of each patient and develops an individualized care plan, with input from a larger interdisciplinary team that includes a geriatrician, pharmacist, mental health professional, and community resource expert. The care plan is carried out in collaboration with the primary care physician and provides ongoing care coordination with proactive transitional care and integration of new treatments or medications into the care plan if the patient is admitted to the hospital [51]. GRACE patients also benefit from evidence-based care protocols for evaluation and management of geriatric conditions, an integrated EMR for documentation and communication with physicians, a web-based care management tracking tool for ensuring care plan implementation, home-based and proactive care management with regular patient contacts, and integration with pharmacy, mental health, and community-based social services. In a randomized controlled trial, GRACE improved quality of care and reduced acute care utilization among a high-risk group [52]. Several successful replications studies have been published [53]. Though financial outcomes vary based on payment models, reductions in emergency room use, hospitalizations, and recidivism create net gains for health systems that cover the costs of the GRACE program while improving value and quality.

Home-based primary care (HBPC) is the use of house calls to manage chronic and acute illness in patients who have difficulty leaving home, a revival of a common approach for delivering primary care. HBPC was developed in the US Department of Veterans Affairs (VA) more than three decades ago [54]. While the details vary across the many different VA medical centers, programs includes an interdisciplinary team that provides care in the home to veterans with complex needs for whom clinic-based care is difficult due to function or disease. The VA model has expanded over time to include mental health services and to facilitate collaboration with other services. In other environments, HBPC is based on elements of programs designed for people who are eligible for both Medicaid and Medicare, home and community-based LTSS programs, and hospital supported physician house call programs. HBPC is the subject of a major Medicare demonstration project [55] and is offered by a number of public and private health systems [56]. Potential benefits of HBPC include the following: (1) increased access to care for people who have difficulty traveling to outpatient medical offices or for whom going to a medical office is contraindicated; (2) better understanding of patients' environments, needs, and constraints that can improve care and ultimately outcomes; (3) decreased hospitalizations and urgent care use when acute incidents are prevented or addressed in the home; (4) potential for prevention or slowing of functional and cognitive decline; (5) better support for and reduced burden on family caregivers; and (6) increased satisfaction of patients and providers. HBPC reduces use of inpatient care and other health services, reduces costs, and improves patient and caregiver experience [57].

Collaborative care for older adults with Alzheimer's disease is a team-based model to improve the outpatient management of patients with this challenging illness. Older adults with Alzheimer's disease (AD) have three times as many hospital stays as others their age and are high healthcare utilizers, which results in rapidly increasing costs in this expanding population of patients. In 2014, the Medicare and Medicaid cost for Alzheimer's disease was $150 billion [58]. Most AD patients and their families face a system of care that is poorly coordinated and staffed by busy practitioners with limited time and expertise. Team care models to support primary care providers are being tested to improve the care of this high-risk population. In one study, care management by an interdisciplinary team led by an advanced practice nurse worked with the patient's family caregiver and integrated care within a primary care setting. The team used standard protocols to initiate treatment and identify, monitor, and treat behavioral and psychological symptoms of dementia, stressing nonpharmacological management. Collaborative care resulted in significant improvement in the quality of care and in behavioral and psychological symptoms of dementia among primary care patients, without significantly increasing the use of antipsychotics or sedative-hypnotics [59]. In 2013, the Centers for Medicare and Medicaid Services Innovation Center initiated a demonstration of a similar model for 1000 patients in Los Angeles [60].

The *Program of All-Inclusive Care for the Elderly (PACE)* is a successful example of an integrated program that brings together Medicare and Medicaid benefits into one delivery system of care for older adults with chronic illness. Dual-eligible beneficiaries are the majority of enrollees in these programs. As of February 2014, there are 100 PACE programs in 31 states, caring for about 40,000 adults [61]. PACE programs tend to be small and personal, serving nursing home-eligible individuals 55 years of age or older who live in the community served by the PACE organization. Individuals managed within these programs are primarily community-dwelling but also include participants who transition to custodial care in nursing facilities. PACE provides coverage for prescription drugs, doctor care, transportation, home care, checkups, hospital visits, and nursing home stays when necessary. Interdisciplinary team-based care directs this comprehensive medical and social delivery program which offers adult day health center services, transportation, and in-home and referral services.

Most PACE programs employ staff providers though some use community physicians, often with PACE advance practice nurses assisting. Care plans are reassessed every 6 months.

PACE programs are capitated, and reimbursement rates are tied to a frailty adjuster based on limitation in activities of daily living. The funding for PACE programs must cover all of the person's health and social needs. PACE plans negotiate a Medicaid rate with their state Medicaid organization and must provide services through a contracted network of collaborating agencies. On average, Medicare and Medicaid pay PACE providers $76,728 a person per year, about $5500 less than the average cost of a nursing home [61].

CMS has evaluated PACE programs and found that they have positive sustainable outcomes for reduced hospitalizations, improved health status and quality of life, and lower mortality rates compared to similar non-PACE cohorts [32]. Recently, Congress has authorized PACE programs to enroll adults under age 55 years, and CMS has opened the PACE program to for-profit sponsors. There is more to read on the PACE program in the chapter on Community Alternatives to Care.

Summary

The American Geriatrics Society (AGS) has prepared a set of guiding principles for the clinical management for older adults with multiple chronic illnesses [62]:

- Maintain an emphasis on restoring and maintaining physical function to maximize independence.
- Allow sufficient time to recover from acute or chronic illness. Older adults are at particularly high risk when discharged from the hospital; ensure adequate support and medical follow-up in the home or subacute setting.
- Assess, strengthen, and support the older person's family and social support system.
- Broaden the health-care team (collaborate with office- and community-based health-care team members).
- Maintain a community orientation, know about the available resources to support older adults, and maintain close ties with a social worker.
- Expand the approach to assessment to include functional problems, e.g., falls, incontinence, and memory loss.
- Apply the best evidence to the care of medical problems, recognizing the limited evidence to guide the care of the very old with multiple chronic diseases.
- Use diagnostic and therapeutic interventions cautiously, recognizing the significant risk of iatrogenic problems. Review medication lists carefully, avoid polypharmacy.
- Use shared decision-making and advocate for the patient to make informed decisions about their health care.
- Accept the legitimacy of death and work to ensure comfortable and dignified deaths. Obtain and support advanced directives and, when desired, facilitate death at home and limit end-of-life transfers to emergency rooms and hospitals.
- Finally, provide continuity of care. Older adults with multiple chronic illnesses see many health-care providers, but one health professional must be responsible for the overall plan and coordination of care. This responsibility can be burdensome and challenging, but without such leadership, the older patient cannot be assured of optimal care.

In addition, the AGS has developed guidelines for the care of an older adult with multiple chronic illnesses during an office visit (Table 25.10).

Table 25.10 American Geriatrics Society guidelines for the clinical management of older adults with multiple chronic illnesses during an office visit

Inquire about the patient's primary concern (and that of family and/or friends, if applicable) and any additional objectives for visit
Conduct a complete review of the care plan for person with multi-morbidity, *or* focus on specific aspect of care for person with multi-morbidity
What are the current medical conditions and interventions?
Is there adherence/comfort with treatment plan?
Consider patient preferences. Is relevant evidence available regarding important outcomes?
Consider prognosis
Consider interactions within and among treatments and conditions
Weigh benefits and harms of components of the treatment plan
Communicate and decide for or against implementation or continuation of intervention/treatment
Reassess at selected intervals for benefit, feasibility, adherence, and alignment with preferences

Adapted from Guiding Principles for the Care of Older Adults with Multimorbidity: An Approach for Clinicians [62]

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Special Population: Adults with Intellectual and Developmental Disabilities

26

Timothy P. Daaleman

Introduction

Adults with intellectual and developmental disabilities (IDD) encompass individuals who have a range of diagnoses (e.g., autism spectrum disorder) and designations (e.g., mental retardation) [1, 2]. An intellectual disability is characterized by significant limitations in both intellectual functioning, such as learning and problem-solving, and adaptive behaviors that generally include social and other everyday skills [3]. These limitations are made manifest before the age of 18 [3]. The term "developmental disabilities" is inclusive of intellectual disabilities and typically is used with individuals who (1) have a severe, chronic disability that is due to a mental and/or physical impairment, (2) are diagnosed with the disability before age 22, and (3) have substantial functional limitations in their activities of daily living [3, 4]. There are multiple causes of IDD which are attributable to different types of risk factors (e.g., biomedical, behavioral, social, educational) and the timing of the exposure to these factors [3]. The most common cause of IDD is Down's syndrome or trisomy 21 [5].

In the United States, there are an estimated 850,000 people with IDD who are age 60 years and older and who live in the community [6]. The number in this age group is projected to double over the next two decades, which is a remarkable development since the average life expectancy of persons with IDD was 59 years in 1976 and 66 years in 1993 [6]. Currently, the causes of death for individuals with IDD are comparable to the general population (i.e., coronary artery disease, cancer, respiratory disease, type 2 diabetes mellitus); however, these individuals are more likely to have multiple comorbidities when compared to the general population [7]. The genetic link between trisomy 21 and Alzheimer's disease has been clearly established, and at least 50% of adults who are aged 60 years and older will have clinical evidence of cognitive impairment and a lower life expectancy due to dementia-associated causes [8].

Persons with IDD unfortunately experience considerable health disparities throughout their lifetime, including decreased life expectancy and greater comorbidities [9, 10]. Individuals with IDD experience poorer health outcomes and greater variation in the quality of their health care when compared to the general population for reasons that go beyond having more than one disease process [11]. Patients can have cognitive challenges in recognizing and reporting symptoms, as well as in comprehending and adhering to treatment recommendations [12]. At the provider level, the lack of formal training in the health-care needs of adults with IDD has resulted in many physicians and care providers who lack experience and may be uncomfortable in providing care to this population [13]. Within practice and other health-care settings, there can be barriers and varying degrees of access to preventive services, such as cancer screening and immunizations, and to primary care for the management of chronic conditions [12]. These organizational barriers and implicit policies may be reflective of larger social and cultural attitudes, which can also be seen in the biases and misconceptions of health-care providers [12].

The tenth anniversary of the United Nations Convention on Rights of Persons with Disabilities was recognized in 2016, a gathering which declared the right of persons with disabilities to "the highest attainable standard of health without discrimination on the basis of disability" [14]. In the United States, the American Association on Intellectual and Developmental Disabilities (AAIDD) also advocated that all persons with IDD should have timely access to high-quality, comprehensive, accessible, affordable, and appropriate health care that meets their individual needs; maximizes health, well-being, and function; and increases independence and community participation (see Table 26.1) [15].

This chapter provides an introduction to the principles and practice strategies of providing health care to adults with IDD and draws upon recommendations and consensus

T.P. Daaleman (✉)
Department of Family Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA
e-mail: tim_daaleman@med.unc.edu

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guidelines developed by the Massachusetts Department of Developmental Services [16], a Canadian guideline working group [17], as well as Cochrane reviews [10]. The first section reviews clinical assessment and management approaches and the general medical care of these vulnerable patients. The second section offers preventive services guidelines and is followed by strategies for managing behavioral and mental health conditions that can arise. The chapter closes with an examination of the organization and delivery of health-care services.

Table 26.1 Key elements of joint position statement by *American Association on Intellectual and Developmental Disabilities and The Arc* on health, mental health, vision, and dental care

Access to care
Health-care systems must be accessible to individuals with intellectual and developmental disabilities (IDD) with respect to facilities and equipment, as well as communication needs and associated accommodations such as sufficient time and interpreters when necessary
Wellness, prevention, health promotion, and a robust public health infrastructure are essential components of health care for persons with IDD
Health-care providers for persons with IDD must meet the highest standards of quality, including a comprehensive approach to treatment, disease prevention, and health maintenance
People with IDD need access to effective strategies to manage their care including care coordination, referral processes, transition assistance, and health promotion efforts in community settings
Nondiscrimination
Individuals with IDD must not experience disability-related discrimination in their health care
There should be parity between mental health and medical care in health insurance benefits
Communication and decision-making
Individuals with IDD have a right to information with appropriate accommodations to assure informed consent including a process that allows an individual, or under appropriate legal conditions, a guardian, a health-care power of attorney, or a surrogate decision-maker of the individual's choice to accept or refuse health-care services
For any procedure for which consent is sought, sufficient information to understand the benefits and risks should be provided in ways that accommodate reading, language, and other limitations that are common among persons with IDD
Individuals with IDD may temporarily or permanently lack the capacity to make some or all health-care decisions. This lack of capacity may not be global, and the individual should always be assisted in making those decisions in which they can participate
When an individual has been determined to lack capacity to make health-care decisions and does not have an advance directive, a surrogate decision-maker should be identified to make these decisions, whenever possible before a crisis arises. When the individual's wishes are not known, the surrogate must follow the person's probable wishes, taking into account the person's known values, and, as a fall back, act in the person's best interests

Adapted from [15]

Clinical Assessment and Management

General Principles

Scheduled and timely well-maintenance visits, which include a structured physical examination, have been demonstrated to improve health and functional outcomes and can be responsive to the unique care needs of adults with IDD [18]. A baseline assessment of intellectual and physical functioning is recommended and may be aided by consultation with a psychologist, physical therapist, and/or occupational therapist [17]. Table 26.2 provides an inventory of functional areas and domains which can organize the assessment [19]. For providers who are seeing patients for the first time, the etiology of the IDD is important to verify since it often guides health-care services that should be offered [20]. In patients who have an uncertain etiology to their IDD or if there is a change in global functioning that is identified

Table 26.2 Functional domains for adults with intellectual and developmental disabilities

	Domains	Assessment modalities
Cognitive	Language, attentional, memory, literacy, problem-solving, social skills, self-direction	Neuropsychiatric or special education assessments
Neuromuscular	Gait, posture, muscle tone, fine and gross motor control, range of motion, sensory processing, swallow If applicable, seizure characteristics, type, length, and frequency	Physical therapy, occupational therapy, speech therapy, neurology, physical medicine and rehabilitation, orthopedics Patient and caregiver video documentation
Sensory	Hearing and vision testing; sensitivity to light, sounds, odors, foods, or proprioception	Audiometry and visual acuity; detailed visual exam
Behavioral/ mental health	Mood, affect, disordered/ordered thinking, agitation and other signs of distress	Neuropsychiatric assessment Note: 1. Stereotyped behavior or emotion lasting less than 3 min (possible seizure) 2. Patient's usual behaviors when in pain or agitated 3. Strategies for managing distress and other escalating behavior

Adapted from [19]

during the health-care visit, referral to genetic counseling should be considered [21, 22].

Adults with IDD can vary in how they adapt to their functioning, and assessments of intellectual and adaptive functioning (Table 26.2) can establish a baseline and help gauge both acute and chronic changes that can inform care planning [23]. If the patient has had a comprehensive assessment during early life or adolescence or if a life transition is anticipated, such as the cessation of school, a functional assessment with an occupational therapist, psychologist, or other specialist familiar with IDD should be considered. Pain and distress are challenging symptoms and signs that often go unrecognized by caregivers and clinicians and can present atypically, especially for patients who have difficulty communicating [24]. Atypical presentations of pain and distress can be assessed using tools that have been adapted for adults with IDD, such as the Non-Communicating Adult Pain Checklist (NCAPC) [25]. Table 26.3 contains domains and symptoms from the NCAPC. In patients who present with pain and distress, consideration should be given to some common underlying medical causes that may be found in this population, such as infection, constipation, and dental caries.

Table 26.3 Domains and symptoms from the non-communicating adults pain checklist

Domain	Symptom
Vocal reaction	Moaning, whining, whimpering
	Crying
	Loud screaming or yelling
	A specific sound or word for pain
Emotional reaction	Not cooperating, cranky, irritable, unhappy
	Agitated, difficult to distract, not able to satisfy or pacify
Facial expression	Furrowed eyebrows, raising eyebrows
	Eye squinting, eyes opened wide, frowning
	Turning down of mouth, not smiling
	Movements of the lips and tongue, such as teeth grinding or tongue pushing
Body language	Moving more or less
	Stiff spastic, tense, rigid
Protective reaction	Gesturing to or touching part of the body that hurts
	Protecting, defending, or guarding part of the body that hurts
	Flinching or moving the body part away, being sensitive to touch
	Moving the body in a specific way to show pain, such as curls up
Physiological reaction	Change in facial color
	Respiratory irregular responses, such as breath holding

Adapted from [25]

The limited life experiences of some adults with IDD, the level of intellectual functioning, learned helplessness, and cognitive impairment can compromise the capacity to give informed or voluntary consent. As a result, the capacity for informed consent varies among adults with IDD, and it is important to assess capacity when proposing diagnostic studies or treatments in which consent is required [26]. For example, a patient who is determined to be incapable of some aspects of decision-making, such as understanding consequences, might still be able to convey their wishes that can inform the judgment of a surrogate [26]. Caregivers can meaningfully contribute to decision-making and may consent to or refuse treatment on behalf of an adult with IDD who is assessed to be incapable of providing informed consent [26].

A key component of effective decision-making is appropriate communication, and the level and means of communication (e.g., nonverbal cues) should be adapted to the patient's level of intellectual and physical functioning [27]. It is important to consider the best interests of the adult with IDD, including his or her perspective in pursuing or forgoing any health-care intervention. This process is particularly important around advance care planning (ACP), which can help guide treatment decisions at the end-of-life, such as initiating palliative care [27]. Since ACP can positively impact the outcome of end-of-life care, a longitudinal process that ideally begins in the outpatient setting should seek to set goals of care and offer treatment options that are responsive to the patient and caregiver's wishes. Advance care planning should be recorded early in a disease course and reviewed annually with the patient and caregiver, or within the context of a hospitalization or significant change in health or functional status.

Medical Conditions and Disorders

There are several medical conditions and disorders that are more commonly seen in adults with IDD. Dental disease is among the most common problem since patients and caregivers can have difficulty in maintaining oral hygiene routines and accessing dental care. Changes in behavior, as noted earlier, can be the result of pain and discomfort from dental disease [28]. Physicians and other health-care providers should promote daily oral hygiene practices as well as scheduled preventive care, such as periodic examinations and fluoride applications by dental professionals [28].

Swallowing difficulties may be associated with dental disease and are not uncommon, particularly among individuals with neuromuscular dysfunction and those taking medications with anticholinergic side effects. These populations are at risk for developing respiratory disorders, particularly aspiration pneumonia [29]. Physicians and other providers

should be alert for possible signs of aspiration, such as throat clearing after swallowing, coughing, choking, drooling, long mealtimes, aversion to food, and weight loss, and should screen at least annually for signs and symptoms indicating respiratory disorders [16, 17].

Gastrointestinal problems, such as gastroesophageal reflux disease (GERD), are common among adults with IDD and can present more atypically than in the general population [30, 31]. These patients have an increased risk of *Helicobacter pylori* infection due to group home living, rumination, or exposure to saliva or feces [32]. Physicians should screen for *H. pylori* infection in symptomatic adults with IDD or asymptomatic patients who have lived in institutions or group homes and consider retesting at regular intervals [32]. The choice of urea breath testing, fecal antigen testing, or serologic testing should depend on the pretest probability of the infection, the availability of the test, and the tolerability of the test by the patient [32]. Symptomatic patients, or those taking medications that can aggravate GERD, or asymptomatic patients who have lived in institutions or group homes, should be screened annually for GERD [16, 17]. Constipation, GERD, peptic ulcer disease, and pica should also be considered if there are unexplained gastrointestinal findings or if there are changes in behavior or weight [17].

Musculoskeletal disorders, such as scoliosis, contractures, and spasticity, can be possible sources of unrecognized pain and occur frequently among adults with IDD, resulting in reduced mobility and activity [33]. These disorders, including osteoporosis and osteoporotic fractures, are more prevalent and tend to occur earlier in adults with IDD than in the general population [33]. Risk factors for these conditions include reduced mobility, the increased risk of falls, the presence of genetic syndromes (e.g., Down's syndrome), and long-term medication use that may contribute to gait instability [34, 35]. For those patients at high risk of developing osteoporosis (e.g., medications, immobility), bone mineral density testing should be considered beginning at age 19 [16, 17]. Osteoarthritis is also becoming more common in this population due to increased life expectancy, and patients and caregivers should receive advice and information that promotes regular physical activity [36]. Physicians and other health-care providers should promote regular physical activity and consider consulting a physical or occupational therapist if there is need for mobility adaptations, such as a wheelchair, modified splints, or orthotic device.

Epilepsy is not uncommon among adults with IDD, and the severity of condition increases with the underlying disability [37]. This disorder can be difficult to evaluate and control, and it has long-term effects on the lives of affected adults and their caregivers. A consensus set of guidelines for the management of epilepsy in adults with IDD noted that there was a dearth of high-quality evidence but issued several recommendations that were Grade B (i.e., based on hierarchy II evidence or extrapolated from hierarchy I) or higher. First, new prescriptions of phenobarbital are discouraged because of the high incidence of behavioral side effects; however, it may be used as a third-line agent if other, more suitable options have been used without success [2].

Topiramate can be considered add-on therapy since it demonstrates no significant behavior side effects [3]. In general, no recommendation can be given for a specific drug of choice in patients with epilepsy and IDD [4]. Next, patients on phenytoin need regular, at least yearly, serum drug concentration measurement; drug monitoring must be combined with clinical examination for side effects [5]. Finally, there is no comparative evidence for the treatment of adults with seizures in Lennox–Gastaut syndrome; however, evidence does exist for the impact of lamotrigine and topiramate on drop attacks [37]. Consideration should be given to specialty consultation regarding alternative medications when seizures persist and possible discontinuation of medications for patients who become seizure-free [37].

Metabolic disorders have a greater prevalence in some subpopulations of adults with IDD [38]. For example, there is a higher incidence of hypogonadism associated with Prader–Willi syndrome [38]. In these and other at-risk patients, laboratory screening for hypogonadism and testosterone may be considered at least once after full puberty is achieved [17]. Regarding routine screening for diabetes mellitus (DM), there are inconsistent data that support the increased prevalence of DM among adults with IDD, with the exception of persons with Down's syndrome [39]. Screening for thyroid disease, however, should be considered in patients who are symptomatic (e.g., fatigue, progressive weight gain), have hyperlipidemia, are obese, or have sedentary lifestyle [17]. In addition, for patients who are prescribed lithium or atypical or second-generation antipsychotic medications, a baseline thyroid function should be measured and tested at lease annually [17].

Cardiac disorders are prevalent among adults with IDD, due to risk factors such as physical inactivity, obesity, and prolonged use of some psychotropic medications [40]. When any risk factor is present, physicians should consider screening for cardiovascular disease earlier than in the general population and initiate primary prevention strategies (e.g., encouraging physical activity, weight management) [40]. Some adults with DD have congenital heart disease and are susceptible to bacterial endocarditis. Antibiotic prophylaxis guidelines for patients who meet criteria or consultation with a cardiologist can help inform treatment decisions [41].

Polypharmacy is not uncommon among adults with IDD, especially those who have medical comorbidities. A medication review should be conducted at regular intervals to determine patient adherence and to monitor for adverse side effects and medication interactions [17]. In general, medications not prescribed for a specific diagnosis should undergo

a trial of reduction and cessation, with timely communication from patients and their caregivers during medication trials to monitor safety, side effects, and effectiveness [42]. The review should target psychotropic medications since they are regularly prescribed to adults in this population – despite the lack of evidence – and are often used in response to problem behaviors [17, 43, 44].

Sexuality is an important but frequently undiscussed area in the care of adults with IDD [45]. Open and patient-centered communication can facilitate understanding about patient or caregiver concerns regarding sexual health issues, such as menstruation, masturbation, contraception, and menopause. This communication approach may also help health-care providers identify abuse and neglect, which occurs frequently in adults with IDD and is often perpetrated by people known to them [46]. There are several behavioral signs and symptoms that may suggest abuse and neglect including unexpected weight changes, aggression, withdrawal or noncompliance with treatment plans, depressive symptoms including sleep or eating problems, poor self-esteem, and inappropriate attachment or sexualized behavior [46]. Caregivers of adults with IDD are at risk for caregiver stress and burnout and should be screened at regular intervals. If abuse or neglect is suspected, physicians and other care providers are generally mandated to report to responsible authorities (e.g., social service or law enforcement) and address any associated physical or mental health issues, such as posttraumatic stress.

Preventive Services

Guidelines for preventive health services (e.g., US Preventive Services Task Force-USPSTF) should be applied to adults with IDD as in the general population with consideration to some modifications [16, 17]. Maintaining up-to-date immunizations is important since adult patients and their caregivers may have a reduced awareness of the importance of vaccines beyond childhood. To begin, both annual influenza and pneumococcal series vaccinations should be current and offered when appropriate. Due to an increased risk of exposure, the need for hepatitis A and B screening and vaccination should be determined [47], and this may include annual screening in high-risk patients (e.g., those with blood exposures) and periodic monitoring of liver function in hepatitis B carriers [16, 17]. Finally, shared decision-making about HPV vaccination should be initiated between patients who are in the preadolescent to early adult age group, their caregivers, and health-care providers.

Cancer screening is an essential preventive service; however, adults with IDD are less likely than those in the general population to receive these services. Recommendations for cancer screening generally follow guidelines established for adults in the general population; however, there are practical and logistical issues when considering invasive testing [16, 48]. Colon cancer is slightly more prevalent in adults with IDD and constipation a common problem, which makes evaluating the onset of colon cancer symptoms challenging to determine [48]. Providers who care for women with IDD do not uniformly encourage mammography for their patients who are in the targeted age groups as recommended by the USPSTF [48]. Cervical cancer screening is controversial since fewer women with IDD are sexually active, when compared to the general population, and many have difficulty communicating their sexual history [48]. The decision and time interval to conduct cervical cancer screening should be individualized based on the patient's risk factors [48]. Finally, prostate and skin cancer screening are routinely performed by many primary care physicians despite the lack of evidence [48].

As noted earlier, physical inactivity and obesity are more prevalent among adults with IDD and are associated cardiovascular disease, diabetes, osteoporosis, and early mortality [49]. As a result, weight and height need to be monitored regularly, and body mass index and other biometric indices should be used to stratify cardiovascular risk [50]. Patients and their caregivers should be counseled annually, or more frequently if indicated, regarding strategies for maintaining healthy nutrition and physical fitness. Among adults who are significantly obese (e.g., BMI >30), more intensive counseling (e.g., referral to dietitian) should be offered [16, 17].

Vision and hearing impairments are often underdiagnosed in the IDD population, and these limitations can impair behavior and adaptive functioning [51]. Office-based vision and hearing screening should be part of the annual exam with the same frequency as recommended for average-risk adults, or when symptoms or signs of visual or hearing problems are identified [16, 17]. Hearing impairment due to cerumen impaction is not uncommon. All patients with IDD should be considered for glaucoma assessment beginning in early adulthood (e.g., age 21) with follow-up examinations every 2–3 years up to age 39 and 1–2 years for ages 40 and older [16].

Managing Behavioral and Mental Health Conditions

Diagnosing Psychiatric Conditions and Mental Health Disorders

Psychiatric disorders and emotional disturbances are more prevalent among adults with IDD; however, some behaviors are normalized or overlooked (i.e., diagnostic overshadowing) in these patients, resulting in delayed diagnoses and treatments [17]. Despite the prevalence, establishing or verifying a psychiatric diagnosis can be complex and difficult;

mood, anxiety, and adjustment disorders are often underdiagnosed; and psychotic disorders are overdiagnosed [52]. Psychotic disorders can be very difficult to diagnose when delusions and hallucinations cannot be expressed verbally and in cases where developmentally appropriate fantasies (e.g., imaginary friends) might be mistaken for delusional ideation [53]. Alcohol or substance use is less common among adults with IDD than in the general population, but these individuals can have more difficulty moderating their intake and experience more barriers to treatment and rehabilitation services.

When screening for psychiatric conditions or mental health disorders, providers should use validated tools that have been developed for adults with IDD according to their functional level. The Aberrant Behavior Checklist-Community [ABC-C] is a rating scale that is designed to be used with community-dwelling individuals with IDD and can be completed by caregivers, teachers, or others who have directly observed the patient's behavior [54]. The instrument asks observers to rate the level of problem behavior (e.g., not at all, slight, moderately serious, severe) across several domains, including physical body movements, social interactions, and mood and affect [54].

The Psychiatric Assessment Schedules for Adults with Developmental Disabilities (PAS-ADD) Checklist is a validated 25-item questionnaire that is designed for caregivers, family members, and others who have direct knowledge of behavior changes of individuals with IDD [55]. The Checklist is a screening tool that can determine if a more complete further assessment is needed, and it can be used to screen groups of individuals, or to monitor at-risk individuals [55]. The tool generates three scores relating to affective or neurotic disorders; neurodegenerative conditions, including dementia; and psychotic disorders [55].

Screening instruments and tools are important; however, meaningful input and assistance from adults with IDD and their caregivers are vital for a more comprehensive understanding and determination of root causes to the problem behavior or emotional disturbances. At the outset, establishing a collaborative approach of working with patients and caregivers that seek input, agreement, and assistance can help identify target symptoms and behavior [17]. Pain and other physical symptoms are often unrecognized and can present atypically, particularly for those patients who have difficulty communicating. Assessment tools adapted for adults with IDD, as noted earlier, can help identify uncharacteristic cues of pain and physical symptoms; collateral information from caregivers is highly useful [17].

Underlying medical causes (e.g., occult infection, constipation, dental disease) may be manifesting as behavioral changes and musculoskeletal disorders, such as scoliosis, contractures, and spasticity, can be sources of unrecognized pain and other physical symptoms [56]. Screening for underlying alcohol or substance use is important. Finally, unexplained changes in weight, noncompliance, aggression, withdrawal, depression, avoidance, poor self-esteem, sexualized behavior, sleep or eating disorders, and substance abuse might also be signals of abuse or neglect, which occurs more frequently in this population and are often perpetrated by people known to adults with IDD [26]. In adults with Down's syndrome, early screening for cognitive impairment and dementia is suggested since the diagnosis can be overlooked [17, 57].

Differentiating dementia from depression and other behavioral disorders can be especially challenging among some adults with IDD, and referral for psychological testing that is inclusive of cognitive, adaptive, and communicative functioning can help clarify the underlying diagnosis [17]. If an underlying psychiatric disorder is suspected, interdisciplinary consultation from clinicians knowledgeable and experienced in IDD is recommended [17]. Collateral information and support from caregivers can effectively help develop and implement treatment plans [17]. Addressing sensory (e.g., overstimulation) and environmental (e.g., lack of space for physical activity) factors is an important part of care planning, and there is increasing evidence of the efficacy of psychotherapy (i.e., cognitive behavioral therapy) for specific emotional problems that might be contributing to aggressive or anxious behavior [58].

Managing Acute Problem Behaviors

In an acute setting, problem behaviors can manifest as aggression, agitation, or self-injury and may be indicative of an underlying medical disorder or disruption in social or emotional supports [59]. As noted earlier, physicians and other providers should establish trust and a functional working relationship with patients and caregivers in order to gather information, determine safety, and gain agreement and assistance in developing treatments that can be implemented and monitored. Non-pharmaceutical behavioral approaches have proven efficacy for alleviating acute problem behaviors, and home and community-based resources are an additional benefit [10, 60]. Providers should actively involve other stakeholders, including community mental health agencies and emergency department staff, in order to develop a proactive, integrated response plan for patients at high risk of injury and those with recurrent behavioral crises [17].

If there are new problem behaviors, other etiologies such as medical conditions, environmental changes, and emotional factors should be thoroughly assessed [17]. It is important to note that problem behaviors, such as aggression and self-injury, are not psychiatric disorders but might be a symptom of an underlying medical disorder or other social

circumstance, such as insufficient support in the home environment [61]. Problem behaviors can occur because environments do not meet the developmental needs of adults with IDD and providers should seek to promote "enabling environments" with family members and caregivers to address unique developmental needs since this approach can markedly reduce problem behaviors [62].

Providers can consider a functional assessment in non-emergent situations when safety and reliable follow-up can be assured. This type of assessment is usually conducted by a mental health-care professional, and an interdisciplinary understanding of problem behaviors can benefit from occupational therapists as well. Consideration should be given to reducing and stopping medications not prescribed for a specific psychiatric diagnosis [42]. If the problem behavior escalates into a crisis, psychotropic medications can be used to ensure safety, ideally as a temporary intervention [17]. Antipsychotic medications are often inappropriately prescribed for behavior problems, and in the absence of a clinical indication, this class of medications should not be considered as first-line treatment [17, 43, 44]. However when psychotropic medications are used to ensure safety during a behavioral crisis, there should be parameters for earlier follow-up – ideally no longer than 72 h – and possible discontinuation [17, 43, 44].

Behavioral crises can occasionally escalate and not be managed in outpatient or community-based settings which subsequently require management in an emergency department [63]. The presenting problem, collateral information, and outpatient interventions that have been tried should be accurately communicated to the emergency department staff prior to the patient's arrival. Across all care settings, it is important to debrief the crisis with care providers in order to minimize the likelihood of recurrence. The debriefing process should include a review of events that led to the crisis events, interventions, and responses, such as behavioral approaches and medications, and the identification of possible triggers and underlying causes [63].

Use of Psychotropic Medications

As noted earlier, psychotropic medications are regularly used to manage problem behaviors in adults with IDD, despite the lack of an evidence base [17, 43, 44]. Psychotropic medications are, however, equally effective in these individuals, as in the general population, for confirmed psychiatric disorders [64]. There is increased risk of polypharmacy in this population and concomitant adverse medication interactions [64]. Some adults with IDD may have atypical responses or side effects at low doses, while others are limited in their ability to describe side effects of the medications that they are taking. Some classes of antipsychotic medications increase the risk of metabolic syndrome and can trigger other effects, such as akathisia, cardiac conduction problems, swallowing difficulties, and bowel dysfunction [64].

Table 26.4 displays the "10 Dos and 4 Don'ts" principle that was developed by a 1995 consensus conference on psychopharmacology and has undergone several iterations [64].

In addition to these principles, there are other practices that can promote the safe prescribing of psychotropic medications. Physicians should "start low and go slow" in initiating, increasing, or decreasing doses of medications, carefully monitoring for side effects, including metabolic syndrome [64]. The need for ongoing antipsychotic medications should be reassessed at regular intervals with consideration given to dose reduction or discontinuation when indicated [64]. Whenever there is a behavioral change, the psychiatric diagnosis and the appropriateness of the prescribed medications for this diagnosis should be reviewed. Prescribing physicians should also arrange to receive regular reports from patients and their caregivers during medication trials in order to monitor safety, side effects, and treatment effectiveness [64].

Table 26.4 Principles for psychotropic medication prescribing for adults with IDD

Do
1. Treat any drug that is used to modify behavior (e.g., OTC sleep agent) as a psychotropic drug
2. Use psychotropic medications within a coordinated care plan
3. Base treatment decisions on a diagnosis or clinical indication
4. Obtain consent
5. Track efficacy by using validated scales and instruments
6. Monitor side effects using rating instruments
7. Monitor for tardive dyskinesia, metabolic syndrome, and other serious side effects
8. Review all medications systematically and regularly
9. Always seek to prescribe the lowest effective dose
10. Monitor medication adherence by patients and caregivers
Don't
1. Do not use psychotropic drugs for convenience or as a substitute for behaviorally intensive activity or the need for changes in physical environment
2. Avoid frequent drug and dose changes
3. Avoid intra-class polypharmacy
4. Seek to minimize:
Long-term as needed (i.e., PRN) medications
Long-acting sedative/hypnotics
Long-term hypnotics or anxiolytics
High-dose antipsychotic doses
Long-term anticholinergics

Adapted from [64]

Organization and Delivery of Health-Care Services

Health care systems are moving to value-based care, which can provide a foundation for the development of integrated networks of primary care, specialized care, and ancillary services for adults with IDD [65]. The patient-centered medical home (PCMH) model provides an organizational platform for addressing the health-care needs of adults with IDD since it tailors and individualizes health-care services by increasing access and managing all aspects of care and through a team-based approach that is led by the patient's personal physician [66]. For example, the Healthy Outcomes Medical Excellence (HOME) project was developed to provide comprehensive care to adults and children with IDD [67]. Since its founding in 2000, the HOME project has resulted in decreased acute hospital utilization and readmissions and has improved quality outcomes such as vaccination rates and compliance with diabetes care management [67].

Interdisciplinary health care has been found to be an effective approach in addressing the complex needs of adults with IDD [10]. Operationally, this strategy involves the patient's primary care physician and other health providers as required (e.g., mental health-care provider, physical therapist, occupational therapist), in addition to a care manager who is responsible for coordinating care across providers and service locations [68, 69]. Care managers are playing an increasingly major role in the redesign of primary care and in the evolution of PCMH by providing patient education in disease self-management skills, by coordinating services across a continuum of care providers, and by linking patients to community and social services [70]. Indeed, home and community-based services that provide more intense services have been found to add benefit to when compared to standard medical services alone [10].

There is growing interest in telemedicine and other health information technologies (HIT) as strategies that can expand the reach of services for adults with IDD into home and community-based settings. A Cochrane review that explored the effectiveness of HIT for people with physical or learning disability or cognitive impairment found a lack of empirical evidence to support or refute the use of these technologies [71]. Among individuals with autism spectrum disorders, one systematic review reported that telemedicine was used in a variety of ways, including diagnostic assessments and consulting, supervision of interventions and training, and program implementation [72].

The National Council on Disability has highlighted several programs that can serve as models for emerging, integrated health-care initiatives for adults with IDD [73].

UCare Complete is a program for Twin Cities (Minnesota) area residents with physical disabilities who are between the ages of 18 and 64, which combines physician, hospital, home care, nursing, home, and community-based services, an integrated care system. The program seeks to maximize independence while providing person-centered care and was designed in response to poor access to health-care services, the lack of accommodations in health-care settings, and the paucity of health-care providers with skills in caring for this population [73]. Program participants work with a nurse to develop individualized care plans that are inclusive of services, such as personal care services to accompany diagnostic procedures or other clinical services, and home or worksite visits instead to promote access to health care [73].

Premier HealthCare provides health care for Medicaid and Medicare individuals who have developmental, physical, and learning disabilities throughout New York City [73]. The program has a comprehensive care practice model, which provides primary care and ready access to specialty and ancillary care offering a variety of services, such as dental, social work, and nutrition. Premier also engages in community outreach projects and seeks to empower patients and family members by providing a community of support and understanding [73].

The Center for Development and Disability (CDD) at the University of New Mexico is a statewide organization that provides a range of individual and family-centered health-care services for individuals with IDD [73]. CDD's work includes coordinating a statewide disability and health alliance, building community groups, running conferences and leadership trainings, and maintaining an inventory of disability resources in New Mexico [73]. There are technical assistance and trainings are that are offered, including at-home online trainings for individuals with IDD. Some programs are embedded in hospital-based settings and provide care for subgroups of individuals with IDD (e.g., visually or hearing impaired) rather than more diverse population [73].

The Westchester (New York) Institute for Human Development (WIHD) is a former affiliate of the Westchester Medical Center and is an institute that coordinates comprehensive health care and provides training and technical assistance for individuals with IDD, caregivers, family members, and health-care professionals [73]. WIHD provides specialized outpatient health care for children and adults with developmental and other disabilities who reside in the metropolitan New York area [73]. Services include primary care, specialty care, and allied health services through a coordinated model that is designed to respond to the complex and chronic health problems of these individuals. Preventive services include health promotion and self-management programs, including nutrition, exercise, hygiene, and tobacco control [73].

Final Comments

Adults with intellectual and developmental disabilities (IDD) continue to bear a disproportionate burden of poor health and access preventive and health-care services at a lower rate than people who do not have disabilities [73]. The lack of provider education and disability cultural awareness and competency creates significant barriers for people with disabilities to receive high-quality care [73]. Stereotypes and bias can lead to ineffective and inappropriate care, either through the lack of accessible equipment, ineffective provider-patient communication, or inadequate time to communicate effectively with patients and caregivers. Adults with IDD receive most of their health care through the primary care providers in the communities in which they live [13]. As more of these patients move through the health-care system, these providers and innovative comprehensive care models will need to take on greater responsibility for providing care that is marked by accessibility, continuity, and comprehensiveness [17].

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Vulnerable Populations

27

Evan Arthur Ashkin

Introduction

For health-care providers, vulnerable populations are generally considered as those groups of individuals with a disadvantaged position in social hierarchies defined by wealth, power, and/or prestige, which place them at risk for poor health [1]. Examples of vulnerable populations include the elderly poor; at-risk youth; formerly incarcerated persons (FIPs); lesbian, gay, bisexual, transgender, and questioning (LGBTQ) persons; immigrants and refugees; military veterans; homeless individuals and families; and persons suffering from mental illness. Vulnerable populations share a number of risk factors for poor health, especially chronic illness, and addressing social determinants of health is key for effective interventions. Many vulnerable populations are also socially marginalized and suffer from discrimination, limited access to health care, and lack of comprehensive social services [1].

Understanding health disparities and social determinants of health is important in considering vulnerable populations. Healthy People 2020 defines health disparities as "a particular type of health difference that is closely linked with economic, social, or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater social or economic obstacles to health based on their racial or ethnic group, religion, socioeconomic-status, gender, age, or mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion" [2].

Social determinants of health (SDH) have been defined by the World Health Organization (WHO) as "the conditions in which people are born, grow, live, work and age" [3]. Specific examples of SDH include neighborhood, recreational opportunities, access to healthy food, environmental exposures, educational opportunities, access to health care, employment opportunities, and exposure to violence. A complex interplay of these factors underlie many health disparities, and these are depicted in Fig. 27.1.

Since many marginalized groups often mistrust the health-care system and can be reluctant to interface with the medical community, this chapter will provide an overview to care of this population. The first section will provide demographic and other data that describes some of the characteristics of these populations. The main section of the chapter will describe the health and health-care challenges for defined vulnerable populations and general principles for health-care providers. Next, several health-care delivery models for vulnerable populations will be presented before the chapter closes with future directions in the field.

Demographic Characteristics of Vulnerable Populations

Low socioeconomic status (SES) is one of the strongest predictors of poor health, and most vulnerable populations fall into that group [4]. Disparities in income and educational attainment are linked to shorter life expectancy, poorer health status, and higher rates of heart disease and diabetes mellitus [4]. Lack of health insurance, also linked with low SES, is associated with poorer health outcomes. Understanding the demographics of poverty is essential when considering vulnerable populations. The US poverty rate in 2015 was 13.5%, with 43.1 million Americans living in poverty; children under the age of 18 had a 19.7% poverty rate. There are significant racial and ethnic disparities in the real median income of non-Hispanic White ($62,950), Black ($36,898), and Hispanic-origin ($45,148) households [5]. Household income is associated with many of the social determinants of health that have an impact on individual and community-level health. In addition, education level is also strongly correlated with living in poverty. For example, individuals

E.A. Ashkin (✉)
University of North Carolina at Chapel Hill, Department of Family Medicine, Chapel Hill, NC, USA
e-mail: ashkin@med.unc.edu

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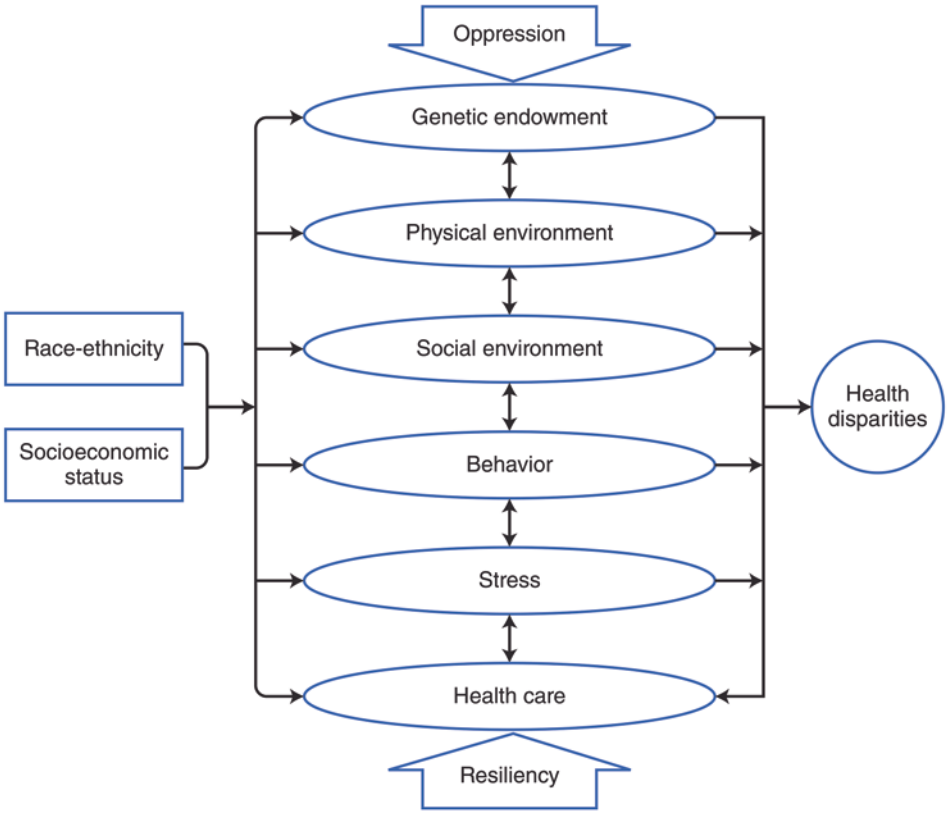

Fig. 27.1 Conceptual model of pathways between demographics and health status (Modified with permission from [1])

Table 27.1 Racial and ethnic differences in poverty rates[a]

Race	Percent of total US population	Percent by race of people living in poverty	Percent of race living in poverty	Number of persons living in poverty
White, non-Hispanic	61.4	41.2	11.6	17.8 million
Hispanic, non-White	17.6	28.0	21.4	12.1 million
Black	13.3	23.2	24.1	10 million
Asian	5.6	4.9	11.4	2.1 million
All races	100	13.5		43.1 million

[a]Data from Income and Poverty in the USA: 2015, US Census Bureau

without a high school diploma have a poverty rate of 26.3%, whereas those with a bachelor's degree or higher have a rate of 4.5% [5]. Table 27.1 presents racial and ethnic differences in poverty rates for the US population.

Individuals with disabilities are representative of a vulnerable population that is also impacted from high rates of poverty. Disabled persons aged 18–64 years old make up 7.7% of the total US population yet represent 17.9% of all people living in poverty.

Vulnerable Populations and Chronic Disease

LGBTQ

Lesbian, gay, bisexual, transgender, and questioning (LGBTQ) people are at increased risk for a number of medical, mental health, and psychosocial problems, such as psychosocial stress, smoking, and alcohol use [6]. The Centers for Disease Control and Prevention (CDC) report higher rates of HIV in gay men than the general population [7]. LGBTQ youth are at higher risk for substance abuse, being victims of bullying and dating violence, suicidal ideation, and suicide [7]. According to the 2013 National Health Interview Survey, 1.6% of the US adult population are identified as gay or lesbian, 0.7% as bisexual, and 1.1% as "something else" [6]. The number of transgender adults in the USA is estimated to be 1.4 million or 0.6% of the population [8]. The National Center for Transgender Equality and the National LGBTQ Task Force survey reported an HIV rate four times that of the general population for transgender people. Among transgendered people the prevalence of a history of a suicide attempt is 41%; this is compared to 4.6% in the general population and 10–20% in the LGBTQ population [9].

When viewing health-care services, transgender people are less likely to have health insurance than other LGBTQ people [9]. Additionally, 19% of respondents to the task force survey reported being denied care because of their transgender status, and 50% stated they needed to teach their providers about transgender health issues [9]. Discrimination toward LGBTQ people has led to significant marginalization and alienation of this vulnerable population. As LGBTQ youth have increased rates of homelessness, establishing trust and rapport is especially challenging, and outreach to homeless youth should stress an openness and acceptance of LGBTQ people and lifestyles. High rates of substance abuse and mental health issues require that care teams include behavioral health providers. Community outreach must intentionally focus on areas where LGBTQ persons are more likely to congregate and work toward building confidential, trusting health-care environments. Health-care screenings should be attentive to histories of emotional, physical, and sexual abuse as well as sexually transmitted infection (STI) testing. Finally, preventive service counseling should provide local support resources for LGBTQ persons.

Elderly Poor

The elderly poor are impacted by challenges such as poverty, as well as social isolation. According to the National Council on Aging, 25 million Americans aged 60 years and older are living below 250% of the federal poverty limit (FPL) [10]. Three million households with a senior over 65 years of age experience food insecurity [10]. Barriers to health include transportation, stable housing that is safe and adequately configured to meet personal needs, health literacy, limited ability to perform activities of daily living (ADLs), and instrumental activities of daily living (IADLs). ADLs include bathing, eating, and grooming, whereas IADLs are shopping, cooking, housework, and other activities related to independent living. Rates of depression are higher than the baseline for the elderly poor when compared to elderly patients with higher SES [11].

Fifty-two percent of persons 65 years and older suffer from two or more chronic conditions and are more likely to report poor mental health and have lower incomes and inability to work [12]. There are many challenges in managing chronic disease in this population. Transitions of care are more frequent in elderly patients due to higher rates of hospitalizations and emergency room use, which may result in increased medication errors and barriers around transportation and health literacy. Additionally, many elderly poor have difficulty affording their medications since Medicare coverage can have substantive co-payments for necessary medications. For example, the 2003 Medicare Prescription Drug, Improvement, and Modernization Act has a gap in benefit coverage known as the "donut hole," coverage that begins once a beneficiary has spent $3310 and has variation in out-of-pocket expenses. Patients on Medicare can qualify to be "dual eligible" and receive Medicaid if they meet specific income requirements. This coverage can assist with co-pays and can provide additional benefits, such as personal care services in the home [13].

Cognitive impairment and dementia are more prevalent with increased age in older adults. Routine and structured dementia screening are recommended since early detection can help in treatment and care planning. Many of the elderly poor have limited resources and family supports and are inadequately equipped to obtain the services and assistance they need to remain independent in their homes. As a result, they are more likely to require care in institutional settings, away from their communities, family, and friends [10].

Immigrants and Refugees

The term "immigrant" has been used to refer to persons with "no U.S. citizenship at birth, and includes naturalized citizens, lawful permanent residents, refugees and asylees, persons on certain temporary visas, and the unauthorized" [14]. The US Census Bureau defines recent immigrants as foreign-born individuals who resided abroad 1 year prior, including lawful permanent residents, temporary nonimmigrants, and unauthorized immigrants [14]. In 2014 there were 42.4 million immigrants in the USA, approximately 13.3% of the population. Forty-seven percent of immigrants are naturalized citizens, and the immigrant population increased by 2.5% or one million people from 2013 to 2014. Approximately 11.4 million immigrants living in the USA are unauthorized with 71% from Mexico and Central American countries, 14% from Asia, 6% from South America, and most others from Europe, Africa, and the Caribbean. Racially, immigrants define themselves as 48% White, 26% Asian, 9% Black, and 15% others. Ethnically, Hispanics or Latinos are the largest group at 46% or 19.4 million people.

Limited English proficiency (LEP) is a significant concern for immigrants, and it impacts 25.7 million people age greater than 5 years old. Spanish speakers account for 64% of the LEP population, and in 2014, 50% of the US immigrants had LEP [14]. Immigrants also have lower levels of educational achievement with 30% lacking a high school diploma when compared to 10% of the native-born population. Most immigrants lack health insurance. For example, in 2014, 27% of immigrants were uninsured compared to 9% of native born [14].

A refugee is defined as "someone who has fled from his or her home country and cannot return because he or she has a well-founded fear of persecution based on religion, race, nationality, political opinion or membership in a particular

social group" [15]. An asylum seeker is a person who has submitted a claim for refugee status. According to the United Nations High Commissioner for Refugees (UNHCR), there are 21.3 million refugees worldwide with half being under the age of 18 [15]. Since 1975 the USA has admitted more than three million refugees across all 50 states [16]. In 2016 approximately 85,000 refugees will enter the USA with approximately 34,000 from the Near East and South Asia (10,000 from Syria); 25,000 from Africa; 13,000 from East Asia; 4000 from Europe; 3000 from Latin America and the Caribbean; and 6000 others depending on need [16]. Many unauthorized immigrants are in the USA without official refugee status but are here for similar reasons.

Immigrants, refugees, and asylum seekers face many of the same barriers to health-care services. It is beyond the scope of this chapter to discuss the many chronic disease and infectious disease problems for specific immigrants and refugee populations; however, refugee health profiles are available from the CDC [17]. There are some conditions that are common across several populations. Infectious diseases, for example, tuberculosis, hepatitis B, malaria, intestinal and central nervous system parasites, and Hansen's disease, afflict many immigrant and refugee populations, and appropriate screenings should be performed if clinically indicated. Additionally, immunization rates vary greatly, and coordinated efforts should be made to obtain records to update and complete vaccination schedules [18].

Immigrant and refugee populations are at increased risk for mental health problems that can be secondary to exposure to violence, severe emotional stress, displacement, and disruptions to family and other support systems. Additional barriers to care include lack of health insurance, LEP, low SES status, transportation limitations, and unfamiliarity with the US health-care system. Clinicians and health-care facilities are often challenged to provide culturally and linguistically appropriate services (CLAS). The US Department of Health and Human Services (DHHS) has developed national CLAS standards to try and assure quality care regardless of a person's county of origin, language, culture, or religion [19]. Many metropolitan areas with high numbers of refugees have developed specialized clinics that focus on care of these populations to better meet the needs of these diverse patients. An example is the Refugee Medical Clinic at the University of California at San Francisco, part of the Family Health Center based at San Francisco General Hospital.

Alcohol and Substance Use Disorders

Alcohol and substance use disorders (SUD) are prevalent, and approximately 17 million people had an alcohol use disorder, and 21.5 million people over the age of 12 had a substance use disorder in 2014. Within that population, 7.1 million used illicit drugs and 2.6 million had both an alcohol use and an illicit drug use disorder [20]. Alcohol and substance use disorders are common in a number of vulnerable populations, especially among homeless persons, military veterans, at-risk youth, incarcerated and formerly incarcerated persons, and people with mental illness. Clinicians and other health-care providers should be attentive to screening for alcohol and substance use disorders and identifying resources for treatment.

In recent years, mortality rates secondary to unintentional overdose of narcotics have skyrocketed in the USA. For example, the number of overdose deaths from opioids has quadrupled in the period between 1999 and 2014 [21], an epidemic that is the result of dramatic increases in prescribing of pain medications. Three quarters of new heroin users report a history of abusing prescription narcotics [21]. Efforts to reduce prescriptions of opioids have been successful, but without adequate treatment programs or other modalities for pain control, many patients are turning to the use of heroin and other street drugs [21]. IV heroin and other drug usage increase the risk for hepatitis B and C, HIV disease, and opiate overdose. Presently, unintentional poisoning deaths are the number one cause of accidental death in the USA [22].

Health-care providers who work with patients with SUD and chronic pain should not simply dismiss them from their care if they violate treatment agreements but should offer treatment for their SUD. Unfortunately, insufficient treatment resources limit these efforts, and patients often turn to street drugs or go from provider to provider to obtain medications. Clinicians in primary care and acute care settings, emergency rooms, and certain specialties can be challenged to provide compassionate and effective care to these patients. Few communities have adequate resources for treatment, and many people suffering from SUD are uninsured or underinsured [21].

Mental Illness

People suffering from severe mental illness (SMI), such as schizophrenia, bipolar disorders, schizoaffective disorder, and other severe affective disorders, represent another highly vulnerable population. In 2014, 4.1% of the US population or 9.8 million people suffered from SMI [20]. Co-occurring mental illness and substance use disorder are reported in 3.3% of the US population [20]. In 2014, 340,000 adolescents aged 12–17 had co-occurring SUD with a major depressive episode [20]. People with SMI have shorter life expectancies than those without SMI, and this disparity is not explained by higher rates of suicide [23]. Chronic diseases such as cardiovascular disease, respiratory disease, and cerebrovascular disease are the main causes of excess preventable death in this population [23]. Schizophrenia is

associated with higher rates of diabetes, metabolic syndrome, and premature death than in the general population.

Societal stigmas surrounding mental health persist, and rates of poverty, homelessness, victimization, substance abuse, and incarceration for persons with SMI are disproportionately high [24]. Additionally, the availability for inpatient mental health treatment is extremely limited. A 2016 US survey of the 50 states, for example, showed that 37,679 staffed beds remain in US hospitals, which when adjusted for population growth is a 17% reduction since 2010 and a 96.5% drop since the 1950s [25]. This rate of 11.7 beds per 100,000 people is lower than any time since the 1850s when the USA ended the criminalization of mental illness. Due to an insufficient community mental health service capacity, the criminal justice system has become the default provider of mental health services in the USA. Persons with mental illness and SMI are overrepresented in the prison and jail population [24, 26]. Table 27.2 presents the incidence of mental illness among prisoners.

The incarceration of individuals with mental illness results in disruptions of care and isolation from support systems and further burdens a criminal justice system that was not designed for the treatment of mental illness.

There are ongoing initiatives to improve systems of care that can address both the behavioral health and physical health needs of persons suffering from mental illness. Traditional mental health services have been separate from medical care, deepening the already substantial access issues faced by persons with SMI. This barrier has likely contributed to the excess morbidity and mortality of chronic disease experienced in persons with SMI. Collaborative care models (CCMs) that utilize case management and link medical care and behavioral health services show promise in reducing this health disparity [27]. Advances in telemedicine also have potential to improve access to behavioral health services in underserved communities.

Addressing issues such as homelessness, substance abuse, food security, health literacy, and other social determinants of health is essential to improve outcomes in this population. Housing is a basic human necessity, and homeless persons suffering from mental illness and SUD are especially vulnerable. "Housing First" (HF) is an example of a program designed to prioritize moving homeless persons with SMI and SUD quickly into housing. HF is designed to assist with initial housing costs including security deposits, first month's rent and essential furnishings, and household items. HF does not require sobriety as a precondition for housing, and this approach has demonstrated improved outcomes for this homeless population [28].

Table 27.2 Prevalence of mental illness in the US prison population compared to the general population[a]

Disorder	Prevalence in state prisons by percent	Prevalence in general population in the USA by percent
Any mental illness	10–32	18
Schizophrenia	2–7	1
Bipolar	5–16	4
Major depression	9–29	7
Generalized anxiety	2–26	6
Post-traumatic stress	2–48	7

[a]Data on US general population from the National Institute of Mental Health website: transforming the understanding and treatment of mental illness. Data on US prison population from Prins, S.J. Prevalence of mental illnesses in US State Prisons: a systematic review

At-Risk Children and Youth

The term "at-risk children or youth" is widely used, but its specificity is limited since it potentially could include most children. For health-care providers, children or youth can be considered "at risk" by way of their compromising social conditions, the lack of a stable family unit, a history of victimization, or their sequelae from mental illness or substance use disorders (SUD). At-risk children and youth come from a number of backgrounds. In 2013 in the USA, there were approximately 641,000 children and youth, aged 0–21 years old, who had spent time in foster care. Unfortunately, abuse or neglect was documented in more than 70%, and more than 80% were exposed to violence [29]. Children in foster care and youth aging out of foster care carry an undue burden of medical and psychiatric disorders [29]. When compared to other at-risk children and youth, this group will often have high rates of adverse childhood experiences (ACEs), which are listed in Table 27.3. High ACE scores, for any child, predict poor mental health and physical health outcomes as well as the development of SUD [30]. Figure 27.2 illustrates the progression of psychosocial dysfunction and eventual poor

Table 27.3 List of adverse childhood experiences[a]

Physical abuse
Sexual abuse
Emotional abuse
Physical neglect
Emotional neglect
Mother treated violently
Household mental illness
Substance misuse within household
Parental separation or divorce
Incarcerated household member

[a]Adapted from SAMHSA website on adverse childhood experiences

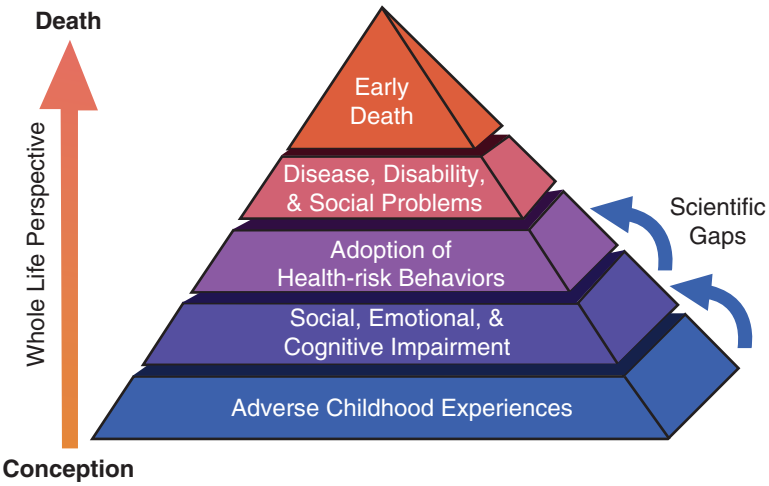

Fig. 27.2 Adverse childhood experiences pyramid (Modified from the Substance Abuse and Mental Health Services Administration (SAMHSA))

health and mental health outcomes experienced by children with high ACE scores.

Homeless children and youth have increased rates of mental illness, SUD, and comorbidities associated with abuse, neglect, and violence. They are also frequently victims of sexual abuse and human trafficking. A survey of homeless youth in New York City in 2013 showed that 48% had engaged in commercial sex to meet basic needs for food and shelter [31]. Children raised in poverty experience similar barriers to health care as poor adults. Additionally, environmental exposures in substandard housing are linked to higher rates of asthma and skin conditions (Fig. 27.2).

Targeted strategies to address the needs of specific at-risk children and youth have been found to be effective. School-based health centers (SBHCs), for example, provide improved access to care for all children but can be especially effective for children facing multiple barriers to comprehensive health-care services. Community-based interventions like the Harlem Children's Zone have demonstrated significant improvements in overall health and education by addressing specific social determinants of health of a defined geographic location [32].

Homeless and Housing Insecure

Homeless and housing-insecure people and families are at increased risk for acute illness and chronic disease. Homeless persons have mortality rates three to four times higher than the general population, with an average lifespan of less than 45 years [33]. Rates of smoking and hypertension are higher among homeless persons than in the general population. Forty-three percent of homeless persons suffer from mental illness or a substance use disorder, with 23% suffering from both [34].

Data from January 2015 showed on a single night that nearly 600,000 people were homeless in the USA, with 61% staying in residential programs and 31% were unsheltered. Families with children were 36% of the homeless, while 64% were individuals. Children under the age of 18 represented 23% of the homeless, with 68% being older than 25 years of age. Unaccompanied youth accounted for 36,907 of the homeless, 13% of those were under 18 years of age [35]. Veterans are at high risk for homelessness and make up more than 12% of the homeless population.

Homeless children have increased rates of sexual abuse and rape, physical violence, depression, and suicide. Homeless adults also suffer from high rates of physical and sexual violence, as well as greater morbidity and mortality from chronic disease such as diabetes and cardiovascular disease. More than 50% of homeless women have been sexually assaulted [34].

Many homeless persons feel marginalized by the health-care system and are reluctant to access services [33]. Although the challenges to effective treatment of chronic medical illness in this population are many, programs that provide services where homeless persons congregate have shown encouraging results in improving their health outcomes [36].

Federally funded programs like Health Care for the Homeless seek to provide care and support services to this highly vulnerable population [37]. Permanent supportive housing (PSH) programs, such as "Housing First," have resulted in improved rates of moving homeless persons with SMI and/or SUD into housing, which is considered a crucial first step to improve overall health for this at-risk population [28]. Another important intervention has been the development of medical respite programs for homeless persons. Homeless people are especially challenged after illness or hospitalization to find secure and safe housing for recuperation. These initiatives can provide stable, secure housing with medical support during treatment or recuperation from illness [38].

Incarcerated and Formerly Incarcerated

There are more than 2.3 million people incarcerated in the USA within 1719 state prisons, 102 federal prisons, 942 juvenile correctional facilities, 3283 local jails, and 79 other facilities. Of the total prison population, 91% are male and 9% are female. There are 34,000 youth under 18 years old in custody. Significant racial and ethnic disparities exist among incarcerated individuals, where Whites make up 64% of the general population and account for 39% of the prison population. Blacks and Hispanics make up 13% and 16% of the general population, respectively; however, Blacks account for 40% of the prison population, and Hispanics account for 19% [39]. Fifty-two thousand persons are incarcerated for immigration-related infractions.

The cycle of release, recidivism, and return to prison and jail is a significant barrier to consistently identifying and addressing medical and behavioral health problems in this population. Annually, over 600,000 persons are released from prison, and there are 11 million entries into jails. One in five incarcerated persons is charged with drug offenses which may indicate large numbers of incarcerated persons who struggle with some form of drug dependency. Many incarcerated persons have had poor access to health care prior to their entry and are diagnosed with chronic disease upon or during incarceration [40]. The Federal Bureau of Statistics reported that in 2011–2012, 40% of federal and state prisoners reported having a chronic medical condition. Thirty percent of prisoners reported having high blood pressure, 9% diabetes mellitus, and 1.3% HIV/AIDS (see Table 27.4). Additionally, rates of diabetes and hypertension increased among the prison population when compared to data from 2002. Seventy-four percent of prisoners were overweight, obese, or morbidly obese [41].

In many areas of our nation, prisons and jails have become the default providers of care services for persons suffering from mental illness and substance use disorders. Twenty percent of the prison population is estimated to have severe mental illness, and 30–60% suffer from substance use disorders [42]. It is estimated that mental health services will be needed by 50% of males and 75% of female prisoners and that a person with severe mental illness is three times more likely to be in a jail or prison than in a mental health facility. In fact, 40% of people with severe mental illness will have been incarcerated at some point in their lives [42].

Care for inmates or formerly incarcerated persons begins by recognizing some of the social determinants of health that can contribute to incarceration. A significant contributor to the high incarceration rates in the USA is the criminal justice policy regarding drug-related arrests, convictions, and sentencing. Although the USA accounts for less than 5% of the world's population, it accounts for nearly 25% of incarcerated people worldwide [43]. In 2014 there were 1.5 million drug arrests. 80% for possession only, and 500,000 people are incarcerated for a drug law violation, which is ten times higher than in 1980 [44]. Sentencing laws and incarceration not only impacts the individual but is highly disruptive to families. Nearly three million children, for example, are growing up with one or more incarcerated parents. Healthcare providers can address their own stigmas about the dangers of working with this population by understanding that incarcerated and formerly incarcerated persons commonly have criminal records only for possession of drugs [44].

Formerly incarcerated persons (FIPs) face many challenges to access health care upon release. There is a rise in the mortality rate for a prisoner during the first 2 weeks post-release [45], largely due to opioid overdose [46]. Many states lack programs to assist FIPs with SUD, as well as those with chronic disease and mental illness, in accessing medical services and behavior health services [47]. From a policy perspective, FIPs living in states that have not expanded Medicaid face barriers to obtain health insurance, and they will likely not qualify for Medicaid unless they are disabled. At the practice level, clinics designed to help FIPs transition back into society have shown promising results in improving health outcomes for this population [47]. A key component of these programs is the use of peer community health work-

Table 27.4 Prevalence of ever having a chronic condition or infectious disease among state and federal prisoners compared to the general population (2011–2012)

Chronic condition/ infectious disease	State and federal prisoners (percent)	General population (percent)
Ever had a chronic condition	43.9	31
Cancer	3.5	
Hypertension	30.2	18
Stroke-related problem	1.8	0.7
Diabetes	9.0	6.5
Heart-related problem	9.8	2.9
Kidney-related problem	6.1	[a]
Arthritis	15	[a]
Asthma	14.9	10
Cirrhosis of the liver	1.8	0.2
Ever had an infectious disease	21	0.2
Tuberculosis	6.0	0.1
Hepatitis	10.9	[a]
Hepatitis B	2.7	[a]
Hepatitis C	9.8	[a]
STDs	6.0	0.1
HIV/AIDS	1.3	0.1

Adapted from the Bureau of Justice Statistics, Medical Problems of State and Federal Prisoners and Jail Inmates (2011–2012) (http://www.bjs.gov/index.cfm?ty=pbdetail&iid=5219)

[a]Data not collected in comparison study, National Survey on Drug Use and Health (2009–2012)

ers that can establish rapport and assist FIPs with various aspects of reentry, including accessing health care.

Care Models for Vulnerable Populations

Case Management

Case management strategies have been employed to improve outcomes and reduce costs for many vulnerable populations. Case management is defined by the Case Management Society of America as "a collaborative process of assessment, planning, facilitation, care coordination, evaluation, and advocacy for options and services to meet an individual's and family's comprehensive health needs through communication and available resources to promote quality, cost-effective outcomes." For example, effective strategies have been developed to assist elderly patients with heart failure (HF), and a team approach including nurses, social workers, pharmacists, and clinicians provides support to patients in the outpatient setting. Individual social workers can also assist patients in addressing barriers to care that may include transportation, food security, housing assistance, and other basic services. Patients are contacted frequently to track symptoms and daily weights, verify medication compliance, and assist with dosage adjustments of diuretics to avoid volume overload and worsening of HF. Although these efforts can be expensive, many have been shown to be cost-effective in their ability to reduce hospitalizations and the use of emergency services [48, 49].

Population health-based interventions that identify patients at high risk for hospitalization, emergency room utilization, and poor medication adherence have shown positive, sustained results. State-wide programs like Community Care of North Carolina (CCNC) have effectively partnered with primary care practices to assist in managing the high-utilizing, high-risk patients and have improved clinical outcomes while reducing costs. CCNC employs a team-based approach utilizing community-based nurse care managers, pharmacists, behavioral health specialists, social workers, and clinical directors, supported by a robust informatics center [50].

Hot Spotting

The concept of hot spotting is based on geographically identifying and focusing interventions on the 5% of super-utilizers of health care, a group that accounts for nearly 50% of health-care costs in the USA [51]. Hot spotting analyzes health-care utilization data to identify super-utilizers for intensive case management. Many of these super-utilizers fall into the vulnerable populations that were described earlier. A leader in this innovation is the Camden Coalition of Healthcare Providers (Camden, NJ), a collaboration focusing on the 1% of super-utilizers that accounted for 30% of their health-care expenditures in an economically challenged region [52]. Initially, the model focused on more traditional care management, but over time this approach has expanded to include assessing several social determinants of health, such as housing and homelessness, food security, mental health and SUD treatment, and community support. Hot spotting has been applied to a number of populations with results that confirm its utility in improving outcomes while reducing costs [51].

Assertive Community Treatment (ACT) Teams

ACT teams are outpatient-based care teams designed to assist vulnerable patients with severe mental illness (SMI) [53]. Patients are visited as often as three times weekly by a member of the team to help patients execute their care plans, an approach that has been found effective in reducing the use of emergency services and hospitalizations. Team members include psychiatrists, nurses, social workers, and other behavioral health specialists [53]. ACT teams are able to monitor patients closely and intervene early to help improve outcomes and maintain control of symptoms. ACT teams have intensive services with a 1:10 ratio of clients to team members and caseloads of 100 clients [53].

Home Care for Elderly

Elderly patients frequently suffer from isolation and have multiple barriers to accessing and affording health care, such as transportation to medical visits. Home visits allow the care team, often a clinician and nurse, to more completely assess the home for safety, gain insight into the patient's living conditions and support the community, more accurately perform medication reconciliation, and confirm adherence. Although widely used, systematic reviews of these programs to date have shown mixed benefits [54].

Programs of All-Inclusive Care for the Elderly (PACE)

PACE programs are cost-effective care models allowing elderly patients with chronic illness to continue living in their homes and communities [55]. PACE programs offer comprehensive outpatient services and transportation to elderly frail patients who would otherwise require institutionalization to meet their needs. PACE enrollees may spend 5 days a week at the central PACE facility where they can

obtain medical care, physical and occupational therapy, nursing care, pharmacy services, and social activities. They are supported by Medicare and Medicaid, but PACE organizations must take full financial risk for the patients that are attributed to the program.

School-Based Health Centers

There are approximately 2300 school-based health centers (SBHCs) in the USA, a model that can play an important role in caring for vulnerable children. SBHCs have been shown to improve both health and mental health outcomes for children as well as improved school attendance and academic achievement [56, 57]. They provide an array of medical, behavioral, and health education services that are easily accessible to school-age children and can help ensure compliance with treatment plans and improve follow-up. When coupled with behavioral health care, they can assist in screening and identifying children with behavioral health needs and provide services at the school. SBHCs have also been shown to improve sexual health, rates of contraception use, and reductions in pregnancies [57].

Permanent Supportive Housing

Homeless people with mental illness and substance use disorders can benefit from permanent supportive housing (PSH) programs [58]. PSH, as defined by the Substance Abuse and Mental Health Services Administration (SAMHSA), is a permanent supportive housing as a direct service that helps adults with mental and substance use disorders who are homeless or disabled identify and secure long-term, affordable, independent housing [58]. The level of supervision and services among PSH programs can vary, but they all share the central principle that housing is the cornerstone of recovery and wellness. In addition to housing, they provide services which may include mental health treatment, substance use disorder treatment, vocational training, life skills, and more. PSH programs have been shown to reduce homelessness, emergency room utilization, and hospitalizations among this vulnerable population.

Health Care for the Homeless

Cities such as Boston and Houston have successful comprehensive health programs that include outreach to geographic locations where homeless persons live, as well as health-care clinics specifically designed to address the needs of the homeless [59, 60]. The Boston Health Care for the Homeless Program (BHCHP) is a citywide program that coordinates care for homeless persons at 78 different sites in the city [59]. BHCHP also provides respite and rehabilitation services for homeless persons during recuperation from an illness or surgery. The program includes comprehensive medical, mental health, and substance use disorder treatment and works toward moving people into secure housing.

Programs that are designed to specifically address the needs of the homeless are crucial to mitigate the marginalization that vulnerable, homeless persons have endured and to assist them in their interactions with a health-care system. Some homeless persons may elect to stay living on the streets, and thus interventions to move them into housing or provide shelter services are not effective. For these individuals, meeting them where they live can help them to engage in their health care and allow them to receive diagnostic testing, treatment, and follow-up.

Community Stakeholders and Partners in Caring for Vulnerable Populations

Addressing the health-care needs of vulnerable populations is greatly enhanced by an approach that recognizes the unique needs of those defined populations. Understanding the societal and cultural issues faced by certain populations, and the social determinants of health that impact well-being, is crucial in developing effective strategies to improve health. These strategies must rely on interventions outside the walls of a traditional clinic and direct attention and resources outside of that setting. Identifying community partners and stakeholders that share concerns for a vulnerable population is key for developing sustainable and effective interventions. The Harlem Children's Zone is an example of a community-based program that works across the spectrum of social services, educational institutions, and health-care organizations to enhance an environment in which children are being raised, resulting in improved outcomes beyond those found in traditional medically based settings [61].

Reentry programs are another example of community-based interventions that encourage and promote participation from multiple stakeholders to improve outcomes for formerly incarcerated persons (FIPs). Successful reentry is enhanced by the coordination of governmental and nongovernmental organizations. At the federal or state level, the prison system has parole or post-release supervision aiming to reduce recidivism. Housing needs for FIP can be addressed through shelters, halfway houses, permanent supportive housing, and other less traditional settings. Local governments often coordinate reentry services such as vocational training, life skills, legal aid, and SUD treatment in a centralized location. As discussed above, coordinating with community medical and

mental health providers is essential for recently released prisoners with chronic disease, mental illness, and/or SUD.

Future Directions in Caring for Vulnerable Populations

There is a growing interest, from both humanitarian and financial sectors, in improving systems of care for vulnerable populations with chronic disease. Advances in population health approaches and in information technology will allow more precise analysis of health-care utilization patterns and the design of interventions for targeted populations. These developments have great potential to guide new interventions that will promote care and subsequently decrease the high rates of avoidable utilization. As payment models move from fee-for-service and toward value-based purchasing, new opportunities will arise to more fully address the social determinants of heath and, concomitantly, provide more comprehensive ways to care for vulnerable populations.

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Part IV

Organizational Frameworks for Chronic Illness Care

Patient-Centered Medical Home

28

Mark D. Gwynne and Timothy P. Daaleman

Introduction

The patient-centered medical home (PCMH) is a conceptual framework and operational model for primary care service delivery that began over a decade ago in response to a progressively fractionated and dysfunctional health-care system in the United States [1]. At that time, the Institute of Medicine published a landmark report, *Crossing the Quality Chasm*, which described a care delivery system that lagged behind medical science and technology, and did not adequately manage the complex medical and psychosocial disease burden of the population [2]. The report directed attention to poorly organized and uncoordinated care models and strategies that inconsistently delivered evidence-based interventions and resulted in worse health outcomes that were especially disproportionate for vulnerable patients and those with chronic illness [2].

Reimbursement indexed to fee-for-service models and a production-based orientation that sought to maximize each unit of health-care service further added to a dysfunctional care delivery system [2]. This reimbursement model drove health-care providers, such as physicians, hospitals, and health-care systems, to provide as much care, to see as many patients, and to do as many procedures, as possible. Health-care services that had demonstrated value, such as facilitated communication between providers, chronic disease self-management, and integrated behavioral health care, were not supported through existing payment models and, invariably, were not standardized and operationalized [2]. From a workforce perspective, medical and associated health-care learners were not entering into primary care careers, emphasizing the need to attract and sustain such a workforce [2].

The PCMH model grew in response to these forces and is now the dominant care delivery model in primary care [3]. This chapter provides an introduction and overview to the PCMH. The first section outlines the intellectual roots that led to development of the PCMH model. The middle portion of the chapter describes key functions of the medical home and assesses the emerging evidence base for this care delivery framework. The subsequent section provides an overview to implementation strategies for PCMH in primary care before the chapter closes with future directions of the PCMH within a changing health-care landscape.

Intellectual Roots of the Patient-Centered Medical Home

The concept of a medical home for patients has been in the primary care intellectual space for decades [4]. The origin of the term "medical home" can be linked to the 1967 American Academy of Pediatrics (AAP) *Standards of Child Health Care*, which described the lack of a complete record and a medical home as a major deterrent to adequate health supervision for children [5]. In some states in the 1970s, however, the term became controversial as legislators misinterpreted the concept as impinging on parental rights and responsibilities. Pediatricians addressed and reframed this orientation and, throughout the 1980s, continued to press the need for accessible care that would be coordinated for children through a medical home [6]. The AAP published the first policy statement about the medical home in 1992 in an attempt to frame the concept and offer an operational definition [6]. The statement clarified that the medical home sought to provide care for children that was accessible, family centered, continuous, comprehensive, coordinated, compassionate, and culturally effective [6].

There was a parallel movement emerging in international health-care circles. The World Health Organization's (WHO) International Conference on Primary Health Care at Alma-Ata

M.D. Gwynne
UNC Chapel Hill School of Medicine, Department of Family Medicine, Chapel Hill, NC, USA

T.P. Daaleman (✉)
Department of Family Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA
e-mail: tim_daaleman@med.unc.edu

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in 1978 outlined a scope of primary care and incorporated concepts that are visible in the contemporary PCMH model: access to care, continuity of care, comprehensiveness and integration of care, patient education and participation, team-based care, and public policy that supports primary care [7]. About that time, the Institute of Medicine (IOM) defined primary care as care that was accessible, comprehensive, coordinated, continuous, and accountable, key principles which informed a report, *Primary Care: America's Health in a New Era*, that would be published two decades later [8]. The report promoted the role of primary care and clarified that it was not a defined group of clinicians but rather a function of health care which would be responsible for providing integrated, accessible health-care services and accountable for addressing a majority of health needs in the context of families and communities [8].

The IOM report emphasized the role of primary care in providing continuity of care and broadened the concept to include continuity or ongoing, sustained care, delivered by a clinical team of professionals with an array of expertise focusing on improving the quality of care [8]. To achieve these aims, the IOM identified the need for new financing mechanisms to support primary care clinician training, to provide access to primary care for all patients, to advance practice-based primary care research networks, and to improve evidence-informed medical decision-making [8]. Barbara Starfield further advocated for primary care as the foundation of a health-care system with several features: the first point of entry to a health-care system; the provider of person-focused (not disease-oriented) care over time; the care provider for the majority of conditions; and key components of the system that integrate and coordinate care [9].

In the late 1990s and early 2000s, Ed Wagner and colleagues at the MacColl Institute for Healthcare Innovation developed the Chronic Care Model as a framework to improve the management of complex and chronic disease [10]. The foundational principles of the care model focused on developing prepared teams of clinicians to proactively deliver care to informed, activated patients [10]. The key concepts of team-based care, care coordination, and quality care that are outlined in the Chronic Care Model are foundational concepts of the patient-centered medical home [10].

The Chronic Care Model and medical home concepts helped inform leading national family medicine organizations of ways to think about transforming ambulatory care delivery and led to the Future of Family Medicine (FFM) project and a new model of practice [1]. The new model outlined several goals: (1) implementing a patient-centered team approach, (2) eliminating barriers to access, (3) utilizing advanced information systems including electronic health records, (4) redesigning practice settings to be more functional, (5) focusing on quality and other specified outcomes, and (6) enhancing practice finance and payment models to support new care delivery [1].

In 2007, four national physician organizations representing over 300,000 physicians and primary care stakeholders—the American Academy of Family Physicians (AAFP), the American Academy of Pediatrics (AAP), the American College of Physicians (ACP), and the American Osteopathic Association (AOA)—issued the joint principles of the patient-centered medical home, a foundational document that helped stimulate the transformation of health care in the United States [11]. The joint principles identified seven principles, and these are presented in Table 28.1.

Table 28.1 Joint principles of the patient-centered medical home (PCMH)

Personal physician	Patients have an ongoing relationship with a personal physician who provides first contact, continuous, and comprehensive care
Physician-directed medical practice	A personal physician leads a team of care providers who collectively take responsibility for a patient's care
Whole-person orientation	The personal physician is responsible for providing all of a patient's health-care needs, including acute, chronic, and preventive services, for all stages of life including end of life care or takes responsibility to arrange for appropriate care with other health-care providers
Care is coordinated and/or integrated	The personal physician and care team coordinate care throughout the continuum of the complex health-care system and the patient's community. Care facilitated by integrated data to assure patients receive evidence-based, culturally appropriate care when and where they need it
Quality and safety: hallmarks of the medical home	Practices provide care that is Based on patient-centered outcomes Compassionate and in partnership with patients and their families Guided by decision-support tools Uses information technology to provide evidence-based care, measures performance, provides patient education, and enhances communication Continuously improved using key principles of quality improvement that involve patients and families at the practice level Responsive to patient feedback
Enhanced access	Patient access to care maximized through concepts of advanced access scheduling, expanded office hours, electronic visits, and new communication options such as patient portals
Payment reform	Payors recognize the value provided by a patient-centered medical home and structure payment models that support non-face-face work including care management and care coordination, use of health information technology for quality improvement, population-based care delivery, and enhanced communication infrastructure and recognize the variation in risk among patient populations in practices

Adapted from Ref. [11]

Table 28.2 National Committee for Quality Assurance patient-centered medical home standards

Standard 1: patient-centered access	Access to team-based care for routine and urgent needs of patients and families at all times
Standard 2: team-based care	The practice provides continuity of care using culturally and linguistically appropriate team-based approaches to care delivery
Standard 3: population health management	The practice uses a comprehensive health assessment and evidence-based decision support based on complete patient information and clinical data to manage the health of its entire patient population
Standard 4: care management and support	The practice systematically identifies individual patients and plans, manages and coordinates care, based on need
Standard 5: care coordination and care transitions	The practice systematically tracks tests and coordinates care across specialty care, facility-based care, and community organizations
Standard 6: performance measurement and quality improvement	The practice uses performance data to identify opportunities for improvement and acts to improve clinical quality, efficiency, and patient experience

Adapted from Ref. [12]

Another group, the Patient-Centered Primary Care Collaborative (PCPCC), was founded in 2006 to promote policies and best practices that support high-performing primary care in achieving the "Quadruple Aim": better care, better health, lower costs, and greater joy for clinicians and staff in the delivery of care [5]. The PCPCC developed eligibility criteria for practices which sought to be recognized as a PCMH in order to create an industry standard and to provide a mechanism for provider reimbursement for PCMH functions [4]. The eligibility criteria for recognition as a PCMH were adopted by the National Committee for Quality Assurance (NCQA) in 2008 and updated in 2011 and 2014 (Table 28.2) [12]. Although the NCQA has been an early leader in PCMH recognition, other accrediting bodies have established recognition programs, including the Accreditation Association for Ambulatory Health Care, URAC (formerly the Utilization Review Accreditation Commission), and The Joint Commission [4].

Key Functions of the Medical Home

The Agency for Healthcare Research and Quality (AHRQ) defines a medical home as an organizational model of primary care that encompasses five functions and associated attributes [13].

Comprehensive Care

The patient-centered medical home (PCMH) is accountable for meeting the large majority of patients' physical and mental health-care needs and requires a team of care providers [13]. Some medical homes may bring together large and diverse teams of care providers, while others link themselves and their patients to providers and services in their communities. Within this framework, the physician is both personal physician and the leader of a team of providers and staff who work together in delivering patient care. In addition to directly managing patients' clinical conditions, physicians practicing within a PCMH need skillsets to both provide care and manage the care provided by other members of the care team [13].

Almost one third of adults with medical disease also have comorbid mental health diagnoses; behavioral and mental health conditions are commonly encountered in primary care [14]. Functional team-based care within the PCMH can operationalize the relationship between medical and behavioral health providers, integrating workflows to support the identification and management of mental and behavioral health disorders, particularly in vulnerable patients. The IMPACT model of depression management is a widely studied and adopted approach to integrating behavioral health approach within primary care [15]. Operationally, this model expands the primary care team to include a care manager, a consultant psychiatrist, and, in some settings, a clinical psychologist to screen and address behavioral health issues, promote evidence-based treatment protocols, and provide direct services when indicated [15]. This team-based approach to managing mood disorders demonstrated a 50% reduction in depression symptoms for half of the patients managed under this model [15].

The evidence base for integrating behavioral health teams into the PCMH compelled 11 major national primary care organizations to endorse the Joint Principles: Integrating Behavioral Care into the PCMH [16]. These groups maintained that patient-centered medical homes could not be successful without systematically addressing key elements of integrated behavioral health care [16] The Behavioral Joint Principles shared characteristics with the principles of PCMH, enhanced access, team-based care, whole-person orientation, coordinated and integrated care, quality, and ultimately payment reform, to address behavioral health needs. In addition, the Behavioral Joint Principles outlined the need for clear role definitions among providers caring for patients' behavioral health needs and interdisciplinary training among care providers and targeted research to identify and implement programs designed to deliver whole-person care in the PCMH [16].

There are other comprehensive care models that are oriented to manage patients who have complex medical needs, significant barriers to care, or other social determinants of health. Peer support, for example, has emerged as a successful strategy to extend care delivery from a medical home into the community and has shown significant outcomes in decreased morbidity and mortality rates, increased life expectancy, improved patient self-efficacy, improved medication adherence, and reduced cost of care through decreased use of emergency services [17]. CommunityRx is another initiative that linked e-prescribing in the electronic health record of primary care practices to a database of local community resources that addressed basic patient services, wellness programs, and community-based disease self-management programs [18].

Patient-Centered

The PCMH ideally provides relationship-based health care that is oriented to the whole person [13]. Partnering with patients and their families requires understanding and respecting each patient's unique needs, culture, values, and preferences. The PCMH recognizes that patients and families are core members of the care team, and medical homes promote patients as full partners in establishing care plans. Personal doctoring is a tenet of patient-centeredness and is based on physicians and patients maintaining meaningful, continuing relationships over time. Continuity of care is central to the medical home and has been demonstrated to improve patient outcomes, including decreased emergency department utilization and hospitalizations, increased preventive services, improved patient satisfaction of care, and reduced cardiovascular mortality [19]. Given the importance of continuity in improving patient outcomes, many medical homes now measure and track continuity in an effort to maximize patient-PCP relationships, balance patient access to care, and actively manage patient panels.

Coordinated Care

The PCMH coordinates care across all aspects of the larger health-care system, including specialty care, hospitals, home health care, and community-based services. Care coordination is particularly critical during transitions of care, such as hospital discharge. Care teams are integral to coordinated care and come in many forms. A care team can be as simple as a physician and one or more medical assistants caring for a panel of patients. The teamlet model enhanced the role of medical assistants to include preplanning for individual patient office visits, promoted patient self-management skills during a visit, and supported patient and provider care goals through after-visit outreach [20]. This approach to team-based care can effectively expand patient access to care when in-office availability is limited [20].

There are other coordinated care models that are designed to manage patients with multiple health-care needs. Physician-pharmacist teams, for example, can manage complex medication regimens that many patents struggle to navigate. Pharmacists who are embedded in medical homes work directly with primary care providers on both direct patient care and population management interventions and have demonstrated improved management of chronic disease and care of patients transitioning out of the hospital [21, 22]. Clinical pharmacists are particularly skilled in simplifying medication regimens, identifying cost effective medications, teaching appropriate medication use such as inhalers and insulin, and identifying current or potentially adverse medication interactions [21].

Accessible Services

The primary care medical home delivers accessible services with shorter wait times for urgent needs, enhanced in-person hours, around-the-clock telephone or electronic access to a member of the care team, and alternative methods of communication, such as email and telephone care [2]. Ideally, the medical home practice is responsive to patients' preferences regarding access [13].

Quality and Safety

High-functioning PCHMs demonstrate a commitment to quality improvement by ongoing engagement in evidence-based medicine and clinical decision-support tools. These approaches can promote individual and practice-based performance measurement and improvement by measuring and responding to the patient care experience, and through population health management strategies [23]. As noted earlier, well-organized care teams can be effective in delivering high-quality patient care. TeamSTEPPS, developed jointly by the Agency for Healthcare Research and Quality (AHRQ) and the Department of Defense, is one model [24]. In this approach, clinicians and staff members have clearly delineated roles and responsibilities, from managing provider schedules to appropriately triaging or responding to patient's phone messages and to providing direct clinical care. TeamSTEPPS concepts promote physician-led care teams, utilizing more staff in direct and indirect patient care, and free up physicians to thoughtfully engage in patients in responding to complex care needs [24].

Evidence Base of the Patient-Centered Medical Home

The Agency for Healthcare Research and Quality (AHRQ) commissioned a study to systematically review the evidence on the effectiveness of the patient-centered medical home (PCMH) model [25]. The review included nearly 500 articles from January 2000 to September 2010 that met the following inclusion criteria: (1) tested a primary care, practice-based intervention with three or more of five PCMH components and (2) conducted a quantitative evaluation of either (a) a triple aim outcome (quality of care, costs (or hospital use or emergency department use, two major cost drivers), and patient or caregiver experience) or (b) health-care professional experience [25]. A total of 14 evaluations from 12 interventions met this criteria, and these are displayed in Table 28.3.

AHRQ developed and applied a formal rating system using rigorous methods and synthesized the evidence of effectiveness that was tied to specific outcomes [25]. Six of the fourteen evaluations were designated with a high or moderate rating for analysis of at least one outcome. The interventions in these studies, such as embedded care managers, varied in their impact on key outcomes. Some had favorable effects on quality and patient and caregiver experience of care while a few unfavorable effects on costs, and many had inconclusive results across all outcomes [25].

- *Quality of care.* In evaluations that were designated as rigorous, there were favorable effects on quality of care: one of three evaluations reported improvements in care processes, and two noted improvements in health outcome measures. The remaining evaluations that measured these outcomes, in addition to evaluations that include mortality, produced inconclusive evidence [25].
- *Cost and service use.* The evidence on cost and service use shows limited favorable effects, some unfavorable effects on cost, and many inconclusive results in the PCMH models that were evaluated. The GRACE initiative (i.e., in-home assessments and care planning by care managers for at-risk geriatric patients) was the only intervention to find evidence of cost savings, and these were limited to the high-risk subgroup of Medicare patients in the latter phases of the intervention [25]. Both GRACE and VA Home-Based Primary Care (i.e., home-based primary care coordinated by interdisciplinary care team) increased total costs during the intervention, while evidence from two other interventions—Guided Care and IMPACT—was inconclusive [25]. Geisinger's ProvenHealth Navigator was the only program to report reductions in hospital utilization for its full panel of patients; two other evaluations (GRACE and VA Home-Based Primary Care) reported

Table 28.3 AHRQ-reviewed patient-centered medical home interventions

Intervention	Description	Reference
Case managers	Nurse case managers in primary care practices to manage Medicare Advantage members and collaborate with the clinical team	Hostetter [44]
Care management plus	Nurse care managers supported by specialized health IT tools embedded within primary care clinics to coordinate care for chronically ill elderly patients	Agency for Healthcare Research and Quality [45]
Community Care of North Carolina	Community-based care management provided through networks of primary care physicians, hospitals, the Department of Social Services, and local health departments	Steiner et al. [46]
Geisinger Health System's ProvenHealth Navigator	Embedded nurse case manager for Medicare Advantage patients in primary care practices to identify high-risk patients, design patient-centered care plans, provide care coordination and care transition support, and monitor patients using patient-accessible electronic health records	Gilfillan et al. [47]
Geriatric Resources for Assessment and Care of Elders (GRACE)	Advanced practice nurse and social worker assess low-income seniors in home and develop and implement a care plan with a geriatric interdisciplinary team, in collaboration with the patient's PCP	Bielaszka-DuVernay [48]
Group Health Cooperative Medical Home	PCMH-informed clinic redesign including changing staffing, scheduling, point of care, patient outreach, health IT, and management, reducing caseloads, increasing visit times, using team huddles, and introducing rapid process improvements	Group Health News [49]
Guided care	Guided care nurse embedded in primary care practice who provides assessments, care plans, monthly monitoring, and transitional care to at-risk Medicare patients	Boult et al. [50]

(continued)

Table 28.3 (continued)

Intervention	Description	Reference
Improving Mood: Promoting Access to Collaborative Treatment for Late-Life Depression (IMPACT)	Behavioral health clinical specialist care manager embedded in primary care practice to provide depression care for elderly depressed patients in coordination with the PCP, a consulting PCP, and a psychiatrist	Hunkeler et al. [51]
Merit Health System and Blue Cross Blue Shield (BCBS) of North Dakota Chronic Disease Management Pilot	Chronic disease management nurse embedded in clinic for diabetic patients to assess the patients' knowledge of diabetes, set goals for disease self-management, facilitate follow-up, and care coordination	Fields et al. [52]
Pediatric Alliance for Coordinated Care	Dedicated pediatric nurse practitioner coordinates the care of children with special health-care needs and make expedited referrals to specialists and hospitals. Parent of a child with special health-care needs provides consultations to the practice	Palfrey et al. [53]
Pennsylvania Chronic Care Initiative	Integrates the Chronic Care Model and the medical home model for patients with diabetes and pediatric patients with asthma	AcademyHealth State Health Research and Policy Interest Group [54]
Veterans Affairs Team-Managed Home-Based Primary Care	Comprehensive and longitudinal primary care provided by an interdisciplinary team that includes a home-based primary care nurse for veterans with complex, chronic, terminal, or disabling diseases	U.S. Department of Veterans Affairs [55]

Adapted from Ref. [13]

cost reductions only for their high-risk subgroups in some follow-up periods [25]. Evidence on hospital use from the other initiatives was inconclusive. Only one program (i.e., GRACE) found reductions in emergency department utilization during a follow-up period, but evidence of cost reductions from the other programs was inconclusive [25].

- *Experience of care.* AHRQ's review of the evidence of the PCMH model on patient and caregiver experience demonstrates some favorable effects, while some areas remain inconclusive [25].
- *Professional experience.* There was a single evaluation on professional experience which was reported as inconclusive [25].

AHRQ concluded that, with the exception of some favorable effects on quality of care, hospital and emergency department utilization, and patient and caregiver experience of care and a few unfavorable effects on costs, the findings on the effectiveness of key PCMH components were largely inconclusive at the time of their review [25]. The review noted limitations and cautioned that the sample size was insufficient to detect plausible effects and that the statistical significance of the effects was potentially overstated owing to lack of adjustment for clustering of patients within practices [25].

Patient-Centered Medical Home Implementation

The Commonwealth Fund, Qualis Health, and the MacColl Center for Health Care Innovation at the Group Health Research Institute initiated a 5-year demonstration project in 2008 to help a network of primary care safety net practices become patient-centered medical homes [26]. The goal of the Safety Net Medical Home Initiative (i.e., the Initiative) was to develop an implementation model for medical home transformation, which called for partnerships between safety net providers and community stakeholders. There were five regional coordinating centers that partnered with 10–15 primary care safety net sites in Colorado, Idaho, Massachusetts, Oregon, and Pennsylvania [26]. The Initiative framework used eight change concepts that were embedded in four stages to guide specific, actionable steps in practice improvement:

- Laying the Foundation: Engaged Leadership and Quality Improvement Strategy
- Building Relationships: Empanelment and Continuous and Team-Based Healing Relationships
- Changing Care Delivery: Organized, Evidence-Based Care and Patient-Centered Interactions
- Reducing Barriers to Care: Enhanced Access and Care Coordination [26]

Engaged Leadership [27]

To facilitate PCMH transformation, leaders needed to be engaged in charting the course for change and support and sustain change efforts. Associated responsibilities included identifying and allocating resources to support PCMH trans-

formation needs and being physically present throughout transformation to sustain staff motivation and to identify and remove barriers to transformation [27]. At the outset, leaders need to make the case for transformation to staff, who need to understand the what, why, and how of PCMH. In addition, to gain financial support for transformation efforts, leaders need to articulate the business case for transformation. Leadership needs to ensure adequate time and resources for transformation work, including quality improvement, team meetings, and other work essential for transformation [27].

Once the burning platform and vision for transformation have been articulated, key tenets of PCMH need to be part of the practice's mission and values, and operationalized into what is expected in everyday work [27]. PCMH concepts should inform hiring and employee performance reviews, since staff will understand expected behaviors and can judge if the practice is a good fit with their own values. Leaders need to identify a team of champions and practice staff who will actively voice support for the initiative through words and actions [27]. These champions can help address areas of concern, refine shared key transformation messages, and act as internal consultants to assist in problem-solving.

Leaders and champions should invest in staff training to ensure that they are prepared to take on new roles and responsibilities and to identify short- and long-term developmental needs [27]. Data are critical to drive and guide improvement, and measures that monitor change and performance need to be vetted and carefully selected [27]. There must be robust data management systems in place that can reliably and expediently collect, analyze, and report clinical quality and operational data [27]. Reports need to provide credible and meaningful data at the team level and dissemination, and communication strategies need to be in place to ensure that staff and other stakeholders can gauge progress toward transformation [27].

Quality Improvement Strategy [23]

Quality improvement (QI) strategies provide the framework and tools to plan, organize, and monitor improvement. Health information technology (HIT) supports the QI information needs of PCMH transformation around operational processes, workflows, and scheduling systems [23]. HIT needs to be deployed and aligned with PCMH transformation strategies to best support processes and workflows. HIT functionalities can include scheduling appointments and monitoring access to care; defining each provider's patient population; tracking care processes, including referrals and abnormal lab/imaging results; maintaining action reports to guide the team's care management activity and a system of outcome reports for monitoring processes of care and population outcomes; optimizing communication between patients and their care team; and promoting decision support at the point of care [23].

To build a QI infrastructure within HIT, it is important to start by creating organizational QI policies that specify quality goals and processes to identify strategic QI priorities [23]. A QI committee or team, with clearly specified roles and responsibilities, should be responsible for organizing, monitoring, and closing out improvement projects. Once a QI team is in place, formal QI models and approaches, such as the Model for Improvement (i.e., aims, measures, and ideas), use of the Plan-Do-Study-Act (PDSA) cycle, or lean methodologies, should be considered [23].

As noted earlier, measurement and data are used to guide and drive improvement. Recognized, standardized individual measures of comprehensive measurement should be selected and employed to reliably capture the work of PCMH transformation. Data can be collected from a variety of sources and is facilitated when data collection is embedded into electronic health record workflows [23]. Once gathered and analyzed, data should be placed in highly visible areas to promote stakeholder engagement. Run charts or line graphs are the most common QI tools, which display performance over time and make it easy to tell if improvements are occurring [23].

Sustaining QI changes require new ways of carrying out the work. It is important to first ensure that change is ready to be implemented and sustained [23]. Time for experimentation allows frontline staff to work through adaptations in new processes while generating support among practice teams. Once new workflows have been adopted and verified by staff, communicate the benefits of the improvement by embedding standardized work processes, where staff follow a defined process [23]. If the change has been successfully adopted and sustained in a clinical unit, seek to spread change throughout the practice or to other parts of the organization/other organizations when you demonstrate success with data and use champions who tested initial changes and who are prepared to help communicate, influence, and train others [23].

Empanelment [28]

Empanelment assigns individual patients to individual primary care providers (PCP) and care teams and is the basis for population health management. The goal of focusing on a population of patients ensures accountability around patient care, which allows the PCP and care team to focus more directly on the needs of each patient [28]. Empanelment affirms the patient-PCP partnership and continuity of care and fosters a health-care environment that allows practices to go beyond disease-specific interventions to address preventive, chronic, and acute patient needs [28]. High-functioning

patient and provider/care team relationships build trust and provide consistency in treatment approaches, controlling costs by reducing duplicate testing, medications, and service orders.

There are specific tasks required for pre-empanelment work. At the outset, policies need to be developed that determine which providers will be empaneled and the reporting metrics and requirements that will be needed [28]. For example, active and inactive patients in the practice need to be identified, as well as the average visits per patient per year (AVPY) [28]. The appropriate panel size for each practice provider (e.g., full-time, part-time, etc.), patient demand for services, and the supply of providers (i.e., number of appointment slots available in the past year) needs to be determined [28].

The four-cut method is one approach to implementing empanelment [28]. In the first "cut," patients who have seen only one provider in the past year are assigned to that sole provider. The second cut identifies patients who have seen multiple providers—but one provider the majority of the time in the past year—and assigns them to the majority provider. The third cut takes patients in which no majority provider can be determined and assigns them to the provider who performed the last physical exam [28]. The fourth cut assigns patients who have seen multiple providers to the last provider seen. Patients need to be informed of their PCP assignment when they first visit the practice or after empanelment occurs; however, they are free to change their PCP/care team if desired or needed [28].

Once panels have been established, they need to be weighted by age, gender, morbidity, or acuity to assure equity across providers [28]. Panel reports are data dependent and need to be analyzed, monitored, and adjusted on a periodic basis. Continuity of care reports, for example, should review the frequency of patients seen by their assigned PCP; the goal is for the patient to achieve 100% continuity by seeing only his/her provider/care team [28]. In addition, the provider appointment supply should be determined at least annual basis or more to ensure that there is availability to meet the demands of current panel size [28].

Continuous and Team-Based Healing Relationships [29]

Care teams are small groups of clinical and nonclinical staff who are responsible for a panel of patients [29]. A care team typically includes the patient; a provider (e.g., physician, nurse practitioner, physician assistant) who is responsible for leading the team; medical assistant(s) who are responsible for pre-visit planning, checking in, and rooming patients, ensuring that post-visit tasks are completed and ensuring patients understand the after-visit plan; nurse(s), pharmacist(s), social worker(s), or health educator(s) who provide self-management support, arrange other resources, and provide care coordination or other services; and front desk staff who facilitate appointments and communication between the patient and care team and who may conduct outreach for preventive services or follow-up care [29].

The empanelment process, which was described earlier, is the first step in implementing team-based care [29]. Patient panels allow the team to recognize each other as partners in care and lays the foundation for time and space to be available for daily huddles and quality improvement meetings [29]. Once teams start meeting regularly, care team members can identify improvement opportunities and respond to common problems for which patients seek care [29].

The care teams should be structured to allow members to function at the maximum of training, skill set, and abilities (i.e., the top of their license), given state regulations for scope of practice [29]. Once these team roles have been designated, infrastructure, skills, and resources need to be in place to sustain high-functioning care teams. Finally, select and monitor metrics, such as continuity and access to care, that can inform improvement efforts and care team processes [29].

Organized, Evidence-Based Care [30]

Organized, evidence-based care (OEBC) is planned and delivered so that the care team optimizes the health of their patient panel [30]. Ideally, OEBC orients each patient encounter to address both preventive and chronic illness needs, using evidence-based guidelines that are embedded into daily clinical workflows [30]. In order to achieve this goal, care must be organized, accurate, and effective, which removes the variability offered by ad hoc decision-making and results in more efficient visits for patients [30]. The concepts behind OEBC were built on more than 15 years of experience in health systems implementing the Chronic Care Model, which was described earlier [10].

Implementing OEBC begins with knowing what patients need and organizing their encounters around delivering those services [30]. Pre-visit planning is an opportunity to create an agenda for the visit including predictable services, such as performing a diabetic foot exam, administering a PHQ-9, or giving a flu shot. These tasks should be prioritized and the patient encounter structured so that specific team members are responsible for identified services [30]. Standing orders are vitally important to facilitate this process and should be guided by evidence-based guidelines and supported by providers and staff in embedded clinical policies. Tools for decision support (i.e., health information technology solutions that help providers in clinical decisions) often use point-of-care reminders based on clinical guidelines [30].

Patients with recurring or complex needs, or who are overdue for services, can be identified via patient registries and engaged prospectively [30]. Unanticipated patient-initiated visits can be mitigated with brief and efficient practice team huddles that can review up-to-date patient information, prioritize patient-directed goals, and outline care tasks for the visit [30]. Care management may be needed for certain segments of the practice population, typically those with high needs and with multiple chronic conditions [30]. In ambulatory practices, care managers can be nursing or social work trained and may be specialized based on patient population (e.g., geriatric care). Care managers are important members of the care team, and their tasks commonly include patient engagement and follow-up, self-management support, the provision of resources for action plans, medication management, counseling and emotional support, and care coordination (see below) [30]. Caseloads should range from 50 to 150 patients, and specific services (e.g., referral facilitation, counseling, etc.) should be delineated by the care team [30].

Patient-Centered Interactions [31]

Patient-centered interactions encourage patients to take ownership in their health-care decision-making, behavior change, and self-management. Collaborating with patients builds patients' skills and confidence in managing their health, especially for patients with chronic conditions, and addresses the needs of patients with low health literacy [31].

Communication barriers can result in low-quality care and poor health outcomes and PCMHs benefit from promoting patient-centered information and skills in providers and staff [31]. At the practice level, the specific cultural and language needs of diverse patient populations can be gauged from patients and families using surveys, focus groups, and point-of-care assessments [31].

Implementing a culture of patient-centered interactions begins by developing meaningful relationships with patients. Dignity, respect, and honoring diverse perspectives can be promoted by providers and staff who communicate and share unbiased information with patients and families in affirming ways [31]. Providers and staff can also build a shared agenda for the visit by opening the patient conversation with concerns and experiences, focusing on patient-identified health goal. Teach-back techniques and literacy resources are other strategies that can help deliver information in a way that patients can understand and use [31]. Brief motivational interview techniques are additional skills that can facilitate patient-identified action plans to improve health outcomes [31].

Many PCMHs are working more meaningfully with their patients to assist in practice-level policy and program development, facility design, and delivery of care [31]. Patient advisory boards are evolving organizational structures that can help guide and conduct quality improvement activities. In these settings, patients draw on their own experiences of care at the facility to inform decisions about changes in care delivery and provide guidance about practice innovations, quality improvement, and other initiatives [31]. Finally, patient advisory boards can add value to practices in very tangible ways: policies and practices for responding to patient messages, guiding telephone protocols, helping decide on office hours including extended hours, and guiding development of patient facing materials including educational, office services and development of patient portals.

Enhanced Access [32]

Enhanced access begins with a commitment to providing patients with 24/7 access to their care team during office hours and access to advice through a live coverage system [32]. Highly functioning PCMHs should have the capacity to provide patients with options that promote practice efficiency and allow the practice to respond to patient needs in ways such as same-day appointments, telephone, email, and group visits [32]. Enhanced patient access is tied to improving patient outcomes and care experience, as well as reducing health-care costs. In addition, it can allow team members to focus on improving patient care and overall practice efficiency [32].

Implementing enhanced access can involve a variety of scheduling options, including extended hours (i.e., night and weekend hours). There are several strategies to promote enhanced access including staggered clinic shifts, which can free up provider weekday availability to the weekend, and on-call systems to connect a patient to the practice during after-hours [32]. This system may utilize an answering service, clinical staff in a local hospital system, a nurse advice line or urgent care clinic, or telemedicine access to a provider after-hours [32]. Robust health information technology systems are critical to allow connectivity between patient and provider, real-time documentation, and closing the communication loop with the primary care team [32]. Finally, some patients have financial barriers to enhanced access, and dedicated staff can assist patients in gaining health insurance coverage through eligibility screening and enrollment assistance. Other patients may face transportation barriers, and PCMH staff can assess and address these concerns and provide alternatives to in-person visits [32].

The PCMH must be able to manage appointment supply and demand to sustain enhanced access. Practice-level policies should address the factors that impact appointment supply and demand (e.g., provider out ill) [32]. Strategies that address and reduce patient no-shows help mitigate variability

in access and should address the root causes [32]. Same-day and next-day appointment templates can meet patient need in real-time, as do telephone, email, and group visits, and telemedicine options [32]. Data can help identify intermediate and long-term trends and identify predictable events that interfere with daily workflow, such as seasonal fluctuations in patient needs [32]. For example, there may be high patient demand on Friday afternoon when providers request time off. Ideally, provider and care team schedules should match patient demand, and coverage plans should prepare for predictable events that may limit supply, such as when a provider is ill or is away.

Care Coordination [33]

Care coordination is becoming a mainstay within the PCMH since it incorporates several activities that reduce care fragmentation and promote integration. PCMHs need to develop relationships with high-value specialty colleagues who provide high-quality, cost-efficient care, hospitals, and community-based services; create protocols to support successful closed-loop referrals and transitions; and develop and maintain information systems to support information transfer [33].

Effective care coordination reduces the risk of communication breakdowns between care providers, unnecessary hospitalizations, duplicate tests and procedures, and medical errors and can increase sharing of common care plans between providers across the continuum of care [33].

Implementing care coordination starts with assuming accountability for patients and populations [33]. A health information technology system should be in place to track and manage health-care services including specialist consults, hospitalizations, emergency department visits, and community-based service agency referrals [33]. Care managers, or other designated staff, should be identified and trained to coordinate referrals and transitions of care and to assess patient's logistical needs and barriers to care (see above).

At the practice level, PCMHs should develop relationship and agreements with specialty groups, hospitals, and community-based service agencies that delineate clear expectations for communication and scope of health-care services [33]. Existing relationships and referral patterns should lead into verbal or written agreements that include guidelines and expectations for referral and transition processes [33]. A shared electronic health record, or other health information technology platform, can facilitate a standardized information flow process, ensuring that referring providers and consultants can efficiently communicate with each other [33].

Future Directions

The patient-centered medical home (PCMH) will be the foundation organizational structure as the US health-care system transforms from volume-based to value-based care. When primary care is well functioning through the PCMH, clinical quality can improve, and utilization and costs of care can decrease, leading to improving the value of care delivered. However, only a portion of care quality and total cost of care is impacted in the primary care ambulatory setting; the majority of cost variation occurs in the post-acute setting, less so for inpatient costs and virtually no variability in ambulatory costs [34]. A reasonable assumption is that the PCMH model is a necessary but not sufficient component to transform the US health-care system. But as part of a larger integrated care delivery system, PCMH may have a more expansive role to improve value, by effectively coordinating care across health-care delivery systems.

The core concepts of PCMH are starting to take hold in patient-centered specialty practices, medical neighborhoods, and health-care systems that are evolving into clinically integrated networks and accountable care organizations. For example, NCQA developed the Patient-Centered Specialty Practice (PCSP) program to recognize specialty practices which invested in systems and care processes that promoted referral and care coordination, communication, access, population-based management, and quality improvement efforts to measure and improve performance [35]. PCSPs will play a key role in evolving medical neighborhoods, particularly for complex conditions that often result in high utilization of health care, such as cancer and end-stage renal disease. Early results are reassuring that specialty practices which adopt the principles of the PCSP improve patient-centered care and value [36, 37].

The medical neighborhood has emerged as a larger organizational concept that seeks to enhance communication and coordinate care between and among all providers who care for a patient, not simply within the medical home [38]. In many medical neighborhoods, provider incentives are not aligned; some providers receive fee for service, while others are partially reimbursed by capitation, episodic care, or other quality incentives. To be successful, care delivery and incentives must be aligned for medical neighborhoods to leverage their networks. Performance needs to be transparent and measured by shared outcomes, including patient experience, which are influenced by all providers in the neighborhood.

Reimbursement models within the neighborhood must ultimately be indexed to value for all providers. The Bundled Payments for Care Improvement (BCPI) initiative, for example, is a Medicare program which pays physicians and hospitals a fixed dollar amount for an episode of care, such as a joint replacement [39]. The payment covers all care provided

within 90 days of the episode, and there are aligned incentives to deliver efficient, quality care among all providers involved. To be successful, providers, hospitals, and post-acute care facilities must have clear lines of communication, promote high-quality care, and minimize adverse events.

The concept of accountable care organizations (ACOs) and accountable care systems (ACS) is another development that seeks to align PCMHs, medical neighborhoods, hospital systems, post-acute care providers, and others in health-care delivery [40, 41]. An ACO is an entity comprised of multiple health-care providers, usually including hospitals and ambulatory providers, that can organize processes across the continuum of care, improve the quality and control the costs of care, and are held accountable for the outcomes [40]. The Affordable Care Act and more recent 2015 MACRA legislation have propelled ACOs into the forefront of health-care delivery organization. For example, the Center for Medicare and Medicaid Services Pioneer ACO, Medicare Shared Savings ACO, and Next Generation ACO models outline strategies and reimbursement schemes to integrate care delivery and enhance clinical outcomes while improving the patient experience of care and reducing the total cost of care. Commercial insurance payors and Medicaid have also followed this lead and are engaging health-care providers in alternative payment models such as ACOs. As of December 2016, nearly 44% of patients in the United States were covered through one form of an alternative payment model (APM) [42].

In summary, the PCMH needs to exist within a high-performing medical neighborhood to achieve the value it promises. Specialists will still need to communicate with primary care providers; primary care providers will still need to provide information to specialists regarding goals for referrals; hospitals and post-acute facilities will need to communicate with all providers when patients are cared for in their facilities. Across these providers and settings, patient care plans will still need to be crafted and shared to ensure efficient, coordinated care that maximizes quality and minimizes error while helping patients navigate a complex health-care system [43].

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Integrated Behavioral Health Care

29

Linda Myerholtz

Introduction

Many terms have been used to describe approaches to incorporating mental health care in primary care settings including collaborative care, primary care behavioral health, embedded care, and shared care. This has created confusion over what constitutes integrated behavioral health care. To resolve this confusion, Peek and colleagues developed a lexicon that defines integrated behavioral health care (IBH) as "the care that results from a practice team of primary care and behavioral health clinicians, working together with patients and families, using a systematic and cost-effective approach to provide patient-centered care for a defined population" [1]. In addition to addressing mental health needs of patients in primary care, many IBH approaches focus on intervening with stress-related physical illness, behaviors contributing to unhealthy lifestyles, adherence issues, and ineffective use of emergency and hospital-based health-care services. The authors of the lexicon also created a "family tree" of interrelated terms that are used when describing the integration of behavioral health and primary care (Fig. 29.1).

The IBH movement gained momentum in the late 1980s due to growing recognition that a fragmented system of care, where the care of the body and the mind are artificially separated, was not meeting the needs of patients, especially those with chronic conditions. While almost half of adults and more than a quarter of adolescents experience a mental illness or substance use concern [2, 3], the majority of individuals with behavioral health disorders do not receive treatment [4, 5]. The reasons for this are complex and include lack of identification of the disorder, stigma about receiving mental health treatment, and lack of access to care. Many individuals may not seek treatment from a behavioral health professional (BHP) but are comfortable visiting their medical provider, making primary care practices well poised to identify behavioral health treatment needs. Twenty percent of primary care visits are mental health related [6], 59% of psychotropic medications are prescribed by primary care clinicians [7], and most patients with depression who do seek treatment reach out to their primary care provider first.

L. Myerholtz (✉)
University of North Carolina, Chapel Hill, Department of Family Medicine, Chapel Hill, NC, USA
e-mail: linda_myerholtz@med.unc.edu

Moving Toward Integrated Care

In addition to the desire to address unmet behavioral health treatment needs, there are other reasons that integrated behavioral health programs are being developed, tested, and disseminated.

Interplay of Emotional and Physical Health

Mental health disorders, specifically depression and anxiety, are among the top five chronic conditions contributing to overall health-care costs in the United States [8]. Individuals with mental illness have higher rates of chronic disease including cardiovascular disease, asthma, diabetes, and cancer resulting in a life expectancy up to 30 years less than adults without serious mental illness [9]. Many chronic conditions are impacted directly and indirectly by emotional well-being and behavioral issues. Integrating behavioral health care within a primary care setting allows for increased opportunity for patient engagement in his or her own health care and skill building with health behavior change.

Removing Barriers to Care

The stigma felt by individuals who seek mental health treatment is significant. A national survey showed that only 57% of adults without mental health concerns and 25% of adults who have mental health symptoms believe that people are sympathetic toward individuals who have mental illness [10].

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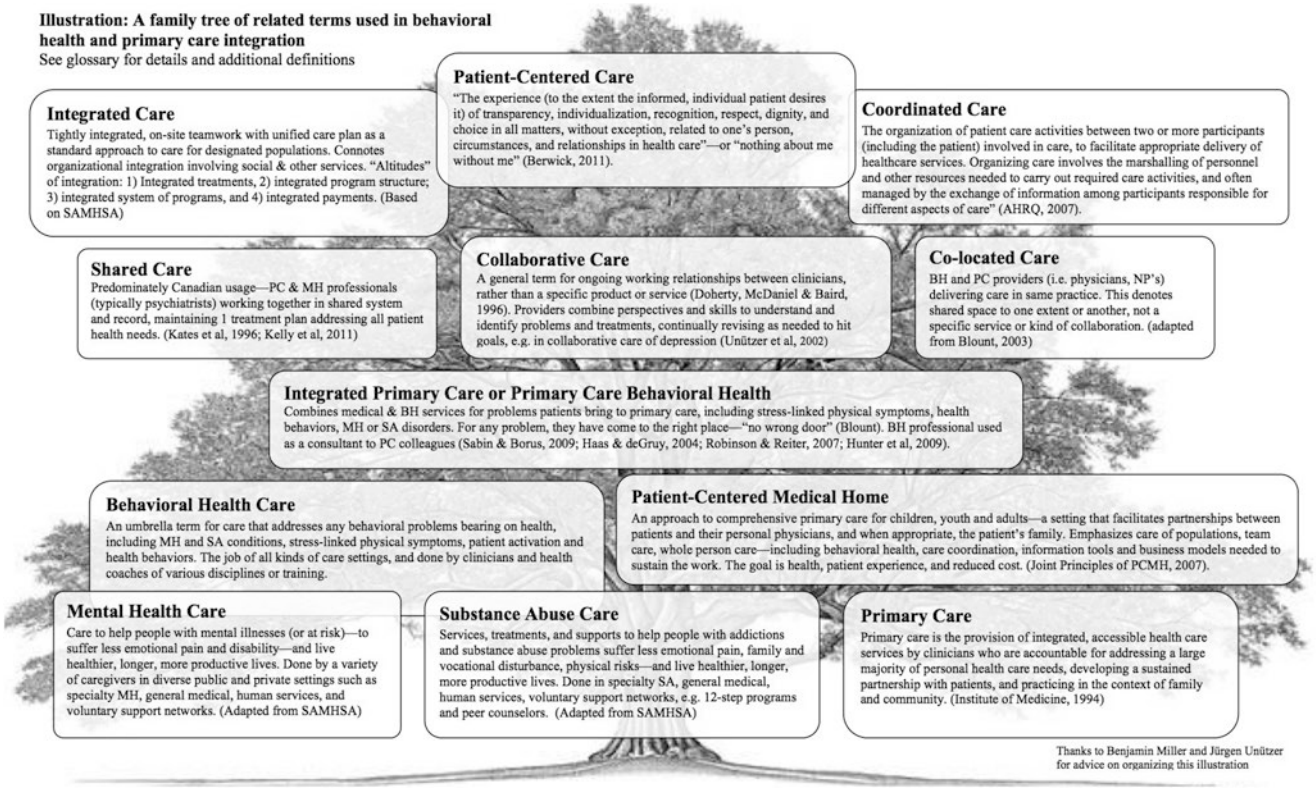

Fig. 29.1 Family tree of related terms used in behavioral health and primary care integration (Permission from Peek CJ and the National Integration Academy Council [1]. Available at http://integrationacademy.ahrq.gov/sites/default/files/Lexicon.pdf)

Stigma toward individuals with mental illness is prevalent among medical students and other health-care providers [11]. Seventy percent of individuals with a behavioral health concern would not access services in a mental health treatment organization that is separate from their primary source of medical care [4]. When mental health treatment is integrated into primary care rather than separated, the stigma of receiving mental health care may be reduced.

Both adults and youth from ethnic minority populations receive less care for mental health concerns than Caucasians [12–14]. This is linked to less willingness to use mental health-care services as well as gaps in cultural awareness among mental health-care providers. Behavioral concerns among minority youth often result in disciplinary action from schools or incarceration rather than treatment [14]. Integrated behavioral health-care models, particularly collaborative care models, reduce these disparities [15].

Improving Access and Continuity

Patients often struggle to access mental health treatment due to lack of awareness or unavailability of resources within their community and payment barriers. A common access point to the complicated US health-care system is via primary care, making it strategically poised to facilitate both medical and mental health care. Individuals needing mental health care may be more likely to consider behavioral health services when provided in the context of a primary care practice where the setting and providers are familiar.

In traditional care settings, primary care clinicians and mental health providers may have different treatment goals for the same patient and may have limited communication with each other due to logistical issues and strict state confidentiality laws governing mental health care. Integrated care allows for continuity and collaboration on treatment plans for patients since communication within a team is not limited by state confidentiality laws in the same manner as between practitioners who are not in the same practice.

Improving Outcomes at Reduced Cost

A significant proportion of patients have chronic comorbid mental and physical health conditions with substantially higher total medical health-care costs than the general population [16]. Integrating care reduces total health-care costs and improves outcomes for patients and providers, which will be discussed later in this chapter. Given these and other benefits of IBH, the American Academy of Family Physicians

recommends co-location of mental health services in primary care settings [17] and has issued principles for integrating behavioral health into patient-centered medical homes (PCMH) [18]. The Institute of Medicine (IOM), Agency for Healthcare Research and Quality (AHRQ), Patient-Centered Primary Care Collaborative [19], and multiple other state agencies have also endorsed IBH as a critical element in the transformation of our current health-care system.

Models of Integrated Behavioral Health Care

There are a multitude of ways that practices integrate behavioral health care including co-located care, consultation models involving telepsychiatry or web-based services, and team-based collaborative care. The different models fall on a spectrum based on the level of integration (from co-location of care to fully integrated engagement of a team of providers), on program structure (from very loose to highly structured using treatment protocols and clinical measures to evaluate clinical effectiveness), and on intensity of behavioral health services offered (from screening and brief intervention to ongoing therapy and psychiatry services). On the most basic level, integrated care may involve co-locating a behavioral health professional in a primary care setting. This BHP may provide consultation to medical providers, conduct brief interventions following a "warm handoff" from a primary care clinician (PCC), and/or provide ongoing therapy services for a small proportion of practice patients. The level of integration of the care in the *co-located care model* can vary a great deal from practice to practice.

Telepsychiatry involves the delivery of mental health services via videoconferencing technology. This mode of care has been used to expand access to mental health services in rural areas, to locations where mental health treatment is not easily accessible, and to populations where language barriers may limit access to care. Telepsychiatry is also used directly in primary care settings and allows the PCC to conference directly with a mental health professional, usually a psychiatrist, for case review, diagnostic clarification, and pharmacological treatment recommendations. In some models the BHP performs a brief assessment and recommends interventions via videoconferencing while the patient is in the exam room at the primary care practice. The Veterans Administration is one large health-care organization that has utilized telepsychiatry to enhance access to care for patients.

Collaborative care is the most widely studied and distributed integrated care model and is based on the principles of Wagner and colleagues' chronic care model [20]. Well-known depression collaborative care programs include the Improving Mood-Promoting Access to Collaborative Treatment (IMPACT) [21] developed at the AIMS Center of the University of Washington, the Depression Improvement Across Minnesota, Offering a New Direction (DIAMOND) program [22], and the Veterans Affairs system [23].

Expert consensus has identified four essential elements of the collaborative care model including care that is (1) team-driven, (2) population-focused, (3) measurement-guided, and (4) evidence-based [24]. Team-based care includes primary care physicians/clinicians (PCP/PCC), care managers, a consulting psychiatrist, nurses, and office staff. Most research has been conducted on programs where the team focus is on the PCC, care manager, and consulting psychiatrist. The care manager role may be fulfilled by a social worker, nurse, psychologist, or other mental health professional. The PCC typically identifies the mental health need in a patient and continues to oversee the care. The care manager conducts comprehensive assessment, provides brief evidence-based interventions (motivational interviewing, problem-solving therapy, brief cognitive behavioral therapy, behavioral activation, etc.), actively engages the patient through frequent phone outreach, and coordinates care among team members.

In collaborative care models, the focus is on provision of care for a defined population, and registries are used to track patient progress and outreach efforts to ensure that no one "falls through the cracks." Treatment progress and response is closely measured through the use of standardized illness-specific measures such as the Patient Health Questionnaire-9 (PHQ-9) for depression and the Generalized Anxiety Disorder-7 (GAD-7) score. The care manager facilitates any needed referrals and treatment with other resources such as community mental health centers and substance use treatment centers. When patients do not respond to treatment, a psychiatrist may be consulted by the team and may meet with the patient. The psychiatrist may also regularly review the team caseload and make recommendations regarding treatment plans. Figure 29.2 illustrates the roles of various members of a collaborative care team.

The goal of treatment in a collaborative care model is to "treat-to-target," meaning that treatment is continuously modified until specific treatment outcome measures are achieved (typically measured with standardized tools such as the PHQ-9 and GAD-7) [25]. The DIAMOND model, for example, considers a "response" as a 50% or greater decrease in PHQ-9 score from baseline at 6 months, and remission is defined as a PHQ-9 score of less than 5 at 6 months. Under the IMPACT model, if the patient has not had at least a 50% improvement in symptoms using a validated measure, the treatment plan is modified every 10–12 weeks.

In addition to treatment response, other metrics are often monitored in collaborative care models including process measures such as access times, cost savings factors (e.g., emergency room visits and hospitalizations), and caregiver and patient satisfaction.

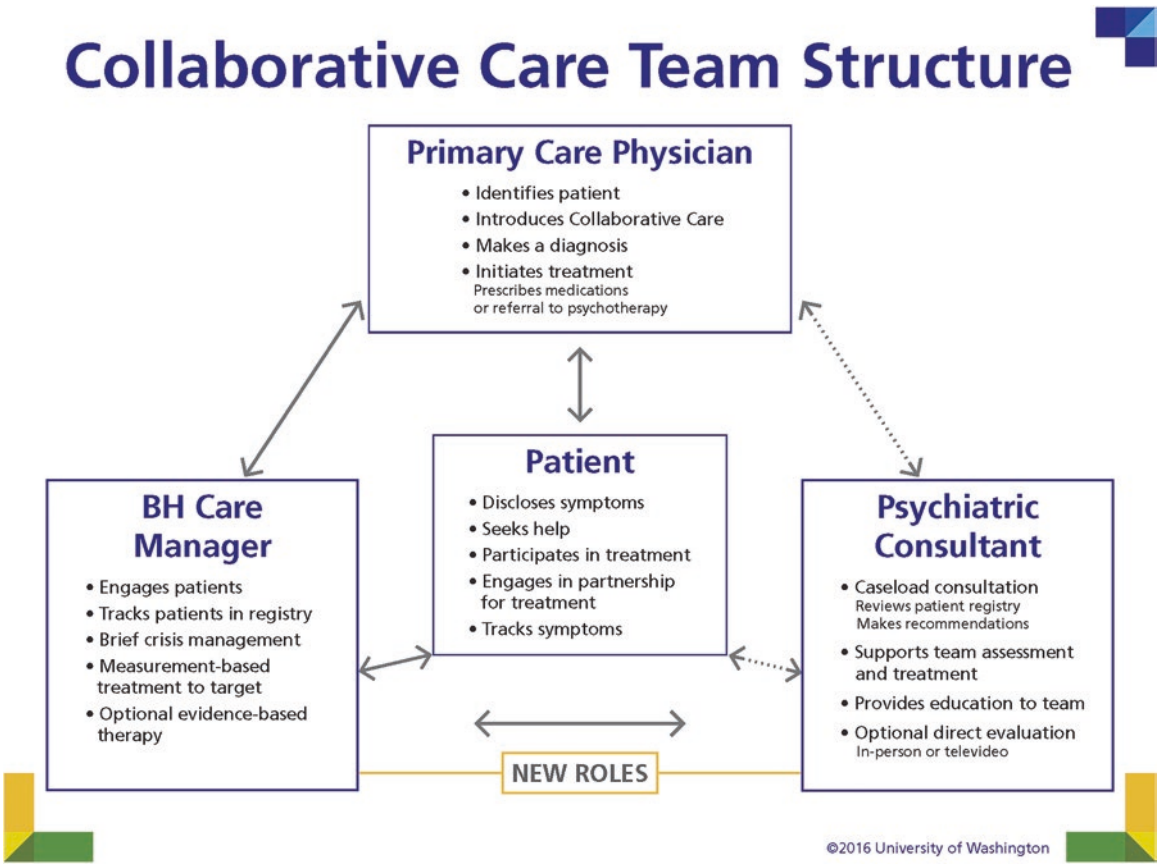

Fig. 29.2 Collaborative care model (Reprinted with permission from The University of Washington)

Historically, collaborative care models for mental health concerns were disease specific, focusing commonly on depression and anxiety. With strong evidence for improved outcomes, additional models have been developed. Re-Engineering Systems of Primary Care Treatment of PTSD and Depression in the Military (RESPECT-MIL) is an initiative within the US Army to improve identification and treatment of service members with depression and post-traumatic stress disorder (PTSD) [26]. The Screening, Brief Intervention, and Referral to Treatment (SBIRT) model is an evidence-based intervention to identify patients with substance use concerns. Identified patients are offered brief interventions, usually by the PCC, and referred for treatment depending on the severity of the substance use concern [27]. Another model, Primary Care Research in Substance Abuse and Mental Health for Elderly (PRISM-E), targets older adults with at-risk alcohol use [28]. Integrated behavioral health is also expanding to pediatric populations [29] and higher risk patients with substantial disease burden. The Care of Mental, Physical and Substance Use Syndromes (COMPASS) program, for example, uses an evidence-based collaborative care management model for patients with depression and diabetes and/or cardiovascular disease [30].

Implementation Strategies and Considerations

Developing and implementing an integrated behavioral health program within primary care can be daunting, but several resources can facilitate the process:

- The "Integration Playbook" – an online, interactive guide for integrating behavioral health in ambulatory care developed by the Academy for Integrating Behavioral Health and Primary Care (AHRQ) (https://integrationacademy.ahrq.gov/playbook/about-playbook).
- *The Organized, Evidence-Based Care: Behavioral Health Integration Guide* and the *GROW Pathway Planning Worksheet* [31] developed by the Safety Net Medical Home Initiative are available online at http://www.safetynetmedicalhome.org/change-concepts/organized-evidence-based-care/behavioral-health.

- *Quick Start Guide to Behavioral Health Integration* developed by SAMHSA-HRSA Center for Integrated Health Solutions (https://www.thinglink.com/channel/622854013355819009/slideshow).
- SAMHSA also has a general listing of other integration tools available on their integrated behavioral health-care website http://www.samhsa.gov/children/behavioral-health-care-integration-resources.

Understanding how to translate IBH models, developed and evaluated as part of randomized controlled trials, to community primary care practices has been a challenge in expanding integrated care nationally. The Advancing Care Together (ACT) program examined methods for integrating care within "real-world" primary care settings [32]. By longitudinally studying the implementation approaches within 11 practices (9 were primary care practices and 2 were behavioral health agencies) over the course of 3 years, ACT identified key strategies and challenges that impact the success of the implementation of IBH. The results of ACT showed that successful integration involves more than adding BHPs and establishing screening protocols and must address critical changes in organizational process and interprofessional relationships. Challenges common among the practices were linked to three common themes – engaging leadership and culture change, workflow and access, and tracking and using data in meaningful ways. The ACT study has been expanded to include eight additional practices [the Integration Workforce Study (IWS)], and the lessons learned from the implementation processes across these practices have been published by the *Journal of the American Board of Family Medicine* [32–39]. Another study of organizations that have successfully integrated behavioral health and primary care identified common key characteristics including support and vision from influential leadership, a focus on vulnerable populations, community-wide collaborations, team-based care including the patient and family, data-driven decisions, and diverse funding streams [40]. The following sections outline some of these basic considerations for developing an integrated behavioral health-care program.

Mission and Vision

In order to guide the transformation process, it is critical that practices develop a shared mission and clear vision for the integration of care. This provides focus and a shared understanding of the goals and enhances commitment among all involved. The mission and vision need to specify the scope of the population that the program is designed to address. For example, will all adult patients be screened for depression, or will the program prioritize screening and intervention among high-risk/high-utilizing patients? The mission and vision also need to address the scope of care that will be offered within the practice.

Staffing and Training

Another critical component in the successful transformation to an integrated care system is building strong interdisciplinary teams. Mutual respect, collaboration, and a willingness to modify traditional care roles, including a shift from the traditional hierarchy of medical practice, are necessary for the success of IBH. Strong interdisciplinary teams require flexibility and an appreciation of the roles and skills that each team member brings to patient care. Given that primary care clinicians and behavioral health professionals have traditionally trained in silos with different languages, culture, and ways of conceptualizing patient care, special attention needs to be given to orienting and training all care team members to work in integrated care settings.

Behavioral health professionals need to learn to adapt traditional assessment and therapy models to brief, solution-focused interventions with limited time spent on assessment. BHPs also need to function outside of the traditional 50 min hour and consider intervention strategies that work within the busy pace and workflow of a medical practice. This can be a substantial cultural shift for mental health providers. A foundation in the interplay of physical illness and emotional well-being, knowledge of common chronic health-care conditions, and knowledge of medical culture is also essential for BHPs to be successful in primary care settings [41]. The American Psychological Association Interorganizational Work Group on Competencies for Primary Care Psychology Practice has delineated six competency domains with associated essential components for behavioral scientists practicing in primary care [42]. These include competency in science related to the biopsychosocial approach, research and evaluation, leadership and administration, interdisciplinary systems, advocacy, and practice management. Additional clinical skills in assessment, intervention, clinical consultation, as well as supervision and teaching are also included. Although more training is now available for BHPs in integrated care models, finding providers able and eager to work in primary care settings continues to be a challenge [35].

Primary care clinicians need to be able to screen patients for common mental health concerns (i.e., depression, anxiety, substance use issues) and recognize variations in signs and symptoms of mental health concerns across the life spectrum. Without standardized screening processes, depression, for example, goes undetected in greater than 50% of primary care patients [43]. Also, PCCs need to be able to consider when and how best to involve a BHP in a patient's care. This includes developing strategies for effectively introducing the BHP to the patient and communicating needs efficiently to the BHP. Nine shared competency domains for PCCs and BHPs working in integrated systems are described in Table 29.1 [44].

Table 29.1 Specific competencies by category [44]

I. Interpersonal communication
The ability to establish rapport quickly and to communicate effectively with consumers of health care, their family members, and other providers
Examples include active listening; conveying information in a jargon-free, nonjudgmental manner; using terminology common to the setting in which care is delivered; and adapting to the preferred mode of communication of the consumers and families served
II. Collaboration and teamwork
The ability to function effectively as a member of an interprofessional team that includes behavioral health and primary care providers, consumers, and family members
Examples include understanding and valuing the roles and responsibilities of other team members, expressing professional opinions and resolving differences of opinion quickly, providing and seeking consultation, and fostering shared decision-making
III. Screening and assessment
The ability to conduct brief, evidence-based, and developmentally appropriate screening and to conduct or arrange for more detailed assessments when indicated
Examples include screening and assessment for risky, harmful, or dependent use of substances; cognitive impairment; mental health problems; behaviors that compromise health; harm to self or others; and abuse, neglect, and domestic violence
IV. Care planning and care coordination
The ability to create and implement integrated care plans, ensuring access to an array of linked services, and the exchange of information among consumers, family members, and providers
Examples include assisting in the development of care plans, whole health, and wellness recovery plans; matching the type and intensity of services to consumers' needs; providing patient navigation services; and implementing disease management programs
V. Intervention
The ability to provide a range of brief, focused prevention, treatment and recovery services, as well as longer-term treatment and support for consumers with persistent illnesses
Examples include motivational interventions, health promotion and wellness services, health education, crisis intervention, brief treatments for mental health and substance use problems, and medication-assisted treatments
VI. Cultural competence and adaptation
The ability to provide services that are relevant to the culture of the consumer and their family
Examples include identifying and addressing disparities in health-care access and quality, adapting services to language preferences and cultural norms, and promoting diversity among the providers working in interprofessional teams
VII. Systems-oriented practice
The ability to function effectively within the organizational and financial structures of the local system of health care
Examples include understanding and educating consumers about health-care benefits, navigating utilization management processes, and adjusting the delivery of care to emerging health-care reforms
VIII. Practice-based learning and quality improvement
The ability to assess and continually improve the services delivered as an individual provider and as an interprofessional team
Examples include identifying and implementing evidence-based practices, assessing treatment fidelity, measuring consumer satisfaction and health-care outcomes, recognizing and rapidly addressing errors in care, and collaborating with other team members on service improvement
IX. Informatics
The ability to use information technology to support and improve integrated health care
Examples include using electronic health records efficiently and effectively; employing computer and web-based screening, assessment, and intervention tools; utilizing telehealth applications; and safeguarding privacy and confidentiality

Practice staff (nurses, medical assistants, etc.) need to have skills in facilitating screening for mental health concerns, interpersonal skills to respond effectively when emotional issues are discussed, and communication skills to facilitate warm handoffs to the providers.

As new staff join the team, orientation and training should help them understand the goals, processes, and cultural expectations involved in integrated care. This can involve shadowing different members of the team, reviewing training manuals that describe the mission and vision, and reviewing the standardized protocols and workflows that support IBH. These efforts solidify an organization's conceptualization and commitment to IBH. Ongoing education and mentoring further facilitates the maturation of a truly integrated care system [35].

The actual staffing model varies depending on the size of the practice and the agreed-upon role of the BHP. In the ACT and IWS practices, staffing ratios varied from one BHP working with anywhere from 1 to 36 PCCs. In practices where the IBH model involved warm handoffs and immediate brief interventions, the staffing ratios were one BHP to two to six PCCs. These practices also employed multiple BHPs so that coverage was available during high demand times and vacations. In practices where IBH followed a

model of internal referral for scheduled brief therapy interventions, the staffing ratio was one BHP to three to five PCCs, but this did not allow for much flexibility for same day care handoffs between providers.

Workflow

Successful IBH practices create processes that meet the patient care needs at the time of care. A model of *consulting*, *coordinating*, *and collaborating* has been described as a flexible approach toward IBH in a team setting [34]. *Consulting* is defined as "a care team member with specific professional expertise or experience seeking advice or input from another clinician with different professional expertise or experience in the context of providing patient care." This involves corroborating perceptions of patient needs and validating care plans. *Coordinating* involves "two or more clinicians working in a parallel back-and-forth fashion to care for the same patient, delivering care to the patient in a manner that has the same goal yet is accomplished independent of the other clinician." Practical issues such as finding the BHP in the building, the briefing process regarding patient needs, timing of treatment suggestions, debriefing following any interventions, and planning next steps are needed to successfully implement the coordination of care. *Collaborating* means "two or more professionals interacting in real time to discuss a patient's presenting symptoms, describe their views on treatment, and jointly developing a care plan." This may involve the care professionals meeting at the same time with the patient. Collaborating is distinguished from coordinating when both care professionals share their understanding to come to an agreement of the patient's needs and treatment plan.

As practices develop their model for IBH, attention needs to be paid to workflow. Developing standardized practice protocols facilitate clarity and process consistency. These protocols should cover screening, communication expectations, treatment guidelines, and referral considerations. Practices need to consider what behavioral health screening to use, the frequency of use, who will be screened, and which staff will administer and score the screening tools. Having a systematic approach to screening helps to identify patients needing service as well as inform the practice on population-based mental health needs. Practices will need to decide on the mental health needs that are feasible to address, however. Full population-based screening for many mental health problems could easily overwhelm the resources available to respond to the identified needs.

Commonly used screening tools in primary care settings include the Patient Health Questionnaire (PHQ-2, PHQ-9) and Edinburgh Postnatal Depression Scale (EPDS) to screen for depression. The Generalized Anxiety Disorder-7 (GAD-7) scale is often used to screen for anxiety disorders, and the Alcohol Use Disorders Identification Test (AUDIT), CAGE questions, and Drug Abuse Screening Test (DAST) are used to screen for substance use concerns. Many of these tools have modified versions appropriate for use with adolescents. The Modified Checklist for Autism in Toddlers-Revised (M-CHAT-R) is used for screening for autism spectrum disorders. Tools such as the Ages and Stages Questionnaire and Parents' Evaluation of Developmental Status (PEDS) Milestone questionnaires are used to assess achievement of expected developmental milestones. These tools are designed for the patient or a parent to complete rather than the provider. This is an important consideration, given that provider ratings can be biased and may miss worsening of symptoms [45]. Tools need to be reliable and sensitive for the population, easy for patients to complete, and simple for staff to score and interpret. These tools must be available in the moment and useful in clinical decision-making. Protocols should be developed regarding how often the measure is administered and what results indicate that treatment is effective verses needing to be modified.

Care Pathways

Practices need to develop care pathways that include coordination of care that take into account the level of care needed to address the behavioral health of the patient. Practices with in-house BHP may use "warm handoffs" where the PCC introduces the patient to the BHP at the time of the visit with the resultant provision of an immediate brief intervention and introduction to IBH services. The care pathways may also involve referral for longer-term or more intense mental health and/or substance use treatment. Developing relationships with community providers, mental health centers, crisis centers, and inpatient psychiatric facilities helps to create a continuity of care for the patient, particularly if the relationships with these external providers include clear expectations about coordination of care and communication of treatment plans and progress.

Workspace Design

Practices need to consider the logistics of workflow and usage of space. Having workspace for behavioral health team members centralized so that the BHP is visible and easily accessed by all practice members facilitates real-time communication and the integration of behavioral health care. Shared or centralized workspace also increases the likelihood of "curbside" consultations and the development of

robust interpersonal working relationships. The advantages of the centralization of workspace must be balanced with the need for privacy at times. Practices should consider if the BHPs will see the patient in the exam room or transition to another space to minimize disruption to the clinician's work flow. There are advantages and disadvantages of different practices regarding space in the clinic. When the BHP meets the patient in the exam room, this can normalize the process for the patient, make it feel like a regular part of patient care, and facilitate follow-up with the PCC who may have moved on to see another patient. However, seeing the patient in the exam room means the room is in use for a longer duration of time, delaying staff's ability to room additional patients. If the BHP is not located in the same area as the medical team, there must be reliable communication between the providers, typically via an electronic health record (EHR).

Schedules

The design of the schedule for the behavioral health professional will influence his or her availability and flexibility regarding patient needs. The ability to quickly access the BHP at the time of need greatly impacts the success and level of integration. In some models, the BHP has no scheduled follow-up visits outside of a return visit with the PCC. In other models, the schedule has a mix of available consultation times interspersed with brief scheduled follow-up appointments, usually 20–30 min, which are aligned with the clinic schedule. Time for making follow-up phone calls for outreach and treatment monitoring is needed for practices that implement a population management approach.

Communication

Clear communication processes are essential for the success of IBH. Communicating impressions and treatment plans through the shared EHR has the advantage of being easy, reducing duplication of documentation, and data consolidation. It should be clear where within the EHR the BHP will document, i.e., within the same note as a physician or a separate note. There should be strategies on how to communicate and collaborate on shared treatment plans. Standardized templates for documenting care can facilitate communication among team members. There are some challenges with shared EHRs, and most EHR systems are not designed with behavioral health-care documentation standards and regulations in mind. Practices may need to create processes that ensure clear communication within the HER that is accessible, meaningfully enhances patient care, and meets regulatory and billing requirements for medical and behavioral health care. An additional consideration for documentation of behavioral health care within an integrated and shared EHR is how to maintain standards of confidentiality and privacy that in some states are stricter than federal HIPPA privacy rules.

A standard process that defines the triggers for a provider to provider "warm handoff" and what should be communicated during that time facilitates integrated care for the patient. Interdisciplinary preclinic huddles, where the team meets to review the clinic schedule and identify possible patient care needs in advance, and complex care team meetings also improve care for the patient and foster collaboration and ongoing training for team members. Finally, it helps to have an understanding among team members regarding the practice of care professionals interrupting each other, particularly when care team members are providing service to other patients.

Practice Improvement

Registries to track patients and monitor program metrics are a critical element in collaborative care models. Successful programs use data and quality metrics to respond to patient needs and enhance the overall program. As practices systematically collect patient-level data tied to behavioral health and other outcomes, they must consider how to use and manage the information. Some EHR systems have the ability to access data over time (i.e., PHQ-9 scores, GAD-7, HbA1c, blood pressure, etc.) and can collate this into reports that measure and track patient-specific health targets. This data can be used to monitor individual treatment response, identify patients who have not been engaged in care for a specified period of time, and inform and evaluate practice change efforts. Data can be powerful and it is important to have adequate infrastructure to use the data. The practice must decide what data to track, both at the individual and population level, what information should be aggregated, and who will run, interpret, and act on the reports. In practices without EHR systems that can access and report data, tracking patient data is challenging.

An important step in designing an integrated behavioral health-care program is the determination of metrics that show whether the program is effective and valuable. These measures should include patient-oriented outcomes, patient and staff satisfaction scales, and costs. While definitions of effectiveness and value may vary from practice to practice, standardized measures allow comparisons across practices which facilitate the process of continuous quality improvement. Practices or programs that perform well on outcome measures can inform other practices. In addition, having a structured continuous quality improvement plan protects against the natural process whereby systems slowly revert to old patterns of care.

Costs and Billing

Data on implementation costs tied to IBH are limited and tend to focus on collaborative care models. An analysis which took into account start-up, program planning, and ongoing implementation costs estimated that expenditures range from $3 to $22 per patient per month [46]. Another study that examined ten practices from the ACT program found that start-up expenses averaged around $44,000 per practice with substantial variation among the programs depending on the duration of the start-up and direct non-staff expenses (which ranged from $914 to $185,949). Direct non-staff expenses included items such as computers, software, and license fees. Ongoing costs averaged $40 per patient per month which also varied considerably among the practices (range $15–$123) [39]. These expenses may present a significant barrier for small practices interested in developing IBH services.

While the Mental Health Parity and Addiction Equity Act of 2008 expanded mental health coverage for Americans and behavioral health care is identified as an "essential health benefit" in the Patient Protection and Affordable Care Act (2010), most current payment models make billing for integrated behavioral health services challenging. Mental health treatment and medical care are often covered by different insurance plans. The mental health plans vary substantially on the types and frequency of services covered. Most mental health coverage is based on a fee-for-service model, and a patient's copay is likely the same whether they receive a traditional 50–60-min therapy service or a 20–30-min brief intervention [41]. While health and behavior CPT codes were introduced in 2002 and allow for billing of shorter visits tied to a particular medical condition, many insurance companies still do not reimburse for these codes and limit the providers able to use them to only those with certain licenses (i.e., psychologist). This varies a great deal by state. The Center for Integrated Health Solutions (SAMHSA-HRSA) has published state-by-state billing guides for integrated care which are available online at http://www.integration.samhsa.gov/financing/billing-tools.

A movement toward accountable care organizations (ACO) may address these direct billing concerns. Under the ACO model, fees are paid for chronic care management for a population of patients rather than traditional fee-for-service payment structure. Moving to value-based reimbursement contracts that include shared saving may encourage the expansion of IBH [46]. Effective integrated behavioral health programs add value and reduced cost by reducing emergency department visits, hospitalizations, and unnecessary testing [47].

Evidence for Integrated Behavioral Health

Integrated behavioral health interventions can be differentiated based on the value they add. For integrated care to be considered a "value-added" service, it must improve patient outcomes and patient experience while conserving healthcare resources [48]. Services that do not meet all three of these outcome domains are described as "clinical enhancements."

One systematic review of basic level integration (co-locating a BHP in a primary care setting to provide counseling services) found that integrated counseling services did yield significantly greater clinical improvement in the short term, but not in the long term when compared to usual treatment within primary care [49]. This review found high levels of patient satisfaction with integrated counseling services, but no cost savings compared to usual care. Another systematic review of behavioral interventions for depression, substance use, and/or chronic pain in primary care settings found small to moderate effects for mindfulness-based and cognitive-behavioral interventions in moderating the impact of comorbid chronic medical conditions [50]. Basic co-located counseling may be a "clinical enhancement," but has not demonstrated "added value" based on currently available outcome research.

A systematic review of telepsychiatry studies examined outcomes for patient and provider satisfaction, treatment outcomes, and cost-effectiveness [51]. While this review did not focus solely on the use of telepsychiatry in primary care settings, it does suggest that telepsychiatry is comparable to face-to-face service in terms of treatment outcomes. Patients and providers were satisfied with services, although providers had concerns about the impact of videoconferencing on the therapeutic rapport with the patient. Telepsychiatry was more cost-effective than traditional face-to-face services in the majority of studies reviewed and has the potential to be a "value-added" method to integrate behavioral health and primary care.

There is substantially more research available on collaborative care models. Multiple systematic reviews and meta-analyses have demonstrated that these types of IBH models add value. In a systematic review of controlled trials, collaborative care models improved antidepressant adherence and depression outcomes for 2–5 years with improved patient experience and provider satisfaction [52]. A review of 79 randomized controlled trials with over 24,000 patients with depression or anxiety compared collaborative care to usual care by a primary care clinician alone or other treatments (i.e., cognitive behavioral treatment, consultation-liaison models) [53]. Collaborative care was associated with significant improvement in depression and anxiety outcomes over the course of 2 years compared with usual care. They also

found improvements in mental and physical health quality of life outcomes, and that patients who received collaborative care were more satisfied with their care.

There is also evidence supporting the clinical effectiveness of integrated care for children and adolescents. A recent meta-analysis of 31 randomized controlled trials compared behavioral health outcomes for children and adolescents receiving usual primary care versus integrated medical-behavioral health care [54]. These studies targeted diverse mental health concerns including depression, anxiety, and behavior problems and found a small but significant advantage for integrated care relative to usual care. The strongest effects were found in trials that focused on treatment rather than prevention and involved collaborative care models.

Collaborative care for depression is associated with improvement in other health-care conditions. Collaborative depression care (IMPACT model) for older depressed patients was associated with substantially fewer cardiovascular events (including fatal events) than usual depression care when these patients were followed for an 8-year period after the intervention [55]. Collaborative care interventions for cancer patients with depression were significantly more effective than usual care, and the reduction in depression was maintained at 12 months [56]. Additional meta-analyses have found benefit for collaborative care in depressed patients with diabetes (improvements in depression symptoms and HbA1c) [57], cardiovascular disease [58], and anxiety [53].

A recent naturalistic retrospective cohort study compared traditional practice management (TPM) to integrated team-based care (TBC) in the Intermountain Healthcare System in Utah [59]. This study examined outcomes in a large health-care system (102 primary care practices) involving more than 113,000 adults. TBC was defined as care aligned with the PCMH standards and included the integration of BHPs in the practices. This study focused on chronic disease and health-care utilization outcomes rather than mental health outcomes. TBC was associated with significantly higher levels of screening for depression, documentation of self-care plans, and adherence to quality metrics for diabetes care, whereas TPM was associated with better blood pressure control. TBC was associated with lower utilization of emergency departments, hospital admissions, and primary care visits. There was no significant difference in visits to urgent care or specialty care physicians. This study also examined financial outcomes, finding that the cost was $10 per patient annually. Within a traditional fee-for-service payment model, the reimbursement received for TBC was $115 less per patient annually when compared to TPM, however. Thus, cost savings for the insurers were demonstrated, but within the context of a fee-for-service payment model, this makes IBH more difficult for practices to sustain financially. Another study using the IMPACT model for older Medicare patients with depression demonstrated a 10% savings in total health-care costs (average savings were $3365 per patient) over a 4-year period [60]. Collaborative care models save between $15,000 and $80,000 per quality-adjusted life-year gained when compared to usual care especially when considering savings from reduced work absenteeism and hospitalization [46]. The growing literature on health-care cost outcomes for IBH highlights the importance of continuing to assess the value that IBH adds from a systems perspective as well as the need to continue to advocate for alternative payment models that incentivize improved clinical outcomes and cost savings.

Future Directions

No one IBH model is likely to address every local population's needs and ongoing innovation, and creativity is needed. While the data supporting the effectiveness of IBH continue to grow, one of the limitations with much of the literature is that the outcome studies have focused on specific diseases (depression and anxiety) in certain populations (e.g., elderly populations). Future research must examine IBH models that address multiple comorbidities, childhood problems, and disorders that fall on the more debilitating end of the spectrum such as schizophrenia and substance dependence. Reverse co-location models (primary medical care offered in the setting of a mental health practice) may be another way to address the complex comorbidities found in adults with severe and persistent mental illness and substance dependence.

High-quality research is also needed concerning non-collaborative care IBH models and how IBH outcomes translate in real-world practices. In addition, we need to expand our understanding of how IBH models can be adapted to meet the needs of culturally diverse populations and families. Family consultations, family therapy, and parenting training are rarely described in studies on integrated primary care programs [61]. Given that the discipline of family medicine represents a substantial portion of primary care practices, future IBH models should consider how we can keep the "family" in IBH family medicine.

Future studies should examine how enhanced resiliency and self-engagement in chronic disease management may improve outcomes and satisfaction while reducing overall health-care costs. Most IBH models focus on moderating the impact of emotional distress that is already present. Integrating resiliency models such as mindfulness-based stress reduction, peer support, and chronic disease self-management may help to improve outcomes for an even broader array of patients.

Summary

The integration of behavioral health and primary care represents a significant transformation in the way that health care is conceptualized and delivered. The current evidence base has demonstrated that integrated care can help achieve the quadruple aim of better health, better patient experience, lower costs, and improved physician experience [62, 63].

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Transitions of Care

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Mallory McClester Brown

With an aging population and advances in medical science, people with advanced diseases are living longer, and chronic care now dominates the health-care system. Effective management of patients with chronic diseases requires a well-developed care continuum that emphasizes patient safety. Fragmentation and discoordination of health care is a significant cause of inappropriate care and increased health-care costs.

One in five Medicare patients hospitalized in the United States is readmitted within 30 days of discharge [1, 2] and 34% are readmitted within 90 days [16]. Seventy-five percent of those rehospitalizations were likely avoidable [2]. "Readmission" is defined by the Centers for Medicare & Medicaid Services (CMS) as hospitalization within 30 days of discharge from a prior acute care admission to a hospital [17]. Cost secondary to readmission is $17 billion for Medicare alone [16]. Poorly executed care transitions negatively affect patients' health, well-being, and family resources, unnecessarily increase health-care system costs (IHI [5]), and raise the probability of readmission [14–16]. Medicare reimbursement penalties have been instituted by the Patient Protection and Affordable Care Act for hospitals with high levels of readmissions in recent years, making the topic of readmissions timely and valuable [2]. Policymakers and providers recognize that avoiding rehospitalizations improves quality of care and reduces health-care costs. Readmissions can be reduced by developing a system that is anticipatory rather than reactionary.

Transitions of Care Defined

Transitions of care is defined as the set of actions taken to ensure coordination and continuity of health care as patients are transferred among various care settings [3]. Transitions of care, when done well, take the patient's safety, goals, and well-being into account. High-quality transitions reduce the use of resources by decreasing emergency room utilization and the need for rehospitalization, decreasing cost to the health-care system, and increasing patient, family, and provider satisfaction.

As an example, consider a frail 70-year-old female with congestive heart failure who is admitted to the hospital for a hip fracture. If she tolerates the procedure, does not have postoperative complications, and stabilizes medically, her care will be transitioned to a skilled nursing facility (SNF) for rehabilitation. Once at the SNF, if she decompensates medically and becomes delirious or has an exacerbation of her congestive heart failure, she will likely be sent back to the emergency room and probably readmitted to the hospital. However, if her rehabilitation at the SNF progresses well without medical complications, she will successfully transition from the SNF to home with home health care and follow-up with her primary care provider and the orthopedic surgeon who did the hip repair. This example shows the possible outcomes of a complex patient moving through our current health-care system, which involves multiple medical providers, various physical locations, and a changing level of care required by the patient. In order to ensure this patient receives the best quality of care, each team of nurses, therapists, physicians, and social workers must work together to successfully transition the patient from one level of care to the next which includes moving from health-care venues as varied as hospitals, acute rehabilitation centers, skilled and subacute nursing facilities, long-term care facilities, assisted living homes, home health care, and hospice facilities.

Hospital Discharge Process

Planning for a transition in care begins while a patient is in the hospital. As part of the Medicare Conditions of Participation, hospitals are required to employ and document a discharge planning process for all patients and must

M.M. Brown (✉)
UNC Dept. of Family Medicine, University of North Carolina, Chapel Hill, NC, USA
e-mail: Mallory_mcclester@med.unc.edu

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identify those who are likely to suffer adverse health consequences after discharge in the absence of adequate discharge planning. Due to increasing pressure to shorten the length of a hospital stay, patients are less likely to stay hospitalized until they feel "better" as was the case in the past. Decreasing length of stays leave limited time for educating patients and families in the hospital [13].

In 2004, a quarter of Medicare patients were discharged from a hospital to a nursing home or rehabilitation facility. A more recent study of Medicare beneficiaries that looked at the 30-day period following hospital discharge showed that 60% of patients made a single transfer, 18% made two transfers, 9% made three transfers, and 4% made four or more transfers [3]. All of this transitioning from one place to the next increases the likelihood that vital information will be lost and care plans will be fragmented [3]. To address this, many health-care systems have instituted transition of care programs that recognize that discharges from the hospital are most successful when a team-based approach is taken, including the physician, nurse, pharmacist, case manager, patient, and caregiver. In the State Action on Avoidable Rehospitalizations (STAAR) trial, a hospital discharge nurse, pharmacist, or social worker identified patients at high risk for readmission and ensured thorough discharge planning including educating the patient [10]. Nurses developed a systematic way of providing information to the patient, with a folder that included information about the patient's care team, follow-up appointments, and treatment plan with educational materials specifically tailored for the patient. Patients were also encouraged to write down their questions, to be answered by the nurse the next day. The discharge nurse also led discussions at multidisciplinary rounds including reaching consensus on the estimated day of discharge for the patient. A pharmacist also worked on the transitions team throughout the hospitalization, anticipating medication issues and changes, educating the patient on the recommended medication regimen prior to discharge, reconciling the medications on the day of discharge, and provided counseling and a discussion about barriers to adherence. The transitions pharmacist often called the patient after discharge to again review the medication list.

Hospital-based case managers also have an important role in the discharge process. Case managers can uncover psychosocial issues or other causes that likely contributed to an admission or readmission. These members of the team are often best equipped to determine the level of care the patient entered the hospital with and to advise on the appropriate services needed at discharge [12].

Physicians play an important role on the discharge planning team. They keep the team informed regarding timing of discharge and predicted needs at the time of discharge. The hospital physician is often the one who contacts the patient's primary care physician for input on medical history as well as updating him or her on the patient's progress. A complete discharge summary available in a timely manner is also an important role of the physician and includes several key pieces of information that can reduce the risk of readmission (Table 30.1).

Table 30.1 Key components of the discharge summary for a patient with high likelihood of readmission

Overall goals of care	Chief complaint, reasons for admission
Functional status (ADLs, IADLs)	Medication list, including changes
Therapy needs	Durable medical equipment
Typical residence	Advance directives
Primary caregiver, support at home	Medical hospital course

Some practices will send a liaison from the practice to the hospital to help coordinate care by sharing information about the patient with the hospital team, alerting the practice of the admission along with the anticipated date of discharge, and ensuring that the practice anticipates post-discharge issues and provides timely follow-up [5].

The patient and the family also play an important role in the discharge process. They help in deciding the next location of the patient's care, when follow-up will occur, and who to contact if a problem arises. They must also understand the updated medication list, when and how to take the medications, and potential side effects. Ideally, they can describe a system for taking their medication prior to discharge. It is also important to ensure that the patient and family have some understanding of the reason for admission and the diagnosis [3].

In all transition models, communication is vitally important. Establishing the patient's health literacy is key in providing effective discharge instructions. The teach-back method (confirming whether a patient understands what is being explained to them by asking them to repeat it back) is an easy, inexpensive way to improve patient education at the time of discharge [14].

Care After Hospitalization

The highest-risk patients will benefit from close follow-up which can include a phone call, a home health visit, or an office visit within 48 h, all of which can reduce the risk of rehospitalization. A report in 2004 suggested that only 50% of the 2.3 million Medicare enrollees readmitted within 30 days were seen by primary care providers in the interim between the hospitalizations [11].

Post-hospitalization phone calls are a cost-effective readmission prevention strategy [5, 16]. These phone calls should include asking the patient if they have filled their prescriptions;

ensuring the patient knows how and when to take the medications; discussing the patient's understanding of critical elements of self-care; reviewing why, when, and how to recognize worsening symptoms and when and whom to call for help; and confirming the date and time of the follow-up physician appointment as well as ensuring transportation is arranged [5]. Follow-up with the primary care provider decreases readmissions especially if scheduled within 1–2 weeks of discharge. Timely appointments require good communication between the inpatient team and the outpatient provider's office. In addition to the timeliness of follow-up, other key components of a successful hospital follow-up office visit include preparing the patient and the office clinical team before the visit, assessing the patient and initiating a new care plan or revising the existing care plan during the visit, and communicating and coordinating the ongoing care plan at the conclusion of the visit with the patient and the care team [5]. The visit should also include a review of the patient's health-related goals to ensure there is agreement between the care team and the patient. The patient should be asked about factors that contributed to the hospitalization or emergency department visit and correct modifiable factors that might reduce the likelihood of a future admission. The medications should be reviewed again to reduce medication errors and increase compliance with an updated medication list printed for them. Follow-up labs, tests, and discussion of the need for additional workup should also be addressed. Patient understanding of the plan is assessed and reviewed in language they can understand along with the opportunity to ask questions. The visit should end with agreed-upon goals of self-management, a scheduled follow-up visit, and instructions on reasons to return earlier. Checklists can help with post-hospital follow-up visits [5]. Note templates can also be created in the electronic medical record.

Reasons for Readmission

The success or failure of transitions of care in preventing rehospitalizations depends on the nature of the intervention, the setting of implementation, and the population of patients [4]. Many tools exist to predict hospital readmission, but inconsistencies in the data prevent us from knowing which risk factors are most predictive [5]. Older age, prior hospitalization, poor family or social support, low health literacy, high medication burden, and numerous specific medical conditions increase the likelihood of readmission [1, 3] (Table 30.2).

In addition to these risk factors, readmissions have other causes including poor communication, medication issues including misunderstandings of instructions during hospitalization or at discharge, inadequate patient comprehension of diagnoses and follow-up needs, and failure to complete planned outpatient diagnostic or treatment plans [9]. The risk of readmission is highest shortly after discharge which is when medication errors are likely to occur and intended or pending tests are not followed up (outpatient test recommended but did not take place). This is likely due to poor communication between hospital physicians and the provider seeing the patient after discharge or between the discharge team and the patient. Patients often do not understand risks and benefits of medication changes, when they can resume normal activity, what questions they should ask, and warning signs for which they should watch. Many patients are discharged from the hospital with intravenous access lines, complex wound care, enteral feeding devices, catheters, surgical drains, and other types of devices that are complicated and can lead to readmission if the patient is not managed appropriately [13].

Table 30.2 Risk factors for hospital readmission

Heart disease	Medicare/Medicaid eligible	Prior hospital stay
History of stroke	Requires caregiver for assistance with ADLs	Cognitive impairment
Diabetes	Inadequate social support	Extensive medication list
Cancer	Inadequate preparation from caregivers	Poor compliance
Depression	Poor health literacy	

Timing of Interventions

Interventions to reduce readmissions can be classified by timing (pre-discharge, post-discharge, interventions that bridge the transition) and use several methods such as discharge planning protocols, comprehensive assessments, discharge support arrangements, and educational interventions [2].

Pre-discharge

Planning ahead while the patient is still in the hospital is considered pre-discharge planning and includes patient education, discharge planning, medication reconciliation, and scheduling the follow-up appointment before discharge [3]. Collaborating with the outpatient provider during hospitalization and asking the patient and caregiver's preference for appointment scheduling after discharge can help ensure optimal outpatient follow-up care [6].

Prior to discharge, the discharge summary is completed and provides a clear, organized, and complete story of the hospitalization [6]. It is a key mode of communication that bridges care from the hospital to the next setting. Medication reconciliation is an important part of this process, as medication errors or effects are a leading cause of readmission [8].

Patient education at discharge helps the patient and caregiver understand the relevant disease process, the events during the hospitalization, medication changes, expected follow-up, and who to contact if concerns arise regarding a change in their health status. For higher-risk patients, a patient "coach" has been shown to be useful in improving self-management skills [6, 18].

Post-discharge

Post-discharge interventions include telephone calls, hotlines, home visits, and timely outpatient follow-up. Follow-up telephone calls have been studied with and without a script. A script may include plans for follow-up, discussion of new symptoms, and review of medication availability [3]. Outpatient follow-up may be best with the patient's primary care provider according to studies that have shown increased risk of admission when seeing an unfamiliar provider [9]. Interventions to reduce hospitalization that include the outpatient are more successful than inpatient-only interventions [4].

The State Action on Avoidable Rehospitalizations (STAAR) trial reported that post-discharge phone calls from the pharmacist found that 52% of patients deviated from medication instructions after leaving the hospital which included patients continuing on medications that had been discontinued during the hospitalization, using over-the-counter medications that were not mentioned during the hospitalization, and confusion regarding proper dosing instructions for medications that were initiated or changed at discharge [10].

Bridging the Transition

Bridging interventions support the patient during a vulnerable time and educate, empower, and activate the resident in his or her own care. Useful strategies include patient-centered discharge instructions (PCDI), transition coaches, and provider continuity from inpatient to outpatient. The PCDI is an inpatient teaching tool that also provides discharge instructions.

For higher-risk patients, a "coach" has been shown to be useful in improving the patient's self-management skills [6, 18]. A transition coach bridges between the inpatient setting where efforts focus on disease-specific education and assessment of social needs and the outpatient setting where the coach focuses on medication adherence, ambulatory follow-up, and symptom monitoring.

Evidence is scarce to support any one strategy over another for reducing the likelihood of readmissions [2]. Single interventions, when evaluated in isolation, have not consistently demonstrated statistically significant changes in readmission rates. Even when interventions are bundled, there is no consistent solution to decreasing readmissions. Still, there is agreement that a multidisciplinary approach to improving care coordination must be a part of effective efforts to reduce avoidable readmissions [4, 21].

Programs in Transitions of Care

A number of studies have looked at effective practices in transitions of care. The Care Transitions Intervention (CTI) utilizes a nurse transition coach who educates and empowers patients to better navigate their own care. The CTI emphasizes four "pillars": medication self-management, a patient-owned health record, follow-up with a primary care provider or specialist, and awareness of "red flags." The intervention lowered 30- and 90-day readmission rates and reduced readmissions [18, 20].

Project Re-Engineered Discharge (RED), developed by Jack and colleagues, addresses both the system and patients' navigation of the discharge process through 11 mutually reinforcing components, many of which have been discussed previously (Table 30.3) [22]. When implemented in an urban university hospital, participants in the program had a lowered rate of 30-day hospital utilization (emergency department visits and rehospitalizations) [7, 19, 20].

Project BOOST (Better Outcomes by Optimizing Safe Transitions) was designed to identify high-risk elderly patients early in the admission process [23]. This program provides resources to optimize the hospital discharge process and minimize issues older patients face after discharge from the hospital. Hospitals may use the BOOST toolkit, which

Table 30.3 Components of discharge planning that reduced hospital utilization within 30 days of discharge [7]

Educate the patient about his or her diagnosis throughout the hospital stay
Make appointments for clinician follow-up and post-discharge testing
Discuss with the patient any tests or studies that have been completed in the hospital and discuss who will be responsible for following up the results
Organize post-discharge services
Confirm the medication plan
Reconcile the discharge plan with national guidelines and critical pathways
Review the appropriate steps for what to do if a problem arises
Expedite transmission of the discharge summary to the physicians (and other services such as the visiting nurses) accepting responsibility for the patient's care after discharge
Assess the degree of understanding by asking them to explain in their own words the details of the plan
Give the patient a written discharge plan at the time of discharge
Provide telephone reinforcement of the discharge plan and problem-solving 2–3 days after discharge

Adapted from: Jack et al. [7]

promotes collaboration and allows programs to learn best practices from each other. It has reduced the 30-day readmission rate and improved communication and collaboration during and after hospitalization.

Summary

Well-executed transitions of care incorporate patient's individual goals, needs, and values [3]. An ideal transition includes effective communication of information, patient education, enlisting the help of social and community supports, ensuring continuity of care, and coordinating care among team members, all done in a timely manner [6]. Anticipating problems that may arise after discharge, related to the disease exacerbation or to a psychosocial dynamic, and then undertaking actions in response to these problems have been effective. Specifically listing issues that require attention at the first follow-up visit is also important in a successful transition. There is little evidence to support one specific plan, and the best approach likely varies with the needs and practices of specific communities [4]. The themes that persist in any plan include the need for a comprehensive approach that promotes transition planning before, during, and after hospitalization. The most successful interventions are flexible and accommodate the individual patient's needs [4]. To reduce readmissions to the hospital, health-care systems must incorporate multiple interventions in an anticipatory manner rather than passively responding to the unwanted outcome of rehospitalization.

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Care Management

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Amy N. Prentice, Rayhaan Adams,
and Timothy P. Daaleman

Introduction

There is increased awareness of how patients' psychosocial circumstances and associated needs impact their health and well-being [4, 5, 16]. As a result, patient care is no longer limited to the medical problems and conditions that are solely addressed in clinical settings by physicians and other health-care providers. A patient with multiple medical conditions, for example, who frequently seeks care in an emergency department, may be isolated from supportive relationships, may lack the financial resources that are necessary for ongoing care, or may have comorbid behavioral health conditions that are unaddressed [5]. The growing awareness of these factors highlights the importance of continuity and coordination of care as critical to a patient's health and health care [4]. Nationwide, as the population ages and the prevalence of chronic illness increases, clinics, hospitals, and health-care delivery systems are becoming increasingly complex, and new approaches to chronic care are needed to address these changes across health-care settings [16].

The shift in health-care delivery from a reactive, episodic approach to proactive, integrative models is responsive to the needs of medically complex patients [4]. This change has created the need for coordinated interdisciplinary care teams, often consisting of social workers, nurses, pharmacists, and allied health-care professionals who work collaboratively across health-care environments [5, 16]. Care management is an emerging strategy that is representative of his multidisciplinary perspective and seeks to extend the reach and enhance targeted interventions to complex patient populations across health-care settings and providers [5, 16]. By expanding the scope of traditional medical care, care management has the capacity to promote continuity of care and mitigate the unnecessary utilization of health-care resources while also supporting disease self-management for individual patients [5, 16].

This chapter provides an overview to care management in the health-care setting. The first section defines and operationalizes care management, as well as the roles and responsibilities that are associated with this function. The subsequent section provides some applications of, and the evidence base for, care management in both community-based and practice settings. The chapter closes with information regarding strategies for implementing care management in health-care settings.

Understanding Care Management

The role of "case manager" first arose in the 1970s as a response to the deinstitutionalization of mental health patients to community-based settings in the United States [6]. The initial focus was to enhance access and continuity of care and ensure some level of accountability and efficiency for patients who were discharged from institutions and often faced confusing and fragmented health and social services [6]. The core components of case management at that time – needs assessment, comprehensive service planning, service delivery coordination, monitoring and assessing health and social services, and evaluation and follow-up – can still be recognized in present-day approaches [7].

Care management was a term that was initially adopted by British social service agencies in 1993 to describe their approach to case management [6]. This concept was a core element in the Care in the Community Programme as outlined in the Department of Health Social Services Inspectorate's guidelines. The term "care management" was preferred to "case management" since at the time, there was

A.N. Prentice • R. Adams • T.P. Daaleman (✉)
Department of Family Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA
e-mail: tim_daaleman@med.unc.edu

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a perception among patients that as the term "case" was considered offensive [6]. Although this concept differentiated care managers from other related workers by their long-term involvement with clients and by their work with multiple, rather than single, teams and services, there was no common understanding as to what care management meant or who should be care managed. As a result, there was confusion as to whether care management described an approach to working with patients or the actual tasks and functions that were required [2].

Clinical case management, a related concept, stressed the importance of small, manageable caseloads that had a wide, inclusive scope, including individualized treatments, programmatic flexibility, outreach, care of patients with serious mental illness, interagency cooperation, and continuity of care [6]. This concept was developed in response to the increased need for a direct patient interface, a focus on small caseloads, and interagency care coordination [6]. The role and responsibilities of a clinical case manager have been adopted, and its central components are comparable to the traditional case manager, since there is a focus on needs assessments, coordination of care, linkage to community resources, and ongoing follow-up, largely in practice-based settings [6].

There are several interpretations of what constitutes care management; however, at its core, care management seeks to improve the coordination and effectiveness of health-care services. Care management can be more formally defined as a collaborative process of assessment, planning, facilitation, and advocacy for options and services to meet a patient's health needs through communication and available resources that promote high-quality, cost-effective care [28]. The overall goal of care management is to optimize wellness and improve the coordination of health-care services while providing cost-effective, evidence-based services. Care management programs apply systems-level strategies, such as practice incentives and access to collateral information, as ways to improve health-care settings and encourage patients and their support system to engage in a collaborative process that manages social and behavioral factors.

Care managers, in turn, are responsible for identifying, coordinating, and monitoring patients' psychosocial needs over a longitudinal timeframe, which is guided by the patient and health-care team [2]. Some duties of care managers may include assisting patients to access needed preventive services, such as breast and colorectal cancer screening. Another task might involve reaching out to patients after emergency room visits or hospitalizations to ensure timely access to primary care and appropriate transitional care. Care managers can also follow up on needs that are identified during outpatient visits and connect patients with other allied health-care resources, such as health educators, nutritionists, social workers, and community-based resources [9, 14, 20, 21, 23–27].

Care Management Functions

The major functions of care management have evolved over the past two decades. The BPHC Health Disparities Collaborative, for example, identified five major functions: developing and maintaining rapport with patients and providers, patient and family education, symptom surveillance, developing and maintaining self-care action plans, and promoting treatment adherence through problem-solving of treatment-emergent problems [2]. With the rise of patient-centered medical homes, care managers have assumed additional duties in these settings, including assistance in coordinating care, providing one-on-one personalized self-management education, and facilitating focused care and attention for patients with complex needs [8].

Care managers serve as liaisons between multiple stakeholders involved in patient care, such as specialists and allied health professionals, health insurance companies, community-based services, and hospital-based services. They often conduct in-depth patient assessments and spend time discussing, locating, and coordinating patient resource needs [19]. As a result of the diverse skill set that is required, care managers are usually nurses, social workers, or other allied health professionals who have the training and expertise to work alongside health-care providers, patients, and ancillary care services [2, 19–22].

When embedded in health-care settings, care managers can be a consistently available resource for patients with chronic health conditions and psychosocial barriers through in-person and telephonic interactions. It is often the continuity, as well as the quality, of the relationship between the patient and the care manager that leads to a level of trust and rapport and empowers patients to be effective self-managers of their health care [8]. The scope of responsibilities for the embedded care manager (ECM) includes many of the previously noted functions – comprehensive patient assessments, patient education, development of individualized care plans, facilitation of care across different care settings – in addition to data gathering for ongoing quality improvement and evidence-based practice [3].

The primary goal of the ECM is to effectively manage patients who are medically vulnerable and at risk for worsening of their disease state and, subsequently, greater health-care utilization [3]. By seeking to maximize patient quality of life and serving as a central point of patient contact within the practice, the ECM has great capacity to optimize the larger health system performance by simultaneously

improving the patient experience of care, improving the health of populations, and reducing the per capita cost of health care ("The IHI Triple Aim," 2013).

One evolving care management model out of Maine Medical Partners Family Medicine focuses on identifying and improving the psychosocial factors that contribute to helplessness and hopelessness in chronically ill patients so that behavior change can take place and be sustained [5]. This approach capitalizes on the relational connections between patient and care manager and is designed to guide patients to be coproducers of their own health [5]. The model seeks to increase patient capacity by developing consistent, validating relationships that are focused on promoting patient agency. This occurs through dialogue with patients about their self-defined medical concerns, which are then co-constructed into patient-centered plans for health [5].

Another approach may incorporate principles from the patient-centered medical home and accountable care organization models of care to promote population health management. Here the focus of care management is on proactive outreach to medically vulnerable patients, who are often high utilizers of health-care resources. Care management services are provided on a continuous basis, rather than a reactive, episodic approach and include patient assessments, resource planning, and facilitation of patient-centered services. This strategy is supported by data that prospectively identifies and stratifies different patient populations, in order to tailor intervention to specific subgroups. Figure 31.1 provides a flow diagram to this approach within a primary care setting.

Many health-care organizations have opted to embed population-based care managers within targeted practices that have a high concentration of at-risk patients to promote greater patient engagement. The use of predictive analytics and the case reviews of patients who are high utilizers of health-care services aid in the identification of prospective patients (Fig. 31.2). In this approach, the care manager would either receive point of care referrals from physicians and other care providers or use an information technology tool that would identify patients who have screened positive, using specific criteria [14].

In either approach, the care manager functions as the advocate for the patient, facilitator of communication between provider and patient, and broker of community resources and services [9]. Commercial vendors and private health insurers have also used this approach to improve the quality of care and decrease health-care costs by providing intermittent telephonic clinical support and home visits to assess the health status of the patient [9]. Given the limited

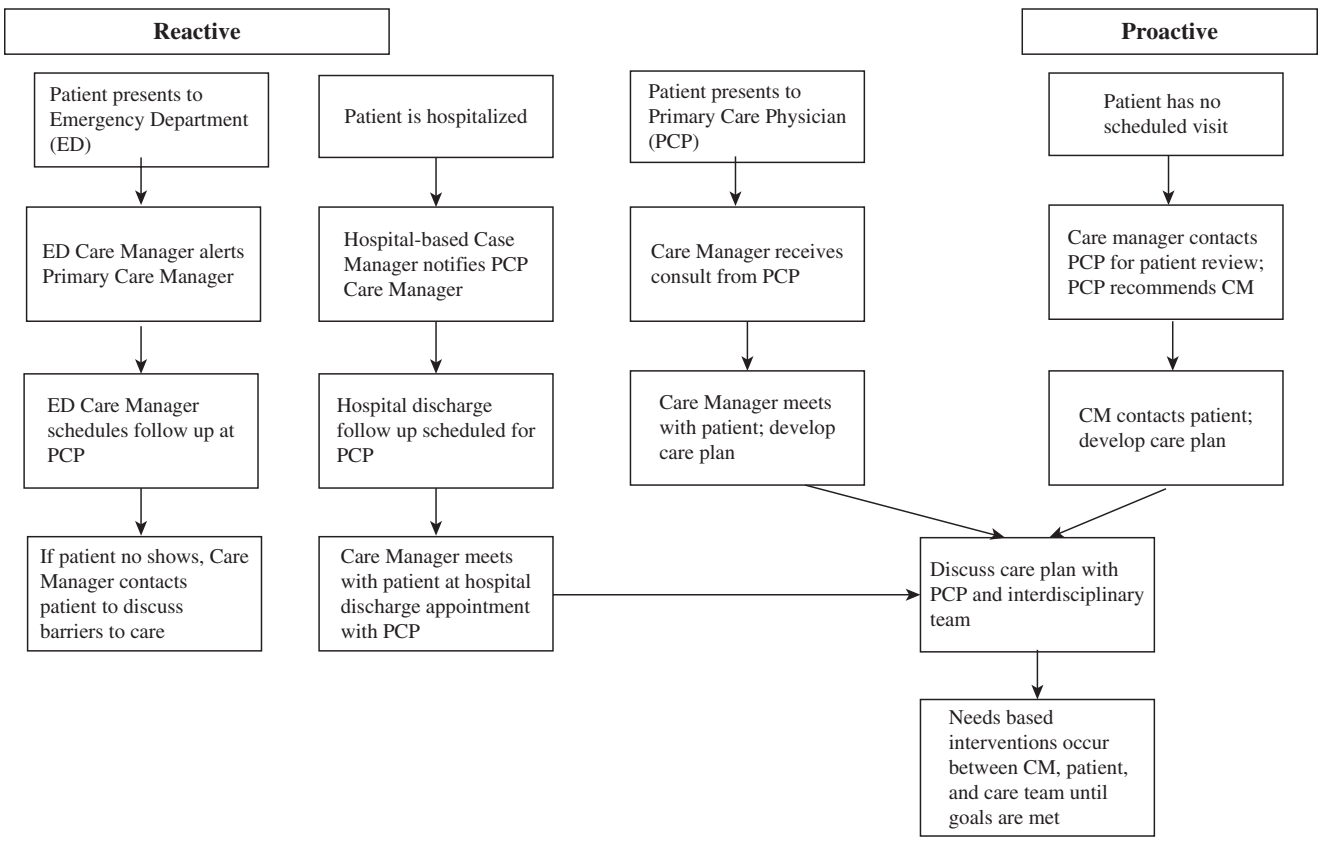

Fig. 31.1 Reactive and proactive care management flow models

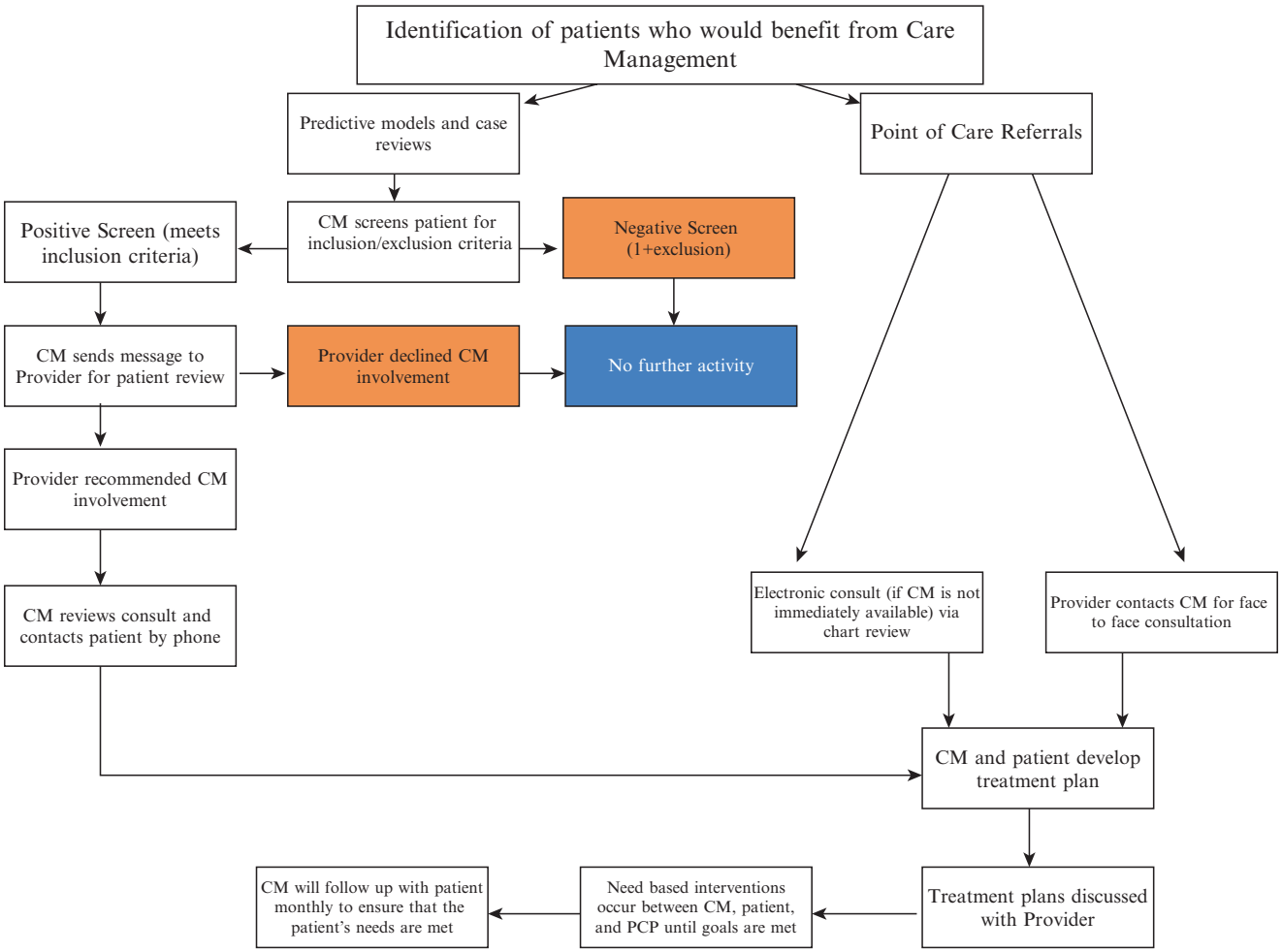

Fig. 31.2 Care management workflows

opportunity for face-to-face interaction and rapport building, engagement and accountability are often low when enrolled in centralized or offsite care management.

Care Management in Clinical Settings

Successful care management models have included community-based care managers, health plan care managers embedded in primary care practices, and health system-based nurse teams working in primary care practices [9]. Over 20 years ago, a literature review examined the impact of case management programs on health-care resource use and outcomes related to patient satisfaction, quality of life, functional status, as well as their cost-effectiveness (Fig. 31.3) [12].

Nine studies met the inclusion criteria, and, of the seven studies examining case management's impact on health resource use, only two found a positive effect [12]. Both successful programs targeted patients with specified disease conditions, and care was supervised by a medical subspecialist. No programs that targeted comorbid conditions or was supervised by generalists reported a positive effect [12]. All six studies examining patient-centered outcomes reported a positive impact, and these effects were unrelated to the patient's conditions or the study personnel [12]. Only three studies examined costs, and all reported nonsignificant cost savings [12]. Patient-centered outcomes were often improved upon but at unknown cost.

Since this review, there have been several multisite trials and natural experiments that have examined the impact of case management within larger health-care systems. A cluster randomized trial tested the effectiveness of a care management model on the treatment of depression in primary care practices [15]. Five health-care organizations and 60 affiliated practices enrolled over 400 adult patients. The intervention involved a systematic approach to the assessment and management of depression by primary care clinicians, with a centrally based care manager providing telephone support for patients [15]. An evidence-based patient health questionnaire was used to diagnose depression, monitor treatment response,

Case Management in Primary Care

Author	Year	Target Group	Intervention	Number of Subjects	Duration of Follow-up	Outcome Measures	Effect (Intervention vs Control)
Mayo et al.[7]	1990	Asthma	Care provided by 1 specialty MD and nurse; emphasis on patient education and improved access; single site	104	8 mo	Readmission rate Hospital days	0.4/pt vs 1.2/pt, $p < .01$ 3.1/pt vs 6.7/pt, $p < .02$
Rich et al.[8]	1995	Congestive heart failure	Nurse-directed patient education; dietary instruction by dietician; medication review by specialist; intense outpatient follow-up by team; single site	282	90 d	Mortality Number of readmissions QOL improvement Hospital days Cost	9.2% vs 12.1%; NS 53 vs 94, $p = .02$ 46.1 pts vs 11.3, $p < .01$ 3.9/pt vs 6.2, $p = .04$ $4,816 vs $5,275; NS
Weinberger et al.[9]	1995	Diabetes	Nurse-directed patient education, monitoring of symptoms, and improved access; telephone follow-up; single site	275	1 year	Glycemic control: FBS GlyHgb HRQL (SF-36) Number of symptoms Patient satisfaction	 174 vs 193 (mg/dL), $p = .01$ 10.5% vs 11.1%, $p = .05$ 46.9 vs 50.8; NS 1.2/pt vs 1.4/pt; NS 14.1 vs 15.0; $p = .01$
DeBusk et al.[10]	1994	Post-MI	Nurse-managed risk factor reduction as inpatient; telephone follow-up; 5 sites	585	1 year 6 mo	Smoking cessation LDL Functional Capacity	70% vs 53%, $p = .03$ 2.77 vs 3.41 (mmol/L), $p < .01$ 9.3 vs 8.4 (mets), $p < .01$
Smith et al.[12]	1988	Post-hospital	Nurse-directed needs assessment, medication review, improved access; telephone and primary clinic follow-up; single site	1,001	6 mo	Nonelective admissions Office contacts	0.85/pt/mo vs 0.92; NS 0.53/pt vs 0.48, $p < .01$
Fitzgerald et al.[13]	1994	Post-hospital	Nurse-directed education, telephone and primary clinic follow-up, improved access; single site	668	12 mo	Clinic visits Nonelective admissions ER visits Mortality	.99/pt/mo vs 1.04; NS .064/pt/mo vs .065; NS .18/pt/mo vs .19; NS 10.5% vs 10.4; NS
Cummings et al.[15]	1990	Post-hospital	VA HBHC, multidisciplinary team (MD, nursing, dietary, social work and physical therapy), home visits and continuity care; single site	419	6 mo	Hospital days Functional status Satisfaction Cost	12/pt vs 14; NS Multiple scales Multiple scales $4,648 vs $5,320; NS
Weinberger et al.[14]	1996	Post-hospital (CHF, COPD, diabetes)	Nurse/primary MD team, telephone follow-up, improved access; 9 sites	1,396	6 mo	Readmission rates QOL Satisfaction	.19/pt/mo vs .14, $p < .01$ Multiple scales Multiple scales
Toseland et al.[11]	1996	Geriatric patients	Nurse and geriatrician directed care which included both outpatient and inpatient settings; single site	160	8 mo	Functional status Well being Hospital rate Hospital days Cost	Multiple scales Multiple scales .64 vs .60; NS 8.75 vs 7.2; NS $7,300 vs $5,900; NS

Fig. 31.3 Case management in primary care (Modified from [12])

and guide treatment changes. Participating primary care clinicians were provided with data, such as patient questionnaire scores.

Patients received a follow-up telephone call from the care manager after their initial visit and were contacted monthly and as needed. Care managers provided assistance to patients in overcoming barriers to treatment adherence and supported self-management practices such as exercise or engaging in social activities [15]. Psychiatrists supervised the care managers through weekly telephone conferences which provided a structure for presenting new patients and following up on treatment. Based on patient questionnaire scores, the psychiatrist could recommend changes either through the care manager or by direct contact with the clinician. Clinicians were also able to contact the psychiatrists for informal telephone advice [15].

Prior to the intervention, care managers received training from 4 to 8 h, psychiatrists received 1 h training, and primary care clinicians took part in a 1–2 h educational program that addressed the diagnosis of depression, assessment of suicidal thoughts, response to management on the basis of responses to the questionnaire, and modification of management to achieve remission [15]. Staff in the intervention practices received a 45-min course on the intervention. The health-care organizations had the autonomy to implement the model and to maintain it through follow-up with the practices. As such, they identified care managers and psychiatrists, who were trained by employees of the organizations [15].

There were several outcomes that were measured, including the severity of depression at 3 and 6 months, response to treatment, and remission. At 6 months, 60% of patients in intervention practices had responded to treatment compared with 47% of patients in the usual care practices [15]. At 6 months, 37% of intervention patients showed remission compared with 27% for usual care patients [15]. Ninety percent of intervention patients rated their depression care as good or excellent at 6 months compared with 75% of usual care patients [15].

The Community Care of North Carolina (CCNC) program created a statewide community health network for managing Medicaid beneficiaries, an organizational structure that included a program director, medical director, and a team of case managers [17]. Medical practices that participated in CCNC partnered with local hospitals, health departments, county health departments, and regional departments of social services. As part of the network, the practices were able to access a team of CCNC case managers who worked with all patients in a defined geographic area [17]. Depending on the patient panel, a single practice would share a case manager with several other small practices [17].

CCNC case managers were predominantly community based, working with several medical practices at the same time. The ratio of case managers to patients was generally high (e.g., 1:4000); however, relatively few patients used a disproportionate share of resources, and the case managers preferentially targeted this group. Medicaid claims data were used to identify patients who were candidates for case management [17]. CCNC patients who had multiple emergency department visits and a high number of medication claims or had diagnoses of asthma, diabetes, or congestive heart failure were identified as candidates for case management [17]. In addition, clinicians in CCNC practices had the capacity to refer patients for case management.

CCNC case managers utilized a care management software package which had several functions: it pulled Medicaid claims in a way that identified high-risk patients; it allowed case managers to review the health-care utilization of their clients; it provided capacity for documenting care management functions; and it provided a means of electronic communication with other case managers [17]. Commercial insurance programs also use care management software and a central care management model; however, CCNC case managers had a personal connection with their respective practices, which fostered a more efficient communication between the case managers and the practices [17].

The CCNC model demonstrated impressive outcomes during its early adoption. Using conservative modeling, CCNC saved the State of North Carolina $60 million in fiscal year 2003, and by 2006, savings had increased to $161 million annually [17]. The largest savings were achieved in emergency department utilization (23% less than projected), outpatient care (25% less than projected), and pharmacy (11% less than projected). In addition to cost savings, CCNC has improved the quality of care for Medicaid beneficiaries. Since initiation of the program, there has been a 21% increase in asthma staging and a 112% increase in the number of asthma patients who received influenza vaccines over a defined time period [17]. Emergency department visits for CCNC children with asthma decreased by 8% during the first year of the program and hospitalization rates have decreased by 34%

Another trial tested a population-based care management intervention to enhance primary care in community mental health settings [1]. Over 400 patients with severe mental illness at an urban community mental health center were randomly assigned to either the medical care management intervention or usual care. The intervention consisted of care management that provided patients with communication and advocacy to medical providers, in addition to health education and support to care integration and mitigating the barriers to primary care [1]. At a 12-month follow-up evaluation, patients in the intervention group received an average of 58.7% of recommended preventive services, compared with a rate of 21.8% in the usual care group [1]. These patients also received a significantly higher proportion of evidence-based services for cardiometabolic conditions (34.9% versus 27.7%) and were more likely to have a primary care provider (71.2% versus 51.9%) [1]. The intervention group also showed significant improvement in self-rated physical and mental health [1].

Across care management models, there is a distinction between provider-delivered care management (PLCM) and more centralized or health plan-delivered care management (HPDCM) approaches. A recent quasi-experimental study compared the effectiveness of PDCM versus HPDCM on improving clinical outcomes for patients with chronic diseases [18]. The study looked at commercially insured patients who had an index chronic disease – congestive heart failure, chronic obstructive pulmonary disease, coronary heart disease, diabetes, or asthma – and were received outreach and were engaged in either PDCM or HPDCM program. Outreached patients were those who received an attempted or actual contact for enrollment in care management; and engaged patients were those who had one or more care management sessions/encounters with a care manager [18]. The outcome measures for the study included blood pressure, low-density lipoprotein (LDL), weight loss, and hemoglobin A1c for diabetic patients at the first year of follow-up [18].

A total of 4000 patients were clustered in 165 practices: 31 in PDCM and 134 in HPDCM. The PDCM model demonstrated a significant improvement in the proportion of outreached patients whose LDL was under control: the proportion of patients with LDL <100 mg/dL increased by

3% for the PDCM group and 1% for the HPDCM group, but this was not a significant difference. The HPDCM approach showed 3% improvement in overall diabetes care among outreached patients and significant reduction in obesity rates compared to PDCM.

Implementing Care Management

The effectiveness of any innovation, such as care management, is dependent on the effective implementation of that intervention [10]. Health-care organizations often quickly adopt complex innovations and subsequently find that sustained implementation proves challenging, time-consuming, and costly [11]. This is an evolving area of research, and three theory-based studies have examined care management implementation strategies, as well as factors that may influence the successful adoption of the intervention. The earlier referenced care management trial for depression was implemented through a strategy that supported practice change [15]. The implementation strategy relied on established quality improvement programs and was informed by diffusion of innovations theory [15].

The implementation strategy was grounded in the three-component model (TCM), a practice change process model that is derived from diffusion of innovations. There were several "readiness" principles for identifying candidate practices and clinicians who would be participants in the study: (1) an interest in the innovation (i.e., enhancing depression care); (2) viewing the innovation as aligned with their needs, values, and resources; (3) having the capacity to pilot the innovation with minimal competing resources; and (4) assessing the impact of the innovation.

The implementation strategy included four steps (Fig. 31.4) [15].

Engagement was the first step and involved getting buy-in from the health-care organization (HCO) leadership before identifying an HCO team that was tasked to work with the study staff. The team generally included the HCO medical director, a representative from the quality improvement program, and a representative from the care management [15]. This group was responsible for identifying and recruiting practices appropriate to the project phase. Step 2 involved building HCO capacity for the care management model. The organizational and study teams developed an initial capacity within the HCO to support the clinical model and practice change strategy and subsequently capacity within the practices to adopt the program. The existing HCO quality improvement program provided practice support in implementing and sustaining the depression care management model [15].

The study team led capacity building efforts in pilot practices, while each respective HCO quality improvement

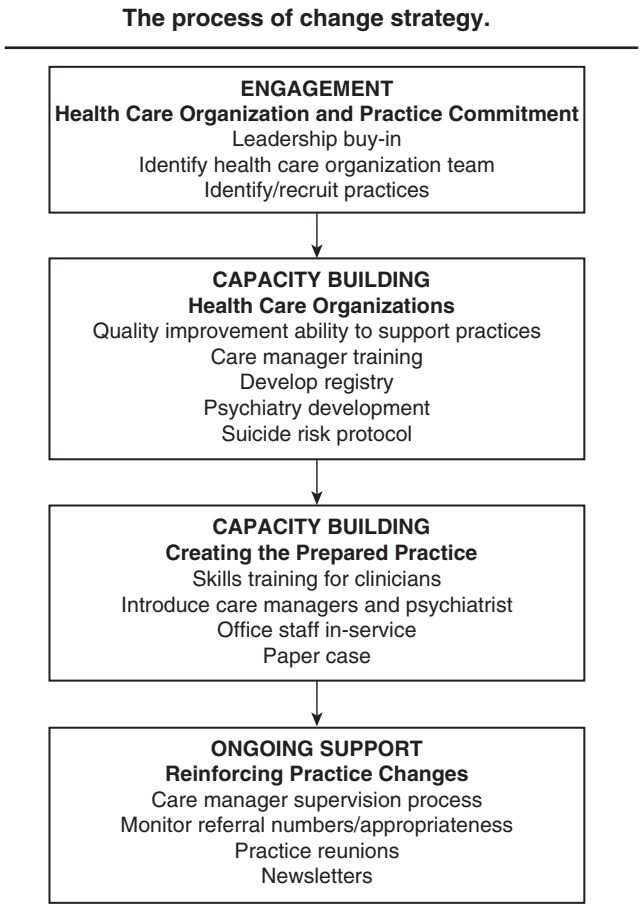

Fig. 31.4 The process of change strategy. (Adapted from [15])

program became the central and sustaining source of ongoing practice support as the care management program was adopted. For example, capacity was developed within the HCO for telephone care management of depressed patients and for a psychiatrist to provide weekly supervision for care managers, as well as needed or requested consultation with primary care clinicians [15]. Care managers and the psychiatrist received standardized training, including a suicide risk assessment protocol and protocols for follow-up interventions for patients at risk. A patient registry was developed to track patients receiving care management and their progress [15].

Step 3 of the implementation strategy involved building primary care capacity for the care management model. Through participation in the "prepared practice" component of the TCM model, clinicians were provided with a 2-h interactive skills training program, including the diagnostic assessment of depressive disorders, the role of care management, and the use of decision support to modify management and achieve remission [15]. Care managers and psychiatrists were introduced to primary care clinicians at these sessions, and office staff received a 1-h in-service session about the clinical model. The fourth and final step of the model

involved ongoing support for maintaining the practice-level change, which was targeted through supervision of care management and provision of feedback on the patient's clinical response to the clinicians [15]. The supervising psychiatrist working with the HCO quality improvement program and study staff monitored referral rates to care management and the appropriateness of referrals. This mechanism provided formative feedback to clinicians who were having difficulty implementing the care management model [15].

The project used both process and outcome measures to provide an assessment of implementation. Clinician surveys and care manager logs were used to describe the process of care. The overall outcome of the intervention was assessed using the PHQ-9 and was measured at baseline, 3 months, and 6 months post intervention through telephone interviews conducted by independent evaluation center staff using validated instruments [15]. Care manager logs and HCO administrative data were used to assess cooperation with implementation and changes in the process of care in each practice [15].

A second study described and evaluated an implementation strategy for embedding a generalist care management program in a patient-centered medical home [14]. Here, implementation was considered as the period during which the intended users of an innovation (i.e., physicians and clinical staff) became skillful in adopting a new program; evaluating the implementation process required determining how well the innovation was consistently used. An organizational model of innovation implementation was used to guide the parameters of implementation and evaluation. This framework looks to determine how courses of action taken to execute a program or innovation result in observed patterns of initial use by examining an organization's readiness for change, the quality of the implementation policies and practices, and the climate for implementation.

There were three phases to the implementation strategy for embedding the care manager. The first phase engaged clinical leadership and identified champions around the concept and evidence-base of care management [14]. Although initial funding for the care manager position was provided through state agency grants for defined populations, such as Medicaid and uninsured patients, an operational decision was made for care management services to be made accessible for all clinic patients. A job description was developed for the care manager position with a requirement of clinical licensure (e.g., RN or MSW), excellent communication and problem-solving skills, and a minimum of 3 years of experience in health care [14].

Phase II began post-hiring and included several promotional strategies to raise the visibility of the care manager, such as screen savers at computer workstations, bookmarks for providers and patients, and attendance and announcements at practice meetings and other clinical venues [14]. The information technology unit created a care management template in the electronic health record during this phase. Phase III of implementation focused on effectively integrating the care manager within the clinic operational structure and workflow [14]. Strategies included locating the care manager workplace centrally within the practice site, securing access to the appointment scheduling and health-care system care management informatics system, embedding the position into ongoing practice quality initiatives, and establishing a plan for reporting interventions and utilization, such as point-of-care contacts and referrals [14].

Physicians and support staff were surveyed, and a majority of physicians (75%) and support staff (82%) reported interactions with the care manager, primarily via face-to-face, telephone, or electronic means [14]. Nearly 70% of the contacts were for facilitating referrals for behavioral health services; however, assistance with financial, social, and community-based resources was also prevalent (60–70%) [14]. Satisfaction with care management services was very high (98% of respondents reporting satisfied or very satisfied), and 79% of the clinician and care staff reported that the care manager was frequently or always accessible when needed [14].

Regarding the implementation strategy, clinicians and care staff noted that the most effective strategy was the outreach and direct contact that the care manager made with stakeholders (80%) [14]. In addition, personal introductions and an ongoing presence at practice meetings were also cited (63%), but other strategies such as handout cards and screen savers on clinic laptops were reported as less effective. Regarding outcomes, over a 24-month implementation period, there was a trend of an absolute decrease of 8 emergency department visits per month and an absolute decrease in inpatient admissions of 7.5 admissions per month [14].

The third and most recent study used normalization process theory (NPT) as a ground to understand the organization of care management implementation in practice [13]. Semi-structured interviews and observations were conducted at 25 practices in five physician organizations. There were two key organizational structures for care management: practice-based care management (i.e., care managers were embedded in the practice as part of the practice team) and centralized care management (i.e., care managers worked independently of the practice work flow and were located outside the practice) [13].

There were differences in normalization of care management across practices, where practice-based care management was more normalized (i.e., part of the practice culture) when compared to centralized care management [13]. NPT theory, in particular the collective action construct, would account for the variance [13]. For example, a trusting professional relationship was developed between practice providers, staff, and care manager when care managers had multiple and flexible opportunities for communication (i.e., interactional

workability); had the requisite knowledge, skills, and personal characteristics (i.e., skill set workability); and had the organizational support and resources (i.e., contextual integration) [13]. When any of these elements were missing, the effective implementation of care management implementation appeared to be negatively impacted [13].

Future Directions

Although care management can enhance delivery of clinical practice, implementing it successfully as a new complex intervention is challenging but feasible. The clinical setting of the patient-centered medical home (PCMH) provides an ideal organizational framework for embedding and advancing the role of care managers in achieving the overall PCMH goals of providing high-quality, cost-effective care with improved health outcomes. Care manager can serve as an anchor to patient-provider care team relationship [8] by assisting in the overall coordination of care leading strategies to reduce fragmented care. Unlike other disease-specific management models, the care manager is an embedded member of the patient's care team. They are able to target care for high-risk or high-utilizing patients through care plans, follow-up visits, regular outreach, extensive support for disease management and self-care, tracking and coordination of speciality and other services, and linkages with community resources [9].

In patients with comorbid severe and persistent mental illness, care management has great potential to provide point of care behavioral health care, including proactive screening and assessment as well as brief therapeutic interventions. Given the historical barriers to care for this population, such as stigma related to seeking treatment, cost of care, and overall service availability, embedded care management may be a viable and welcomed approach to meet unmet needs in this patient population. The evidence base around the feasibility and efficacy of these strategies needs to be developed as are the fiscal models to support this type of care.

The adoption of care management reimbursement schedules provides some indication of a sustained funding model; however, operationalizing required face-to-face and asynchronous contact will be a challenge [11]. Finally, with the recent, rapid expansion of care management services, it will be important to identify key measures to determine the efficacy of bundled and independent interventions, as well as cost savings within health-care systems. With the advancement of health information technologies, the applied use of data will be important and will need to expand beyond previous metrics that have focused on utilization of emergency care services, hospital admissions, and no-show rates. Such data will help illuminate the specific functions and interventions of care managers, demonstrating value to the patient's quality of care and overall experience of health care.

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Team-Based Care

32

Yee Lam

Introduction

Team-based care is a growing trend in chronic disease management. In 2001, the National Academy of Medicine (formerly the Institute of Medicine) released *A New Health System for the Twenty-First Century* which stressed the importance of primary care teams [1]. This effort has evolved largely to address the growing complexity of both the health-care system and patients' needs which is particularly evident in chronic disease care [2]. Successful integration of team-based care into practices improves outcomes for patients while decreasing costs associated with chronic illness [3]. Clinicians and staff also benefit from the team approach due to increased career satisfaction. As health care evolves to rely more heavily on primary care, team-based care will continue to be crucial in providing quality care while optimizing resources and minimizing costs [3–5].

Defining Team-Based Care

In a complicated and ever-changing health-care system, the traditional model of a single clinician assuming all responsibility for the patient's care is enhanced by incorporating the skills and resources of a health-care team. In 2010, the American Board of Internal Medicine defined team-based care as the provision of health services to individuals, families, and/or their communities by at least two health-care providers who work collaboratively with patients and their caregivers within and across settings to accomplish shared goals for coordinated, high-quality care [6]. Teams vary in size, ranging from one clinician and a medical assistant to large groups of care managers, physical and occupational therapists, speech therapists, psychologists, pharmacists, nurses, and clinicians. Teams are facile and can address patient needs in numerous health-care settings, which is particularly applicable for chronic disease [7]. Teams allow health-care professionals to work in a complimentary and collaborative manner, which improves the quality and cost-effectiveness of care.

History

Teams in healthcare are not a recent innovation. In the early 1910s, Massachusetts General Hospital created teams of physicians, health educators, and social workers. More than 50 years ago, Montefiore in the Bronx, New York, and Yale outpatient clinics in New Haven, Connecticut, developed team care models [8]. These models were not widely adopted due to challenges overcoming traditional hierarchical roles, communication problems, limited payment for the additional services, and time constraints [2]. Though some of these challenges persist, team-based care is now widely acknowledged as essential, particularly in chronic disease care. The Improving Chronic Illness Care program is a product of the MacColl Center for Health Care Innovation and the National Institutes of Health (NIH) and guides the establishment of team-based care using models of successful practices across the country [9, 10]. These recommendations emphasize the importance of clear objectives, shared goals, effective communication, and practical payment systems.

Models of Team-Based Care

There are many modern examples of team-based care, most of which are applicable to chronic disease management. First developed in 1967 by the American Academy of Pediatrics, the patient-centered medical home (PCMH) was intended to serve as a single source of medical information about a

Y. Lam, MD, PhD (✉)
University of North Carolina Hospitals, Department of Family Medicine, Chapel Hill, NC, USA
e-mail: yee_lam@med.unc.edu

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patient. Since then it has grown to encompass comprehensive health care that is provided by members of an interdisciplinary health-care team working together [11]. Group Health Collaborative in Seattle, WA, has been implementing these strategies in chronic disease care for over a decade and has demonstrated improvements in patient outcomes and diseases in costs while improving provider satisfaction and decreasing burnout [12, 13].

Developed in the 1990s by Wagner and colleagues, the chronic care model provides a framework for illness management that includes elements such as system issues, self-management, communication, and community [14]. One of the recommended components in an effective chronic disease management system is team-based care [15]. Implementing some or all of these elements improves outcomes and to some degree quality of life in people with chronic diseases [16].

The healthy learner model applies team-based care to children with chronic diseases from kindergarten through 12th grade. The program focuses on coordinating care with nursing, families, and social support. It has thus far mostly been applied to asthma but is expanding to include young people with diabetes [17].

Improving Patient Outcomes

Caring for patients with chronic disease has become increasingly complex. Advances in pharmacology, diagnostics, and treatment coupled with the growing availability of community resources provide increasing options for patient care but also new challenges to the clinician who does not always have the time or expertise to implement and coordinate all of these facets of care. Teams of health professionals working together and communicating regularly can provide such care more effectively. This improves patient outcomes in various chronic diseases and allows health-care team members to utilize their skills and training. Team-based care has been shown to be effective in four particular chronic diseases: diabetes, heart failure, chronic pain, and depression.

Diabetes

If current trends continue, one third of children born today will develop diabetes by the time they are adults [18]. In addition to the large epidemiological burden, management of an individual's diabetes can be complex as the disease affects multiple organs, requires significant medical knowledge to control well, and is influenced by many social determinants of health. Given this, a team approach can be helpful in supporting patients who are trying to manage their diabetes. This approach is recognized and supported by the National Institutes of Health and Centers for Disease Control [19, 20].

The patient-centered medical home uses a team-based care approach to caring for patients with chronic illness including diabetes. Successful models have demonstrated that patients who attended the chronic care clinic receive significantly more recommended preventive procedures and helpful patient education. They attend more primary care visits and have fewer specialty and emergency room visits, lower hemoglobin A1C levels, improved secondary outcomes, lowered payment costs, and higher patient and provider satisfaction [13, 21]. The providers in this model consist of a physician, nurse, clinical pharmacist, and nurse educator. The framework for care includes group education and peer support sessions during visits.

Most of these team approaches are based in the primary care outpatient clinic setting where diabetes is most often managed. Various team-based care models for helping people manage their diabetes are used internationally and show improved patient well-being, self-care, and diabetes control [22]. The chronic care model for diabetes care was shown in a meta-analysis to improve hemoglobin A1C levels but not quality of life for the patient [16].

The benefits of team-based care in managing diabetes has become so widely accepted that the US National Institutes of Health Diabetes Education Program has published a Team Care Guide which addresses challenges and outlines strategies that create successful care teams [9].

Heart Failure

Heart failure is another complex chronic condition that affects multiple organ systems and often requires frequent monitoring with subsequent adjustments in medications as well as lifestyle modification. Difficulty with these aspects of care leads to frequent clinic visits, emergency room encounters, and hospitalizations, all at great cost to the health-care system. Team-based care helps patients and families better manage heart failure. Teams include primary care clinicians, cardiologists, nurses, physical and occupational therapists, dieticians, behavioral health providers, social workers, and pharmacists. The American Heart Association encourages multidisciplinary integrated care for heart failure [23]. Collaboration between physicians, nurses, nurse practitioners, physician assistants, pharmacists, and other health-care workers improves care delivery, reduces hospitalization rates, and improves patient outcomes [24–26].

Many models exist to guide team-based heart failure care [27]. The most common model involves using clinicians, nurses, and care managers to bridge care from the hospital to the outpatient setting, which is either in a specialty clinic or with the primary care provider. While special cardiology clinics that focus on heart failure management are helpful, many patients do not have ready access to such clinics. Integrating primary and specialty

care for heart failure management is effective. Patients receive focused individual and group education sessions at the specialty clinic and are taught to record medication and body weight [28]. Patients who alternate these visits to the specialty heart failure clinic with visits to their primary care provider have improved quality of life and reduced total hospital admissions and total bed days.

Home-based team care models are also effective [29]. These models typically use home health agencies often led by nurses who provide education, medication management, and monitoring. This model may limit interaction with other members of the care team and can be resource and cost intensive due to long visits and travel time.

Home telemonitoring is another emerging model for team-based care that helps bridge the gap between clinic and home care [30]. This technology may decrease hospitalization and readmission rates when used alone or in combination with clinic- and home-based strategies [27].

Chronic Pain

Chronic pain is another illness where a team approach can be effective. Chronic pain affects millions of adults in the United States. This has contributed to skyrocketing incidences of opiate dependence and abuse, necessitating guidelines on safe management of chronic pain. Chronic pain is a complex condition and often has multiple comorbidities including other chronic diseases, depression, and substance use disorders. While hospitalizations are infrequent, chronic pain impacts the individual as well as the community and economy due to lost productivity and diminished quality of life [31].

Over 50% of patients with chronic pain are managed by their primary care providers in an outpatient clinic [32]. The traditional model of primary care clinician prescribing medication or referring to therapy is often insufficient to address the many aspects of care for patients with chronic pain. This model often leads to frustration for both patient and provider.

A model of team care for patients with chronic pain that includes physicians, behavioral therapists, case managers, and pharmacists in a single setting may be applicable to other chronic diseases that are associated with chronic pain [31]. Collaborative care in treating chronic pain in primary care clinics at the Department of Veterans Affairs Medical Center showed significant improvements in patient-centered outcomes [33]. The intervention was based on the Chronic Care Model and utilized a psychologist care manager and an internist who is attending training in chronic pain and shared decision making. The model showed significant improvements in pain disability and intensity and depression severity, with patients reporting improvement as well.

The PCMH model has shown some benefit to a team-based approach in managing chronic pain [34]. Practices who had received or were in the process of pursuing PCMH certification have higher rates of documenting the recommended safe practice guidelines for chronic pain management, though the impact of this on actual outcomes is not clear. Multidisciplinary care appears to be effective in treating chronic pain with more work needed to identify which aspect of treatment or what patient variables most influence the success of such an approach [31–35].

Depression

The need for a team of professionals to provide quality care for patients' medical, psychiatric, and social needs is clearly evident in behavioral health [36–43]. There is a long tradition of team-based care in behavioral health, from Assertive Community Treatment (ACT) teams to multidisciplinary teams in hospital settings. Teams that also include a pharmacist show increased rates of patient and clinician satisfaction [37]. Adding a patient educator to teams of primary care providers and psychiatrists also improves patient satisfaction and decreases depressive symptoms [38].

Team-based care that addresses behavioral health issues improves the management of other chronic diseases, given the impact of behavioral health on chronic disease management and comorbidity. Collaborative care, based on the chronic care model and the PCMH, improves chronic disease outcomes for patients with diabetes and heart disease and concomitant depression [40]. The patient care team in this model centered on a nurse care manager and included primary care providers, psychiatrists, and psychologists. Patients who received this team care had improved disease outcomes including improved hemoglobin A1C and LDL cholesterol levels, lower systolic blood pressure, and better depression scores [40].

The Improving Mood-Promoting Access to Collaborative Treatment (IMPACT) model, developed at the University of Washington, has been adopted in over 500 clinics nationwide to help manage depression [41]. Trained primary care providers work in close collaboration with embedded behavioral health professionals (usually nurse practitioners or licensed clinical social workers) in an outpatient practice with psychiatric consultation available. Patients who receive this collaborative care have significantly more depression-free days compared to those treated with usual care [42].

A meta-analysis reviewing 37 randomized studies of 12,355 patients with depression demonstrated short- and long-term improvements with collaborative care in the primary care setting [43]. In addition to the IMPACT model, other structured programs that use team care in addressing behavioral health issues include the Cherokee Health Systems and the Massachusetts Child Psychiatry Access Project.

Improving the Health-Care System

Workplace Improvement

Patients are not the only beneficiaries of a team-based approach to chronic disease care. Health-care team members have increased satisfaction from working together in a collaborative model [44–47]. High-performing primary care practices where providers are satisfied with their work often have team-based models of care, increased clinical support staff per physician, and frequent forums for team communication [46]. The PCMH model is also associated with decreased physician burnout [13]. A recent small study of primary care practices, however, showed no improvement in burnout for physicians, physician assistants, and nurse practitioners with a team approach [48]. These different observations may reflect the many variations in practice teams, patient populations, and resources.

Cost Efficiency

In addition to improved patient and provider outcomes, team-based care reduces costs and improves efficiency and utilization in the health-care system. The PCMH model can reduce costs by $10.30 per patient per month, reduce emergency room visits by 29%, and contribute to 6% fewer hospitalizations over a 2-year period [13]. Providers in practices using various team-based models have reported increased revenue as well [44, 47]. Team-based interventions may increase costs under the current fee-for-service model of primary care but are likely to decrease costs in an accountable care organization [49]. As the national health-care landscape evolves, improved patient-centered outcomes from team-based care will likely influence new reimbursement models.

Adopting Team-Based Care

Guidelines exist for creating and integrating effective teams in primary care, most of which are based on the PCMH or chronic care models [2, 7, 8, 10, 11, 13, 15, 20, 50–52]. In 2014, the Agency for Healthcare Research and Quality commissioned an Atlas of Instruments to Measure Team-based Primary Care [53]. The National Institutes of Health (NIH) also provides some general components for building successful teams (Table 32.1) [20]. Teams must be maintained in order for improvements to be sustainable. Establishing partnerships with patients and their caregivers to promote patient satisfaction, quality of life, and self-management is crucial. Improving community support and maintaining internal communication between team members and ensuring follow-up are also important.

Table 32.1 Components for building successful teams, adapted from the National Institutes of Health Diabetes Team guidelines

Committed leadership	• Well-respected leader to increase interest among colleagues
	• Buy-in from office staff (physicians, clinical staff, financial staff)
	• Involve team members in early stages of decision making
Identify team members	• Clearly define roles
	• Mutual respect
Identify patient population	• Risk stratify within disease groups (complications, hospitalizations, emergency room visits)
	• Data from chronic disease registries
Assess resources	• Strengths and weaknesses of available resources
	• Support staff
	• Education materials
	• Equipment/supplies
	• Home care services
	• Support groups
	• Community resources
Determine payment mechanisms	• Staff services
	• Equipment/supplies
Develop a system for team-based high-quality care	• Set team objectives, philosophy
	• Set up system for data collection (registries)
	• Determine structure and scope of services (medical care, education, nutrition, psychosocial counseling, coordinating specialist referrals)
	• Evidence-based practice guidelines for different conditions
Evaluate outcomes and adjust as needed	• Periodic self-evaluations
	• Quality improvement
	• Patient satisfaction assessments
	• Document clinical, behavioral, and financial outcomes
	• Program visit from outside observer

Adapted from Ref. [20]

Although the benefits of team-based care, particularly in chronic disease management, are generally well accepted, this practice change is not easily implemented. Common barriers to effective medical team building include the resistance to change in job descriptions, balancing workload, time for training, and extending scope of practice [54]. The current fee-for-service primary care reimbursement structure also creates financial barriers to team-based care, which is particularly burdensome for smaller practices. From both the patient and provider perspective, the move toward care teams may be seen as disruptive to their relationship. As clinicians incorporate other

health professionals into their care teams, it is important that the trusted continuity relationship between the provider and the patient is maintained [55].

International Examples

Other countries face many of the same challenges in managing chronic disease as the United States and similarly seek innovative solutions, many of which involve team-based care. For example, the Netherlands has a national program of chronic disease management where primary care is organized in a manner that improves care coordination and communication between providers and care teams [56, 57]. Nurse practitioners with chronic care expertise are important team players who improve coordination of care, communication, and task integration among multiple providers, resulting in improved process and outcome measures for patients in the Netherlands. One especially successful model is a team-based care system to manage patients with Parkinson's Disease, where patients need primary care providers, therapists, and specialist care, with no single provider responsible for outcomes which often leads to fragmented care. In response, the Dutch created ParkinsonNet which features more than 60 regional multidisciplinary networks, including approximately 3000 allied health professionals who are committed to caring for patients with Parkinson's disease using evidence-based guidelines, with an emphasis on home and community-based care [58]. The networks include neurologists, geriatricians, primary care physicians, nurse specialists, physical and occupational therapists, speech therapists, dieticians, psychologists, pharmacists, and social workers. Nurses and physical therapists serve as local coordinators and team leads, maintaining the network and organizing local educational programs. This innovative team-based and multidisciplinary approach to caring for patients with Parkinson's disease has improved patient satisfaction and reduced costs [59].

Conclusion

As the health-care landscape continues to change, team-based care is increasingly important in advancing quality patient care and optimizing resources while minimizing costs. Managing chronic disease poses challenges to the traditional provider-patient model which can be addressed with a team of well-trained health-care professionals. Many of the existing models of team-based care can be applied across various populations. As more practices adopt these models, continued innovation will help address existing barriers to implementation and reimbursement. Increasing communication and collaboration will enhance the care of the large number of people with complex chronic disease.

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Direct Primary Care and Concierge Practice

33

James O. Breen

Introduction

In the United States, primary care has struggled to provide timely, comprehensive, and accessible care in a healthcare delivery system that is oriented to procedural and subspecialty care, relying on a payment model which is at odds with the goals of primary care [79]. There are a host of payment incentives and practice-level regulations which limit the effectiveness in the delivery of care. For example, the fee-for-service payment model and the associated billing practices often result in clinically unnecessary care, or delayed care, and can contribute to patient dissatisfaction due to prolonged wait times for appointments and minimal time spent with the doctor [51, 78].

Primary care practices are responsible for increased administrative costs, and an ancillary industry has emerged to ensure appropriate and timely reimbursement, adding an estimated 40% to overhead costs [42]. The opacity of pricing for medical services and the wide variations in negotiated charges have contributed to price inflation [89], often disadvantaging uninsured individuals who are often the most ill-prepared to pay the full charge for services [40, 54, 70]. A plethora of healthcare-related data-reporting requirements and certification processes have added additional cost and regulatory burdens to primary care practices, which have been estimated to cost as much as $40,069 and 785 h annually per physician [20].

Direct primary care and concierge medicine have grown in response to an increasingly dysfunctional primary care delivery and payment model that has dominated American medicine for over a generation [77, 93]. These factors have contributed to growing levels of physician frustration, dissatisfaction, and burnout. In consequence, a larger number of physicians have sought alternative forms of practice that reduce or eliminate their dependence on third-party payers by relying on direct payment from patients outside of the third-party reimbursement model [69]. This chapter will first describe the larger historical context for the emergence of direct-pay medicine in the United States and provide some operational definitions of DPC and concierge medicine. The next section will outline the similarities and differences between DPC and concierge care models, highlighting the various ways they create value and interface with the larger US healthcare system. This will be followed by practical applications of the DPC model, both organizationally and fiscally, with specific attention to chronic illness care. The final section will provide a perspective to the challenges and future trends in DPC and concierge care.

History of Concierge Practice and Direct Primary Care

Concierge practice, which preceded DPC in the mid-1990s with the formation of MD2 by Dr. Howard Maron [64], is rooted in the idea that uncoupling primary care practice from dependency on high-volume and insurance-based payment models will allow physicians to focus on service and patient care. In 1994, Dr. Garrison Bliss and two associates launched a novel primary care practice, Seattle Medical Associates, based on the concept of providing care to patients in return for a monthly subscription fee. The success of the practice led Bliss and cousin Dr. Erika Bliss in 2007 to found Qliance, a direct primary care practice that has been scaled to serve over 41,000 patients at its peak, and to partner with employers and the State of Washington's Medicaid Managed Care program [19, 91]. In the early 2000s, similar practice experiments in direct-pay medicine were also taking shape in other regions of the country. An example of one such practice was Access Healthcare, founded in Apex, NC, in 2003 by Dr. Brian Forrest [49].

J.O. Breen (✉)
Moses H. Cone Memorial Hospital, Department of Family Medicine, University of North Carolina at Chapel Hill, Greensboro, NC, USA
e-mail: james.o.breen@gmail.com

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Largely influenced by the micropractice movement (later termed Ideal Medical Practice) and publicized by Dr. Gordon Moore, this movement sought to simplify primary care practice design by reducing patient barriers and increasing access [65], with a goal to increase the value of services. The strategy lay in minimizing overhead that did not directly enhance patient care. While its initial target population was patients who were without insurance coverage, Access Healthcare flourished because of its appeal among both the uninsured and those with insurance, an unanticipated outcome [49]. In the decade following the inception of the DPC model, the proliferation of these type of practices has led direct primary care to be dubbed "concierge care for the masses" [24, 55].

In the early 2000s, more practices began to emerge that blended the ideals of the micropractice movement with the concept of subscription medicine, effectively broadening the reach of the concierge concept to a wider socioeconomic patient base. These pioneer DPC practices sought to create value that did not depend on patient insurance status and began to create a space for primary care where the patient—rather than insurance plans—was seen as the primary consumer and purchaser of services. In 2003, the not-for-profit Society for Innovative Medical Practice Design (now the American Academy of Private Physicians, or AAPP) was created to advocate for a growing number of physicians practicing in direct-pay arrangements [9, 10, 51]. The growth of direct primary care began to accelerate at the advent of the first national DPC conference, the 2012 DPC Summit in St. Louis, organized by the Family Medicine Education Consortium [36].

Defining Direct Primary Care and Concierge Care

There are varying definitions as to what constitutes a direct primary care practice, but one unifying characteristic is a model that focuses on direct contracting with patients, rather than third-party payers, in order to maintain the financial sustainability of the practice [1]. Many practices consider a further key characteristic to be a financial model based on a periodic subscription fee (e.g., monthly or annual), rather than a fee-for-service model, as payment for services [41, 42]. Some DPC practices exist as "hybrid" practices that accept a limited number of third-party contracts alongside a panel of subscription patients, a strategy which may be the practice's business model or simply a transition strategy for those transitioning from conventional insurance-based practices to the DPC model.

In contrast to pure DPC practices, many concierge practices continue to submit claims to third-party payers for services covered under insurance contracts, charging retainer fees to patients for enhanced physician access and other services outside of these contracts [44, 51]. A result of these retainer fees is a marked reduction in the size of patient panels for concierge physicians. Because many concierge physicians retain the practice of billing third parties for covered services, they maintain a higher degree of overhead on average than do pure DPC practices, which forego third-party billing. Table 33.1 below compares the characteristics of DPC and concierge practice.

There are other notable differences between DPC and concierge medicine. For one, DPC practices typically are priced far below the retainer fees of concierge practices, giving them a broader socioeconomic appeal. Another distinction is direct primary care practices' foregoing insurance contracting, unlike many concierge practices which maintain contracts with insurance plans and charge retainer fees for services not included in these contracts [44]. Examples of such non-covered services include annual executive physicals, direct telephone access to the physician, convenient same-day and extended appointments, access to networks of concierge practices when patients travel, and enhanced access to subspecialists when referral services are recommended.

DPC and concierge medicine's similarities include the promotion of their value directly to patients, making the case that the improved access, personalized care and responsiveness, and—in the case of DPC—negotiated discount rates on ancillary services such as labs, medications, and radiology services represent an attractive value proposition for patients. Increasingly, DPC practices are forming relationships with self-funded employers, who find the DPC model attractive for its cost reduction and improved service, with the promise of a fixed primary healthcare spend and the potential to reduce the use of more costly medical services, such as emergency room, subspecialty referral, high-end imaging, and hospitalizations. Internal data collected by one of the country's largest DPC practices, Qliance, suggests that claims of reduced downstream costs associated with DPC are not without merit [80].

Table 33.1 Comparison of direct primary care and concierge medical practices [42, 55]

	Direct primary care	Concierge practice
Charge recurrent membership fee (monthly or annually)	Yes	Yes
Bill insurance for services	No	Yes
Financed exclusively from patient memberships, resulting in lower overhead	Yes	No
Enhanced patient access	Yes	Yes
Average membership fee	$73/month [42] (average range $25–85/month) [55]	$182/month [42]

Prevalence of DPC and Concierge Practices

Concierge practices and DPC practices are difficult to categorize, since they are, by nature, heterogeneous entities [42]. Attempts to determine the prevalence and growth of DPC practices have found that many practices are small and locally owned and operated [82]. A defining feature of not contracting with insurance carriers is that they do not appear on insurance plan network rosters or other commonly referenced registries. The DPC Mapper, a service of the website Direct Primary Care Frontier, maintains an updated listing of DPC practices across the country and categorizes them as either pure DPC, hybrid, or unknown [43, 34].

According to the 2015 Physicians Practice Survey, as many as 10% of respondents were either in the self-pay model or planning a transition; 43% were considering making the change [69]. Data from the American Academy of Family Physician's annual Practice Profile showed that between 2013 and 2015, the number of respondents who were unfamiliar with the term "direct primary care" declined from 58% to 36%, while the number who were already practicing in the DPC model increased from 1.5% to 2.5% over the same time [6–8]. While the number of such practices continues to grow at an accelerated pace, the most recent update of the DPC mapper estimates the numbers of DPC practices in the United States to number slightly over 738 across 48 states and the District of Columbia [43].

DPC Practice Models

Organizational Components of DPC Practice

In 2001, Dr. Gordon Moore opened a radical *micropractice* that cut overhead costs to a bare minimum and in which he was the sole staff person in his 150 ft^2 subleased office. In so doing, he attempted to reduce the functions and workflow of his practice to only the essentials needed to maximize access and value from the patient perspective [65]. The lesson of Dr. Moore's micropractice experiment was an eloquent description of the value of time in a direct primary care practice. By choosing to tear down time constraints that are a barrier in many volume-based practices, DPC physicians place emphasis on restoring time with patients, which is seen as the rate-limiting step in value-based care. This increased availability and time is freed up largely because DPC minimizes "pent-up demand" by offering multiple vehicles by which patients may contact their doctor at virtually any time they have a need. The expansion of meaningful doctor-patient interactions by the application of information technology where clinically appropriate allows for a more efficient use of time and a larger focus on patient needs rather than on visit volumes and billing codes [48].

For patients with complex health needs, direct primary care practices offer longitudinal care from a personal doctor, with facilitated access to care. The direct care aspect of the model focuses on the DPC doctor as the responsible party to coordinate care outside of the scope of primary care. A key tenet of DPC is to keep as much of patients' care within the practice as possible. Cost transparency is central to the direct primary care model, and many DPC practices enhance practice revenue by including certain ancillary services, such as basic labs and office-based procedures, to patients as part of the membership fee. Other practices serve as a "pass-through" for such ancillaries, offering them at cost to their patients. These services may include in-office medication dispensing (in states which allow physician dispensing), in-house phlebotomy services and reduced rates on laboratory testing, and negotiated rates for contracted subspecialty consultations and procedures, radiology, and pathology services. Many DPC practices have a knowledge of area subspecialists' charges for consultations and procedural services, which allows them to inform patients about referral options and their costs [22, 23]. Additionally many DPC practices employ innovative online consult services to obtain subspecialty expert opinions when clinically indicated [72]. These strategies may reduce the cost of services to a level that would be lower than co-payments and deductibles paid by patients who have health insurance [23].

The characteristics of DPC practices outlined above result in a physician and patient experience that is markedly different from that of a conventional, insurance-based practice. From a patient perspective, the payment of a monthly subscription fee (often paid monthly as an automated draft payment) means that visits or other interactions with the practice are not associated with fee-for-service billing. The reduction in this economic barrier encourages early consultation with the physician at the onset of illness, rather than postponing treatment due to cost concerns. The elimination of administrative and billing concerns in the office also results in a more streamlined patient experience when visiting the practice.

From the physician perspective, the workflow of a DPC practice is entirely different from what is experienced by clinicians practicing in conventional practices. For one, the elimination of administrative billing and coding requirements frees up clinician time to consider clinical concerns posed by patients either in-office visits or by remote contact. The absence of insurance contract requirements to create "billable events," such as face-to-face interactions, means that physicians are free to adapt their patient interactions to match the clinical necessity of the circumstance, rather than conforming to billing standards. Because of this, DPC physicians may conduct a significant amount of their clinical care via electronic portals and telephone compared with doctors who practice in conventional practice, where these

types of communications do not add significant remunerative value to the practice. While the primary care setting for DPC physicians is the outpatient office, many also offer visits in other settings such as patients' homes or skilled nursing facilities [28, 37]. It is not known how many DPC physicians include hospital care when compared to primary care physicians in general; however the latter has reported a gradual decline in practice scope in recent decades [30]. It is also not clear whether this decline reflects limitations posed by hospital privileging requirements, such as Medicare participation.

Financial Models of DPC Practice

There are variations in DPC financial models. A large number of DPC providers exclude fee-for-service in their business models, since it mitigates the appearance of financial incentives to perform a greater volume of services [13]. Some practices charge a fixed monthly or annual subscription fee in exchange for clinical services. This periodic fee allows patients access to all services provided by the practice, including office or remote visits, as well as office-based procedures. In some practices, this periodic fee is fixed for all patients, while other practices create price tiers based on age or numbers of family members who enroll (e.g., family plans). A summary of market trends in DPC in 2015 estimates that for a majority of DPC practices nationwide, the monthly amount of individual membership fees averages between $25 and $85 [82].

Another type of fiscal model for DPC combines a recurring membership fee and a utilization fee for services such as office visits or medication refills. In these models, patients pay a reduced monthly membership fee and then are assessed visit fees, with the intent of discouraging over-utilization of office visits. In addition to the two models discussed above, there are "cash-fee-for-service" practices that align themselves with DPC because of their absence of insurance contracting. There is debate among many in the DPC community as to whether such practices adhere to DPC principles, because of their maintenance of a strictly fee-for-service billing structure (personal communications: various).

A growing number of DPC practices are partnering with self-insured businesses. These practices offer primary care services to business employees, providing fixed-cost primary care with an expectation of reducing the utilization of downstream healthcare services [61]. Companies that contract with DPC practices seek to decrease their healthcare costs while still complying with Affordable Care Act requirements, which may be met through pairing of DPC practices with certain wraparound insurance products [53]. This business model targets the self-funded employer market, and some DPC organizations offer on-site clinics for large employers who have a critical mass of employees in geographic proximity. Seattle-based Qliance, for example, established a practice near the Bellevue office of Expedia, as well as a full-service clinic that serves the city's firefighters adjacent to Seattle Fire Station #2 (personal communication: Erika Bliss, MD).

Many DPC practices exist as sole proprietorships or as limited liability corporations; however some practices have chosen to organize as nonprofit organizations [67]. The not-for-profit St. Luke's Family Practice in Modesto, California [81], creates a cross-subsidization between enrolled "benefactor" patients and the practice population of uninsured agricultural workers, many of whom are not eligible for government-funded health insurance programs. Termed the "Robin Hood" model, benefactors' membership fees provide the financial capacity for St. Luke's to provide care to uninsured patients [50]. Another example of a DPC with a nonprofit status is Community Supported Family Medicine in Englewood, CO, founded by Dr. Robin Dickinson, which focuses its attention on the care of young families, many of whom are of low socioeconomic status [29].

Direct Primary Care and Outcomes of Care

The World Health Organization (WHO) and the Institute of Medicine (IOM) have described six defining essential elements of quality, stating that quality healthcare should be (1) safe, (2) effective, (3) efficient, (4) accessible, (5) acceptable/patient-centered, and (6) equitable [15, 18, 56]. A host of evaluation protocols to quantify processes and outcomes in healthcare delivery have been advocated by federal and private payers, professional organizations, and consumer advocates with a goal to make medical care safer and more effective [27, 88, 92]. The elements of the IOM and WHO definitions of quality that are most easily demonstrated in DPC practices include acceptability and patient-centeredness (e.g., honoring the individual preferences of patients), efficiency (e.g., avoidance of waste), and accessibility, in terms of reduced barriers to care and timeliness in obtaining care [16, 17].

The recent emergence of direct primary care as a cohesive and articulated care model has resulted in limited published data comparing DPC to conventional care. Nonetheless, preliminary data—largely focused on economic impact—point to improvements in cost control and reduced downstream utilization when DPC is adopted among large populations. For example, an analysis of claims data comparing cost for the 44% of employees of Union County, North Carolina, who enrolled in a DPC option sponsored by the county demonstrated an average of 23% reduction in total healthcare expenditures, resulting in a savings of $260 per-employee-per-month (PEPM), and $1.28

million overall for the period from April 2015 to 2016. Nearly 60% of the employees enrolled in the DPC option had at least one chronic condition, and 35% carried multiple chronic disease diagnoses. Over 90% of the patients who had moderate to severe chronic conditions reported heavy engagement with their healthcare [71].

Claims data gathered in 2013–2014 by DPC giant Qliance, a multisite DPC practice that contracted with employers in Washington State, reported a 19.6% reduction in total claims expenditures, with a demonstration in lower downstream health system utilization. For example, 4000 Qliance patients showed a 14% reduction in emergency room visits, 60% reduction in total inpatient days, and a 58% increase in primary care visits, resulting in annual savings of $678,000 per 1000 employees, when compared with employees of the same companies who were not patients of Qliance [80].

At the state and national levels, pilot programs evaluating the impact of DPC on quality and cost in Medicare [21] and Medicaid [87] suggest trends that would support the value of DPC on quality and cost of care in these populations. The Centers for Medicare and Medicaid Services (CMS) has awarded Transforming Clinical Practice Initiative (TCPI) grants to compare quality and cost metrics between innovative practice models and conventional practices. The most recent funding opportunity, providing $10 million in funding, was announced in June 2016 and is planned to conclude in September 2019 [35].

Direct Primary Care and Concierge Medicine Applied to Chronic Disease Management

The principles of direct primary care and concierge medicine are concordant with approaches to provide patient-centered, integrated care for patients with chronic illness. The four practice characteristics that contribute to chronic disease management are (1) the presence of a longitudinal relationship between patients and their personal physician, (2) a reliance on payment models that are not based on fee-for-service, (3) the successful implementation of information technology (IT) to reduce communications barriers and enhance care coordination efforts, and (4) enhanced accessibility and expanded time with the physician during office visits [76].

An appealing aspect of DPC and concierge medicine for both patients and physicians is the development of a personal relationship in the course of care. While longitudinal care has long been at the heart of primary care [32, 45, 46, 86], the environment of a high-volume insurance-based practice model favors time efficiency over continuity, with many patients receiving care from a clinician other than their primary doctor. The small-scale and intimate level of care offered in most DPC and concierge practices places relationship-based care as the cornerstone. It has been suggested that this form of therapeutic relationship can improve patients' adherence to treatment and thus may have an association with improved clinical outcomes [14, 47].

The reliance on a payment model that is removed from fee-for-service (FFS) medicine offers practical and psychological advantages in the care of all patients, especially for patients with chronic health conditions. One of the key drawbacks to FFS models is the dependence on patient volumes, in order to generate sustained revenue for practice operations [73]. In addition, FFS models that are financed by third-party payors result in a claims process that can delay payment from the time services are rendered, compounding the financial pressures on practices [84].

A subscription financial model mitigates the pressure to increase visit volume by relying on a more even revenue flow for operating expenses. This steady revenue stream also decouples practices' services from the need to create "billable events" with third parties and thus frees up physicians to provide care that is determined by what is most medically appropriate for their patient. DPC physicians may offer IT-supported "remote" visits, to address patient concerns by telephone or asynchronous electronic communication and to offer extended visits to their patients when needed. The subscription model also changes the organizational workflow and use of time during office visits, reducing the amount of visit time spent on billing and administration and expanding the amount of face time spent between patient and clinician [44]. A telephone call or electronic communication with a patient preceding the visit, for example, often provides collateral information for the office encounter and facilitates the data gathering when the patient arrives and ensures the clinical necessity of in-person office visits.

Information technology (IT) in direct primary care (DPC) practices is vital to promoting enhanced patient communication and the delivery of care. DPC practices are often able to nimbly implement IT solutions that favor improved care and convenience for both patients and staff at the individual practice level. There is a great degree of innovation among developers of IT products to support the DPC community. Examples of small-scale electronic medical records, such as AtlasMD [12], include subscription billing platforms, pharmacy inventory platforms for dispensing physicians, and integrated phone and text communications within an encrypted and HIPAA-compliant software program. Other IT products that respond to the patient-focused mission of DPC practices include secure texting and remote visit platforms, as well as online scheduling and subscription management software. Most notably, the implementation of these IT platforms is significantly less costly than many industry-standard products, in keeping with DPC practices' emphasis on increasing value and reducing overhead.

Establishing a DPC Practice

Physicians who practice in the direct primary care model describe their work as a source of professional fulfillment. For many, the model's simplicity and focus on service to the patient has promoted professional satisfaction not found in other practice arrangements. However, there are challenges in starting or transitioning to a DPC practice model, and it is important for physicians to be aware of the challenges inherent in the change. It is also important that physicians considering DPC be comfortable embracing a degree of uncertainty. Among the most important elements to consider are the motivations for changing to a DPC practice, the primary target population the practice will reach, the level of comfort in starting a small business, whether or not to opt out of Medicare, and the financial and personal challenges inherent in starting a practice [36, 83].

Those contemplating a DPC practice should have a clear vision for the practice, such as why they are choosing this type of practice [4]. The prospective DPC practitioner should consider the unknowns regarding the fiscal realities of this type of practice, such as start-up and operational costs, as well as number of existing patients who will transition over to the DPC practice. The rate of new patient growth is highly variable and depends upon demographic and local economic conditions, target populations, marketing efforts, degree of penetration of healthcare system practices, and the existence of other primary care and DPC practices in the area. Many physicians who have transitioned from an established practice to DPC have found that transfer rates of existing patients are usually low (often estimated around 10%) and depend largely on how physicians communicate the anticipated transition to their existing patients.

Projected revenue for DPC practices can be challenging to determine when mapping out a business plan; the experience of physicians who have made the transition in a comparable market area can be a guide for projected new patient enrollment. In areas with a high degree of market share by a health system, there may be limited options to contract for ancillary services such as imaging, laboratory, as well as subspecialty care. However, such market space can be favorable to a DPC practice by allowing it to differentiate as a patient-focused alternative to larger, potentially more impersonal, system practices (personal communication, Josh Umbehr, MD).

Physicians who decide to adopt a DPC practice model should give careful consideration to their Medicare payor mix. Physicians may choose to participate in Medicare and agree to submit claims for Medicare beneficiaries, or they may decide to opt out of the program, which permits private contracting with Medicare beneficiaries once certain criteria are met. The process for opting out of Medicare includes filing an affidavit with the Center for Medicare and Medicaid Services to communicate the physician's intent to opt out, as well as documenting private contracting with Medicare beneficiaries that notifies them that the physician's services are not covered by Medicare; this process must be renewed every 24 months [31, 66]. In the start-up phase, physicians should identify complementary revenue streams to their DPC practice, such as employment in urgent care centers or emergency rooms. Because physicians who opt out of Medicare may not return to the program for at least 24 months, such a decision may affect the physician's practice options in the event of a change in practice plans. It is advisable for physicians to seek legal advice from a qualified attorney prior to making a decision about their Medicare assignment [26, 66].

Some DPC physicians choose to work with consultants or with a larger DPC parent company that has experience and a track record with DPC start-ups. Whatever the start-up strategy, it is important to assemble a knowledgeable team of advisors in various nonclinical aspects of practice. Experts in areas such as healthcare law, architecture and building codes, practice financing, business incorporation and accounting, website design, and practice marketing should be considered for the specific subject matter expertise they possess. Perhaps the most valuable resource for start-up DPC is the knowledge and experience of those physicians already in practice. Widely used electronic resources include the AAFP DPC Member Interest Group listserv [5], the AtlasMD DPC curriculum [85], and the Direct Primary Care Frontier website [43].

While a large number of DPC practices are independently operated by their physician-owners, the direct primary care business model has attracted the attention of venture capitalists and large healthcare organizations for its potential to disrupt the marketplace through innovation in care delivery [25]. Among the companies offering scaled-up DPC services to individuals or business clients are such companies as Iora Health [57] (Cambridge, MA), Paladina Health [68] (Denver, CO), and MedLion [63] (Las Vegas, NV). Each of these companies offers unique features to their business models. For example, Iora Health has partnered with Grameen America to establish a primary care and wellness center for Latina women in the Bronx, New York, using a monthly membership fee that allows access to a range of medical and wellness services [52].

Challenges in Direct Primary Care

There are many questions regarding the impact of direct primary care practices on primary care and the healthcare delivery for chronically ill patients: the impact of DPC on an already overburdened primary care workforce, a perception that DPC may exclude patients who have limited financial

resources and/or have multiple comorbidities, and the perception that the DPC model encourages individuals to forego health insurance [90]. To begin, some express concern that the smaller patient panel sizes of DPC practices will exacerbate the problem of access to primary care, citing the AAMC's projection of a shortage of up to 35,600 physicians by 2025 [11]. While estimates of conventional primary care practices average over 2300 patients per full-time physician, studies indicate a more appropriate panel size—to conduct all necessary preventive and chronic care—is closer to 1300 patients per physician with some delegation of supportive tasks [3]. An average DPC physician's patient panel ranges from 400 to 1200 patients [42], a finding that is reassuring about DPC's impact on primary care capacity. However, it still remains unclear if an overburdened primary care workforce is capable of responding to the level of care needed for even further increases in service demand.

A second concern is that an expansion of direct primary care practices may limit access to primary care by financially challenged patients, members of ethnic minority communities, or those with complex health problems [38, 59, 90]. Conceptually, patients with limited economic resources and who also may lack health insurance may find DPC practices to be a more affordable way to receive longitudinal care, due to the price transparency, increased access, and physician accountability. In terms of total costs of care, DPC practices may be less costly (e.g., deductibles, co-payments, etc.) than a traditional medical practice. Additionally, because many DPC practices have negotiated reduced fees on other ancillary services for their patients, the combined savings on prescription medications, radiology, and laboratory services may cover the out-of-pocket costs of membership for both insured and uninsured patients [23].

There may be concerns that direct-pay practices will selectively enroll patients without complex medical conditions (i.e., cherry picking) [38, 90]. However traditional practices, which are subject to greater external risk/reward payment models based on quality and process outcomes, are at greater risk in providing care for highly complex patients since these patient panels contribute to marked variation in outcomes and subsequently their reimbursement [58]. There is heterogeneity among DPC practices in their access for patients who are Medicare and Medicaid beneficiaries. While some DPC practices do participate in Medicare and Medicaid, a substantial number of DPC physicians choose to opt out of the Medicare program. In consequence, patients enrolled in Medicare who wish to remain in the DPC practice must sign a waiver recognizing that physician services may not be billed to Medicare and that the patient will be responsible for all charges [31].

Medicaid beneficiaries who receive care from a DPC practice that does not participate with Medicaid may have higher out-of-pocket costs, inasmuch as they pay out-of-pocket for membership in a DPC practice whose orders for referrals and ancillary services are not recognized—and therefore not covered—by Medicaid. This may limit the appeal of DPC practices to Medicaid recipients under the current organization of state Medicaid programs. One approach advocated by direct-pay practices that can reduce individuals' insurance costs while incorporating DPC is for individuals to pair enrollment in a DPC practice with a high-deductible health plan (HDHP). While the Patient Protection and Affordable Care Act (ACA) has authorized direct primary care practices to be listed in the insurance exchanges in conjunction with a wraparound Qualified Health Plan (QHP) covering non-primary care services, the first such DPC/QHP pairing only appeared on the Washington state insurance exchange in January 2015 [38].

Concern has been expressed that the location and distribution of DPC practices and patient recruitment may limit participation for patients in rural communities and the economically disadvantaged, particularly racial and ethnic minorities. Although DPC practices are more likely found in urban and suburban areas with higher population densities, the model has succeeded in rural communities [2], as well as among populations with low socioeconomic status. The experience of St. Luke's Family Practice in Modesto, California, which supports care for uninsured migrant farmworkers by cross-subsidization from more affluent patients, is but one example [50]. Grameen Vida Sana is another example of how DPC practices may facilitate comprehensive primary care for patients who are ineligible for government assistance programs or ACA subsidies, such as undocumented immigrants. The project, sponsored by Grameen America and founded by Nobel Peace Prize winner and microfinance creator Muhammad Yunus, is partnering with DPC provider Iora Health to serve undocumented Latina women in New York City. Grameen Vida Sana is a health center offering primary care, language-concordant group meetings about healthy living, and the services of a health coach, for a monthly cost of $49 per member [26, 52]. The reduced overhead of the direct-pay model, coupled with an innovative spirit to meet the unique needs of minority communities, has unleashed creative approaches to care that are restricted in the predominant delivery model. The overall applicability of DPC to broad populations has caused some analysts to muse, "If there is a 'two tier healthcare system' it is higher income people getting the short end of the primary care stick" [26].

Future Trends in DPC

The rise in high-deductible health insurance plans for patients, coupled with the increased economic and administrative burdens on medical practice, is fueling greater inter-

est in direct primary care among patients and physicians [55]. As existing DPC practices grow, many are expanding capacity by hiring physicians and adding clinical sites in their communities. The expansion to larger DPC entities that offer DPC-style primary care for large employers also provides organizational alternatives for physicians who may wish to align with the practice model but do not want to assume the risk of starting an independent practice [45]. These developments—both the growth of smaller DPC practices and the expansion of larger corporate models—will make employed DPC practice an attractive and viable option for an emerging physician workforce [17].

A larger question looming on the horizon for direct primary care has to do with its integration into the rapid-paced changes in healthcare as a whole [39]. In the current climate, the growth of high-deductible health plans, the restricted networks of individual insurance plans, and the rise in physician burnout all point to the continued growth of DPC for patients and in the medical community. The movement to value-based reimbursement by the Centers for Medicare and Medicaid Service [62] and some commercial insurers, coupled with the potential changes in the Affordable Care Act and Internal Revenue Service regulations around the use of health savings accounts to pay for direct-pay subscriptions with pretax dollars, will impact the future growth and direction of DPC [33]. As the number of direct primary care practices continues to expand, it is likely that health insurers and healthcare systems will respond either by accommodation or resistance [60, 74, 75]. In the meantime, DPC practitioners continue to construct their vision for the future of patient-focused, effective, and sustainable primary care.

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Health Information Technology

34

Carlton R. Moore

Introduction

Health information technology (HIT) is a broad concept that encompasses an array of technologies that collect, store, share, and analyze electronic healthcare information [1]. HIT includes a range of functionality from medical billing systems to electronic health records (EHRs). EHRs are repositories of electronically maintained longitudinal records of patients' health status and healthcare. Many EHR systems have additional information management tools that facilitate computerized order entry, clinical reminders and alerts, and linkages to knowledge sources for clinical decision support. In 2004, less than 25% of ambulatory practices were using electronic health records (EHRs); however, one decade later, the number of practices using EHRs increased to more than 80% (Fig. 34.1) [2].

This chapter will provide an overview of HIT, particularly as it applies to chronic disease management. The first section will give a historical perspective to the development of HIT, as well as an operational understanding of its many elements. Next, the expansion of HIT into applications of chronic disease management will be discussed. The subsequent section will outline the policy and operational components of Meaningful Use (MU) and be followed by an assessment of the effectiveness of HIT in chronic disease management. The chapter will close with an appraisal of the state of the science and future trends in HIT.

C.R. Moore (✉)
Department of Medicine, Division of Hospital Medicine,
UNC Hospitals, University of North Carolina School of Medicine,
Chapel Hill, NC, USA
e-mail: crmoore@med.unc.edu

From Paper to Electrons: A Historical Perspective of HIT

There are many factors that led to a dramatic increase in the use of health IT and away from paper-based medical records in clinical care. The modern paper chart arose in the nineteenth century as clinical casebooks, daybooks, and diaries commonly used by physicians to record observations and treatment plans for their patients [3]. They served as longitudinal medical records that were updated on a regular basis as patients' medical conditions and treatment plans changed. Early on, clinical notes in paper charts were handwritten with few formatting requirements or standards which specified the necessary information that should be included in the notes. This led to communication and other challenges related to the legibility of handwritten notes, as well as significant variability in completeness and accuracy of information that was documented in medical records. Additionally, a single patient that was cared for by multiple physicians would have multiple paper charts distributed across various hospitals and/or physician offices. This partitioning of paper records contributed to poor coordination of care.

Most early advances in paper-based medical records were developed in academic teaching hospitals and then slowly disseminated to ambulatory care settings and private physician practices. For example, a major innovation to improve patient care, based on models from industry, was introduced in 1907 at St. Mary's Hospital and the Mayo Clinic in order to address the problem of scattered, disorganized patient information. In this setting, new patients were assigned a unique clinic number, and all data for that patient were combined into a single paper medical chart, designated by the assignment number. An early study found that the charts consistently listed chief complaint, objective and subjective symptoms, and diagnosis [3].

From these early days, as practices and hospitals grew, laboratory and other diagnostic study results were added to

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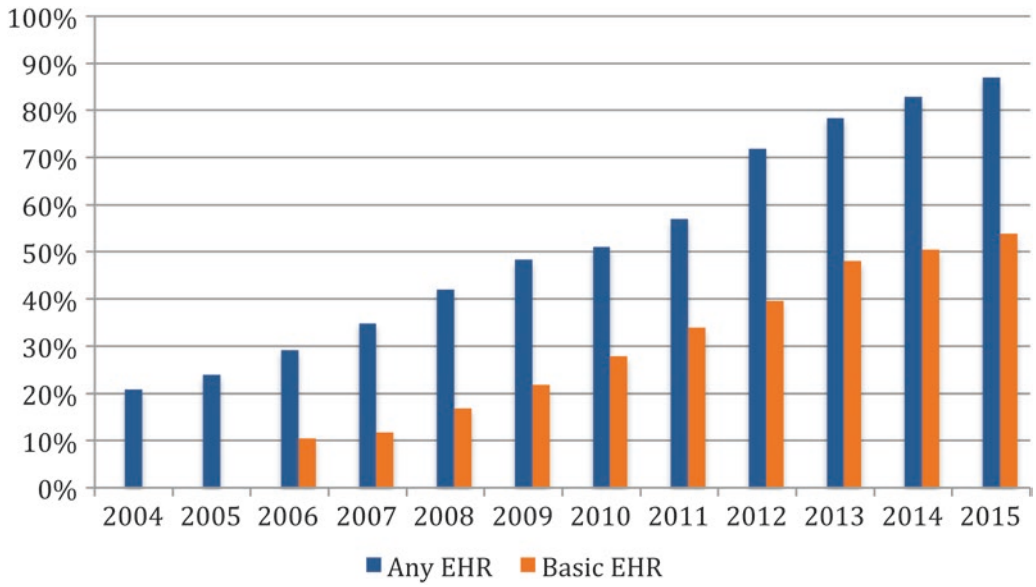

Fig. 34.1 Percentage of office-based physicians with electronic health records

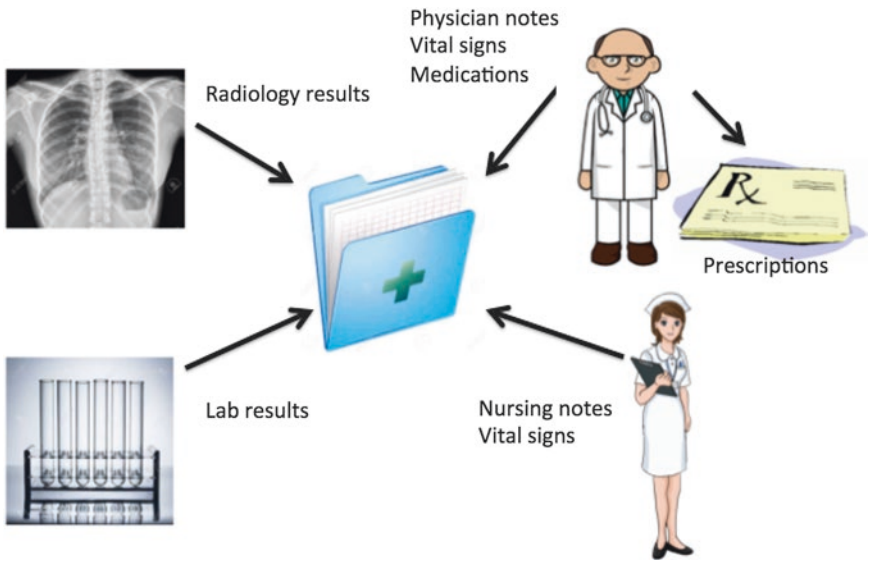

Fig. 34.2 Inputs to the medical record

the paper chart. Typically blood specimens were sent to outside labs, and the results were facsimiled (faxed) back to the office, and results were placed in the corresponding patient chart; there was a similar workflow for radiology and pathology studies. Additionally, notes from nurses and other healthcare professionals involved in patient care were added to charts (Fig. 34.2). For office practices with many patients, medical records were filed away in a medical records room where they were stored until needed for subsequent patient encounters.

This system was prevalent in ambulatory practices throughout the USA prior to the expansion of EHR use shown in Fig. 34.1. The advantage of the paper chart was that it provided a relatively quick and easy way of documenting and viewing a patient's medical information, once a chart was obtained from the medical records location. However, for patients with chronic disease, there were several disadvantages of the paper system [4]. The first was difficulty in determining the quality of care provided to chronically ill patients. Due to the unstructured manner in which information was stored in paper charts, it became both time and resource intensive for individual physicians and practices to identify specific subsets of chronic disease patient populations, in order to assess the quality of care being provided.

The paper-based system also did not facilitate identifying high-risk patients for quality improvement efforts. For example, a primary care physician who wanted to find and aggregate patients with poorly controlled diabetes (i.e., hemoglobin A1c $\geq$ 9.0%) would have to manually review paper charts to create a list and then proactively schedule these high-risk patients for appointments to optimize medication regimens. Often, paper-based rosters utilized software programs to create spreadsheets in which data was manually entered as each individual chart was reviewed. This process would need to be repeated for other chronic diseases or conditions, and the information would need to be updated over time. For physicians and physician practices with large patient panels and limited support staff, this was an impracticable process.

A second challenge was having a single user of the information at one time, which limited accessibility for any other user. Inaccessibility of the paper chart, especially in large organizations, is a major limitation of paper records. For example, a patient's chart may be unavailable to other providers for days while the physician completes documentation of his clinical note from the patient visit. Also, researchers may borrow paper charts for data abstraction in clinical studies, during which time the charts may not be available for patient care.

The lack of remote access to paper charts can also compromise patient care, particularly in situations when physicians do not have access to patients' clinical information. For example, an after-hours call to a physician about a patient complaining of chest pain is problematic, since the provider cannot view the patient's chart to determine if this is a new or long-standing complaint or if there are pertinent diagnostic test results (e.g., a recently performed cardiac stress test) that would inform appropriate triage for the patient. Documentation clarity was another limitation of the paper record. Since physician notes and medication prescriptions were handwritten, legibility was frequently a problem. This resulted in substantial rates of adverse drug events, due to incorrectly prescribed or administered medications.

One study that reviewed 1411 handwritten prescriptions from an internal medicine clinic in a large health system found that approximately 28% of the prescriptions contained one or more errors or potential errors [5]. Another study of four adult primary care practices found that prescribing errors occurred in 7.6% of outpatients' prescriptions and many could have caused patient harm [6]. One example of a prescription error described [7] involved an elderly nursing home resident who was prescribed oral hydroxyzine, 10 mg every 6 h, to alleviate itching. The pharmacist misread the physician's handwriting and dispensed oral hydralazine (a blood pressure medication), 10 mg every 6 h instead.

The inability to support clinical decision-making is another limitation with paper-based medical records. As a passive recording tool that documents clinical information about patients, it requires that clinicians manually search for key information needed to make evidence-based clinical decisions during patient encounters. For example, if a physician wants to make an informed decision about which antihypertensive to prescribe, she must know about relevant medication allergies, potential drug-drug interactions, relevant laboratory results (e.g., creatinine and potassium), as well as disease-specific recommendations. This patient-specific information is either hidden or difficult to access in the paper chart (e.g., relevant laboratory results and allergies), or the disease-specific guideline and recommendations reside outside of the paper chart. As a result, a physician must actively search for, acquire, and then process this information prior to prescribing. The process must be repeated for multiple medications and for multiple patients with multiple chronic medical conditions.

This process not only applies to medications but also to other chronic disease management interventions such as diagnostic screening. Physicians must be cognizant of preventive service and care guidelines which is daunting. A primary care physician, for example, is estimated to require over 7 h per working day in order to counsel and provide preventive services based on 75 US Preventive Services Task Force recommendations [8]. This workflow is in the context of an environment in which there are competing demands during patient encounters, such as troubleshooting acute medical issues and addressing psychosocial barriers to care [9]. Unsurprisingly, patients only received approximately 50% of recommended services in the era of paper charts [10].

The intersection of two events spurred expansion of EHRs from large healthcare systems and academic medical centers and into small medical groups and community practices, publication of the Institute of Medicine's (IOM) 2001 report *Crossing the Quality Chasm: A New Health System for the 21st Century* [11] and the 2008 Great Recession.

Crossing the Quality Chasm: Putting a Spotlight on the Health Care System's Failures

The IOM report, *Crossing the Quality Chasm*, admonished that the US healthcare delivery system did not provide consistent, high-quality medical care to all people, that patients were harmed too frequently, and that healthcare failed to deliver its potential benefit [11]. The report highlighted that Americans were living longer, due in part to advances in medical science and technology; however, the aging population was associated with an increase in the incidence and prevalence of chronic conditions. Although these conditions, including heart disease, diabetes, and asthma, are now the leading cause of illness, disability, and death, the contemporary health system remained overly focused on acute, episodic care [11].

The failures described in the IOM report were corroborated in a study that reviewed medical records from adult patients living in 12 US metropolitan areas to determine if they received evidence-based recommended care for several chronic medicine conditions [10]. The study concluded that patients received less than half of the recommended care for their chronic medical conditions. For example, only about 24% of participants in the study who had diabetes received three or more glycosylated hemoglobin tests over a 2-year period [10]. The gaps in quality of care highlighted here and by other researchers led the IOM to conclude that the current healthcare system required major redesign in order to effectively improve outcomes for patients with chronic diseases.

A major redesign proposed by IOM was an effective use of health IT and EHRs in patient care [11]. There was a strong belief that IT must play a central role in the redesign of the healthcare system if a substantial improvement in healthcare quality is to be achieved during the coming decade. A final recommendation was for a national commitment to building an information infrastructure to support healthcare delivery, consumer health, quality measurement and improvement, public accountability, clinical and health services research, and clinical education. A goal of this commitment was the elimination of handwritten clinical data by the end of the decade [11].

An Opportunity Through the 2008 Great Recession

The American Recovery and Reinvestment Act (ARRA) of 2009 [12], commonly referred to as "The Stimulus," was a financial incentives package enacted by the US Congress in February 2009 and signed into law on February 17, 2009, by President Barack Obama. It was a response to the 2008 Great Recession, and its primary objective was to quickly promote jobs in an economy in which the unemployment rate was increasing. A secondary objective was to invest in infrastructure, education, and healthcare, most notably the development of the health IT infrastructure described in the IOM report. In consequence, a key component of ARRA was the Health Information Technology for Economic and Clinical Health Act (HITECH Act) [13] that was designed to stimulate the adoption of EHRs and support health IT. HITECH sought to provide incentive payments to individual physicians (and hospitals) if they achieved "meaningful use" of "certified" EHR technology. The rule also established payment penalties in future years for healthcare providers who did not meet the requirements for the "meaningful use" of EHRs.

The HITECH Act included funding of approximately $22 billion, with the majority of funding allocated as follows: (1) $18 billion allocated to Center for Medicare and Medicaid Services (CMS) for Medicare and Medicaid reimbursements to incentivize hospitals and physicians to adopt and "meaningfully use" EHR systems, (2) $2 billion to the Office of the National Coordinator (ONC) for health IT to develop regulations for the certification of EHRs and for advising CMS on defining EHR "meaningful use" criteria, and (3) $677 million to establish Health Information Technology Regional Extension Centers (RECs) to provide technical assistance, guidance, and information on best practices to support and accelerate healthcare providers efforts to "meaningfully use" EHRs (Fig. 34.3).

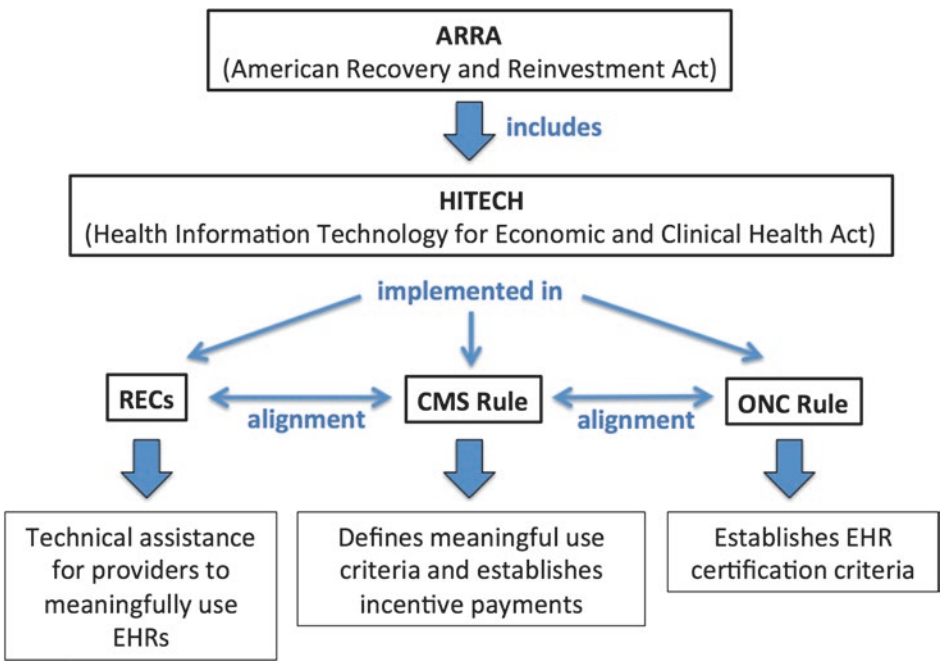

Fig. 34.3 ARRA support for EHR adoption

Electronic Health Records (EHRs)

Although the historical development of the paper-based medical record parallels advances in clinical care, the advancement of health IT and EHRs was more closely associated with changes in reimbursement models. Starting in the early 1980s with the advent of managed healthcare, reimbursement started to shift from a fee-for-service model (i.e., providers are paid based on the quantity of services provided) to a fixed-fee model (i.e., providers are paid a fixed amount per patient). As a result, there began a transition to environments in which the adoption of health IT tools could facilitate cost-effective and efficient care outside of hospital settings. Additionally, the ambulatory environment was changing from a model in which a single physician was responsible for all or a majority of a chronically ill patient's care to a model in which teams of healthcare providers, often from multiple medical specialties, would provide care to a single patient. In consequence, ambulatory medical records started to become complex information sources, containing large amounts of data, such as comprehensive clinical notes written by different healthcare providers from multiple specialties, laboratory and pathology results, and radiology images and reports.

The contemporary EHR goes beyond a simple computerized version of the paper record and can be characterized by the following functional components: consolidated view of patient data, clinical decision support, computerized physician order entry (CPOE), access to medical knowledge resources, and integrated communication support for clinicians [4]. A key function of an EHR is its capability to provide a single portal of access to, and visualization of, all patient data. Before the advent of comprehensive EHRs, patient data resided in independent databases, and clinicians had to access one computer system to view lab results, another system to view radiology images, and still another to view pathology reports (Fig. 34.4). EHRs moved to consolidate patient data from disparate clinical data systems – often manufactured by different vendors – by connecting to each individual system, thus providing clinicians with the ability to view all patient data (e.g., labs, radiology, etc.) via an EHR interface (Fig. 34.5) [4].

To enable this functionality, EHR administrators (i.e., IT specialists responsible for maintaining EHR systems) are required to revise the coding format of each clinical data system to match the coding format of the EHR, a task that is accomplished by the Interface Engine (Fig. 34.5). An Interface Engine is a translational buffer that allows clinical data systems manufactured by different vendors to communicate with one another [4]. Most clinical data systems and EHRs use a standardized format called Health Level 7 (HL 7) to transfer data, but clinical data systems occasionally deviate from this common format, and EHR administrators have to modify the formatting via an interface engine for compatibility with the EHR. As a result, hospitals and ambulatory practices can connect to different vendor clinical data systems and achieve consolidated access to all clinical data via the single EHR interface.

The consolidated access to patient data provided by EHRs thus enables robust capacities for clinicians to access and review data. EHRs can provide summary views of patient data on a single screen that shows the active problem list, medications, allergies, health maintenance reminders, and other summary information relevant to chronic disease

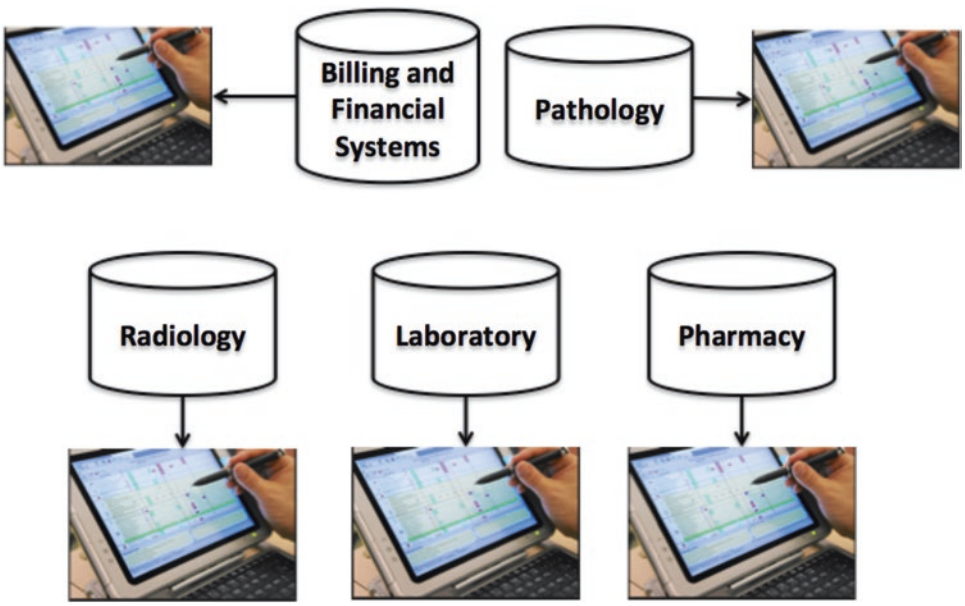

Fig. 34.4 Separate log-on required for each clinical data system

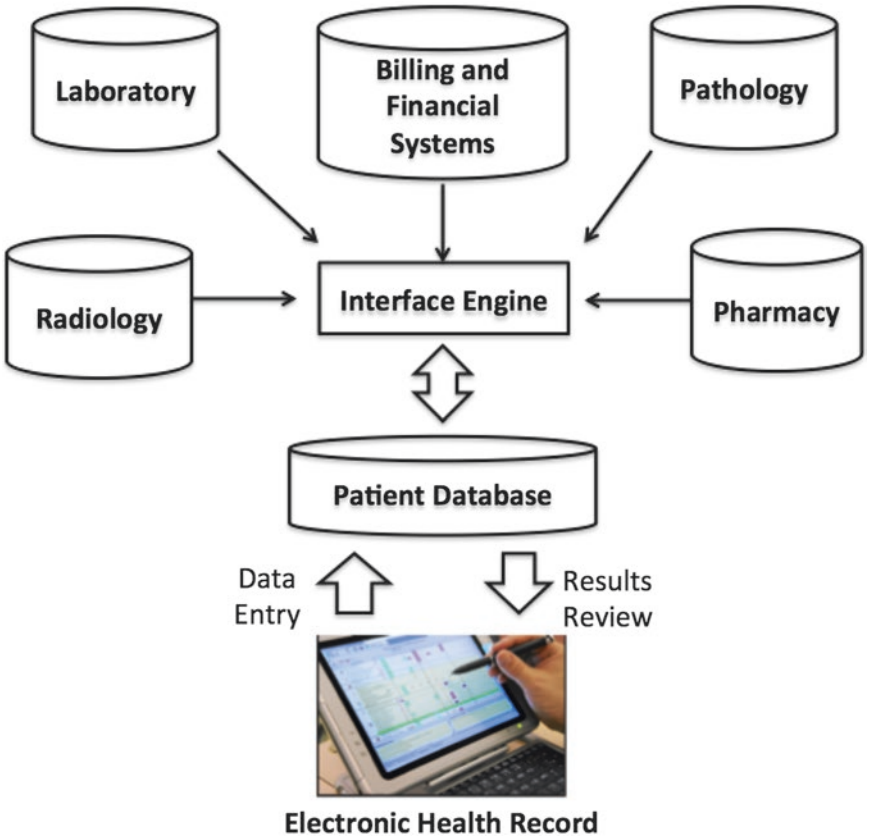

Fig. 34.5 Single EHR log-on to access all clinical data systems

management. Lab results can be trended over time in a flowsheet format or as graphs (see Fig. 34.6), and chest X-ray images can be annotated by clinicians to measure the size of pulmonary nodules.

Clinical decision support (CDS) is a key feature of EHRs that is relevant to improving chronic disease management. CDS is defined as the use of computers to bring relevant knowledge to bear on the healthcare and well-being of patients [15]. Decision support is most effective at the point of patient care, when the clinician is processing clinical information and starting to make decisions regarding diagnostic testing and treatment plans. This may take the form of a health maintenance reminder or an alert that a diabetic patient has not had a hemoglobin A1C checked in over 6 months. There are several key elements that contribute to successful implementation of CDS [16, 17]. The first is that decision support should be provided automatically as part of provider workflow at the time and location of decision-making. CDS should provide actionable recommendations with the philosophy that "the user is always right" and that users should have the ability to override nearly any CDS recommendation. Next, CDS systems often lack sufficient detail to accurately anticipate every patient's unique clinical situation, and CDS recommendations may need accommodation.

To avoid "alert fatigue" (i.e., prompting providers with numerous clinically insignificant or inappropriate alerts), providers should have some control over the alerts they receive by giving them the electronic capacity to modify or turn off certain alerts. An important activity is seeking user feedback with regularly scheduled meetings in order to develop user-friendly systems and to troubleshoot problems. Finally, system downtime needs to be minimized and quickly resolved since providers have limited tolerance for systems that are slow or behaving erratically.

Clinical physician order entry (CPOE) is an electronic functionality allowing clinicians to order lab and other diagnostic tests, as well as prescribing medications. Before the advent of modern EHRs, these were stand-alone computer systems that clinicians had to access separately. Most advanced CPOE systems are integrated with CDS so that alerts are generated if, for example, clinicians are ordering a drug that the patient has a known allergy, or if there is a potential drug-drug interaction. Also, many systems generate alerts if the dose of an ordered drug is adjusted, based, for example, on the patient's most recent glomerular filtration rate. Another EHR functionality is real-time access to medical information sources. This may range from links to widely disseminated sources such as PubMed or UpToDate® or "Infobuttons" that link information sources to "homegrown"

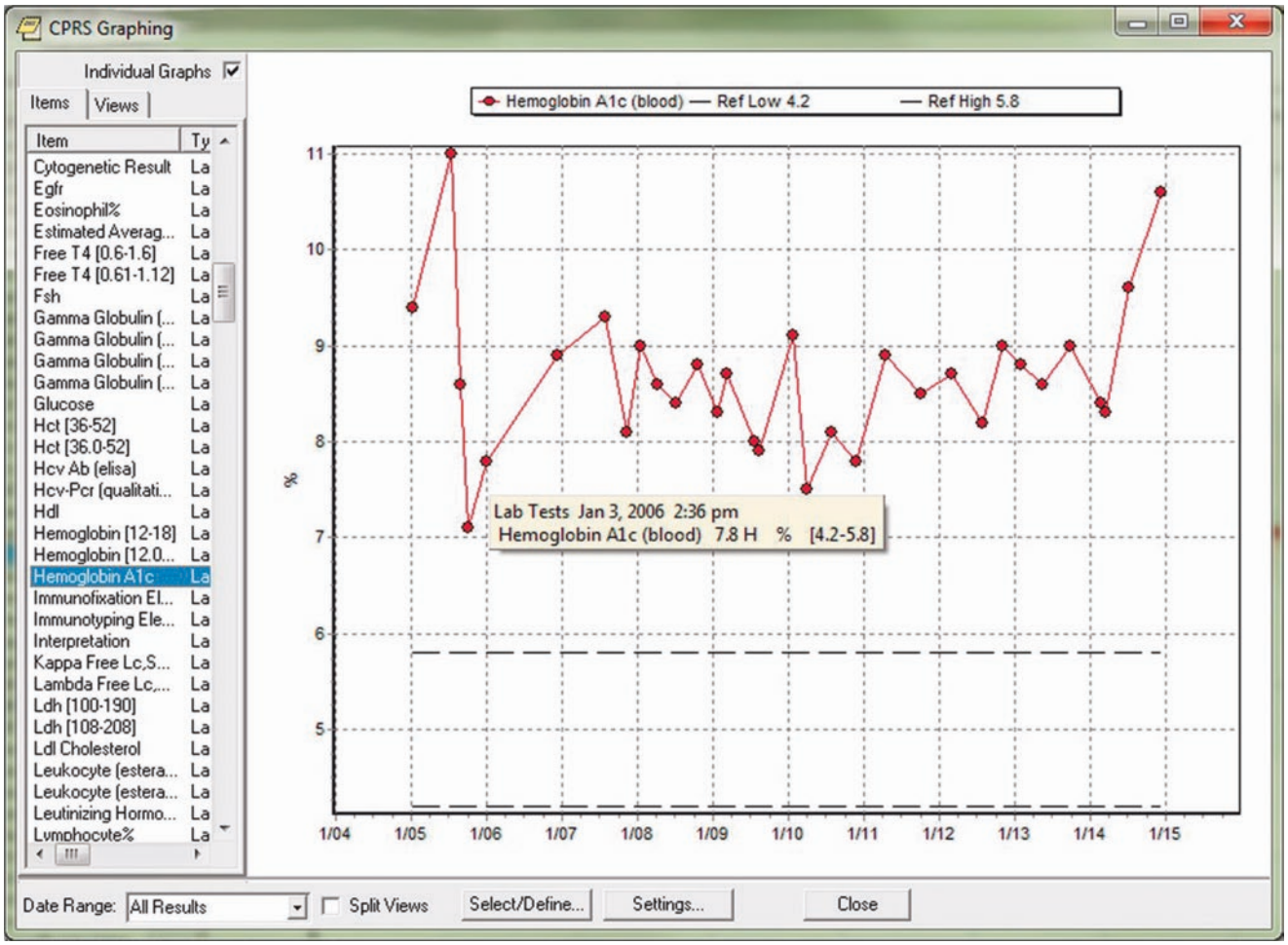

Fig. 34.6 Sample EHR screenshot showing graph of a patient's hemoglobin A1c [14]

or institutionally specific resources [18]. Finally, most EHRs have robust systems to facilitate communication between providers. This may take the form of communication that is "pushed" from one provider to another via email or pager services or "pulled" in by a provider during a patient encounter while using the EHR.

The Meaningful Use (MU) of EHRs

As noted earlier, the HITECH Act included funding to incentivize hospitals and physicians to adopt and "meaningfully use" EHR systems and empowered the Office of the National Coordinator (ONC) for health IT to develop regulations to certify EHRs and to define EHR "meaningful use" criteria. The overall objectives for meaningful use (MU) are to:

- Electronically capture key patient health information in an accurate and comprehensive manner.
- Use electronic patient information to facilitate clinical decision support (CDS) that informs evidence-based decision-making by providers.
- Facilitate quality reporting of care processes and patient outcomes in order to inform quality improvement efforts and to facilitate pay-for-performance reimbursement structures.
- Engage patients (and families) in their care and encourage patient self-management.
- Facilitate sharing of patient information among treating providers in order to improve transitions of care [13].

The ONC defined the EHR certification criteria and specified "what" an EHR system must be able to do, while meaningful use criteria (defined by CMS) specified "how" a certified EHR system must be used by providers for patient care. Table 34.1 provides an overview of the various objectives of Stage 1 (i.e., the first phase of implementation) MU with the corresponding components.

Table 34.1 Stage 1 meaningful use objectives [13]

Objectives	Components	Details
1. Electronically capture health information in a standardized format	Record demographics	Gender, age, race, ethnicity, date of birth, and preferred language
	Record vitals	Document changes in heart rate, blood pressure, height, weight, calculate, and display BMI
	Medication and medication allergy list	Maintain active medication and active medication allergy list
	Problem list	Maintain an up-to-date problem list of current and active diagnoses
	Lab/test results	Incorporate clinical lab test results into EHR technology as structured data
	Smoking status	Record smoking status
2. Use electronic patient information to facilitate clinical decision support (CDS) that informs evidence-based decision-making	Drug formulary	Implement drug-formulary checks
	Drug-drug/drug-allergy check	Implement drug-drug and drug-allergy interaction checks
	Computerized physician order entry (CPOE)	Use CPOE for medication orders directly entered by any licensed healthcare professional who can enter orders into the medical record
	e-Prescribing	Generate and transmit permissible prescriptions to pharmacies electronically
	Decision support rules	Implement one clinical decision support rule relevant to specialty or high clinical priority along with the ability to track compliance with that rule
	Create reports by condition	Generate lists of patients by specific conditions to use for quality improvement, reduction of disparities, research, or outreach
3. Facilitate quality reporting of care processes and patient outcomes	Quality reporting	Report ambulatory quality measures to Center for Medicare and Medicaid Services or the state-level agencies
	e-Report registry	Capability to submit electronic data to immunization registries or immunization information systems and actual submission in accordance with applicable law and practice
	e-Report public health	Capability to provide electronic syndromic surveillance data to public health agencies and actual transmission in accordance with applicable law and practice
4. Engage patients in their care and encourage patient self-management	Patient clinical summary	Provide clinical summaries for patients for each office visit
	Patient e-health information	Provide patients with an electronic copy of their health information (including diagnostic test results, problem list, medication list, medication allergies), upon request
	Prevention and follow-up reminders	Send reminders to patients per patient preference for preventive and follow-up care
	Patient education	Use certified EHR technology to identify patient-specific education resources and provide those resources to the patient if appropriate
5. Facilitate sharing of patient information among treating providers in order to improve transitions of care	Electronic information exchange	Capability to exchange key clinical information (e.g., diagnostic test results, problem list, medication list, medication allergies), among providers of care and patient authorized entities electronically
	Transition summary	The eligible provider who transitions their patient to another setting of care or refers their patient to another provider of care should provide summary care record for each transition of care referral
	Medication reconciliation	Physicians who receive patients from other settings of care for providers of care should perform medication reconciliation

As originally conceived by ONC, MU would be rolled out in three distinct stages. Stage 1 would focus on electronically capturing health information in a standardized format as well as reporting quality measures. Part of the data capture involved transitioning from paper prescription and test ordering to electronic prescribing and computerized physician order entry (CPOE). Stage 2 focused on using structured data for clinical decision support in order to

improve processes of care. Additionally, during the transitioning from Stage 1 to Stage 2, there would be a greater requirement to provide patients with online access to their health information along with patient-specific educational material to promote patient self-management. Finally, Stage 3 of meaningful use would focus on enhancing and further utilizing EHR tools developed in the first two MU stages to improve patient outcomes.

MU Objective #1: Electronic Capture of Health Information in a Standardized Format

Electronically capturing clinical data in a standardized format, and subsequently using the data for patient care, is the foundation for all other MU objectives, and it is the primary advantage EHRs have over paper-based records. There are trade-offs between coded or structured data and narrative or unstructured data. The major advantage of coded data entry into an EHR is that information is standardized and can easily be used in clinical decision support (CDS), quality improvement (QI), billing, and research. Standardized codes allow computers to "understand" and "interpret" clinical information and therefore process it to help inform clinical decision-making. For example, if the diagnosis of diabetes is entered into the EHR as coded data, the EHR's CDS system will "understand" the diagnosis and can send reminders to the treating clinician about evidence-based health maintenance recommendations. However, if the diabetes diagnosis is entered into the EHR as free-text, the computer cannot "understand" the data and, therefore, cannot use it for CDS. Another important example is coded medication lists. If medications are not entered into EHRs as structured or coded data, CDS systems that support drug-allergy and drug-drug interaction alerts would not be possible.

The major disadvantage of coded data is that it often does not provide the detailed and nuanced description of patients' symptomatology when compared with narrative free-text. For example, the coded patient symptom "chest pain" is much less informative than a free-text clinical narrative describing the patient's symptoms (e.g., "the patient presents with burning epigastric chest pain that worsens when he eats fatty foods and improves when he takes antacid medication"). Because of the trade-offs between structure and narrative data, MU does not completely prohibit free-text unstructured data entry, it simply mandates that specific clinical variables (described in Table 34.2) that are key for implementation of the remaining MU objectives be collected and maintained as structured data.

EHR vendors and end users determine the balance of how other clinical information is entered and stored in determining the balance between structured and narrative data entry, which is the art of EHR interface design and implementation. The optimal balance is determined by several factors (Fig. 34.7) including medical specialty (e.g., PCPs may be more likely to prefer narrative data entry vs. ophthalmologists who may prefer a more structured or templated format), personal clinician preference, and end-user data needs (QI, billing, reporting, etc.)

MU Objective #2: Clinical Decision Support (CDS) Systems

Clinical decision support can be defined as the use of health IT to bring relevant knowledge to the management of healthcare for an individual patient [15]. A key point is that support means the facilitation of clinician decision-making, rather than computer-generated recommendations about patient care. Relevant means the selection of information that is pertinent to patient care [15]. For a CDS system to optimally function, it must have the following features: access to structured or coded data in the EHR relevant to the patient (e.g., age, gender, diagnoses, lab results, medications, and allergies); a high-quality, evidence-based medical knowledge source; a software program or algorithm (e.g., rules engine) for processing the medical knowledge and patient-specific data to generate an output (e.g., patient-specific treatment recommendations); and a mechanism for presenting the prompt or recommendation to the clinician (information automati-

Table 34.2 Clinical decision support (CDS) intent and key issues with implementation

CDS intent	Delivered	Potential for workflow disruption	Key issues for success	Example
Reminder of actions user intends to do, but should not have to remember	Automatic	Low	Timing	Reminder for influenza vaccination
Provide information when user is unsure what to do	On demand	Low	Speed	Link to clinical knowledge database (e.g., UpToDate®)
			Ease of access	
Correct user's errors and/or recommend user change plans	Automatics vs. on demand	High	Timing	Alert about a potential drug-drug interaction
			Ability to override alert	
			Minimize false-positives	
			Minimize alert fatigue	

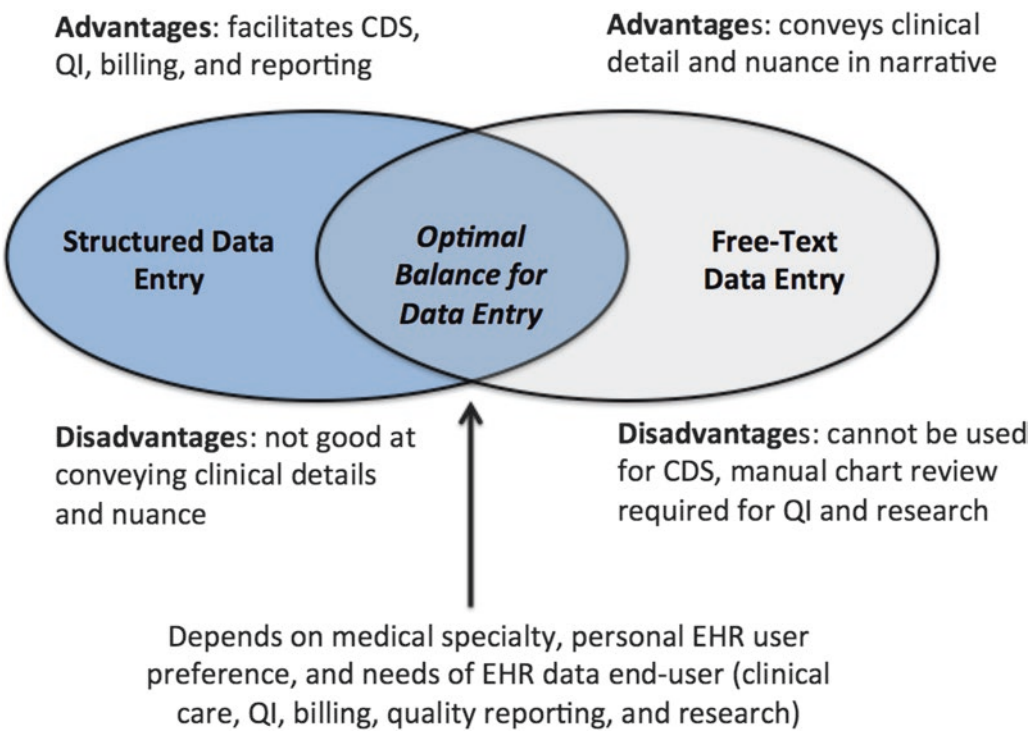

Fig. 34.7 Trade-offs between structured and unstructured data entry

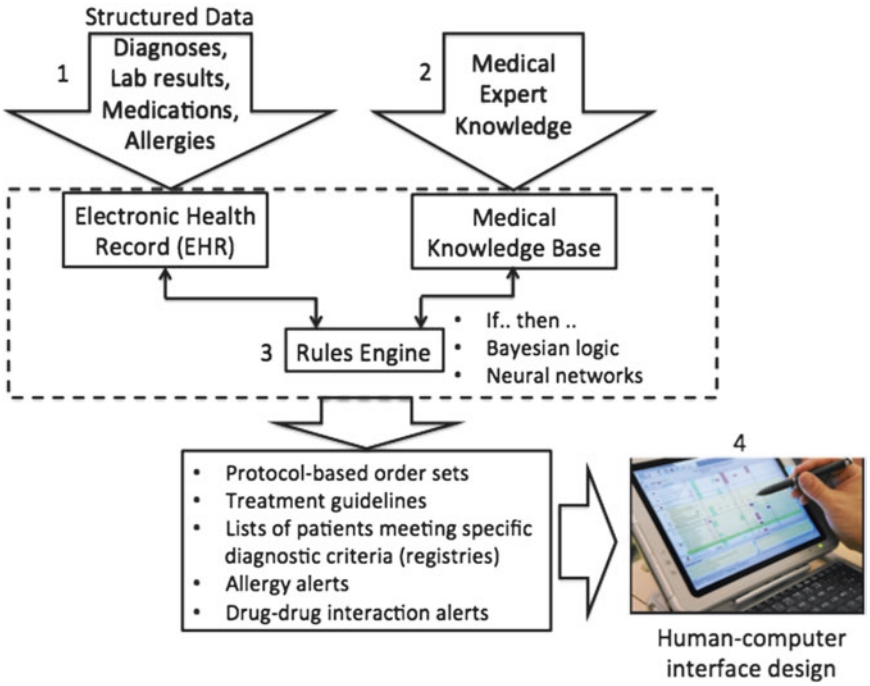

Fig. 34.8 Architecture of clinical decision support systems [19]

cally presented to clinician vs. information only presented at request of clinician – "on demand"). Figure 34.8 shows a diagram of the typical architecture of a CDS system [19].

The data accessed by the CDS system is usually processed via a rules engine that can range in complexity from simple if … then … logic to an artificial neural network. The outputs of CDS systems are reminders, alerts and/or diagnostic and therapeutic recommendations. CDS systems can range in complexity from simple systems that generate alerts and reminders that a diabetic patient is due for screening for diabetic retinopathy to a more complex system that recommends starting a patient on a statin medication because her

10-year risk of atherosclerotic cardiovascular disease is ≥7.5% [20].

At first glance, implementation of CDS systems may appear to be straightforward. For example, from a programming viewpoint, creation of an if … then … rule for checking that a patient's age is ≥50 years *and* there is no procedure code in the EHR database indicating the patient has ever had a colonoscopy appear to be fairly simple. The larger problem with successful implementation of CDS systems has less to do with technology and more to do with human-computer interaction, clinical workflow, and organizational commitment. For example, a CDS rules engine needs to be optimized to avoid false-positives (minimizing alert fatigue), or the CDS system should complement existing provider workflow rather than disrupting it (e.g., generating reminders not relevant to the current patient encounter). In addition, the information sources grounding the CDS system rule needs to be updated over time, as evidence-based guidelines change [21].

CDS-generated alerts, reminders, and recommendations can be designed to remind clinicians of things they intend to do, but should not have to remember, provide information when clinicians are unsure what to do, and identify potential errors clinicians have made in prescribing medications. A key factor in CDS effectiveness in improving care processes and patient outcomes is the way in which CDS output is rolled out to clinicians. The IOM has emphasized that health IT and CDS systems should be optimally designed to make it "easy (for clinicians) to do the right thing" [22].

CDS systems differ in how much control users have over decisions to use CDS-generated alerts, reminders, and recommendations. These decisions involve not only whether information generated by CDS systems is displayed on demand, so that users have full control over whether information is displayed, but also the circumstances under which users can, after viewing CDS recommendations, choose to accept them. A key issue involved in CDS implementation is the balance between clinician autonomy with their workflows and adherence to guideline-based care. Table 34.2 outlines several key implementation areas.

Some of these implementation issues have been addressed by research studies [15, 17, 23–27]; however, there are few accepted guidelines regarding standardization, in part because clinicians often differ in their preferences and approaches to care. However, one consensus opinion is that, CDS systems needs to be minimally disruptive to "cognitive workflow" to be successful. For example, clinicians receiving multiple inappropriate alerts can start exhibiting "alert fatigue" which results in ignoring alerts and/or overriding alerts and reminders. There is a risk that the few clinically significant alerts will be buried in the numerous alerts [28]. For CDS to be integrated and consistently used in clinician workflow, unique customization to local processes and adaptations to previous clinical workflows may be required [17].

MU Objective #3: Facilitate Quality Reporting of Care Processes and Patient Outcomes

This MU objective seeks to facilitate tracking and reporting of clinical quality measures (CQMs) to payers (e.g., CMS) and for public reporting. As discussed earlier, about half of patients with chronic illness receive recommended care, and low value care is provided to patients from 20% to 30% of the time [10, 29]. In this context, a primary goal of CMS in implementing MU is promoting the transition of the US healthcare system from a free-for-service model to a pay-for-performance model. A prerequisite for a functioning pay-for-performance system is the capacity to capture and report CQM to payers. Over the past several years, CQMs have become an integral part of CMS and commercial payor strategies to improve quality of care and reduce costs for their beneficiaries. Meaningful use EHRs assist in the collection and reporting of this data, which may be increasingly tied to future reimbursement schedules for healthcare providers.

MU Objective #4: Engage Patients in Their Care and Encourage Patient Self-Management

This MU objective focuses on using EHR technology to engage patients in their care by providing electronic access to personal health information (e.g., lab results, radiology reports, etc.), as well as evidence-based information sources to promote patient-informed decision-making and self-management. The EHR systems that facilitate this process are personal health records (PHRs) and patient web portals [30]. A PHR is a comprehensive health record where data is housed within (e.g., imported from EHRs, pharmacies, patient-entered data, etc.) and where patients have access and input to the data.

There are three types of PHRs. Free-standing PHRs are completely controlled by the patient and usually hosted by an Internet-based platform (e.g., Microsoft HealthVault). The PHR is not usually associated with any other record or healthcare providers. The second type is called a tethered PHR, which is hosted by the patient's healthcare provider and linked to the EHR. In a tethered PHR, patients can view a subset of the personal health information contained in the EHR and, for example, trend their lab results over the last year or view their immunization history. Finally, a sponsored PHR is provided by a patient's employer or health insurance plan and generally contains information based on insurance claims data.

A model for advancing PHR functionality to enable patient-centered care and self-management is displayed in Table 34.3.

First generation PHRs function at Level 1 and are simply electronic replacements for the home medical file; data is manually entered by patients and stored on a secure website.

Table 34.3 Advancing personal health record functionality [31]

Level	Functionality
1	Collect patient information, such as self-reported demographic and risk factor information (e.g., health behaviors, symptoms, diagnoses, and medications)
2	Integrate patient information with clinical information through links to the EHR and/or claims data
3	Interpret clinical information for the patient by translating clinical findings into lay language and delivering health information via a user-friendly interface
4	Provide individualized clinical recommendations to the patient, such as screening and on evidence-based guidelines

The amount of medical detail entered is patient-dependent, and the information may be inaccurate or inconsistent. More advanced PHRs (Level 2 and above) address this problem by linking electronically to clinical information in EHRs (i.e., tethered PHR). At the next level, PHRs have functional capacity that can translate technical medical information in ways that are understandable to patients (Level 3). Finally, at Level 4, the PHR can make patient-specific recommendations on issues such as preventive services and screening tests that are indicated or health behavior prompts that based on an individual patient's specific risk factors.

A patient web portal is a secure website for patients that is usually maintained by a patient's healthcare provider and offers access to functions and services linked to an EHR [30]. This functionality can include secure messaging, protected health information (e.g., lab results, medication lists, diagnoses), appointment scheduling, a tethered PHR, and patient self-management programs. Patient web portals can provide functionality that allows communication between patients and providers (i.e., secure messaging), chronic disease self-management tools, and administrative tools (e.g., appointment scheduling).

MU Objective #5: Facilitate Sharing of Patient Information Among Treating Providers

The full potential of health IT system integration into healthcare cannot be realized if EHR information is housed in data silos and impedes the ability of EHRs to exchange patient data. The compartmentalization of patient information by EHRs does not support high-quality transitions of patient care across different healthcare providers and organizations. For example, if a patient with several chronic illnesses changes primary care providers, it is important for the new provider to have complete information regarding the patient's medication regimen, previous lab results, diagnoses, preventive screening history, previous diagnostic testing (e.g., cardiac stress test), etc. Historically, this transfer of information occurred by the patient requesting paper records from the previous provider and transferring documents to the new provider who then reviewed the information and incorporated it into the new record.

The promise of the health information exchange (HIE) (Fig. 34.9) is that an information transfer process occurs seamlessly and that relevant clinical data is automatically transferred from previous provider(s) to current provider(s) via their respective EHRs, even if the EHRs are from different vendors. By facilitating the sharing of information between providers, healthcare will plausibly become more efficient by reducing the redundancy of healthcare services (e.g., repeating a cardiac stress test performed by previous provider).

A focus of MU, especially Stage 2, is that healthcare systems and providers demonstrate that their certified EHR can exchange clinical data among providers outside of their respective systems. Nearly $600 million in federal funding was designated to support statewide HIE organizations, and a few states have invested additional funding [32]. Currently, more than 100 organizations facilitate HIE among healthcare providers, and 30% of hospitals and 10% of ambulatory practices participate [33]. The key issues to facilitate HIE and EHR interoperability include establishing standards for clinical data exchange between EHR systems, the need to identify and consistently use unique patient identifiers or establishing patient identity using demographic data across different providers, a framework for assuring patient privacy, and a model for the financial sustainability of the HIE infrastructure.

A 2015 systematic review [34] concluded that use of HIE likely reduces emergency department usage and costs via reductions in repeat imaging studies. However, the impact on other health outcomes are unknown, and further study is needed to identify and understand the role of HIE in chronic disease management, as well as factors for successful HIE implementation [32]. A major limitation in this field is that relatively few of the more than 100 operational HIEs in the USA has been studied. Additionally, many HIEs are struggling to establish a fiscal model, and the factors for achieving sustainability will likely change over time. Table 34.4 shows themes and examples of the benefits and barriers to HIE in primary care practices identified in a systematic review [35].

Effectiveness of Health IT in Chronic Disease Management

A systematic review was performed to better understand the effects that various components of health IT have on chronic disease processes of care and health outcomes [36]. The review included 109 articles involving 112 health IT systems, and the index chronic diseases included diabetes (42.9% of articles),

Fig. 34.9 Health information exchange (HIE)

Table 34.4 Benefits and barriers to primary care practice participation in health information exchange

Benefits	**Examples**
More efficient workflow	Less time spent handling laboratory results
	Improved access to clinical data
	Streamlined referral process
Improved quality of care	Fewer prescribing errors
Cost savings	Eliminating cost of storing paper records
	Reduce redundant testing
Increased revenue	Government incentives to use health IT
	Pay-for-performance incentives
Barriers	**Examples**
Cost	Cost of establishing and maintaining links between EHRs and HIE networks
Security and privacy issues	Patients and providers concerned about privacy when sharing personal health information in an electronic environment
Leadership, strategic planning, and competition	Misaligned incentives (who pays and who benefits from HIE)
	Providers reluctance to relinquish control of patient information to competing systems
Technical barriers	Lack of interoperability among EHRs
	Lack of IT training and support

heart disease (36.6%), and mental health (23.2%). About one third of studies addressed multiple chronic disorders. Most of the studies (60%) used health IT systems implemented in the outpatient setting, including 59% in primary care and 28% in specialty care. Physicians were most frequently the intended users of the systems (39%), with nurses and patients being the intended users 39% and 17%, respectively. The impact on processes of care and health outcomes (positive, neutral, or negative) that were associated with implementation of health IT is shown in Table 34.5.

Most studies showed some improvements in chronic disease processes of care or outcomes, with the most impressive gains in screening (100% of studies positive), cost (91% positive), documentation (83% positive), guideline adherence (79% positive), and treatment adherence (67% positive). Referral rates and scores on standardized instruments (e.g., depression) showed least improvement (0% and 30% positive, respectively). Figure 34.10 below shows correlations between various components of health IT systems and quality measures [36]. The category of Health Information and Data refers to connection to an EHR system, while order entry (advanced features) is associated with disease-specific checks and corollary order templates and facilitation of care plan elements, such as referral to a specialist.

Table 34.5 Impact of health IT on processes of care and health outcomes [36]

Processes of care and outcomes	Examples	Intervention effect		
		Positive	Neutral	Negative
Guideline adherence	Screening for target disorders, conducting lab tests on recommended schedule	79%	21%	0%
Visit frequency	Decrease in emergency visits	50%	50%	0%
Documentation	Provider documentation of diagnostic criteria for specified disorder	83%	17%	0%
Treatment adherence	Adherence to medication regimens	67%	33%	0%
Referral rate		0%	100%	0%
Screening and testing		100%	0%	0%
Cost	Typically involving analysis of health IT system cost and savings to the organization	91%	9%	0%
Changes in lab values	Glycosylated hemoglobin	50%	50%	0%
Scores on standardized instruments	Depression	30%	60%	10%
Hospitalizations	Number of hospitalizations	43%	57%	0%

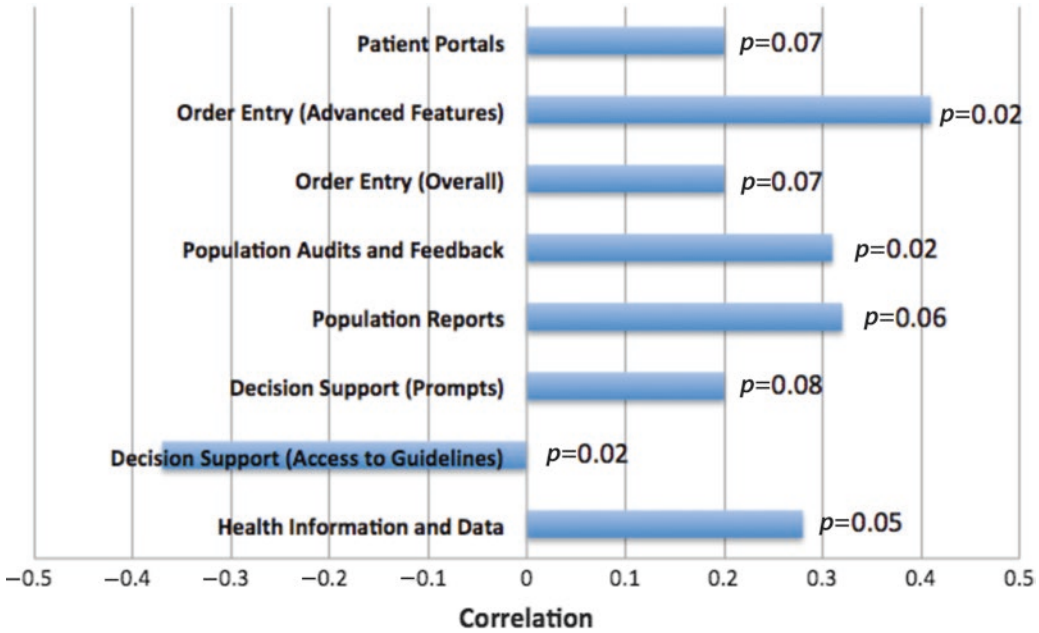

Fig. 34.10 Correlation between health IT components and improvement in quality measures

Computerized order entry with advanced features, such as disease-specific checks and corollary order templates, showed the highest correlation with improvement in quality measures ($r = 0.41$), while decision support in the form of computerized prompts correlated with improvements in quality ($r = 0.2$). However, decision support that only provided access to guidelines was significantly correlated with reduced quality of care ($r = -0.37$). When reviewers looked at sociotechnical determinants for successful implementation of health IT systems, they found that involving end users in the development process, responsiveness to end-user feedback, and adequate training were important factors [36]. A major barrier to success was failure to consider increased time for clinicians to use the system (i.e., performance usability) and/or significant alterations in clinical workflow resulting in health IT implementation.

Future Trends in HIT Chronic Disease Management

Mobile health (mHealth) and gamification will be trends to watch in HIT chronic disease management. It is projected that by 2018 there will be nearly 3.4 billion smartphone users worldwide and approximately 50% will have downloaded at least one mHealth application [37] such as Weight Watchers Mobile [38]. Chronic disease management is the largest focus of mHealth applications, with 56% mHealth application developer primarily targeting users with one or more chronic diseases (Fig. 34.11) [37].

mHealth applications will have the potential to play an important role in self-management in patients with chronic illness such as obesity, diabetes, and asthma.

A growing feature of mHealth applications to improve self-management behaviors is gamification, which is the application of game design elements and game principles in non-game contexts (e.g., chronic disease self-management). Badges (i.e., achievements or trophies), leaderboards, points and levels, challenges and quests, and social engagement loops are among the most commonly used mechanics of gamification that produce the enjoyable interaction provided by popular video games that compel continued play [39]. These same mechanics and human-computer interactions can be leveraged to facilitate chronic disease self-management. Table 34.6 shows gamification mechanics that bolster usability and compel continued play [39].

Few studies have investigated the best approaches to apply gamification concepts to mHealth applications in order to improve patient self-management. The success of gamification applications will be tied to user experience, since the first minute of using a specific application significantly determines whether the user will continue to use the application [39]. A common strategy to improve the likelihood of continued use involves a tutorial that quickly and comprehensively walks the user through use of the application [39].

A final trend will be related to HIT implementation strategies, since factors like performance usability, user training, and integration into existing clinical workflow are critical yet inadequately described in most HIT studies [44]. Translating and applying results from trials to clinical settings is challenging, because the success (or failure) of a system has as much to do with the implementation strategy, as it does to system functionality and technical specifications. In consequence, the future success of health IT in reducing costs and improving quality in chronic disease care will have less to do with advances in technology and more to do with viewing health IT as a key tool that must be successfully integrated into clinical workflows to support the chronic care model [44]. For this to occur, there must be ongoing support from healthcare organizations, payers, and government policymakers to align financial incentives to maintain and build the US health IT infrastructure.

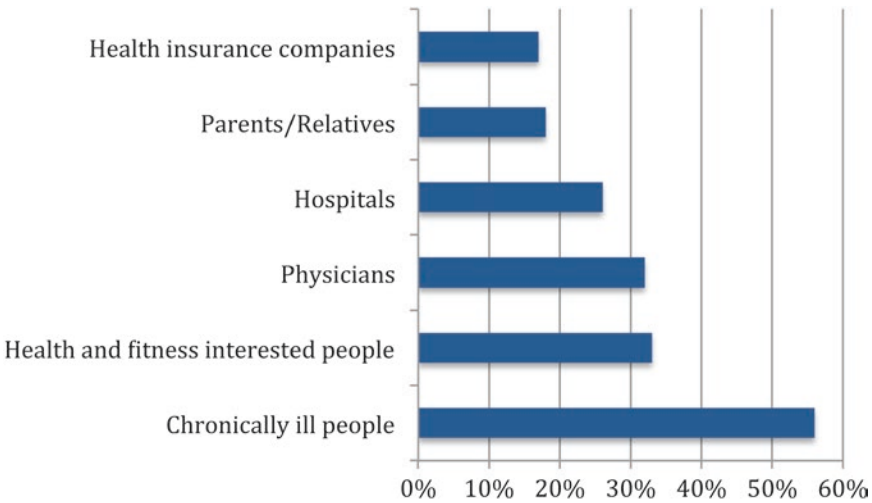

Fig. 34.11 Primary users targeted by mHealth application developers

Table 34.6 Health-related gamification features that promote usability

Feature	Description	Examples
Badges	Used to identify and reward individual accomplishment or achievement. Can be absolute (achievement of a benchmark) or relative (achievement relative to peers)	Fitocracy [40] is a mHealth fitness tracker application that uses badges that allows users to visualize their performance in comparison to their peers. Badges are awarded by meeting objectives such as running a specified distance over the course of a week
Leaderboards	Dynamically ranks individual users progress and achievements as compared to their peers	Runkeeper [41] is a global positioning satellite (GPS)-enabled fitness application that tracks a number of fitness goals. The application has a leaderboard based on syncing with the user's social network
Points and levels	Points and leveling systems rate users based on their level of familiarity or mastery of knowledge or expertise using the system. This is achieved through calculating the additive point values and assigning users titles or levels as they progress through the system	Mango Health [42] is a medication manager application that enables users to input their medications and set reminders to take their medications. Users earn points for inputting their medications and taking them as scheduled. As users accumulate points, their level increases, and the higher their level, the greater chance they have of winning a prize
Challenges and quests	Through continued challenges or quests, users are motivated to continue using the application. There is usually an underlying story or narrative with checkpoints and benchmarks indicating that the user is progressing through the system	mySugr Companion [43] is a diabetes management application that enables users to manually input their blood glucose readings, indicate their mood, provide nutritional information, and take pictures of their food. Completing daily challenges updates a dashboard progress bar that when full, "tames" their "diabetes monster"
Social engagement loops and onboarding	Patients build social capital with, and support from, peers by sharing their information with those using the same application. Loops mediate onboarding whereby new users as brought into the system via invites from existing users	Runkeeper [41] leverages socials engagement loops to promote onboarding

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Quality Improvement

35

Dana M. Neutze and Lindsay Stortz

Introduction

Health-care systems across the United States have growing interest to improve the quality of care, reduce the cost of care, and improve patient satisfaction [1]. The transition from a production-based to value-based paradigm for reimbursement has further heightened these efforts across a wide range of health-care settings [2], especially in patients with chronic health conditions. Consequently, there have been ongoing development and implementation of health information technology and the adoption of quality improvement strategies and tools in hospitals and clinics [3].

Quality improvement (QI) has become an increasingly important aspect of health care. Fundamentally, QI is the process by which providers and organizations strive to improve outcomes, decrease cost, improve accessibility, and improve the care experience for providers and staff. This chapter provides an overview of quality improvement in the health-care setting. The first section surveys the roots of quality improvement in other industries and looks at the genesis of the movement in health care. Next, basic QI principles are introduced and described in relation to health services. The subsequent section outlines several QI models and approaches and is accompanied by key areas of change management and managing data. The chapter closes with some future directions for quality improvement.

D.M. Neutze (✉)
Department of Family Medicine, University of North Carolina, Chapel Hill, NC, USA
e-mail: dana_neutze@med.unc.edu

L. Stortz
Practice Quality and Innovation, UNC Health Care System, Chapel Hill, NC, USA
e-mail: Lindsay.Stortz@unchealth.unc.edu

Movements and Initiatives Promoting Quality Improvement

The roots of quality improvement in health care may be found in other industries, particularly manufacturing. Henry Ford revolutionized the car industry with the institution of flow production to create the Model T in 1908. Before this time, cars were custom-made and expensive, resulting in only a few cars being produced. By systematizing and perfecting the assembly line, Ford was able to streamline production, which resulted in providing a car for the masses. However, Ford's system could not adapt to dynamic changes, as illustrated by his model T cars, which were only available in one color. From 1948 to 1975, Taiichi Ohno and Eiji Toyoda went a step further in the automotive industry by creating the Toyota Production System (TPS). The focus of TPS was on decreasing waste while improving production, which led to better service to customers and greater profits [4].

Over the course of the twentieth century, the manufacturing industry came to realize that quality control and serving the customer were essential for business. It was not until the turn of the twenty-first century that this idea crossed over into health care. Toward the end of the twentieth century, health-care delivery was changing from predominantly acute episodic care to the management of chronic illness. In 1999, the Institute of Medicine's (IOM) Committee on the Quality of Health Care in America released the groundbreaking report *To Err is Human: Building a Safer Health System* [5] citing that at least 44,000 deaths a year occur in US hospitals because of medical errors. The committee had been formed a year earlier with the charge to improve America's health care over the next 10 years, and the IOM report was seen as a wake-up call in health care.

A second report, *Crossing the Quality Chasm: A New Health System for the 21st Century* [6], was published by the IOM in 2001. This subsequent report provided an outline for how the health-care system should be changed to make it "safe, effective, patient centered, timely, efficient, and

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Table 35.1 The six aims for better health care (source: *Crossing the Quality Chasm*)

Aim	Purpose	Example
Safe	Health care should cause no harm to individuals	Electronic health records automatically checking for drug interactions
Effective	Should be based on the latest scientific evidence without doing unnecessary interventions	Cervical cancer screening for women limited to ages 21–65
Patient centered	Providing care based on the values of the patient and respect for the patient	Shared decision-making
Timely	Reducing waits and delays	Same-day appointments
Efficient	Reducing waste of supplies and equipment	Stocking only necessary supplies so that they do not expire
Equitable	Providing care to everyone that is the same irrespective of race, gender, and socioeconomic status	Free prevention screenings that can be accessed by all individuals

Adapted from [6]

equitable." Table 35.1 displays the six aims proposed as key areas necessary to deliver high-quality patient care.

The report challenged health-care providers, patients, administrators, and lawmakers to rethink the ways in which care was delivered and to restructure the system to support new models of care. These two landmark reports set the stage for subsequent models of care and launched federal initiatives to test and implement new approaches. Fundamentally, *Crossing the Quality Chasm* identified both the need and the framework to redesign America's health-care system and promoted an impetus to move from pay for performance to pay for value [6]. At the time, there were no strategies or initiatives in place to kick-start this; however it was in this era that several national programs, including the patient-centered medical home, and organizations, such as the National Committee for Quality Assurance, started to take shape.

A driver of QI has been the National Committee for Quality Assurance (NCQA), which is a private, not-for-profit organization that was established in 1990 [7]. NCQA provides consulting, data analytic, and accreditation services to clinics, hospitals, and other health-care entities that meet specified organizational and performance standards. Certification programs, such as NCQA, are voluntary, but some insurance payers link their contracting with participation in various programs. One such program is the patient-centered medical home (PCMH), which has three levels of accreditation that are indexed by patient-centered access, team-based care, population health management, care management, care coordination and care transitions, and performance measurement and quality improvement [8].

The Institute for Healthcare Improvement (IHI) was founded in 1991 as an independent not-for-profit organization based on the work of the Committee on the Quality of Health Care in America and the National Demonstration Project on Quality Improvement in Health Care [9]. The mission of the organization is to revolutionize health care along the six aims set out in *Crossing the Quality Chasm* (Table 35.1). In 2007, the Institute for Healthcare Improvement introduced the Triple Aim with the goal of "improving the individual experience of care; improving the health of populations; and reducing the per capita costs of care for populations" [10]. This has led to new initiatives by national organizations such as Family Medicine for America's Health [11] and new approaches to health care including telemedicine [12]. More recently there has been a call to address the Quadruple Aim, which further includes improving the experience of clinicians and staff [13].

Furthermore, the work of the IHI has included developing and spreading best practices such as the 100,000 Lives Campaign to ensure patient safety. The campaign was an 18-month initiative to decrease mortality of hospitalized patients by avoiding medical errors and improving efficiency [14]. There were six key practices targeted: rapid response teams, medication reconciliation, prevention of central line infections, prevention of surgical site infections, prevention of ventilator-associated pneumonia, and evidenced-based care for myocardial infarction [14]. While there was uncertainty whether the goal was indeed met [15], it helped focus the attention of the health-care industry.

In 2006, the American College of Physicians (ACP) issued a policy statement that called for the creation of advanced medical homes that would promote a patient-centered, physician-guided model of health care [16]. A later iteration – the patient-centered medical home (PCMH) – was endorsed by the American Academy of Pediatrics, American Academy of Family Physicians, and the American Osteopathic Association the following year [17]. The key elements of the PCMH include (1) a personal physician responsible for all of a patient's care, (2) an emphasis on quality and safety, and (3) an enhanced access to care for patients. Since existing payment models were fee-for-service based, the ACP recommended reimbursing physicians differently if they participated in the PCMH [16]. The ACP believed that PCMH should be a voluntary practice model that providers would choose to participate in, based on enhanced reimbursement, and patients would choose based on the quality and safety of care.

The federal government is the single largest payer of health care in the United States through the Centers for Medicare and Medicaid Services (CMS), an agency that has also promoted QI. In 2006, the Physician Quality Reporting System (PQRS) was established as a strategy to align payment with reporting quality data [18]. Initially there were

incentive payments up to 2% for data provided, but these ended in 2014. In 2010, penalties for non-reporting data were introduced, and providers were incented to submit data on a subset of over 200 different metrics. These metrics included preventive measures such as vaccine and cancer screening rates and chronic disease targets such as hemoglobin A1c control.

PQRS was reconstituted under the Medicare Access and CHIP Reauthorization Act (MACRA) of 2015 and expanded the push to value-based payments by focusing not just on quality but also on total costs of care [18]. Part of the reimbursement will be for demonstrated quality, such as decreasing readmission rates and providing preventative care. Most of these models share risk with the health-care organizations in order to incentivize good health outcomes at a lower cost. As a result of these programs and initiatives, the ongoing transition from a production-based to value-based model for reimbursement has focused QI efforts across a wide range of health-care settings [2].

Quality Improvement Principles

There are four key principles which are important for any QI project, irrespective of the models and methodology that are used [19]. The first is that QI work should be viewed as systems and process. Health care is complex with many inputs, processes, and outputs which comprise a system. Processes can be further divided into what care is provided and how is it delivered [19], and altering one factor within the system can have both positive and negative effects. When approaching QI it is important to look, not only at the individual outcome metric or behavior change but at the underlying system. One useful tool is a process map, which provides a visual overview of the different steps in workflows and stakeholders that may be contributing to them. A process map can allow team members to understand the workflow process on a more global scale – from start to finish – since most members typically think and work in a limited part of the organization.

The second principle is a focus on patients. Improvements in health care should primarily center on patient wellness and experience. QI initiatives can get sidetracked by paying more attention to process measures, than to the patients who are receiving care. Teamwork is the third principle, highlighting that different members of a health-care team understand different aspects of clinical processes and contribute distinctive skills. It is important to build a diverse but cohesive team for a QI intervention to be successful not only in the short-term but in the long-term as well. A team approach creates buy-in, which can be a deciding factor in the success of a program.

The fourth principle is the use of data, which is essential to ensure that an intervention is necessary and has made an impact. Collecting data allows a team to learn from an intervention rather taking a simple trial-and-error approach [20]. Both quantitative and qualitative data are important to gauging progress. Qualitative data, including surveys and interviews, are often overlooked but provide crucial information, such as calibrating organizational culture, which cannot be determined from quantitative data alone.

Quality Improvement Models and Frameworks

Deming Cycle/PDSA

W. Edwards Deming (1900–1993) was a proponent of continual improvement to advance processes, and much of his work was in the Japanese manufacturing industry. He furthered the work of his mentor, Walter Shewhart, to produce the now classic Plan-Do-Study-Act (PDSA) model otherwise known as the Deming Cycle (Fig. 35.1) to provide structure for a test of change [21]. An initial plan determines the experiment and outlines the proposed metrics (Plan). The experiment is carried out (Do), and the lessons learned from it are evaluated (Study). The success and failures of the experiment are then used to inform the next set of experiments (Act). In this way, one trial informs the next, leading to ongoing and iterative gains in knowledge and advancement.

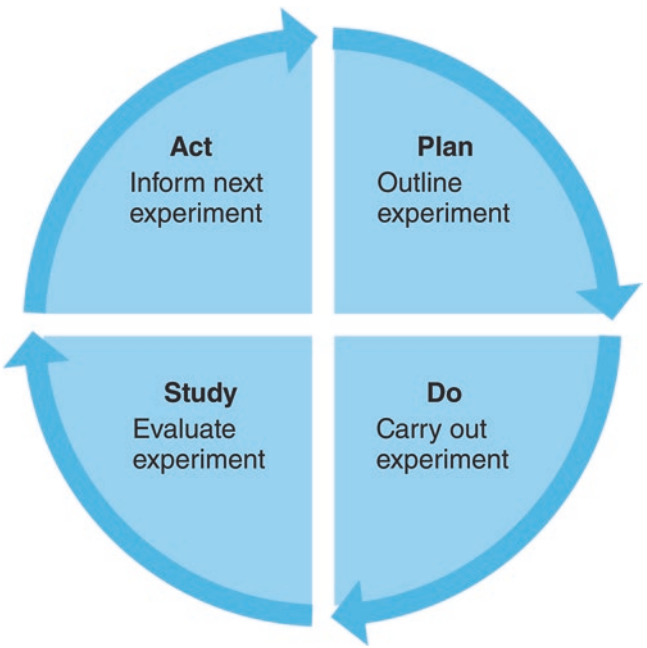

Fig. 35.1 PDSA cycle [6]

IHI Model for Improvement

One of the IHI's biggest contributions to the science of improvement has been the Model for Improvement (Fig. 35.2).

The model was designed by the Associates in Process Improvement in 1993 and is based on the work of Deming, placing the PDSA cycle within a larger framework [20, 21]. Prior to initiating the PDSA cycle, the model asks three key questions that determine the aim, measurement strategies, and interventions of a project: "What are we trying to accomplish?" (Aim), "How will we know that a change is an improvement?" (Measure); and "What change can we make that will result in improvement?" (Selecting changes).

Forming the Team

Teamwork is critical for a successful QI project, and there are three key players who have different roles [20]. The clinical leader is the individual who has the authority to ensure that changes can be made within the organization. He or she should have some expertise in knowing the organization and how changes will affect the system as a whole. The technical expert knows the process being improved and can give recommendations. Sometimes a technical expert may also have increased knowledge of QI methodologies. Finally, the day-to-day leader is responsible for the daily work being done to ensure that tests of change are implemented and that data are being collected. Effective teams should ideally have all three types of members; however there may be more than one of each, and some participants may fill multiple roles.

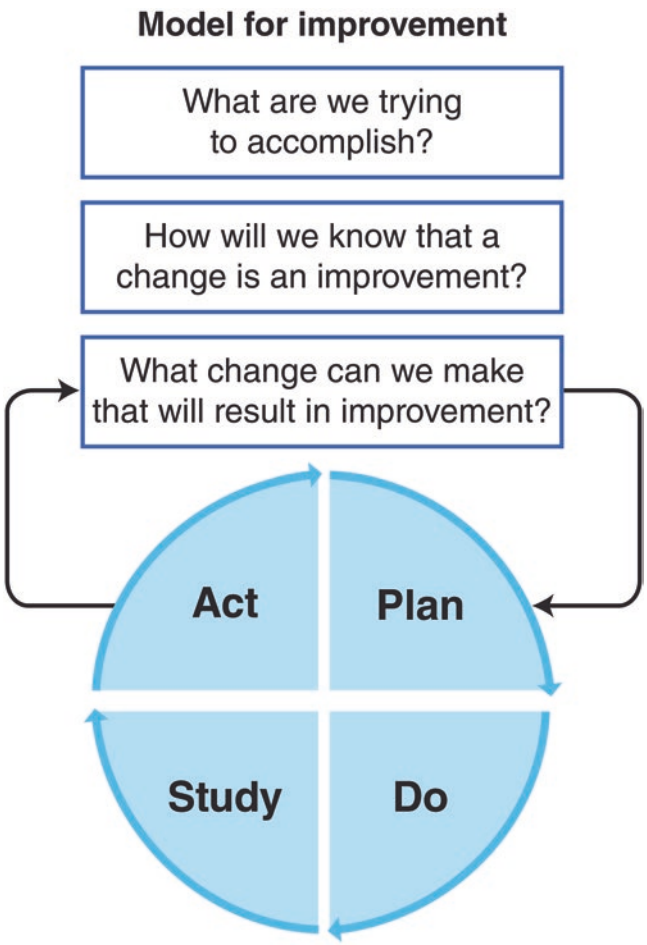

Fig. 35.2 The Model for Improvement. (Adapted from [20, 21])

Setting Aims

Once the team has been formed, the next step is to set the aim of the improvement project. Aim statements should be *s*pecific, *m*easurable, *a*ttainable, *r*elevant, and *t*ime-bound (SMART). A clinical example of an aim statement would be to increase cervical cancer screening rates by 5% in the next 3 months.

- Specific: Cervical cancer screening in women ages 21–65.
- Measurable: The change in the percent of women getting screened.
- Attainable: A 5% change is a realistic goal for the time frame.
- Relevant: Screening detects cancers early. Screening has been shown to impact the lives of patients.
- Time-bound: 3 months.

Selecting Measures

There are three types of measures that can be collected during PDSA cycles: outcome, process, and balancing [20]. Outcome measures are metrics that indicate the ultimate desired effect of the change and can include biometric measures such as hemoglobin A1c or rates such as screenings, morbidity, and mortality. Process measures look at the protocols and procedures that are used during PDSA cycles and are important if there is a time dependency to demonstrate a change with outcome measures. Some process measures gauge participation rates among health-care staff or adherence to the standard work of the improvement. These metrics, for example, could include rates of referral for screening tests, even if the screening has not been completed. Process measures can be useful to identify and remediate improvements to the QI process itself. Balancing measures are key in ascertaining how QI interventions in one area positively or negatively impact other areas of clinical operations. For example, visit cycle time – the total time that a patient spends during a clinical encounter – may be lengthened when changing workflow patterns around preventive screening services in a clinic.

Selecting, Testing, Implementing, and Spreading Change

Change can be selected for a variety of reasons, and one approach includes thinking about the current process and using logical thinking to come up with opportunities to make

it work better. A second approach generates novel approaches as to how the workflow could be modified to get a different result. Not all change initiatives result in the desired outcome, so it is critical to evaluate and test any adopted changes. The PDSA cycle, discussed above, is at the heart of this evaluation. After a process has gone through PDSA cycles to ensure it is effectively adopted on a small scale, the change is implemented into standard work, becoming the new way the process is carried out. Once a change has been successfully implemented, it can be disseminated across the organization. For example, a change that becomes standard practice in one clinical team can be spread to the other teams.

Lean

Lean is an improvement system and philosophy based on two pillars: the concept and practice of continuous improvement and the power of respect for people [22]. With roots in the Toyota Production System [23], Lean seeks to reduce waste (i.e., *muda,* Japanese terms are used in Lean to refer to ideas and concepts and are included in this chapter for reference) and bring value to the customer through continual improvement (i.e., *kaizen*). An integral component of Lean is going to *gemba*, in order to see what is really happening in the process rather than what is believed to be happening. *Gemba* means the place of truth and is tied to observing what is happening on the operations floor or in the clinic to truly understand the process [22]. Lean methodology has been used across many manufacturing industries, including automotive and airplane production, and it is increasingly being applied to health care [24].

There are several core principles of Lean. The first specifies value from the viewpoint of the customer or patient. This is followed by delineating a set of specific actions that are required to identify and eliminate steps which do not create value. The next principle empowers customers/patients to determine how much value is created, and when, by customer demand. Throughout the process there is an aim for perfection by continually removing wasteful steps and using flow and pull to create perfect value [25]. In determining what is of value to the patient, waste, called *muda*, is identified for elimination, and the different types are displayed in Table 35.2.

Underpinning Lean is a way of thinking and approaching problems, commonly called A3 thinking. The term A3 refers to a standard paper size – 11 by 17 in. – and has come to connote a standard consensus-building and communication tool that is used to study and solve a problem and then to communicate that change. A3 thinking is a transparent, logical, and structured tool to drive change [22]. While A3 processes and reports can take on varying recording and reporting formats, the concept remains unchanged. One format of a 9-box A3 Report is displayed below (Table 35.3), although different organizations may adopt slightly different formats.

Table 35.2 Types of *muda* or waste

Muda	Description	Health-care example
Waiting	Waiting for information, people, or materials	Patients waiting for discharge clearance
Overproduction	Doing more work than is absolutely required, over-processing	Ordering more lab work than is necessary to treat a patient
Rework (or defect)	Having to undertake remedial work of any kind because it was done incorrectly the first time	Medication sent to the wrong pharmacy
Motion	The movement of human beings, when not necessary	Nurses walking 5 miles in a single shift
Transport	The movement of information, materials, and equipment	A form moving from person to person or department to department
Processing	Undertaking any activity that is explicitly not required	Redundant information gathering and charting
Inventory	Any unnecessary materials, unnecessary queuing of people, tasks, or forms	More medication on hand than is necessary
Talent	The waste of expertise of human beings by asking them to do something better undertaken by someone else	Staff not being given the opportunity to improve a process. Staff not using the full scope of their licensure
Excess processing	Extra steps that do not provide value	Having to fill out multiple copies of the same paperwork

Adapted from [26, 27]

In brief, the Reason for Action (Box 1) lays out the problem and associated important statements and answers the "burning platform" question of why are we addressing this and what is involved [26, 27]. The Current State (Box 2) and Target State (Box 3) help participants depict the existing workspace, both subjectively and objectively, as well as an ideal, future state [27]. Box 4 identifies gaps that are existing between the current and target state and uses a root cause analysis for a deeper dive into why these gaps exist. There are different tools that can be used at this stage of the project such as the 5 Whys and a fishbone diagram. This analysis determines what countermeasures or solutions, presented in Box 5, would help solve the problem [27]. Depending on the complexity of the problem, solutions can be straightforward and readily implemented such as purchasing and test new ergonomically correct supply carts to decrease physical strain to staff [27].

Table 35.3 A3 nine-box A3 report template

Box 1 Reasons for Action *Why is this problem important, and why are you talking about it now?* Business case	Box 4 Gap Analysis *Why are we experiencing the problems, and what constraints prevent us from the goal?* Root cause analysis	Box 7 Completion Plan *What is the specific work plan for testing various solutions?* Who will do what and when Ensure ongoing PDSA
Box 2 Current State *What is the condition that the business or operation feels?* Metrics, description, visual displays	Box 5 Solution Approach *What alternatives and options will be considered to solve the problem?* Ideas to remedy root causes discovered in Box 4	Box 8 Confirmed State *What was achieved related to the current state?* Metrics gathered and reported at regular intervals
Box 3 Target State *What is the specific change that you want to accomplish, and how will you measure success?* Target metrics, description of target state, visual displays	Box 6 Experiments *What will you do to test the alternatives and options?* Gantt chart or other project plan Indicators of performance	Box 9 Insights *What did we learn from this experience, and where are the opportunities for improvement?* Plus (+)/deltas Aha moments

Adapted from [26, 27]

Box 6 outlines the project plan or experiments, which includes metrics, process owners, and timelines. Several mini PDSA cycles are often contained within experiments as these cycles are the heart of A3 thinking [28] Box 7 delineates a completion plan with attention to remaining issues and unintended consequences [27]. Box 8 examines what was achieved through the experiments and relies on the regular collection and reporting of data to verify change. Finally, the end of a project is a prime time to discuss lessons learned and insights for future work [26].

A3 thinking, and indeed all Lean tools, can be applied at any level of the organization. These include a small project contained in one clinic or an integrated health-care system [26]. Ideally, an organization commits to Lean and uses its philosophies and tools to transform the entire enterprise in what is called a Lean transformation. Lean goes beyond an improvement model since it often requires a culture change in an organization. As a result, there needs to be support from organizational leadership and buy-in from those who participate in the process [22].

The Lean process begins by identifying value streams, which are all of the actions, both value-creating and nonvalue-creating, required to bring a product or service from order to delivery within an organization [26]. Once a value stream is identified, a value stream analysis can help determine on which problems to focus first. The value stream analysis team is made up of leaders and frontline workers who are familiar with the work and can help guide the change that will come out of the analysis and is assisted by A3 thinking [26]. Procedurally, the value stream is first mapped to find waste and opportunities for improvement [26]. A future state value stream map is then created. The main deliverable from the value stream analysis is an improvement plan that will help achieve the future state [22]. This improvement plan includes simple actions to do immediately called "do its," Kaizen Events, and other projects [22].

The word "kaizen" means "change for the better" in Japanese; a Kaizen Event is generally a week-long event which brings together stakeholders, problem solvers, and frontline workers in a focused quality improvement event. Like a value stream event, Kaizens use A3 thinking and can be reported out on using an A3 Report [22]. Finally, standard work is a critical tool of Lean, and this is a written standard of what work is to be done by whom and under which circumstances. By laying out the work in a standard fashion, the workflow process is made transparent and can be studied in order to improve productivity. Standard work is posted publically in the work area, updated regularly, and audited frequently [22].

Six Sigma

Six Sigma is a process improvement strategy that was developed by Motorola in 1986 and focuses on eliminating defects and decreasing variability [29]. However, like Lean, its roots go back to the early days of manufacturing, and it builds on the work of quality control pioneers such as Walter Shewhart and W. Edwards Deming [30]. The term Six Sigma derives from the manufacturing industry's desire to reduce variability in products or processes to within six standard deviations of the mean (represented by σ) designating that their products are statistically 99.9997% free of defects. Six Sigma projects primarily use the DMAIC methodology: Define the system, Measure the process, Analyze the data, Improve the process, Control the future state [30]. DMAIC works by identifying defects in the system and using analytics and statistics to identify why they are occurring. Once defects are identified, the process can be redesigned to prevent them in the future. The control stage is essential for maintaining a zero-defect process through continuous monitoring.

Unlike Lean, Six Sigma creates a hierarchal structure that is dependent upon training and certification and is often designated by use of colored belts seen in martial arts. Black Belts and Green Belts, trained in statistical analysis and Six Sigma, manage projects throughout the organization. There are differences in the approaches and methodologies of Lean

and Six Sigma, but their principles and tools can be combined to reduce both waste and defects [31]. Six Sigma principles and methods have been applied to health care, including improving the delivery of preventive services [32] and diabetes care [33].

Practice Level Quality Improvement

As noted earlier, there are several quality improvement strategies, such as PDSA cycles, that can be used at the practice level. This may be illustrated by a primary care clinic that found only 55% of their patients had lipid surveillance for cardiovascular disease prevention and that approximately 68% of these patients were prescribed statins. An improvement team was assembled, agreed that this performance could be improved, and used an IHI framework to guide their quality improvement project. First, the team defined their problem (Aim) and chose a process measure (i.e., percentage of patients that received yearly lipid panels) as well as outcome measures (e.g., low-density lipoprotein (LDL), total cholesterol). In addition, they identified the data management approach that would be used to track their initiative. A first test of change within the PDSA cycle was to create and implement an automated system to remind clinical support staff that a patient was due for yearly cholesterol screening (Plan-Do). After implementation, the improvement team found that screening rates improved from 55% to 64% with the changes.

While this was a significant improvement, the team decided to build on their intervention by reviewing their experience and by using this information to inform and refine their activity (Study-Act). For the next PDSA cycle, the team generated a list of patients with diabetes mellitus who were due for cholesterol screening and involved front desk administrative staff. At patient check-in, administrative staff were asked to first direct the patient to the laboratory, where there was a standing order for drawing a lipid panel. After implementing this change in the workflow, the team found that screening rate went from 64% to 75%.

For the third PDSA cycle, the team provided ongoing data to administrative staff regarding their performance for the initiative (i.e., directing eligible patients to the lab). In addition, the team set a process measure of greater than 90% fidelity for directing patients to the lab and provided incentives, such as individual recognition and social events, such as a pizza party. Initially there was 94% fidelity to the process, and, remarkably, fidelity was sustained at nearly 90% for over 2 years after the incentives were discontinued. The workflow that screened patients at the start of the visit, allowed physicians to use that information to make decisions at the point of care regarding statins and other interventions. Over the same period, total cholesterol fell from 185 to 170 mg/dL. LDL fell from 99 to 81 mg/dL. Figure 35.3 is a run chart of total cholesterol and average lipids for the patient population.

System Level Quality Improvement and Transformation

Some hospitals and health-care systems have embarked on a process to transform their entire organizations in a way that is guided by quality and value across every aspect of the enterprise. Three health-care systems that have done this include Virginia Mason Medical Center, ThedaCare, and the Veterans Health Administration. All three systems have successfully lowered cost and improved the quality of care by changing how they approached quality improvement, putting quality at the center of all of their planning and operations, and creating central support and directives for quality [34, 35]. While each has had different approaches, all have demonstrated strong evidence for organizational-level transformation.

Approximately 20 years ago, Virginia Mason Medical Center (VM) was a 336-bed acute care hospital with multiple outpatient clinics around Seattle that was losing money in consecutive years. In light of the IOM reports noted earlier, it was clear that VM needed to transform as an organization if they were going to survive. In a drive towards patient-centeredness, the organization began to investigate different management frameworks that would help the organization transform into a patient-centered, high-quality organization. VM decided on Lean, as embodied in the Toyota Production System, and began sending leaders and staff to manufacturing plants in Japan and the United States to learn how to create value for the patient by eliminating waste [34–36].

Virginia Mason credits Lean with their ongoing success. For example, improvements that targeted reducing wasted, non-patient-focused activity of nursing staff were able to decrease wasted motion so that now 90% of a nurse's shift is focused on patient care [34]. Using Lean methods, the VM Kirkland Clinic was able to create a standardized diabetes care plan that resulted in 82% of diabetic patients having hemoglobin A1c levels of less than 8. VM not only improved care but was able to achieve positive margins every year since beginning their Lean journey [34]. Professional liability decreased 27% from 2007 to 2008 and then dropped an additional 12% [34]. Leadership and staff now teach their management and improvement methods via the Virginia Mason Institute [34].

ThedaCare is a health-care system in northeast Wisconsin made up of five hospitals and associated outpatient clinics that began their "Lean Journey" in 2003. In addition to ongoing QI projects, ThedaCare has changed the way they lead and manage by implementing a Lean Management System,

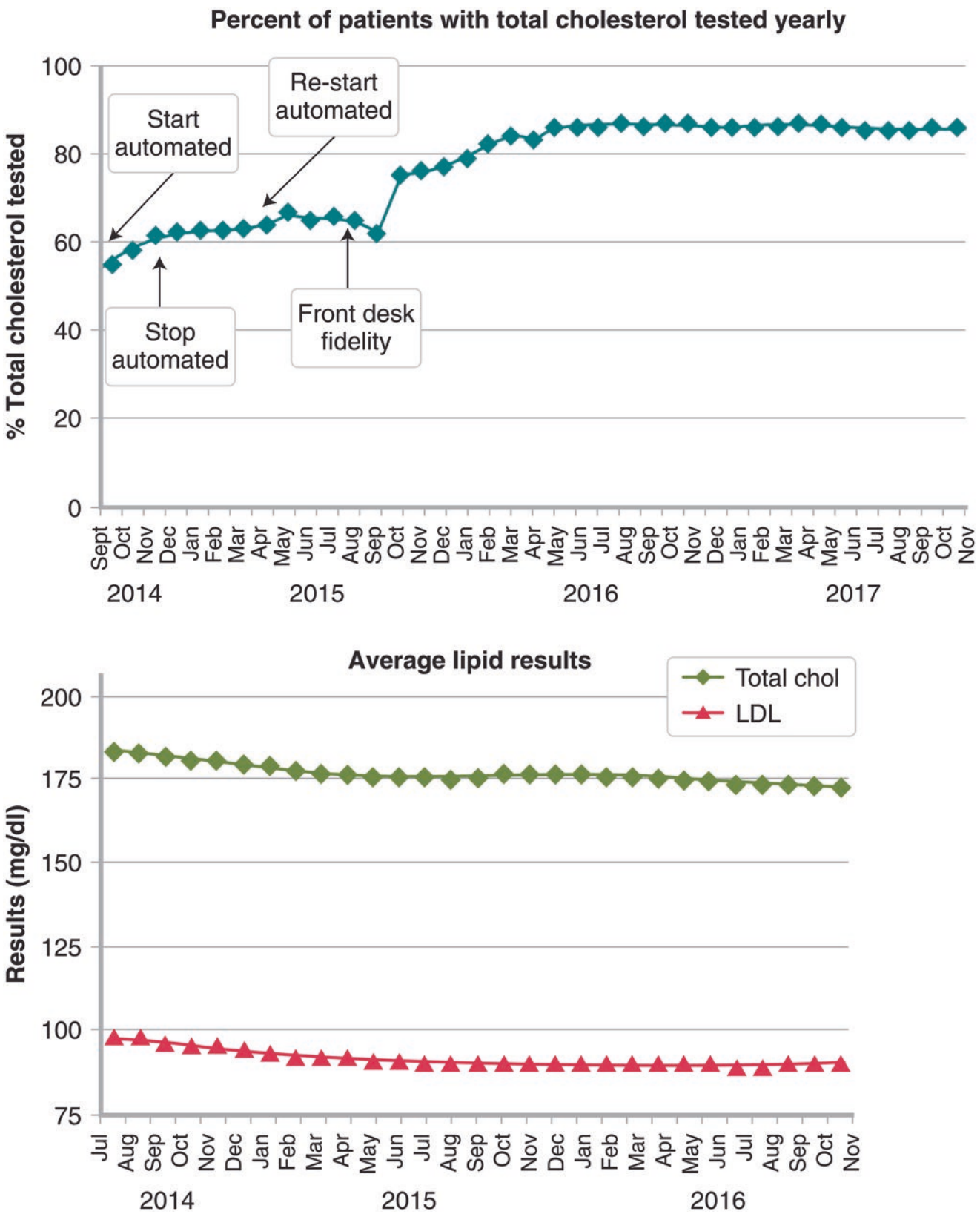

Fig. 35.3 Run charts of total cholesterol and lipids for a patient population

which they refer to as a Business Performance System or BPS [37]. Although there are limited evaluation studies of the ThedaCare experience, prior CEO John Toussaint points to Lean as the method by which the organization was able to decrease inpatient costs by 25%, improve patient satisfaction to 100%, and commit zero medication errors when a pharmacist was involved in medication reconciliation [35]. He also cites one area surgery center that was able to improve its non-operative time by 50%, when compared to the main surgery center [35]. From 2004 to 2009, their operating income doubled, and as of 2013, it has remained at or above 4% of revenue [38].

The Veterans Health Administration (VA) is another organization that strives to implement quality improvement at the enterprise level. In the mid-1990s, the VA was known for low-quality care and launched a major initiative at that time to reengineer how they delivered care by focusing on: outcomes, information technology, and integration of services [36]. In a short period of time, the VA was able to show marked improvement in multiple quality domains. For example, from 1994 to 2000, the pneumococcal and influenza vaccination rates among veterans more than doubled [36]. Colorectal screening rates doubled, and mammography and cervical screening rates improved by about 40% [36]. During that time frame, the quality of care for veterans for preventive services far exceeded the care provided to Medicare patients. For example, 90% of appropriate patients received a screening mammogram in the VA population while just 77% did in the Medicare population [36].

In addition to improving rates of preventive service screenings and indicated vaccinations, the VA was able to reduce medication errors through several interventions, most notably a bar code medication administration, which was implemented in 1995 and was spread throughout the system in 2000 [39]. Many other health-care systems have followed this lead. The VA also showed marked improvements in surgical outcomes by tracking outcomes and through performance self-assessment tools, structured site visits, and dissemination of best practices. Thirty-day postoperative mortality was decreased by 27% and 30-day postoperative morbidity by 45% [40]. This surgical quality program, known as the National Surgical Quality Improvement Program, is now a national program that extends outside of the VA network [40].

Change Management

Change comes with quality improvement, which can be challenging for both individuals leading and following change and for organizations. Because every improvement is a change, it is important to not only create a change but to sustain the change over time. Change management is the process of creating change and sustaining it within an organization, and the Kotter model is an empirically based approach to understanding and guiding change management [41]. The following section reviews the model, which is a useful paradigm for creating and sustaining change.

There are eight steps of change management in the model, which are sequenced to improve performance. The first step is establishing a sense of urgency or creating a "burning platform" that clearly identifies crises, potential crises, or major opportunities within the organization [41]. To achieve this feeling state, a majority of stakeholders need to realize that the status quo is more threatening than change. The second step is building a guiding coalition, which is done by establishing a group that has a shared commitment, the power and energy to lead and support a collaborative change effort [41]. While a movement for transformation can start with just one or two people, it must achieve a sufficient mass early on in order to be successful. Any effort to change can fail if it is simply a grouping of projects and directives, which highlights the third step; there must be an overarching vision that is compelling, clear, and simple enough to communicate in 5 min [41, 42].

According to Kotter's research, organizations attempting to transform often under-communicate by a factor of 10, and step 4 communicates the vision at every opportunity. Rather than communicate the vision at a few big meetings and via a few communiques, the vision should be embedded into all communication methods, from business trainings to yearly reviews to company newsletters. Once the vision is communicated, others should be empowered to act on the vision, which can encourage risk taking and nontraditional ideas. In this step, systems or processes that undermine the vision must be changed, and any barriers, be they systems, departments, or people, must be removed [41]. The organization must demonstrate successes in the first 12–24 months in order to build momentum, and step 6 plans for, and creates, short-term wins. Because success does not simply occur, these short-term wins must be actively planned for and achieved, and participants who carry out these wins should be rewarded and celebrated publicly [41].

Once change momentum has started to accelerate, improvements should be consolidated and additional change demonstrated (step 7). It is important not to declare victory too soon, ensuring these short-term wins are seen as only that and not as a final victory, lest the organization celebrates too early and retreats from the change process [41]. As performance increases, it is important to institutionalize the new approaches and communicate that the change is due to the transformation (step 8) [41]. These changes must be rooted in the culture of the organization. As management turns over, successors must be champions of the transformation [41].

Data Management

Data management is an integral part of all quality endeavors. Globally, data are collected to determine a baseline level of performance and identify possible root causes of underperformance and then analyzed and interpreted to decide on the best course of action. The data are then remeasured in order to ensure that a change results in sustained improvement over time [43]. There are several key processes to effective data management.

Collecting Data

A data collecting method should be mapped out in advance of quality improvement initiatives: what will be collected, how often, and by whom. The plan should include the operational definition of each measure, including the numerator, the denominator, and any exclusions to each measure [43]. In considering the QI program from the primary care clinic that was described earlier, the team focused on what percent of patients had their cholesterol tested. Cholesterol levels are not routinely tested in all patients, and the operational definition used for the QI program is listed in Table 35.4.

These data were collected weekly. The QI team did not have access to an electronic medical record that had the capacity to collect, aggregate, and report this data from the system automatically. Chart audits, using manual data collection, were required and employed a sampling methodology, such as auditing 30 randomly chosen charts per week and using those data to estimate overall performance [43].

Tracking Data

Once measures have been identified and defined, they must be tracked, and the frequency of tracking data varies depending on the project scope and systems and processes that are actively being modified. After the conclusion of a project, data can be monitored less frequently in order to determine if the change has been sustained and performance is stable [43]. Performance data should be shared with the whole organizational unit [43] and are commonly displayed as run charts (see Fig. 35.3) or control charts. Similar to run charts, control charts include "control limits" which are mathematically defined, typically a fixed number of standard deviations from the mean [43]. Data points that fall outside of the control limits signify changes that are far enough from the mean that they cannot be explained by the natural variation of a process. Control charts are commonly used in Six Sigma organizations and teams, and it is this statistical control where the name Six Sigma is derived from [30]. Other graphs such as pie charts and histograms are also useful [43]. Dashboards are data displays that show multiple performance graphs at a glance. For example, diabetes dashboard may include two to six different performance graphs [43].

Table 35.4 Data elements and operational definition for cholesterol QI program

Data element	Operational definition
Denominator	Patients greater than or equal to 18 years of age who were seen at the practice for an office visit in the last 18 months
Numerator	Patients in the denominator whose total cholesterol was tested within the last 365 days of their appointment. This test must have been performed in office, or if performed elsewhere results must be documented in the chart noting date performed
Denominator exclusion	Patients who are receiving only palliative care, as indicated by an applicable diagnosis code on the problem list

Analyzing and Interpreting Data

The processes of analyzing and interpreting data are critical in reviewing performance to determine whether goals are being achieved. Interpreting data seeks to draw meaningful conclusions that can also be used to evaluate and improve activities, identify gaps, and plan improvement [43]. Returning to earlier example of cholesterol screening, annotations on the run chart in Fig. 35.3 such as "front desk fidelity" were noted at specific time points and allowed the QI group to visually track the impact of the intervention and to help plan future changes [43]. Benchmarking, or comparing results to external references, is another approach to interpreting data, and there are many organizations that can be used for this purpose [43].

Acting on Data

The analyzed data allows the study team to engage in the Act phase of the Plan-Do-Study-Act cycle. If the project is going well and has demonstrated improvement and sustainability, it may be time to determine how to spread insights to other parts of the health-care system or to work on other metrics within the same organizational unit [43]. If the analyzed data show that progress has been insufficient, steps and course corrections can be taken to remediate the situation. In addition, the team would also look to ensure that data are being collected accurately, reanalyze their interpretation to determine if they are addressing the right root causes, reevaluate their changes to ensure they are being implemented consistently, or increase the rate at which they are making changes [43].

Disseminating Data

Data can be shared and disseminated in many forms and modes: in graphs and charts; in newsletters, emails, on bulletin boards; and in other communiques. Increasingly, data can also be presented as a digital "dashboard" (e.g., a Microsoft Excel file or charts integrated into the EMR). Dashboards are visual displays of multiple charts showing changes over time, comparisons between different entities, or progress toward a goal. This tool can track and report data at several levels, such as practice level or provider level. Figure 35.4 is an example of a provider dashboard for diabetes care.

At the organization or practice level, all metrics that are important to the organization should be displayed on a continuing basis. Some candidate measures include on-time clinic starts, operating revenue, and the percent of patients who received indicated preventative services. Data, however, can become overwhelming, and organizations can lose focus on their vision and strategy if changes in metrics repeatedly lead to immediate action. As a result, some organizations have defined core metrics that are most critical to their mission. These "True North Metrics" are vetted and ultimately approved and promoted by the leadership of the respective unit [23].

ThedaCare, for example, uses metrics, such as employee safety, to align their strategic process and determine focal areas of improvement [44]. Other organizations may use a balanced scorecard, which shows a variety of performance data, tied to strategic initiatives. Metrics that are important to their current strategy, for which managers must have an action plan when poor performance is evident, are called "Drive Metrics." Metrics that are being tracked but do not warrant immediate action despite falling performance are

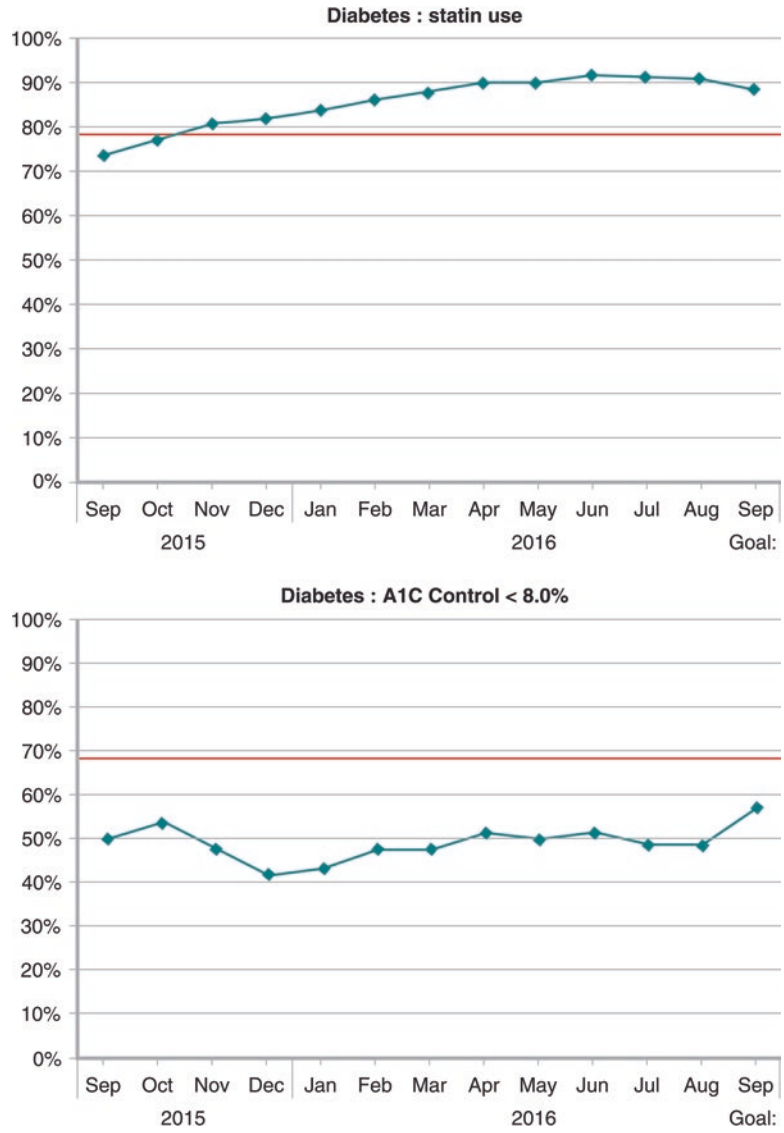

Fig. 35.4 Provider dashboard for diabetes care

called "Watch Metrics." When an organization creates a hierarchy of performance indicators, it can help the organization maintain focus.

Future Directions

Contemporary and future physicians will be expected to not only provide quality care, but will also be engaged in continuous quality improvement (QI). The increased emphasis on quality is already seen in the national initiatives discussed at the beginning of the chapter. Physicians in practice can expect that the quality metrics of their patient panel will be publically available and that their incentive plans will also be tied to these quality outcomes. Ingraining this in future physicians is evident in the quality improvement curricula that have become part of medical education [45]. Physician leader positions will be expected to have mastery in QI language, strategies, and tools to help their patients and their organizations achieve better outcomes.

QI will also increasingly involve patients, since they must be actively engaged in their care in order to achieve healthcare goals. In addition to traditional methods of patient engagement, some organizations provide patients with a "report card" of their health, identifying the health maintenance services that need to be completed. On an organizational level, practices, hospitals, and health-care systems are involving patients directly in the quality improvement process. Many organizations, for example, have created patient advisory councils or comparable structures to solicit patient input in clinical operations [46]. These patients, and other engaged stakeholders, can also serve on QI teams, providing invaluable input into how to create patient-centered processes.

Health care continues to move away from production-based to value-based models of reimbursement for services in order to decrease cost and increase quality [47]. While these models will continue to evolve, organizations will continue to grapple with understanding and defining value, achieving value-based outcomes, and successfully reporting these data for reimbursement [48, 49].

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Part V

Social and Environmental Determinants of Chronic Disease

Social Determinants of Health

36

Robert L. Ferrer

Introduction

Human health is socially produced. This reality is illustrated by the 33-year difference in life expectancy between Japan and Sierra Leone, which is not attributable to innate differences in human biology, but rather to the effects of economic, social, and political forces. Those same forces can also account for a 19-year difference in male life expectancy across counties in the United States [1] and the 15-year gaps across ZIP (postal) codes in San Antonio, Texas.

Evidence that health is socially stratified dates back across millennia, a narrative that comes alive in ancient gravesites, where skeletons with taller stature and better bone health lie alongside artifacts suggesting an elite station in life. Ancient civilizations were aware that social status was linked with longer life, [2] but scientific exploration of such disparities took hold when public health took up more empiric inquiry in the seventeenth century. Pioneers such as John Graunt, Edwin Chadwick, and Friedrich Engels in England, Rudolf Virchow in Germany, [3] and Louis-René Villermé in Paris began to unpack the associations between living conditions and mortality rates, observing higher mortality among the less affluent [4–6]. Most of the deaths they tabulated were due to infectious disease. Yet in the epidemiologic transition from infectious to chronic disease that followed – in 1999, for the first time, infectious diseases were no longer the most common cause of death in the world [7] – the role of social factors in shaping health and illness did not diminish but continue in importance to this day.

The organization of society has enduring effects on health and illness, and our social groupings and larger human populations reflect the social, cultural, and physical environments that we inhabit [8]. Fundamentally, social determinants of health are a system of ideas for describing how health is socially patterned, exploring causal pathways between social conditions and human health and illness. Figure 36.1 is a framework that displays how "upstream" social determinants at the institutional level contribute to "downstream" health effects, such as health-risk behavior, morbidity, and mortality.

Beyond understanding mechanisms, a principal motivation for documenting and explaining inequalities in health status is identifying factors that can be alleviated or prevented. In clinical practice and in social services, this means mitigating the effects of social determinants on individuals; in public health and policy, it means creating societies in which opportunities to flourish are widely shared. The most important – and contentious – discussions in these analyses concern accountability and agency.

This chapter presents an introduction to social determinants of health. The first section provides an orientation to this field and defines key terms and related concepts. The next section situates social determinants within the context of chronic illness and highlights many research findings. An overview of several conceptual and theoretical frameworks is described in the subsequent section, and this content area is followed by practical approaches to address social determinants. The subsequent section introduces a capability approach to social determinants before the chapter closes with future direction in the field.

Understanding Social Determinants of Health

Social determinants of health fundamentally seek to describe and explain the social patterning and social causation of illness [9]. Most studies of social patterning have applied a traditional epidemiological framework, treating social risk factors as exposures similar to other hazards [10]. Social risk factors can include person-level attributes, such as sex and

R.L. Ferrer (✉)
Department of Family and Community Medicine,
UT Health San Antonio, San Antonio, TX, USA
e-mail: FerrerR@uthscsa.edu

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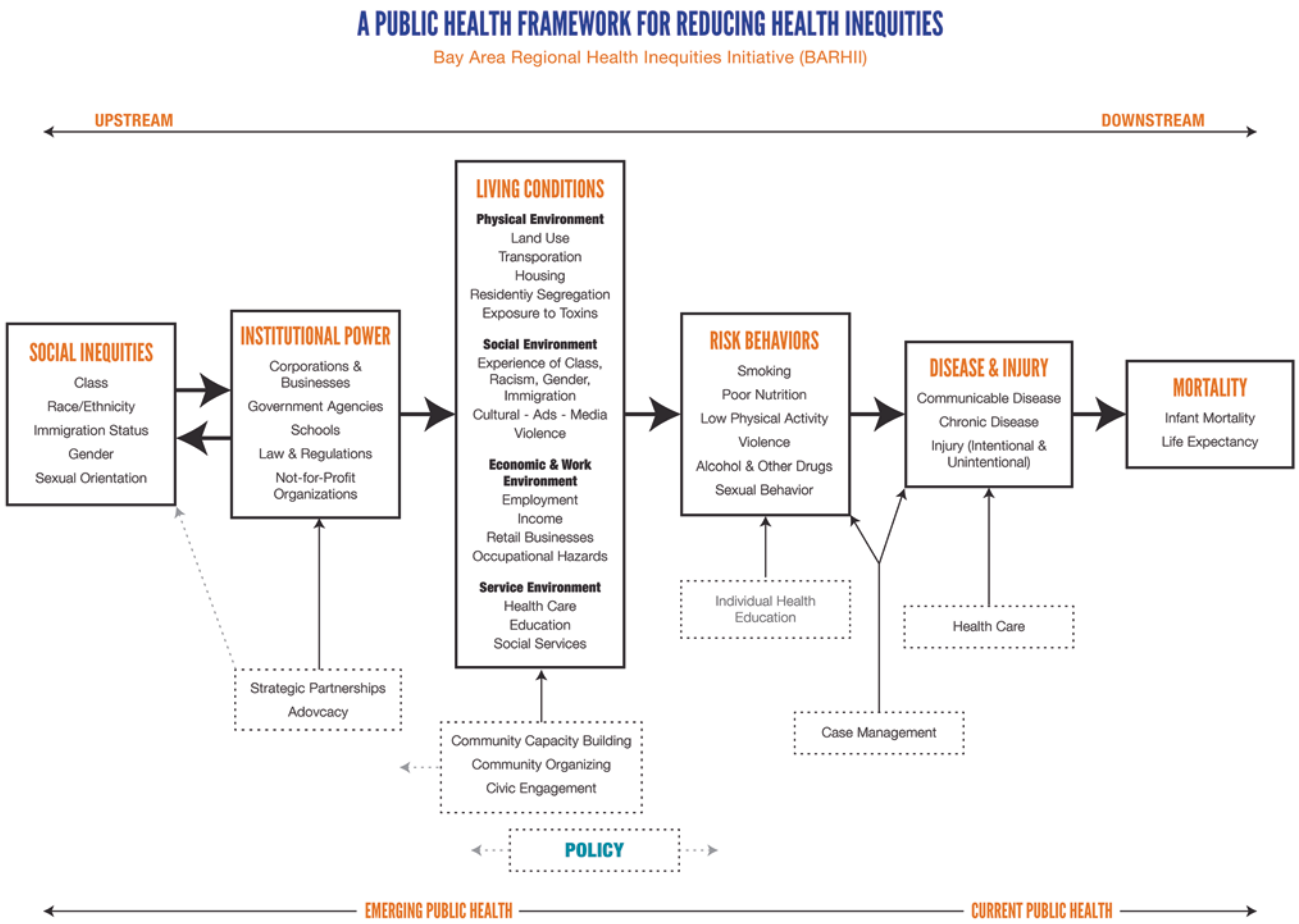

Fig. 36.1 A framework for social determinants of health (Source: Bay Area Regional Health Inequalities Initiative. http://barhii.org/framework/ Accessed 8 April 2017)

gender identification, race and ethnicity, income and wealth, and educational attainment. These attributes determine an individual's position in hierarchies of power, social status, and economic resources.

A second focal area is on the circumstances in which people live. These circumstances include the availability of healthy food and adequate housing, effective public education, community safety, safe employment that pays a living wage, infrastructure for physical activity, diverse transportation options, social and cultural norms for healthy living, social policy that mitigates health or employment shocks, political inclusion, and many others. These community–level influences are often the product of directed policy decisions shaped by deliberations about the role of government in supporting health and well-being, stakeholders' political power, and public financing decisions. Although altering these root social causes of poor health is potentially more impactful than mitigating their effects on individuals, addressing root social causes introduces ethical quandaries about what a community or society ought to do in the face of competing interests. Such deliberations might include, for example, how to balance the free operation of markets with the distribution of products like tobacco and alcohol that harm many users.

Social determinants raise complex, multilayered questions that span disciplinary boundaries including molecular biology, physiology, psychology, sociology, economics, and political science. Combining perspectives from multiple disciplines is necessary to explain paradoxes, such as why the poor spend more than the wealthy on health-harming products such as cigarettes [11] or make less use of health-protecting resources such as seat belts [12] even when there is no monetary cost. Although chronic diseases such as cancer and heart disease were once considered diseases of affluence, the highest rates of these maladies are observed in the poorest nations and in the poorest inhabitants of wealthy nations. Once a nation surpasses the annual income threshold of USD $1000 per capita, chronic diseases surpass infections as the leading causes of death [13]. Overall mortality rates do not paint a full picture, so it may be more illustrative to note that about half of chronic disease deaths worldwide occur before age 70 [14].

There are many definitions of social determinants. The one in widest use was created by the World Health Organization in 2008 [15]: "The conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels." Table 36.1 defines key concepts that are related to social determinants of health.

An essential understanding about the concept of socioeconomic status (SES) is that there is no single underlying "SES" attribute that its indicators measure. Instead, each SES measure has a more precise application in specific circumstances, depending on whether financial resources, knowledge, or social networks offer the most explanatory power for a specific health problem [20]. Terms such as "inequality," "disparity," and "inequity" have different implications when assigning responsibility for unequal outcomes. "Inequality" and "disparity" are often used to document differences in outcomes across social risk factors without reference to who or what is generating the differences. A close reading of US government reports on population health, for example, suggests that their authors adopted "disparities" as a neutral word that referred to between-group differences, without assigning responsibility for the differences or even framing the question. Inequities, or the structural forces that created them, received little attention in the reports [21].

Table 36.1 Key concepts linked to social determinants of health

Concept	Definition
Social determinants of health	The conditions in which people are born, grow, live, work, and age. These circumstances are shaped by the distribution of money, power, and resources at global, national, and local levels [15]
Health inequality	Differences in health outcomes among defined groups, without a judgment about their fairness
Health inequity	Avoidable, unnecessary, and unjust differences in health outcomes among defined groups [16]
Health disparity	Usually a synonym for health inequality; occasionally for health inequity
Social justice	Ethical reasoning about the political processes and structures that govern the distribution of benefits and burdens in society
Social capital	Social networks and their shared norms, values, and understandings that enable cooperation within or among groups [17]
Social risk factors	Person-level attributes that place people in socially defined hierarchies. These attributes include race and ethnicity, sex, gender identification, level of education, income and wealth, and occupation
Socioeconomic status (SES)	Measured by education, occupation, or income/wealth
Socioeconomic position (SEP)	Concept of where people stand in relation to one other in social stratification hierarchies
Social class	A tiered structure of economic, social, and cultural power, controlling economically relevant assets, authority, or social relationships [18]
Social epidemiology	The branch of epidemiology that studies the social distribution and social causation of health and illness
Population health	The health outcomes for a defined group, including how outcomes are distributed within the group (Kindig:2003br)
Discrimination	Adverse judgments or actions taken against people outside one's social group
Structural racism	Racial inequities normalized in the routine operation of economic, social, or political systems [19]

At the population level, epidemiology's prevailing questions and methods have evolved over the past two centuries to keep step with the changing paradigms of disease causation. Originally concerned with the social causation of illness, epidemiology shifted its focus to individual-level risk factors for disease during the latter half of the twentieth century [22]. Even the largest, most rigorous investigations, such as the Framingham Heart Study, explained only about half the variation in cardiovascular risk from person to person. Recognizing the limitations of an overly individualistic approach, more socially oriented epidemiologists pushed epidemiology to expand its scope, and Geoffrey Rose articulated the most coherent and powerful account of disease causation.

Rose emphasized three key principles for population health [23]. First, determinants of population rates of disease are distinguished from the determinants of individual risks of disease. For example, "why do some individuals suffer from x?" is a different question than "why do some populations have a high prevalence of x?" Genetic variability tends to account for individual cases within defined populations, where people tend to share similar environmental exposures, including social and cultural forces. Variations in disease prevalence between populations are created by differing social and behavioral exposures. For example, diet explains little variation in cholesterol levels within a population, since basic dietary patterns are shared with minor differences, but much of the variation between populations, due to major differences in dietary norms.

Cross-national comparisons highlight the striking variation in the prevalence of different diseases [24]. The major causes of death in industrialized societies can vary dramatically across different populations, and such marked differences far exceed known genetic variation [25]. These variations across countries have been attributed to differences in behavior and environmental exposures and can be illustrated by the low incidence of heart disease in Asian societies with little intake of dairy products or fatty meats [26]. The distinction between individual and population health is also supported by studies describing the phenomenon

that when people emigrate from their country of origin, they eventually assume specific disease risks that are prevalent in their new domicile [27].

A second principle in population health is that almost all exposures and diseases in populations exist as a continuum, rather than a dichotomy. Japan and Finland, for example, differ not only in the prevalence of high cholesterol but also in the distribution of dyslipidemia across their respective populations, which is lower in Japan than it is in Finland [23]. This principle recognizes that entire risk factor distributions can shift over time, such as the bell curve of US body mass index during the years of the obesity epidemic [28]. When considering interventions, population prevention is most powerful when it shifts the risk distribution of entire populations.

The final principle is that moderate risk applied to a large number of people generates a greater absolute number of cases than a high risk applied to a small number of people. For instance, the many people in Western societies with average cholesterol levels account for more cases of coronary heart disease than those with very high cholesterol levels [23]. Rose's alternative to the "high-risk" strategy was a "population" strategy that targets population-wide behavioral shifts. In this way of thinking, small shifts in the population distribution of a risk factor, such as body weight or blood pressure, would sharply reduce the number of people at high risk. By changing population norms rather than asking individuals to do what is not "normal" in their society, a population strategy can be behaviorally more actionable.

Social Determinants and Chronic Disease

The relationship between social determinants and chronic disease is well established. To begin, at the population level, higher per capita income is associated with better health, and this linkage is robust across many health indicators, including life expectancy, chronic disease burden, and self-rated health status [29]. The association between health and per capita income is evident at multiple levels of observation, from neighborhoods to regional and global levels of analyses. Life expectancy and other health status indicators also correlate with educational attainment, occupational status, and social class [30]. Within countries, the relationship is curvilinear, so that life expectancy gains are steepest as income rises from the lowest levels and gradually level off, but the effects do not disappear at the highest income levels.

Chronic disease incidence and mortality are higher among the least affluent residents of wealthy nations [13]. Across countries, life expectancy rises steeply as per capita income increases until annual per capita income reaches about $30,000 USD, after which the curve flattens. In less affluent countries, mortality due to chronic disease occurs at higher rates [14]. The strength of the relationship between social position and chronic disease burden can differ markedly from country to country [31]. Chronic illness in middle age substantially raises the risk of disability, [32] producing personal and family consequences. This point is critical at the public health and policy level because disability reduces earnings and diminishes access to employment-based health insurance, potentiating risks for the disabled [33, 34], and triggering a cascade that contributes to interpersonal and intergenerational transmission of social class gradients in health [35, 36].

Figure 36.2 displays the relationship between functional status and age, education level, and chronic disease that is derived from 1997 to 2006 National Health Interview Survey data among 221,195 adults aged 25–64.

In this analysis, functional limitation was defined as severely limited ability to stand, walk, climb steps, stoop, reach, or grasp, and chronic disease was identified by self-report of coronary disease, stroke, diabetes mellitus, chronic obstructive lung disease, or cancer. The figure highlights that disability is strongly predicted at every age by the presence of at least one of the five chronic diseases (adjusted OR 3.73 (95% CI 3.59–3.76)).

The relationship between income inequality and health outcomes is more mixed and nuanced. There is heightened interest in the health effects of income inequality – the unequal distribution of income across a population – given the progressive growth in inequality over the last three decades. For example, from 1942 to 1982, the share of income going to the top decile of American earners never exceeded 35%. In subsequent years, the top decile's share has climbed steeply, passing 50% in 2012, and most of those gains went to the top 1% of earners [37].

A 1992 landmark study looked at nine developed countries and reported a significant association between life expectancy and the percentage of income (i.e., income inequality) going to the least wealthy 70% of families [38]. This study has launched descriptive and explanatory studies on income inequality and health, as well as substantial disagreement about the whether the effect is real or confounded by other variables. There are four plausible explanations to account for relationship between income inequality and health. The first points to the steep rise in life expectancy as income increases from the lowest levels, which then levels off as the top incomes are reached. As a result, when the poor earn a greater share of the wealth, their lives are lengthened to a greater degree than the lives of the wealthy are shortened when they earn a smaller share of wealth. The result is a net increase in population life expectancy.

A second explanation is that larger income gaps make the less affluent feel more deprived. Deprivation creates psychological stress that may trigger maladaptive coping mechanisms, such as spending beyond one's means to keep

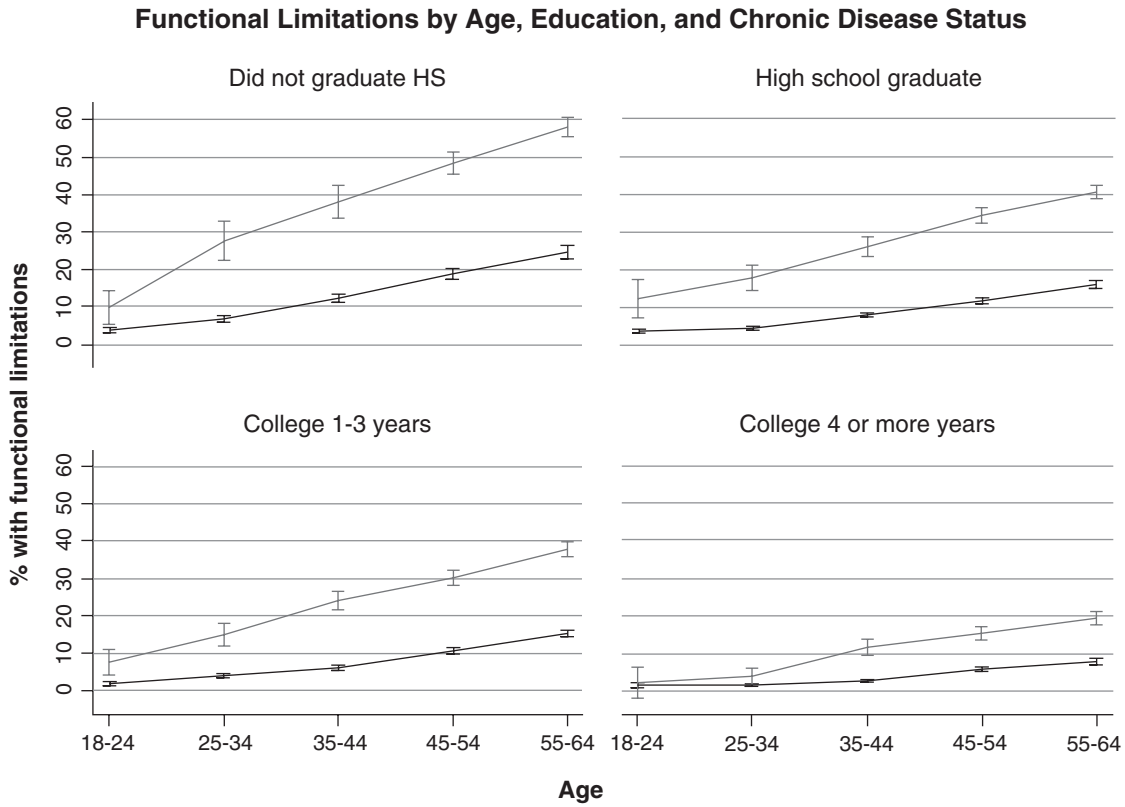

Fig. 36.2 Functional status and age, education level, and chronic disease. (Adapted from [37])

pace with social norms. Third, societies with greater income inequality underinvest in human capital, including education, income support, health care, housing, and other critical areas [39]. Underinvestment occurs because income inequality leads to political inequality. A final explanation contends that income inequality creates a negative society-wide effect on both rich and poor, metaphorically characterized as social "pollution" that erodes health for everyone; more unequal societies are less cohesive societies [40].

Race and ethnicity are additional powerful social determinants. Major disparities in mortality by race and ethnicity in the United States appear by middle age, with most of the excess deaths accounted for by common chronic diseases [41]. Income is a major contributor to the disparities, but measured income does not have the same meaning among African Americans as it does in non-Hispanic Whites, since at any given income, African Americans' accumulated wealth is substantially lower [42]. In addition, the link between income and residential environment differs markedly for African Americans. While the great majority of poor non-Hispanic Whites live in neighborhoods with low poverty levels, less than 20% of African Americans live in these areas. Conversely, only 10% of poor non-Hispanic Whites live in extreme poverty areas, while the proportion is 50% for African Americans [43].

Even as race, class, and income are entangled, racial and ethnic minorities are subject to the additional burdens of discrimination and institutional racism. The degree of residential segregation is tied less to purchasing power than historical patterns of discrimination and institutional racism in residential opportunities. Racism negatively affects many other health determinants, including inequities in access to education, employment opportunity, and risk of incarceration.

The direction of racial/ethnic disparities sometimes differs by indicator, and this is illustrated in Fig. 36.3.

The figure shows that Hispanic men lose fewer years of life to respiratory disease than non-Hispanic Whites, whereas Hispanic men lose more years to liver disease. These differences are attributed to prevalence of health behaviors such as smoking and alcohol consumption [44]. Hispanics also have lower prevalence of multiple chronic conditions than non-Hispanic Blacks or Whites. More broadly, the all-cause Hispanic mortality advantage is especially prominent for Hispanics born outside the United States, with a smaller effect observable among those born in the United States. There are several theoretical frameworks and conceptual models that can cast light on the mechanisms underlying social determinants of health.

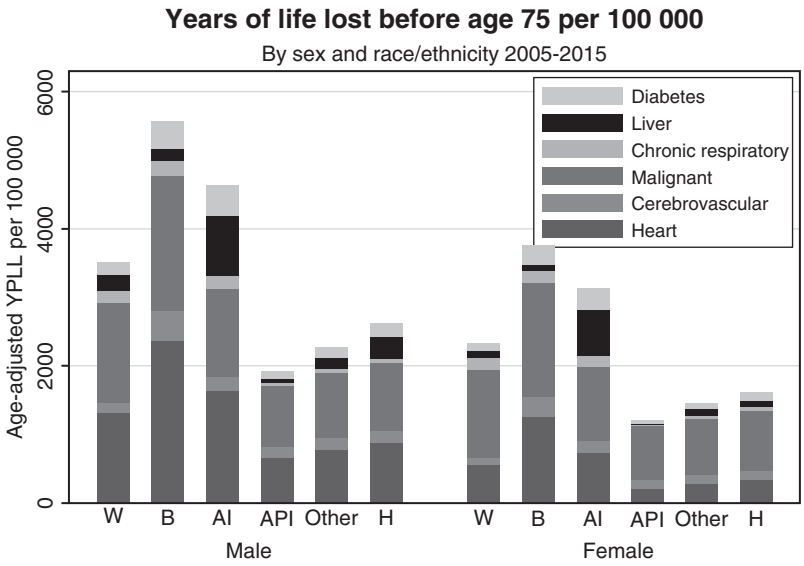

Fig. 36.3 Sex, race/ethnicity, and years of life lost before age 75 (Source: Centers for Disease Control and Prevention https://webappa.cdc.gov/sasweb/ncipc/ypll10.html. Accessed January 15, 2017

Conceptual and Theoretical Frameworks

Biomedical Framework

Biomedical frameworks explain how adaptations to socially derived stress activate pathophysiological pathways in neurological, immunological, endocrine, and cardiovascular systems. How social stress and disordered physiology give rise to chronic disease is increasingly understood in both animal models and humans. A chain of events beginning in utero creates long-term consequences for dysregulation in multiple physiological systems [45]. Large population cohort studies provide evidence for the fetal programming hypothesis. In this model, infants with low birth weight have a higher risk of cardio-metabolic disease as adults, including coronary heart disease and diabetes [46, 47], and the effects are hypothesized to occur through epigenetic changes created by maternal undernutrition or other stressors [48]. These changes give rise to a "thrifty phenotype" characterized by insulin resistance, which predisposes to obesity when food is readily available. Early life effects are also evident in the positive associations between achieved height, cognitive test scores, and later occupational attainment [49].

Childhood experiences exert a powerful effect on risk of chronic disease [50]. Critical periods in brain development and its subsequent regulation of endocrine, cardiovascular, and immunological pathways portend that adverse child experiences cast long shadows into adulthood [51]. Longitudinal studies following a Dutch famine have documented lower birth weight in the grandchildren of women born during the famine [52]. Laboratory experiments with primates demonstrate similar sequelae of adverse rearing conditions [53, 54]. Whether in childhood or later in adult life, repetitive psychosocial stress is distributed along a social gradient [55]. This theory posits that social stratification results in a hierarchy of "life chances," the unequal distribution of opportunities in residential areas, housing quality, employment, finances, leisure time, access to medical care, and exposure to discrimination and crime. Social stratification emphasizes that economic wealth is not the sole determinant of life chances and that there are other political and social processes at play.

Evidence for the life chances theory has accumulated in several decades of sociological studies. Social gradients in stressful circumstances are measured by the number of adverse life events, but even stronger evidence exists for the gradient in chronic strains [56]. Strains result from the mismatch between what one has been socialized to expect (e.g., a good job, happy family life] and one's actual experiences [57]. This sociological perspective points to the naturalistic origins of stress arising out of ordinary life pursuits, as opposed to abnormal responses to unusual circumstances [58]. Stress is universal but it is also unevenly distributed.

The consequences of stress can be operationalized as allostatic load. Allostasis refers to the maintenance of stability through change, whereby an organism adapts its physiology to external or internal circumstances in order to protect essential physiological systems [59]. When encountering a dangerous situation, for example, it is advantageous to rapidly increase pulse and blood pressure to fuel the muscles needed to flee. The external to internal link is provided by the brain, which perceives the threat and, through both neurological and chemical pathways, sets in motion both the act of running and the changes in the physiological environment that sustain physical activity.

Allostatic changes in physiology promote resilience – survival in response to acute danger – at the expense of stability. Unfortunately, human resilience mechanisms did not

evolve in response to the stresses of a modern society, such as financial setbacks or stressful jobs that offer little control. These life events tend to be frequent, repetitive over long timeframes, and differentially distributed by social position [60]. Evidence for allostatic stress responses is strong in both humans and other animals living in social hierarchies [61, 62]. Health consequences of allostatic load include cardiovascular disease, cognitive impairment, and all-cause mortality [62].

Lifestyle Framework

A lifestyle framework focuses on unhealthy behaviors and acknowledges the direct and powerful effects of behaviors on chronic disease risk. About 80% of chronic disease is linked to several unhealthy behaviors: tobacco use, inadequate physical activity, unhealthy diet, and risky patterns of alcohol usage [63]. All four behaviors display social patterning, with more smoking, less physical activity, and less healthy diet reported among socially disadvantaged groups, [64] while any binge drinking is more common among higher status individuals, although the frequency and intensity of binging is less [65].

Health behaviors do not arise in a vacuum but are influenced by social norms and the availability, convenience, and price of products and services that promote or erode opportunities for health. In turn, markets are governed by policy and regulations enacted through a political and legislative process. These larger forces are illustrated by the wide distribution and marketing of tobacco products, social norms encouraging smoking, government subsidies for tobacco growers, and international trade agreements, cumulative factors that resulted in the deaths of 100 million people in the twentieth century [66, 67]. More recently, tobacco use has diminished in countries that enacted laws restricting smoking in public venues, imposed taxes, and mandated prominent product warnings. Evolving social norms, especially among the more educated, have discouraged smoking. Cigarette manufacturers' organized effort to suppress scientific findings on their products' harms has also come to light.

Food production and marketing are subject to many of the same forces as tobacco, with unhealthy products widely distributed and aggressively marketed [68] especially to low-income consumers. In addition, economic analyses document how food consumption has increased as the time-cost of food preparation has decreased, with fewer meals made at home and more restaurant meals and ready-made foods consumed [69].

The influence of these larger economic and policy forces tempers targeting individual choice as a chief determinant of health behaviors. Approximately 3% of the US population maintains four primary healthy behaviors – nonsmoking, healthy diet, adequate physical activity, and normal BMI [70] – and only 16% meet three of those four criteria. As such, focusing solely on individual behaviors without accounting for more widespread structural drivers is unlikely to succeed.

Fundamental Social Causes

Fundamental social causes theory, formulated by Link and Phelan [33], accounts for the observation that socioeconomic status continues to powerfully influence health, even as diverse societies evolve over time with major changes in the prevailing causes of morbidity and mortality. The socioeconomic status (SES) effect on health endures because higher status bestows advantages including money, knowledge, prestige, power, and beneficial social connections that protect health regardless of the prevalent mechanisms that can compromise health at any given time [74]. Those who have these advantages have reduced exposure to known risks, while those with low SES have much less control over their risk exposures.

This theory would predict that social gradients should appear only when there are effective interventions to reduce or eliminate a health risk [75]. For example, there was a widened disparity in rates of sudden infant death syndrome following a campaign to educate parents that putting babies to sleep on their backs lowered risk of SIDS [76]. Fundamental social causes theory has two main limitations. First, it does not illuminate actionable pathways to mitigate social determinants' impact on specific illnesses. Also, while it highlights the cluster of individual circumstances that shape risk exposures, it does not address what gives rise to those circumstances.

Public Policy Influences

Many circumstances of everyday life are ultimately shaped by policy decisions in areas such as education, poverty reduction, housing, protections against discrimination, labor laws, occupational safety, transportation networks, public health and health care spending, environmental protection, agricultural policy, and voting rights [77]. As the preceding sections have shown, these sectors all have health implications, and policies responsive to the needs of citizens across the spectrum of SES are therefore a key determinant of outcomes. A study analyzed a data set comprising 1779 public opinion surveys on pending congressional votes between 1981 and 2002 [78], disaggregated respondents by income level, and compared their preferences with the legislative outcome. The study's conclusion was that legislators' votes strongly align with the preferences of the highest income

Americans, but are virtually unconnected to the preferences of poor or middle income Americans. Another report that examined both the United States and other high-income European and Asian countries reached similar conclusions [79, 80].

Social Ecological Models

Studying the interaction between organisms and their environment defines the field of ecology; when applied to human health, the approach is known as eco-epidemiology or ecosocial theory [8]. This set of theories considers influences from natural and man-made ecosystems, including infectious agents, agriculture, urbanization, technological developments, economic systems, and climate [81]. Ecological understanding requires careful attention to history and context. For example, the association of obesity with higher SES in low-income countries reverses as affluence increases [82]. The monetary and time costs of food and its preparation fall for everyone, making calories more available even as the need for manual labor decreases. Norms for healthier diet and leaner body shape evolve more quickly among the affluent, who more quickly become knowledgeable about the risks of obesity.

Central to social-ecologic models is their use of complexity science, an umbrella term for scientific approaches to study how a system's behavior emerges from the interactions of its parts. When the parts are autonomous and adaptive, systems are subject to nonlinear, unpredictable behavior such as epidemics and tipping points. Social environment strongly influences individuals, but human activity creates the social environment [83]. For example, social norms on tolerating secondhand smoke influence individuals' decision about when and where to smoke, which in turn, shape evolving social norms.

Addressing Social Determinants

A 2010 WHO report on the social determinants of health identified four leverage points for action [87]: (1) intervene in the health-care system to reduce consequences of illness among disadvantaged people, (2) reduce the vulnerability of disadvantaged people to health-damaging factors, (3) decrease exposure to health-damaging factors associated with lower socioeconomic position, and (4) decrease social stratification.

Health-Care System Interventions

The notion that health care should take on social determinants is a rediscovery of past initiatives. Sydney Kark, for example, pioneered community health centers in South Africa in the 1940s and believed that the main factors which determine a community's health are to be found within the community itself [88]. By the 1970s, a social medicine movement was influential enough to shape the Declaration of Alma Ata (1978) [89] which proposed that primary care would coordinate health-promoting action in education, housing, food, public works, communications, and other sectors. Unfortunately, sustained focus on social determinants was at odds with health care's emphasis on biomedicine and specialized workforce [90].

There is a renewed emphasis on social determinants as key drivers of population health, one that is motivating hospitals and health-care systems to refocus their attention. One force catalyzing this movement in the United States is the changing structure of health-care payment models [91]. Evolving payment mechanisms are increasing seeking to reward quality of care and cost containment while accounting for social risk profiles of patient populations. More ambitiously, new accountable care organizations aim to link health-care and social services to deliver integrated care for defined populations [92].

As these trends unfold, health-care organizations are taking initiative to assess and manage their patient panels for social risk factors and to capture the data in electronic health records. A report from the National Academy of Medicine recommends broad categories of social and behavioral variables in such data collection, such as education, race/ethnicity, residential address, neighborhood median household income, patient financial strain, tobacco use, alcohol use, stress, depression, physical activity, social isolation, and intimate partner violence [93]. Collecting social risk factor data is a first step; clinical teams must use the data to design impactful interventions.

The Centers for Medicaid and Medicare Services is testing an "accountable health communities" model that seeks to identify patients with social needs, provide navigation to appropriate resources, and create a community structure that ensures adequate capacity, tracking, and performance improvement for the community network [92]. One caution with this approach is that screening for social risk factors could adversely affect patients if poorly implemented. Other potential pitfalls include not considering patient perspectives when making referrals, inadequate tracking to ensure successful connections to community resources, and failure to focus on family assets as well as deficits [94]. In such efforts maintaining and building patient dignity is an important outcome in its own right.

Evidence is accumulating about social risk factor screening. Three family medicine clinics in Albuquerque, New Mexico, for example, participated in a pilot of screening patients with a social needs questionnaire, successfully screening 3048 patients over that time. In their safety net populations, 46% of patients screened positive for at least one need; 63% of those had more than one. Trained medical assistants and community health workers connected patients

with resources. Most social needs were previously unknown to the clinicians. Patient outcomes were not reported, however [95]. Another study, a randomized trial conducted in pediatric clinics at safety net hospitals in the San Francisco Bay area, examined the effect of having student volunteers trained to act as navigators, arranging resources for families with social needs. Among the 1809 participating families, the most frequent needs included food insecurity (41%), insufficient funds to pay utilities (41%), trouble finding employment (31%), not having a place to live (29%), and an unhealthy living environment (23%). Four months after enrollment, families in the intervention arm, when compared with controls who received written materials on resources, had small decreases in unmet social needs [96].

Reduce Vulnerability of Disadvantaged People

There is substantial variability across health-care institutions in the quality of care received by socially disadvantaged patients. Social risk factors can be associated with inequalities in doctor-patient communication, as well as diagnoses and treatment decisions. Much work has focused on racial and ethnic disparities at several levels [101]. Unintended biases may influence clinical decisions at the patient-provider level [102]. At the facility level, geographic accessibility, accomodations for low levels of health literacy, cultural appropriateness, and the ability to accommodate multiple languages are important determinants of care quality. Minority patients are often concentrated in a narrow segment of health-care institutions (e.g., federally qualified health centers) that disproportionately serve vulnerable patients. Many of these institutions have historically provided lower quality of care, but recent evidence shows that between-institution quality differences are narrowing over time. Quality gaps among racial/ethnic groups at the same institution are also observed, but these account for a smaller proportion of racial/ethnic differences and are also diminishing.

A National Academy of Medicine report identified several practices that show promise in caring for socially at risk populations [105]. The first practice is committing to health equity by being accountable for achieving equitable outcomes across diverse populations. For example, senior managers can create a culture that values equitable outcomes, including training staff appropriately. Second, as noted earlier, data systems and measures to assess equity within the health system should standardize collection of social risk factor data, followed by a regular review of outcomes and trends disaggregated by social risk factors. A third process seeks to identify unmet clinical and social needs by engaging patients as participants in identifying barriers and creating solutions. Fourth, both within and outside organizations, collaborative partnerships should be fostered to deliver services identified in the needs assessment, such as transportation, housing, and food. Fifth, continuity of care needs to be emphasized since patients transition across multiple clinical care settings (e.g., primary and specialty care, hospital, mental health) and social services. The final practice is actively engaging patients in care that is tailored to their needs. Tailoring may involve understanding the patient's prioritized health goals, ensuring cultural appropriateness, adjusting information for the patient's level of health literacy, or accommodating a patient's desired site of care.

Decrease Exposure to Health-Damaging Factors

It is critical to reduce exposure to health-damaging factors. The 3.0 transformation framework, promoted by the US Department of Health and Human Services and other partners, provides evolving goals and an operational model for population health. A fundamental assumption is that health depends on early life experiences, multisector influences on health, and the integration of community and health-care services [117]. Reducing the burden of chronic disease remains central and is tied to linking disease management with people's goals and their overall functioning.

Decreasing exposure, particularly in the context of preventing chronic disease, also focuses on accountability. There is growing interest in an "accountability system" that brings together government, industry, and other stakeholders who agree to benchmark and track progress, set and enforce incentives or sanctions, and continuously modify the accountability system in response to how effectively it functions [118]. Table 36.2 displays stakeholders and responsibilities in an accountability system.

One example of such a system is the Access to Nutrition Index, which evaluates 25 of the largest multinational food corporations on their policy and products related to obesity, undernutrition, and breast milk substitutes [119]. An independent agency reports on corporations' performance in areas such as governance, product formulation, marketing, and labeling. The 2016 report found that 15 of the 22 companies earned 0% of their global sales on healthy products (or did not disclose the percentage), 5 earned less than 50%, and 2 earned more than 50% (2016 report, p. 10).

Political Influences

In 1986, the Ottawa Charter declared that health cannot be ensured by the health sector alone but that coordinated action – by governments, health and other social and economic sectors, nongovernmental and voluntary organization, industry, and by the media – is required to mediate between

Table 36.2 Accountability system stakeholders and responsibilities

	Government > private sector	Civil society > government	Civil society > private sector
Legal	Laws, regulation, monitoring, compliance, procurement	Formal inquiries, litigation	Consumer protections, litigation
Quasi-regulatory	Legislation, oversight of private sector initiatives	Codes of conduct, ethical guidelines, conflict of interest, disclosure of interactions	Codes of conduct, ethical guidelines, voluntary commitments
Political	Policy directions, inclusion of civil society in rule making	Formal advisory committees	Shareholder activism
Market based	Taxes, subsidies, concessions		Investment, disinvestment, boycotts
Public communications	Feedback to corporations via public media	Advocacy, polls, social media, watchdog organizations, demonstrations	Advocacy, polls, social media, watchdog organizations, demonstrations
Private communications	Private feedback from government officials	Private feedback to government officials	Private feedback from civil society

Table abridged from Swinburn et al. [118]. Arrows point away from the party seeking accountability toward the responsible party

differing interests in society for the pursuit of health [120]. Many jurisdictions throughout the world are now adopting a "health in all policies" approach to governance [121]. The objective in this approach is to incorporate health in a set of forecasted consequences. For example, in addition to estimating the extent to which bicycle lanes might reduce traffic congestion, a municipality might project delayed onset of chronic disease among the projected users, as well as the net effect on road injuries.

The degree to which governments support poverty reduction, education, public health, environmental protections, active transportation, fair wages, and other determinants influences population health [122]. Case studies and comparative longitudinal observations offer important insights. In Russia after the Soviet Union dissolved, life expectancy dropped by 6 years for men and 3 years for women between 1990 and 1994 [123]. The mortality spike was attributed to cardiovascular, infectious, neoplastic, alcohol-related, and violent/trauma etiologies, although the principal cause was cardiovascular deaths (35.7% of the increase). There were several hypothesized causal factors, including large declines in per capita income, a resurgence in alcohol consumption, increased stress and depression, and the collapse of the health-care system. Not surprisingly, the largest increases in mortality were seen in the lowest educational groups, but other findings were unexpected. For example, the age range with the steepest mortality increase was the 25–54 age group, and mortality increased disproportionately in the most urban and economically developed parts of Russia, perhaps because of social network effects.

An analysis of mortality trends in 15 European Union nations from 1980 to 2005 revealed that social welfare spending, other than health care, had the strongest relation with reductions in all-cause, cardiovascular, and alcohol-related deaths [124]. The financial crisis of 2008 demonstrated that economic policy can rapidly and powerfully influence health. In subsequent years, trends in health outcomes were more favorable in the Nordic countries, which chose to invest in social protections, than in Greece and Spain, which implemented austerity measures [125].

A Capability Approach to Address Social Determinants

Given the powerful role of social circumstances in shaping health, there is a strong basis for societal attention to health equity. Operationalizing equity by deciding what constitutes a fair and ethical allocation of resources has been a principal interest of political philosophers going back to Aristotle [129]. A modern theory of justice, the capability approach (CA), defines flourishing in a person-centered frame: individuals' opportunity to pursue and achieve the outcomes they have reason to value [130]. This account of justice differs from others in which individuals are due a set of primary goods, (e.g., income, freedom of speech, association, voting, opportunity to hold responsible offices [131]) or fundamental liberties [132].

The CA's chief proponents, Amartya Sen [133] and Martha Nussbaum [134], argue that social justice requires more than access to the same set of primary goods or to be free of interference from others. Societies should focus on providing equitably distributed feasible opportunities to live the life one values. What is feasible depends partly on available resources in the environment and partly on individuals' ability to take advantage of the resources. A common set of resources will not suffice for people whose disabilities or disempowerment limits their capacity to make use of them.

Adequate opportunities allow people to choose from a set of potentially achieved states (i.e., capabilities) to be and do what they value (i.e., functionings) [133]. Focusing on the conditions

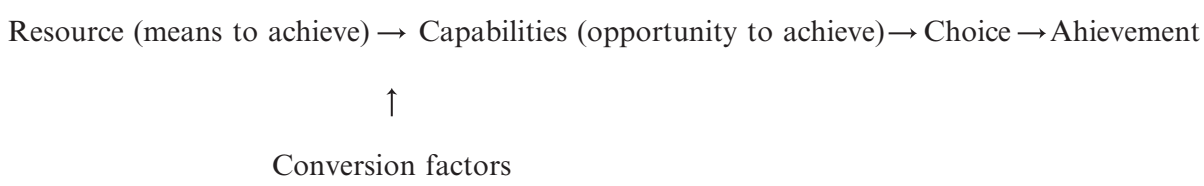

Fig. 36.4 Capability approach framework

that create substantive opportunities, at both the individual and community levels, is what distinguishes the capability approach from other social justice frameworks. It is important to recognize that people's ethical claim in the CA framework is to feasible opportunities for health, rather than health outcomes. To the extent that feasible opportunities are present, however, people are accountable for their health outcomes [135].

Figure 36.4 conceptually illustrates the capabilities framework [136].

The means to achieve are provided by the available market and nonmarket resources and by individuals' available income or in-kind support. Circumstances such as literacy, disability, family support, and social context (called "conversion factors") influence whether an individual can take advantage of available resources. Together, resources and conversion factors establish a person's set of feasible opportunities. A person then chooses whether or not to take up the opportunities to reach a desired state. That choice is influenced by individual preferences, motivation, and social preference.

To illustrate how the capability approach applies to chronic disease, consider the practical opportunities necessary to buy and consume healthy food. The capability set of feasible opportunities is shaped by inputs that include locally available goods and services (e.g., fresh supermarket; community gardens) and personal income or food stamps available to purchase food. Conversion factors, including support for healthy eating within the household and health literacy for food selection and preparation, are necessary to turn resources into opportunities. In the final step, an individual chooses what to eat from the available opportunities.

Recent studies have applied the capability approach in chronic disease prevention. A qualitative study in a disadvantaged neighborhood identified opportunities and constraints for diet and activity. Figure 36.5 illustrates the prevalence of the diet and activity resources.

A second cross-sectional study with 746 patients sampled from seven clinical sites across Texas assessed whether the capability measures were associated with diet and activity intentions (i.e., choices) and three functionings: achieved diet, activity, and BMI. Capabilities predicted both behavioral intentions and functionings [138].

Final Comments

A fundamental concept of social determinants is that different health outcomes in different groups do not define inequity. Inequity, rather, is judged by the process through which health outcomes are produced, and our knowledge of that process is growing, including the path from individuals' SES to unhealthy behavior, to chronic disease. Social, economic, and political forces structure the landscape of behavioral options that are available, affordable, convenient, and widely embraced, the landscape on which individuals with varying resources, constraints, abilities, and attitudes conduct their daily lives. These structured chances generate morbidity and mortality gradients across socially constructed categories including gender, social class, and race/ethnicity.

What is less clear, however, is how to move from documenting inequities to achieving equitable health outcomes. Progress on identifying effective leverage points calls for rebalancing strategies. A critical decision is the balance between addressing downstream effects such as health behaviors or the social conditions that generate them. Given the difficulty of enacting policies that reduce social inequalities, it can appear more feasible to focus on changing health behaviors. But the SES influences on health continue to be strong and pervasive, even after accounting for the effects of unhealthy behaviors such as smoking, inactivity, and alcohol use [144]. In addition, lessons from longitudinal international comparisons demonstrate that increasing spending on social protections is associated with increases in life expectancy [145].

The need to honor complexity is what unifies the different streams of action on social determinants. Chronic disease determinants, in particular, are shaped by history, social and cultural norms, economic systems, and power hierarchies. In complex systems, a series of strategic questions guide change [146]. What mechanisms bring about health behavior change? Who is monitoring health disparities in the community? What authority and accountability do they have? How are community members involved in designing the systems that are intended to reduce disparities? What is the place of health literacy and the demand environment as well, particularly in areas of misleading claims in food advertising or lax regulations on food labeling? Finally but fundamentally:

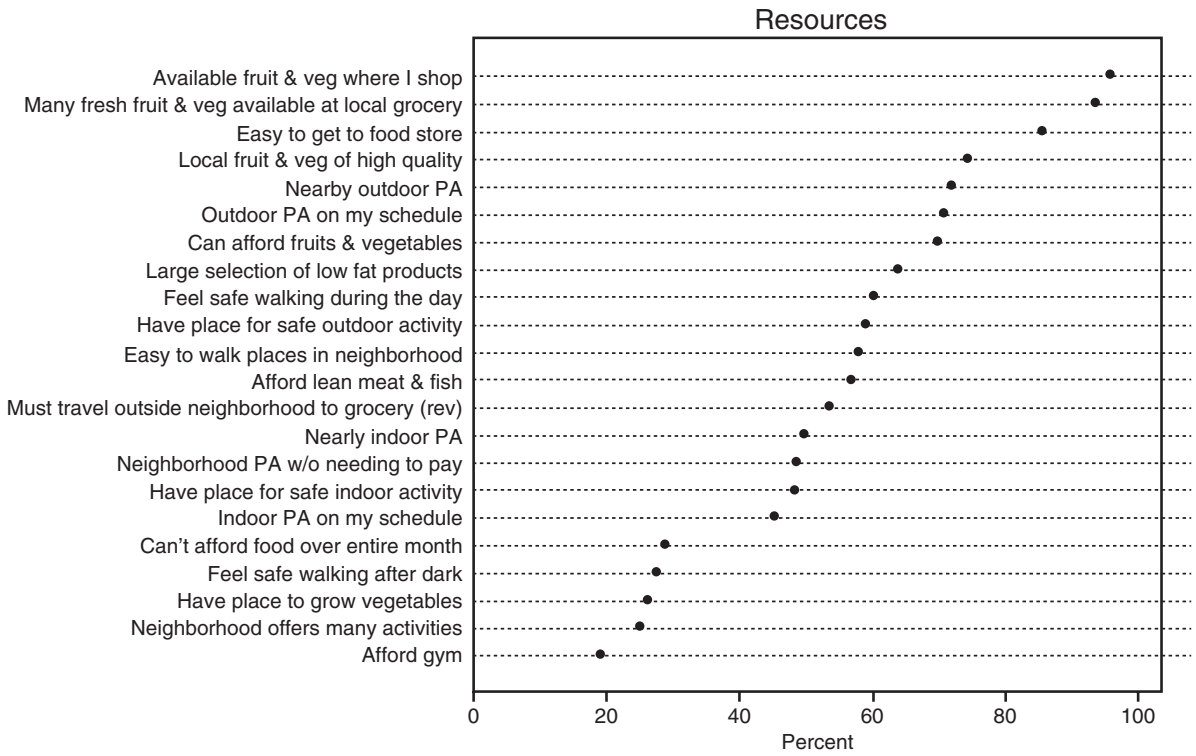

Fig. 36.5 Diet and activity resources in a vulnerable population

is health viewed primarily as an individual or communal and public responsibility? Our response to the last question holds the key to success in promoting health, moving us to a future state when social determinants of health are invoked as the foundation of well-being, rather than the root of our problems.

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Environmental Determinants of Health

37

Jacqueline MacDonald Gibson

Introduction

Since the discovery of DNA's structure in 1953, researchers have debated the relative influence of genetic versus environmental factors as determinants of health. Estimates of the environmental contribution to disease have ranged from as low as 13% [1] to as high as 90% [2]. These differences arise in part due to varying definitions of "environment." For example, a recent World Health Organization (WHO) assessment of the environmental contribution to preventable disease defined the environment as including "exposure to pollution and chemicals (e.g., air, water, soil, products), physical exposures (e.g., noise, radiation), the built environment, other anthropogenic changes (e.g., climate change, vector breeding places), related behaviors and the work environment" [1]. The WHO estimates that 13–32% of the global disease burden is attributable to these environmental determinants. In contrast, thought leaders have suggested that in the extreme, all diseases are environmental because "genetic factors are actually also environmental, but merely on a different time scale" [3]. An intermediate viewpoint defines the environment as all factors external to the genome. However, based in part on prior studies of twins that computed the fraction of diseases attributable to genetic versus nongenetic factors, somewhere between 70% and 90% of disease risks may be attributable to differences in environments [2].

This chapter adopts a perspective of environmental determinants of health consistent with that of the WHO and focuses on chronic diseases related to pollutants in outdoor air, household indoor air, workplaces, and drinking water. Like the WHO, the chapter also considers exposure to lead—which can occur through ingestion of dust, soil, air, water, or food—as an environmental determinant. In addition, consistent with the concept of the built environment as a health determinant, the chapter also discusses the mounting evidence of the profound health impacts unintentionally created through automobile-centric urban designs of the post-World War II era. Overall, the chapter emphasizes environmental factors that are potentially modifiable by changes in individual behaviors or public policies, which physicians may be able to influence.

The chapter begins with an overview of how WHO and others have estimated the burden of chronic diseases attributable to environmental factors. Next, it provides background information on the environmental determinants included in this discussion: outdoor air pollution, household air pollution, drinking water contamination, occupational exposure to hazardous materials, lead exposure, and built environments that discourage physical activity. The final section provides guidance for physicians on incorporating concerns about environmental determinants into their healthcare practices.

Estimating the Burden of Disease from Environmental Determinants

In 1990, the World Bank commissioned the first comprehensive study to characterize the contribution of various risk factors to preventable diseases, in order to help define intervention packages for countries in different development stages [4]. Carried out by the WHO and published in 1996, the study assessed the global and regional disease burden attributable to ten different risk factors, including four environmental determinants (poor water supply and sanitation, air pollution, occupational exposures, and physical inactivity) [4, 5]. A follow-up burden of disease study, published in 2004, added an additional 16 risk factors [6]. Subsequent updates, the most recent published in 2015, were prepared by the Institute for Health Metrics and Evaluation (IHME)

J.M. Gibson (✉)
Department of Environmental Sciences and Engineering, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA
e-mail: Jackie.macdonald@unc.edu

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[7, 8]. The global studies have led to similar efforts at the national level [9–11], including in the United States.

Method for Estimating the Environmental Burden of Disease

All of the global burden of disease projects and their national-level counterparts have used a similar process that involves combining epidemiologic, environmental, and public health data. Disease burden studies begin by compiling evidence linking exposure to a given risk factor to specific health outcomes. Typically, these risk factor-disease pairs are identified through a comprehensive review of epidemiologic studies. Table 37.1 summarizes the health outcomes linked to risk factors discussed in this chapter, as determined from a review of evidence in previous global burden of disease studies [7, 8, 12].

Table 37.1 Selected environmental determinants of health

Risk factor	Associated health outcomes
Built environment not conducive to walking or cycling for transportation (leading to physical inactivity)	Breast cancer
	Colorectal cancer
	Diabetes
	Ischemic heart disease
	Ischemic stroke
Outdoor air pollution (particulate matter)	Chronic obstructive pulmonary disease (COPD)
	Ischemic heart disease
	Lower respiratory infections
	Lung cancer
	Stroke
Lead exposure (via corrosive water, soil, dust, and/or food)	Mild mental retardation (childhood exposure)
	High blood pressure (adults)
Household air pollution from second-hand smoke	Hemorrhagic stroke
	Ischemic heart disease
	Ischemic stroke
	Lower respiratory infections (children)
	Lung cancer
	Otitis media (children)
Household air pollution from radon	Lung cancer
Occupational carcinogens	Lung cancer
	Ovarian cancer
	Leukemia
	Nasopharynx cancer
Occupational particulate matter	COPD
Occupational asthmagens	Asthma
Waterborne carcinogens	Bladder cancer (disinfection byproducts)
	Lung/bronchus cancer (arsenic)
	All cancer (gross alpha radiation)
Waterborne pathogens	Diarrheal diseases

Once these risk factor-health outcome relationships are determined, the next step is to estimate a quantity known as the population attributable fraction (AF)—the fraction of observed diseases that could be prevented if exposure to a specific risk factor were curtailed. AF can be estimated from the following equation [9–11, 13, 14]:

$$\mathrm{AF} = \frac{\int_{x=0}^{m} \mathrm{RR}(x)P(x)dx - \int_{x=0}^{m} \mathrm{RR}(x)P'(x)dx}{\int_{x=0}^{m} \mathrm{RR}(x)P(x)dx} \quad (37.1)$$

where x is the pollutant exposure concentration or dose, RR(x) is the relative risk of an adverse health outcome at exposure concentration or dose x, $P(x)$ is the current population exposure distribution, and $P'(x)$ is an alternative (or counterfactual) exposure distribution. When the exposure is eliminated, then RR($x = 0$) = 1, and the integral on the right side of the numerator reduces to 1. The number of observed cases attributable to the exposure of concern (D_{attrib}) then can be calculated from

$$D_{\mathrm{attrib}} = \mathrm{AF} \times D_{\mathrm{total}} \quad (37.2)$$

where D_{total} is the total number of observed cases. Relative risk functions for each exposure and health outcome are estimated from meta-analyses or systematic reviews of prior epidemiologic studies. The population distribution of exposure is typically estimated from a combination of environmental data collected by state and federal agencies, along with behavioral data from a number of sources, such as the Behavioral Risk Factor Surveillance System [15].

To provide a common metric for comparing disparate health outcomes, such as premature mortality and chronic diabetes, or chronic diabetes and chronic asthma, the WHO developed a concept called the disability-adjusted life year (DALY). The DALY combines two quantities: the years of life lost due to premature mortality (YLL) and the years of life lived with "disability" (YLD). For each affected population age group, these quantities are calculated as

$$\mathrm{YLD} = I \times \mathrm{DW}\ X\ L \quad (37.3)$$

$$\mathrm{YLL} = N \times L \quad (37.4)$$

where I is the annual number of incident cases, L is the illness duration (for YLD) or the remaining life expectancy at the age of death (for YLL), and DW is the "disability weight," intended to represent the relative level of discomfort and interference with daily activities of life from each disease. The WHO has developed standard disability weights for different conditions. The weights were developed from surveys asking health professionals how many imaginary patients with a specific condition they would trade for 1000 healthy,

Table 37.2 Disability weights used in global burden of disease studies

	Untreated form					Treated form				
	Age group (years)					Age group (years)				
Sequela	**0–4**	**5–14**	**15–44**	**45–59**	**60+**	**0–4**	**5–14**	**15–44**	**45–59**	**60+**
Diarrheal episode	00.119	00.094	0.086	00.086	00.088	00.119	00.094	00.086	00.086	00.088
Mild mental retardation	00.361	00.361	00.361	00.361	00.361	00.361	00.361	00.361	00.361	00.361
Lower respiratory infections										
Episodes	00.280	00.280	00.276	00.276	00.280	00.280	00.280	00.276	00.276	00.280
Chronic sequelae	00.099	00.099	00.099	00.099	00.099	00.099	00.099	00.099	00.099	00.099
Upper respiratory infections										
Episodes	00.000	00.000	00.000	00.000	00.000	00.000	00.000	00.000	00.000	00.000
Pharyngitis	00.070	00.070	00.070	00.070	00.070	00.070	00.070	00.070	00.070	00.070
Cancers—preterminal										
Colon and rectum	00.217	00.217	00.217	00.217	00.217	00.217	00.217	00.217	00.217	00.217
Trachea, bronchus and lung	00.146	00.146	00.146	00.146	00.146	00.146	00.146	00.146	00.146	00.146
Bladder	00.085	00.085	00.085	00.085	00.085	00.087	00.087	00.087	00.087	00.085
Leukemia	00.098	00.098	00.108	00.112	00.112	00.083	00.083	00.093	00.097	00.097
Cancers—terminal	00.809	00.809	00.809	00.809	00.809	00.809	00.809	00.809	00.809	00.809
Diabetes mellitus										
Cases	00.012	00.012	00.012	00.012	00.012	00.033	00.033	00.033	00.033	00.033
Diabetic foot	00.137	00.137	00.137	00.137	00.137	00.129	00.129	00.129	00.129	00.129
Neuropathy	00.078	00.078	00.078	00.078	00.078	00.064	00.064	00.064	00.064	00.064
Retinopathy—blindness	00.600	00.600	00.600	00.600	00.600	00.493	00.491	00.488	00.488	00.488
Amputation	00.155	00.155	00.155	00.155	00.155	00.068	00.068	00.068	00.068	00.068
Ischemic heart disease										
Acute myocardial infarction	00.491	00.491	00.491	00.491	00.491	00.395	00.395	00.395	00.395	00.395
Angina pectoris	.0.227	00.227	00.227	00.227	00.227	00.095	00.095	00.095	00.095	00.095
Congestive heart failure	00.323	00.323	00.323	00.323	00.323	00.171	00.171	00.171	00.171	00.171
Cerebrovascular disease—										
First-ever stroke	00.262	00.262	00.262	00.268	00.301	00.224	00.224	00.224	00.224	00.258
COPD	00.428	00.428	00.428	00.428	00.428	00.388	00.388	00.388	00.388	00.388
Asthma—cases	00.099	00.099	00.099	00.099	00.099	00.059	00.059	00.059	00.059	00.059

Sources: World Health Organization. All outcomes other than mild mental retardation: http://www.who.int/healthinfo/global_burden_disease/tools_national/en/. Mild mental retardation: http://www.who.int/healthinfo/global_burden_disease/GBD2004_DisabilityWeights.pdf

imaginary people [16]. Table 37.2 shows disability weights for some of the health outcomes discussed in this chapter.

Current Estimates of the Environmental Burden of Disease

Globally, the most recent burden of disease estimate attributed 11.4 million annual deaths (21.2% of total deaths globally) and 354 million DALYs (16.3% of the global total) in the year 2013 to the environmental determinants discussed in this chapter. The published global estimate does not provide details for each country; however the IHME published a separate estimate for the United States for the year 2010 [12]. Figure 37.1 combines IHME estimates of the burden of disease from outdoor air pollution, household air pollution, occupational exposures, and built environment factors (through their influence on physical inactivity) with our own estimates for drinking water pollution, described below in the section entitled "Drinking Water Pollution." In total, 15% of all 2.6 million US deaths in 2010 and 8.9% of all 82 million DALYs are attributable to these determinants. The following sections provide background information on each determinant shown in Fig. 37.1.

Outdoor Air Pollution

Deadly smogs in Donora, Pennsylvania, in 1948 and London in 1952 spurred research to understand the impacts of air pollution on public health in the United States and Europe [20, 21]. In Donora, a smog so thick that daytime was as dark as night sickened about half of the population of 14,000 and led to 20 deaths [20]. In London, a similar smog led to a death toll estimated at the time to be 4000; later reanalysis placed the toll as high as 12,000 [21].

A large body of epidemiological, toxicological, and clinical research since the smogs of the mid-twentieth century has provided strong evidence linking adverse health

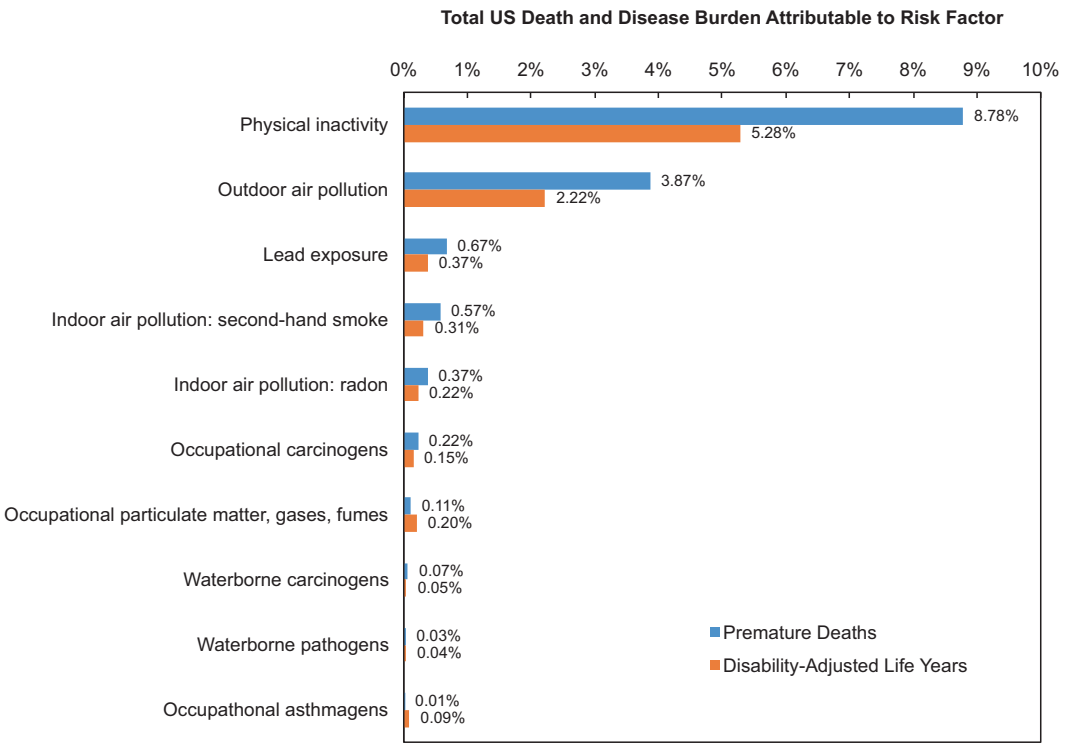

Fig. 37.1 Estimated contribution of environmental determinants to premature deaths and disability-adjusted life years in the United States (Developed from data in [12, 17–19])

impacts to exposure to three categories of common air pollutants: particulate matter (PM), ozone (O_3), and nitrogen dioxide (NO_2) [21, 22]. All three pollutants are strong oxidants that can affect health directly through oxidation of lipids and proteins and indirectly through activation of intracellular oxidant pathways [23]. Strong evidence supports causal associations between these pollutants and all-cause mortality, cerebrovascular disease (including stroke), ischemic heart disease, chronic obstructive pulmonary disease (COPD), lower respiratory tract infections, and trachea, bronchus, and lung cancers. Evidence also supports associations with bronchitis in children and adults and with elevated incidence of asthma symptoms in asthmatic children [24].

The Global Burden of Disease Project estimated that in 2013, more than 2.9 million deaths (5.4% of total deaths) and 70 million DALYs (2.8% of total DALYs) globally were attributable to ambient air pollution [7]. The IHME study attributed 103,000 US deaths (3.9% of total deaths) and 1.8 million DALYs (2.2% of total DALYs) in the year 2010 to ambient air pollution. To avoid double counting due to co-occurrence of pollutants, these estimates include only risks from particulate matter pollution so should be considered conservative.

Indoor Air Pollution

Insufficient ventilation has been recognized as dangerous to health since biblical times. However, until relatively recently, concerns about indoor air quality were driven by the need for odor control and comfort [25, 26]. During the 1980s, however, indoor air pollution rose to prominence, at first due to concerns about radon. Radon pollution of indoor air made national news in 1984 when a worker at the Limerick nuclear power plant in Pennsylvania triggered the radiation monitoring system at the power plant when he arrived at work; tests revealed that the source of his exposure was not occupational, but instead the air inside his household was contaminated with radon originating from underlying geologic formations [26, 27]. This incident focused national attention not just on radon but also on other sources of indoor air pollution, including formaldehyde, mold, and, more recently, environmental tobacco smoke. In addition, recent research in the developing world has spotlighted household air pollution arising from combustion of solid fuels indoors for cooking and heating.

In developed countries, recent evidence suggests that the household indoor air pollutants with the largest impacts on chronic disease are environmental tobacco smoke, radon,

and mold. A meta-analysis found that children of parents who smoke have twice the risk of hospitalization for serious respiratory infections as those with nonsmoking parents [28]. Similarly, studies have found elevated risks of asthma in children and chronic lymphocytic leukemia, lung cancer, and cardiovascular disease in adults among nonsmokers living with smokers [29–34]. Multiple studies, including several meta-analyses, have found consistent associations between visible mold in the home and the development and exacerbation of asthma in the United States and Europe [35–37]. A meta-analysis of studies from North America and Europe showed consistent associations between the presence of visible mold in the household and the risk of asthma and other respiratory outcomes (such as chronic coughs) in children aged 6–12 [36]. More than 20% of US asthma cases are attributable to mold in the home, according to one study [38].

Recent research also has documented associations between a variety of adverse health effects and indoor emissions of volatile chemicals from modern building materials [39–41]. Among the studied chemicals, evidence is strongest for formaldehyde [39, 40]. Formaldehyde has long been known to irritate the eyes and nasal passages in children and adults [40]. Multiple studies have linked development of childhood asthma and asthma exacerbations among those with previously diagnosed asthma to formaldehyde [39, 42]. Although some authors have questioned the strength of this evidence [40], a meta-analysis published in 2010 concluded that "results indicate a significant positive association between formaldehyde exposure and childhood asthma" [42]. Toxicologic research using rats and mice has linked formaldehyde exposure to increased risks of nasopharyngeal cancer, but recent research using molecular methods, in combination with epidemiologic evidence, suggests that these risks are much smaller than suggested by the animal studies of the early 1980s [41, 43].

The main indoor source of formaldehyde is emissions from composite wood products such as fiberboard, particleboard, and plywood [40]. Current guidelines suggest that formaldehyde exposure at concentrations less than 0.1 mg/m^3 are unlikely to cause adverse health effects. Measured mean indoor concentrations are generally lower than this level, but in some circumstances indoor concentrations can exceed this value. For example, in 2006, formaldehyde exposures in trailers distributed to hurricane Katrina victims by the US Federal Emergency Management Agency received a great deal of media attention. An independent scientific investigation found that the median formaldehyde concentration measured in four such trailers was 0.54 mg/m^3, and the highest level was 1.1 mg/m^3—more than 5 and 11 times the recommended exposure limit, respectively [44].

The Global Burden of Disease Project estimated that in 2013, 3.3 million deaths (6.2% of total deaths) and 92 million DALYs (3.8% of total DALYs) were attributable to indoor air pollution [7]. Most of this burden occurred in the developing world and was associated with indoor use of solid fuels for cooking and heating. The IHME study attributed 25,000 deaths (0.94% of total US deaths) to indoor air pollution: 9900 due to radon and 15,200 due to secondhand smoke [12]. Estimates of deaths and DALYs from mold and formaldehyde were not included in either the global or US studies. However, burden of disease studies elsewhere indicate that these two health determinants—especially mold—may pose a substantial disease burden. For example, a study in the United Arab Emirates attributed 12% of adult asthma and 8.6% of child asthma to exposure to mold indoors [11]. In addition, the study attributed 1.4% of children's visits to medical facilities for asthma to formaldehyde exposure [11].

Occupational Exposure to Environmental Pollutants

Although accidents, such as trips and falls, and ergonomic problems contribute substantially to the occupational disease burden, this review focuses on exposure to chemicals and airborne particulate matter in workplace environments. Physicians have recognized occupational pollutants as an important health determinant since at least the eighteenth century, when Percival Pott attributed scrotal cancer among young chimney sweeps to their exposure to soot [45]. Previous estimates of the disease burden from occupational pollutants have divided these exposures into three categories: [1] occupational asthmagens; [2] occupational particulate matter, gases, and fumes; [3] and occupational carcinogens [46, 47]. For all three categories, the most common resulting diseases overall are respiratory illnesses, including asthma, COPD, and lung cancer [48, 49].

Globally, estimates have suggested that 11% of asthma is associated with occupational exposures [46]. The American Thoracic Society has estimated that approximately 15% of asthma is attributable to occupational exposure [50]. Hundreds of biological and chemical agents in workplaces can trigger asthma. Biological agents include grains, flours, plants, wood dusts, and furs and other animal parts. Chemical agents include welding fumes, chlorofluorocarbons, alcohols, and metals and their salts [46]. Prior studies have found that occupational risks for asthma are highest among those employed in mining, manufacturing, service work, agriculture, and transportation. A recent study found that workers most at risk for exposure to airborne contaminants causing new-onset asthma, when compared to exacerbation of preexisting asthma, include nurses, cleaners, bakers, spray painters, and agricultural workers [51]. In addition to increasing the risk of asthma, exposure to occupational particulate

matter can contribute to COPD, silicosis, asbestosis, and coal workers' pneumoconiosis, the latter two of which are essentially exclusively occupational illnesses [46].

Among the hundreds of potential occupational carcinogens, those with the strongest evidence linking occupational exposures to health outcomes and contributing the most to occupational cancers are asbestos, diesel engine exhaust, secondhand smoke, and silica [8]. A survey of occupational exposure to 139 carcinogens in European Union workplaces, which is used as the basis for current estimates of the disease burden associated with occupational carcinogens, found that the occupations with the highest risk of exposure to these substances are mining, construction, transportation, and manufacturing [46].

The Global Burden of Disease Project estimated that in 2013, 561,000 deaths (1.0% of total deaths) were attributable to occupational exposures: 304,000 (0.56%) from carcinogens; 205,000 (0.38%) from particulate matter, gases, and fumes; and 52,000 (0.10%) from asthmagens [7]. In addition, 17.4 million DALYs (0.71% of the global total) were attributable to these occupational exposures: 5.80 million (0.24%) to carcinogens; 8.80 million (0.36%) to particulate matter, gases, and fumes; and 2.77 million (0.11%) to asthmagens.

In the United States, the occupational disease burden is lower than that globally, due to stronger occupational health and safety regulations than in developing countries. In total in 2010, 9000 US deaths (0.34% of total deaths) were attributable to occupational exposures—about one-third of the global attributable fraction. Of these deaths, 5900 (0.22%), 2900 (0.11%), and 200 (0.0075%) were attributable to carcinogens, particulate matter, and asthmagens, respectively. Of total US DALYs, 362,000 (0.44%) were attributed to occupational exposures, which is about 38% lower than the global attributable fraction. Of these, 120,000 (0.15%) were attributable to carcinogens, 167,000 (0.20%) to particulate matter, and 75,200 (0.092%) to asthmagens.

While burden of disease analyses are useful indicators of the potential magnitude of risks from environmental exposures, research suggests that the occupational disease burden may be substantially underestimated. Causes of underestimation include the long latency periods between occupational exposures and the onset of some diseases, the multiple potential causative factors for any given disease, and the lack of recognition by primary healthcare providers that workplace pollutants could have contributed to a patient's health status [52]. A US study designed to assess the impacts of underreporting of occupational illnesses found that 39% of patients in general medical clinics believed their illness could be "possibly caused by work," and 66% thought it could be "possibly worsened by work," even if not caused by work [53].

Drinking Water Pollution

Control of microbial contaminants in drinking water has been heralded as the greatest public health advance of the twentieth century in the United States. Between 1900 and 1940, US mortality rates declined by 40%, and life expectancy at birth increased from 47 to 63 years. Nearly half of these gains have been attributed to the reduction in population exposure to waterborne pathogens brought about by installation of drinking water chlorination and filtration systems in major US cities [54]. Nonetheless, waterborne disease outbreaks—albeit sporadic—continue to occur in the United States, and some populations are at increased risk, as compared to others.

The vast majority of waterborne disease outbreaks are unreported [55, 56]. Nonetheless, a CDC database including all outbreaks reported since 1971 provides some insights into the nature of waterborne illnesses (Fig. 37.2) and etiologic agents (Fig. 37.3) that continue to pose risks to US population health [58]. Among 762 reported outbreaks attributed to contamination of drinking water from public water supplies or individual wells, 88% resulted in acute gastrointestinal illnesses (AGI) caused by a range of intestinal pathogens (Fig. 37.2). Next most common were hepatitis A (4% of outbreaks) and acute respiratory illness caused by *Legionella* (3% of outbreaks).

Outbreak data indicate that the rate of *Legionella* outbreaks is increasing; during the period 2001–2006, *Legionella* caused 29% of reported outbreaks, all from growth and dissemination in premise plumbing, pipes, and storage infrastructure (including two outbreaks in healthcare settings). In addition to outbreaks of AGI, hepatitis A, and *Legionella*, one outbreak of primary amebic meningoencephalitis (caused by *Naegleria fowleri*) occurred, along with several outbreaks of skin rashes. About 11% of outbreaks were caused by chemicals, most commonly copper but also including fluoride, nitrate, arsenic, and other chemicals.

Although AGI arising from waterborne pathogens is usually self-limited, in rare cases these infections can lead to serious chronic or even fatal conditions. For example, *Campylobacter* is associated with Guillain-Barre syndrome; *Salmonella* and *Shigella* with reactive arthritis; *Giardia* with failure to thrive, lactose intolerance, and chronic joint pain; and *E. coli* O157:H7 with hemolytic uremic syndrome [56]. Furthermore, waterborne contaminants associated with self-limiting AGI in healthy populations may lead to severe complications and mortality among sensitive populations, such as the elderly, immunocompromised, pregnant women, and young children. For example, the largest US waterborne disease outbreak in recent history occurred due to contamination of the Milwaukee, Wisconsin, water supply with

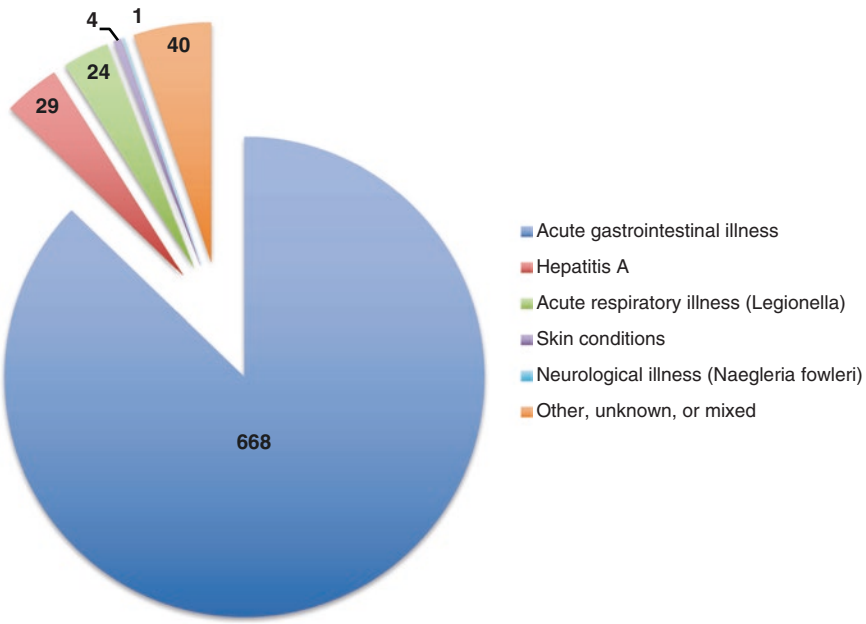

Fig. 37.2 Illnesses in reported US waterborne disease outbreaks, 1971–2006 (developed from data in [57])

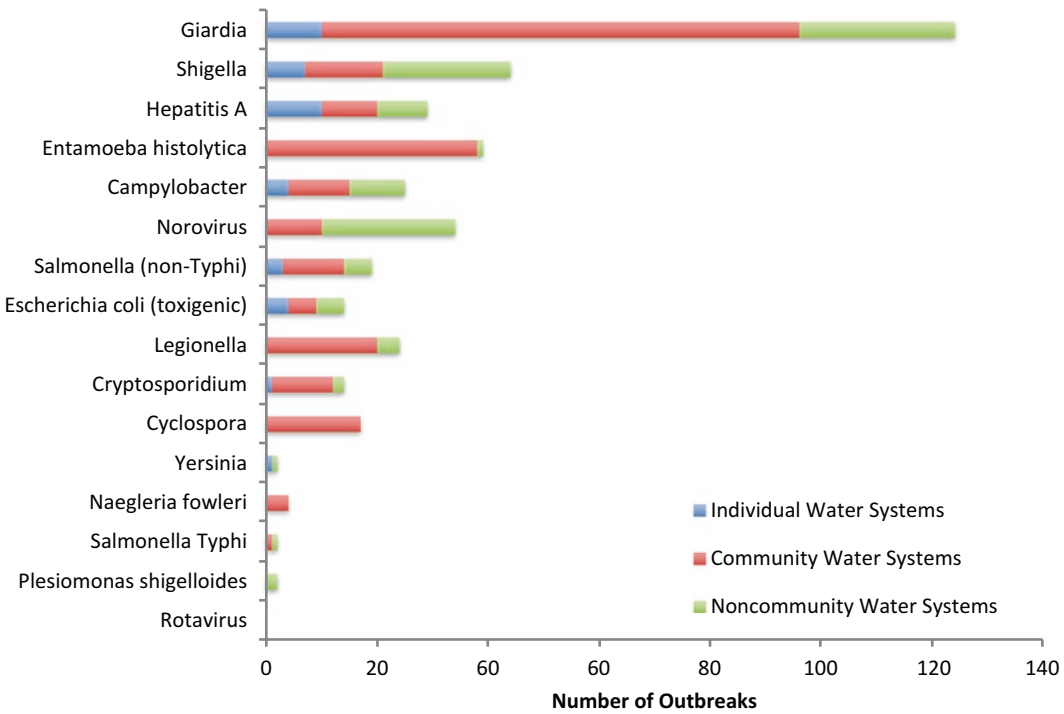

Fig. 37.3 Etiologic agents associated with reported US waterborne disease outbreaks, 1971–2006 (of 456 infectious disease outbreaks with known etiologies; developed from data in [57])

Cryptosporidium for 2 weeks in 1993 [59, 60]. This outbreak sickened more than 400,000 people and caused 50 premature deaths, 85% of them among AIDS patients. Recent evidence suggests that repeated infections with *Cryptosporidium* among infants aged 0–2 can lead to malnutrition, impaired growth, and decreased educational performance during later childhood [61].

While waterborne disease outbreaks are generally rare in large municipal water systems, breakdowns in these systems occur. In addition to the Milwaukee example, one recent highly publicized example of the failure of a municipal system was the case in Flint, Michigan, where city residents were exposed to elevated levels of lead in their drinking water. The increase in lead exposure was caused by a switch in the city's water supply, from Lake Huron water treated by the City of Detroit to the corrosive water of the Flint River, as part of an effort to save money for the bankrupt city. Recent research has found that the incidence of elevated blood lead levels in children more than doubled (from 2.4% to 4.9%) during this time period [62], placing the exposed children at increased risk of neurocognitive impacts such as reduced IQ and overall life achievement.

About 14% of the US population obtains their drinking water from private wells [63]. These wells are not regulated by the Safe Drinking Water Act, which covers only public water systems—those serving more than 25 people or 15 service connections year-round (community systems) or those regularly serving the public (non-community systems, such as campgrounds, gas stations, and schools, factories, or hospitals with their own water systems). Recent research has shown that those relying on private wells for their drinking water are at increased risk of AGI from waterborne pathogens. For example, a study in North Carolina found that 7.3% of emergency department visits for AGI could be attributed to microbial contaminants in drinking water; of these visits, 99% were associated with contamination of private wells [17].

Also at higher risk of exposure to contamination are those relying on small or very small water systems—those serving fewer than 3300 or 500 people, respectively. These systems lack the economies of scale of larger systems and are more likely to be financially stressed, causing difficulties with appropriate monitoring and maintenance of treatment systems. In a typical year, nearly 90% of violations of the Safe Drinking Water Act occur in small and very small water systems [64–66].

In addition to illnesses tracked in the CDC's waterborne disease surveillance system, contamination of drinking water is associated with other illnesses not easily recognized as waterborne due to multiple etiologies and a lag between exposure and disease onset. These other illnesses include lead poisoning, such as in the Flint, Michigan, case, and cancers. Among carcinogens in drinking water, disinfection byproducts formed by the reaction of disinfectants (such as chlorine) with natural organic compounds in the water (from decayed vegetation and other sources) appear to pose the biggest health impact, followed very distantly by arsenic, which is naturally occurring. Despite the increased cancer risks that may be caused by disinfection byproducts, studies have shown that the benefits of reduced infectious disease risks far outweigh the cancer risks [67].

Arsenic is a naturally occurring chemical concentrated in selected geologic regions. Acute exposure to high levels of arsenic in drinking water causes skin lesions, including blackfoot disease. However, such acute exposures are generally not observed in the United States. At lower exposure levels such as those that could occur in US groundwater in some geologic regions, chronic exposure to arsenic in drinking water is associated with skin, bladder, kidney, and lung cancer; heart disease; neurological abnormalities; and diabetes [68, 69]. In the United States, health risks from arsenic exposure are likely to be highest in private wells, due to the lack of regulation [70]. Public water systems, in contrast, are required to monitor for arsenic and remove it to very low levels if detected.

The Global Burden of Disease Project attributed 1.25 million deaths (2.3% of the total) and 75.1 million DALYs (3.1% of the total) to unsafe water sources. These estimates are based on the fraction of the population in each country with access to improved water and sanitation facilities, as defined by the WHO/UNICEF Joint Monitoring Programme for Water Supply and Sanitation (Table 37.3). The fraction without access to improved water sources is assumed to have a 35% increased risk of AGI and typhoid, in comparison to those with improved water access.

Because the vast majority of US residents have access to improved drinking water sources, the IHME estimation approach may not provide the most accurate information for US policymaking. The approach is not based on US-specific water quality data, and it does not include noninfectious disease risks, such as cancer, that may be of concern.

For this chapter we estimated separately the burden of disease in the United States from waterborne pathogens and carcinogens based on water quality and health outcome data. To develop these estimates, we applied AF estimates from

Table 37.3 WHO/UNICEF definitions of unimproved and improved water sources

Unimproved	Improved
Unprotected spring	Piped water into dwelling
Unprotected dug well	Piped water to yard/plot
Cart with small tank/drum	Public tap or standpipe
Tanker truck	Tube well or borehole
Surface water	Protected dug well
Bottled water	Protected spring
	Rainwater

recent comprehensive studies in North Carolina that are based on measured concentrations of microbial and chemical contaminants in public water supplies and private wells [17–19]. These studies estimated that 7.3% of acute gastrointestinal illnesses and 0.30% of cancers are attributable to microbial and chemical contaminants in drinking water, respectively. We multiplied these fractions by IHME data on deaths and DALYs from AGI and all cancers in the United States in 2010, in order to estimate the US burden of disease from drinking water pollution [12]. Using this approach, we attribute 2600 deaths (0.097% of total deaths) and 66,000 DALYs (0.081% of the total) to waterborne contaminants. Among the deaths, 1900 (0.071%) are attributable to carcinogens and 710 (0.027%) to pathogens. Among DALYs, 37,000 (0.045%) are attributable to carcinogens and 29,000 (0.036%) to pathogens. By contrast, the IHME estimate attributed 300 deaths and 10,700 DALYs to unsafe drinking water in the US, considering only effects on AGI and typhoid due to lack of access to an improved water source.

Lead Exposure

Lead toxicity has been recognized for more than 2000 years. For example, during the first century AD, Roman scholar and naval commander Pliny, in his *Naturalis Historia*, described poisoning among shipbuilders along with pallor among miners exposed to lead [71, 72]. Nonetheless, until the first cases of childhood lead poisoning were documented in the late nineteenth and early twentieth centuries, lead exposure was thought to occur only in certain high-risk occupations [73]. Recent events in Flint, Michigan, in which lead concentrations in the municipal water supply peaked due to the switch to a corrosive water that leached lead from water pipes, has refocused national attention on health risks of lead exposure [74, 75].

Exposure to lead may occur though ingestion of lead-contaminated dust, water, soil, or food or from inhalation of contaminated air. Until lead was banned from gasoline in progressive stages beginning in 1980, the major source of exposure was ingestion of soil and dust contaminated with airborne lead released by motor vehicles [76]. Dust from lead in household paint is another major source. Lead was banned from household paint in 1978 [77], but homes built before then remain at risk. Even if covered with additional paint layers, household residents (especially children) are at risk of exposure via dust from flaking paint, for example, in window casings where friction can erode upper layers and leave a dust residue on window sills. Consumer products, such as glazed ceramics from certain countries, also can be sources of lead exposure.

Lead solder in food cans is a dietary source, although the food industry has collaborated with the Food and Drug Administration over the past three decades to virtually eliminate the use of lead-containing materials in food storage containers manufactured in the United States [78]. As a result of bans on lead in gasoline, household paint, and food cans, blood lead levels in children and adults have declined progressively since the 1980s. For example, according to the CDC, the fraction of children with blood lead levels above 10 μg/dl decreased from nearly 8% to less than 0.5% during the time period 1997–2015 [79]. Nonetheless, each year an estimated 120,000 children under age 5 have blood lead levels above 10 μg/dl (the CDC's threshold for elevated blood lead before 2012, when the definition of elevated blood lead changed to 5 μg/dl).

Over the course of the twentieth century, concern about lead exposure increased as studies demonstrated risks at increasingly lower exposure levels. In the United States, the first documented case of childhood lead poisoning was recorded in 1914 [73]. At the time, the prevailing wisdom was that a child who survived acute poisoning would recover fully. However, in 1943, the first follow-up study of acutely lead poisoned children found that 19 of 20 subjects exhibited cognitive difficulties, including behavioral problems, learning difficulty, and failure in school many years later [73]. In the 1970s, researchers began to document cognitive effects of lead in children who had been exposed but showed no clinical signs of acute poisoning. As subsequent research has built on these findings [80–83], the CDC has progressively lowered its definition of elevated blood lead concentrations from 60 μg/dl in 1960 to the current 5 μg/dl. Recent research suggests that adverse impacts occur even below 5 μg/dl [73].

At high exposure concentrations, lead can cause acute clinical symptoms in children and adults. The concentration at which acute symptoms occur varies by individual but is generally in the range of 60 μg/dl. In adults, symptoms of acute lead poisoning include peripheral neuropathy with wrist or foot drop, slowed peripheral nerve conduction, colic, clumsiness, clouded thinking, weakness, and paralysis. In addition, acute lead poisoning increases the incidence of stillbirths and female and male infertility. In adults, lead toxicity should be considered in the differential diagnosis of abdominal pain, arthralgia, hypertension, severe headache, increased intracranial pressure, CNS dysfunction, anemia, and renal dysfunction. A blood lead level >10 μg/dl should be considered elevated, even though clinical symptoms are rarely seen below 60 μg/dl [73].

Children are more vulnerable to adverse health effects from lead exposure due to their still-developing central nervous systems, increased lead absorption, and more frequent hand-to-mouth behavior. Clinical symptoms of acute exposure, which usually manifest at blood lead levels above 60 μg/dl, may begin with abdominal pain and arthralgia, progress to clumsiness and staggering with headaches and behavioral problems, and in the worst cases lead to encepha-

lopathy (though the latter is rare in the United States). Beginning in the 1970s, researchers began to document associations between permanent IQ loss in children and exposure to lead, even at low exposure levels [80]. Recent meta-analyses have found a loss of about 1.3 IQ points for every 5 μg/dl increase in blood lead levels in children [84]. New research shows adverse impacts on social behavior and associated increases in aggression and delinquency later in life. One study of bone lead levels in a juvenile cohort found that 11–38% of delinquent behavior could be attributed to early lead exposure on the basis of bone lead measurements [85]. However any child with growth failure, abdominal pain, behavior change, hyperactivity, language delay, or anemia should be tested for lead toxicity [73].

When blood lead levels exceed 40 μg/dl, patients should receive chelation therapy, with a 5-day course of EDTA (sodium calcium edetate) or a 19-day course of dimercaptosuccinic acid (succimer). A repeated course may be required if blood lead levels do not stabilize. Critically, the source of exposure must be identified through a home inspection (or, for workers, work site investigation). Unfortunately, chelation therapy does not eliminate the cognitive damage in children, and the only remedy for low-level lead exposure is therefore primary prevention [73].

WHO and IHME estimates of the burden of disease attributable to lead exposure emphasize the risks of relatively low but widespread exposures, rather than acute exposures. On the basis of the strength of available evidence, they focus on IQ loss leading to mild mental retardation in some children, gastrointestinal effects in children, elevated blood pressure in adults, and anemia in children and adults. Globally, the IHME estimated that 853,000 deaths (1.6% of the total) and 17 million DALYs (0.69% of the total) could be attributed to lead exposure in 2013 [8]. In the United States, 17,900 deaths (0.67% of the total) and 306,700 DALYs (0.37% of the total) could be attributed to lead exposure in 2010 [12].

Automobile-Centric Urban Designs

Since World War II, Americans have become much less physically active due to declines in physically active transportation (e.g., walking and biking), occupations, and household activities [86]. Overall, only about 45% of Americans meet the CDC's recommendation of 150 min of moderate to vigorous physical activity per week [87]. While about 36% of Americans are aware of the CDC's physical activity guidelines, fewer than 1% could correctly identify the amount of activity the CDC recommends [88]. Failure to meet these guidelines is associated with increased risks of multiple chronic diseases, including breast and colorectal cancers, diabetes, ischemic heart disease, and stroke [12, 89–92].

The decline in physical activity and associated rise in chronic disease rates is in part attributable to automobile-centric urban designs of the post-World War II era, along with increases in automation reducing physical activity at work and home [93–96]. In the United States, highway construction projects and suburban sprawl of the twentieth century in effect eliminated physical activity as a means of transportation for many Americans. For example, only 3.4% of Americans reported walking or biking to work in 2012 [97]. Recent research has shown that US residents who walk to work spend an additional 19.8 min per day walking, when compared to those who drive, and bicycle commuters exercise 32 min a day (28 min due to cycling and 4 due to walking) more than automobile commuters [97].

These results suggest that at least some Americans could achieve most or all of the recommended physical activity by switching from driving to either walking or cycling to work. Similar benefits can be gained by switching from driving to using public transportation. For example, a study in Charlotte, NC, showed that residents who began using a new light rail stop to commute reduced their BMI by 1.18 kg/m^2, on average, over 1 year—equivalent to a weight loss of 6.45 lbs for someone who is 5′5″ tall [98]. Multiple simulation studies have also shown substantial health benefits of reduced chronic diseases, mediated through physical activity, of compact neighborhoods with accessible public transportation, infrastructure (such as sidewalks and bikeshare programs) to support walking and cycling, and mixed land uses, in comparison to sprawling suburban neighborhoods lacking in such infrastructure [99–102].

The Global Burden of Disease Project attributed 2.18 million deaths (4.1% of total deaths) and 45.1 million DALYs (1.8% of the total) in the year 2013 to physical inactivity [8]. Relative to other environmental determinants, the physical inactivity risks are much higher in the United States than globally. The IHME attributed 234,000 deaths (8.8% of the total) and 4.32 million DAYLs (5.3% of the total) to physical inactivity [12]. Thus, the proportion of disease attributable to physical inactivity is three times as large in the United States as globally when measured as DALYs and more than twice as high when measured as deaths.

Addressing Environmental Risk Factors in Chronic Illness Care

This chapter highlights that all of the most common chronic diseases in the United States can be triggered or exacerbated by exposure to pollutants in the ambient, home, or workplace environment. In addition, modern urban designs that discourage physically active transportation (e.g., walking and cycling) in favor of reliance on personal automobiles are now widely recognized as an environmental risk factor affecting

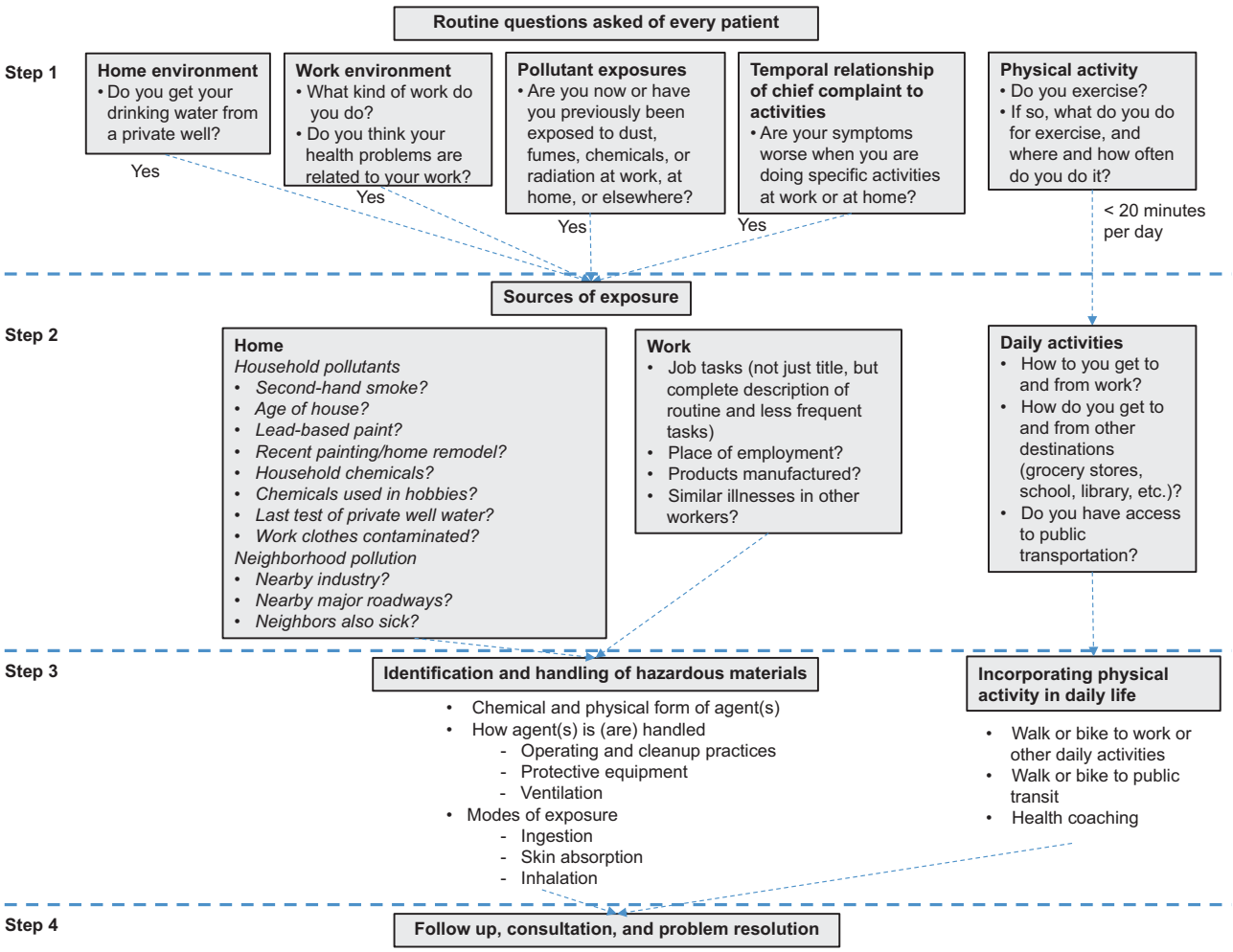

Fig. 37.4 Systematic approach to diagnosing potential environmental contributors to patient health

chronic disease prevalence. Given the multitude of environmental factors influencing health, untangling the potential role of any one of these factors—or combinations of them—in illnesses presenting to a physician or other healthcare provider may be daunting. Nonetheless, identifying underlying environmental factors may be critical to effective treatment or management of a patient's disease.

To help physicians uncover whether environmental factors may be contributing to a patient's disease, specialists in environmental and occupational medicine have developed systematic approaches to eliciting patient histories and diagnosing environmental or occupational illnesses. Fig. 37.4 provides an example, which is adapted from previous questionnaires by physicians at the Harvard School of Public Health and Yale University School of Medicine to include questions about risk factors related to the built environment [103, 104].

The approach for eliciting environmental health histories from patients shown in Fig. 37.4 occurs in three stages, proceeding from the general to the specific. The first stage includes several broad screening questions. The first few questions elicit information to help the physician determine whether the patient may have been exposed to pollutants at home or at work. In addition, these screening questions ask whether the patient has observed a temporal relationship between symptoms and exposures (e.g., decreased symptoms during vacations). If such relationships exist, then the suspicion that an underlying environmental risk factor may have triggered or exacerbated health symptoms increases. In addition, due to the mounting evidence of the deleterious effects of modern environments on physical activity, the screening stage includes two questions about whether and how much the patient exercises. Based on the answers to the screening questions, the physician may or may not proceed to a second, more detailed line of questioning. In this stage, the physician should ask not only about job titles or home locations but also about detailed job tasks, hobbies, and other infrequent activities that could lead to exposure. For example, there is a case of a retired executive who experienced myocardial infarction as a result of using methylene chloride to strip varnish from a wooden chest in an unvented basement; methylene chloride is rapidly metabolized to carbon

Table 37.4 Occupational and environmental health organizations in the United States

Organization	Mission	Contact information
Agency for Toxic Substances and Disease Registry	Federal public health agency that provides health information to prevent harmful exposures and diseases related to toxic substances	Telephone: 800-232-4636
		Website: http://www.atsdr.cdc.gov/
American College of Occupational and Environmental Medicine	Organization representing physicians and other healthcare professionals specializing in the field of occupational and environmental medicine	Telephone: 847-818-1800
		Website: http://www.acoem.org/
Association of Occupational and Environmental Clinics	A nationwide network of more than 60 multidisciplinary clinics and more than 250 occupational and environmental medicine professionals	Telephone: 888-347-2632
		Website: http://www.aoec.org/
National Institute for Occupational Safety and Health	Federal agency responsible for conducting research and making recommendations for the prevention of work-related illness and injury	Telephone: 800-232-4636
		Website: http://www.cdc.gov/niosh/
Occupational Safety and Health Administration (OSHA)	Federal agency responsible for enforcing safety and health legislation. OSHA also offers free on-site consulting to small- and medium-sized businesses. Consultations are separate from enforcement and do not result in penalties	Telephone: 800-321-6742
		Website: http://www.osha.gov/

Source: Re-created from Taiwo et al. [104]

monoxide, which can place substantial stress on the cardiovascular system. For patients whose health symptoms could result in part from physical inactivity, in this stage the physician can also inquire about potential opportunities to incorporate walking and cycling into the patient's daily routine.

The third step is to characterize health effects of exposures uncovered during the first and second stages. Table 37.1 lists health outcomes associated with risk factors discussed in this chapter. For additional information about specific hazardous chemicals, physicians can consult material safety data sheets, which employers are required to provide to workers or their physicians, reference manuals, occupational safety and health organizations (see Table 37.4), or poison control centers. Other references include [103] *Dreisbach's Handbook of Poisoning* [105] and *Clinical Toxicology of Commercial Products* [106], available in medical libraries.

The last stage involves identifying options for treating or managing the patient's condition, along with developing a follow-up plan. In some cases, eliminating exposure to the risk factor can treat the illness. Examples include installing a home water treatment system where water contamination is a source of illness or wearing personal protective equipment to guard against occupational exposures. In some cases, such as for chronic beryllium disease, a change of jobs may be essential. Medical treatment (e.g., chelation therapy for lead exposure) is available for some environmental exposures. In other cases, a physician can refer patients to specialists in occupational medicine or other related fields. Physicians can also report suspected environmental and occupational illnesses to public health officials, trade union health specialists, and workplace managers, thus potentially leading to protections for others. In the case of exposures in the workplace, physicians can help patients to apply for workers' compensation to help cover their medical expenses. In some states, workers can claim these benefits even if occupational exposure was not the primary cause if the work environment "precipitated, hastened, aggravated, or contributed to the ... illness" [103].

When illness is associated with lifestyle choices that may be impacted by the modern built environment, one option is to prescribe health coaching. Over the past decade, health coaching has emerged as a complimentary approach to combating chronic disease [107, 108]. While the definition of health coaching continues to evolve, commonly it includes one-on-one, telephone, or web-based consultations to help patients set and achieve goals for health-promoting behavior changes. Coaching methods are drawn from research in behavioral psychology. Several universities now offer certificate programs in integrated health coaching. Additional information about health coaching can be found at http://guides.mclibrary.duke.edu/integrativecoachingpatients.

Reporting Requirements for Environmental Diseases

When a physician suspects an environmental or occupational factor may have contributed to clinical symptoms in a patient, in some cases those illnesses must be reported to the health department. These reportable illnesses are in two categories: infectious and occupational. The lists of reportable illnesses vary greatly by state, as illustrated in Table 37.5, which compares reportable infectious diseases in California and North

Table 37.5 Comparison of reportable conditions in North Carolina and California (as of December 2016)

Condition	State	Condition	State
Acquired immune deficiency syndrome (AIDS)	North Carolina	Lymphogranuloma venereum	North Carolina
Amebiasis	California	Malaria	Both
Anaplasmosis	California	Measles (rubeola)	Both
Anthrax	Both	Meningitis, pneumococcal	North Carolina
Babesiosis	California	Meningitis, specify etiology: viral, bacterial, fungal, parasitic	California
Botulism	Both	Meningococcal infections	Both
Brucellosis	Both	Middle East respiratory syndrome	North Carolina
Campylobacteriosis	Both	Monkeypox	North Carolina
Chancroid	Both	Mumps	Both
Chickenpox (varicella) (outbreaks, hospitalizations and deaths)	California	Nongonococcal urethritis	North Carolina
Chikungunya virus infection	Both	Novel influenza virus infection	North Carolina
Chlamydia trachomatis	Both	Novel virus infection with pandemic potential	California
Cholera	Both	Paralytic poliomyelitis	North Carolina
Ciguatera fish poisoning	California	Paralytic shellfish poisoning	California
Coccidioidomycosis	California	Pelvic inflammatory disease	North Carolina
Creutzfeldt-Jakob disease	Both	Pertussis (whooping cough)	California
Cryptosporidiosis	Both	Plague	Both
Cyclosporiasis	Both	Poliovirus infection	California
Cysticercosis or taeniasis	California	Psittacosis	Both
Dengue	Both	Q fever	Both
Diphtheria	Both	Rabies, human	North Carolina
Domoic acid poisoning (amnesic shellfish poisoning)	California	Rabies, human or animal	California
Ehrlichiosis	Both	Relapsing fever	California
Encephalitis, arboviral	North Carolina	Respiratory syncytial virus (only report a death in a patient <5 years of age)	California
Encephalitis, specify etiology: viral, bacterial, fungal, parasitic	California	Rickettsial diseases (non-rocky Mountain spotted fever), including typhus and typhus-like illnesses	California
Escherichia coli, Shiga toxin-producing	Both	Rocky Mountain spotted fever	Both
Flavivirus infection of undetermined species	California	Rubella (German measles)	Both
Foodborne disease	Both	Rubella congenital syndrome	North Carolina
Giardiasis	California	Salmonellosis	Both
Gonococcal infections	California	Scombroid fish poisoning	California
Gonorrhea	North Carolina	Severe acute respiratory syndrome (SARS)	North Carolina
Granuloma inguinale	North Carolina	Shiga toxin (detected in feces)	California
Haemophilus influenzae, invasive disease	Both	Shigellosis	Both
Hantavirus infection	Both	Smallpox	Both
Hemolytic uremic syndrome	Both	*Staphylococcus aureus* with reduced susceptibility to vancomycin	North Carolina
Hemorrhagic fever virus infection	North Carolina	Streptococcal infection, group A, invasive disease	North Carolina
Hepatitis A, acute infection	Both	Streptococcal infections (outbreaks of any type and individual cases in food handlers and dairy workers only)	California
Hepatitis B	Both	Syphilis	Both
Hepatitis C	Both	Tetanus	Both
Hepatitis D	California	Toxic shock syndrome	North Carolina
Hepatitis E	California	Trichinosis	Both

(continued)

Table 37.5 (continued)

Condition	State	Condition	State
Human immunodeficiency virus (HIV) infection confirmed	North Carolina	Tuberculosis	Both
Human immunodeficiency virus (HIV) infection, stage 3 (AIDS)	California	Tularemia	Both
Human immunodeficiency virus (HIV), acute infection	California	Typhoid (cases and carriers)	Both
Influenza virus infection causing death	North Carolina	Typhus, epidemic (louse-borne)	North Carolina
Influenza, deaths in laboratory-confirmed cases for age 0–64 years	California	Vaccinia	North Carolina
Influenza, novel strains (human)	California	Vibrio infections	Both
Legionellosis	Both	Viral hemorrhagic fevers, human or animal (e.g., Crimean-Congo, Ebola, Lassa, and Marburg viruses)	California
Leprosy (Hansen disease)	Both	West Nile virus infection	California
Leptospirosis	Both	Whooping cough	North Carolina
Listeriosis	Both	Yellow fever	Both
Lyme disease	Both	Yersiniosis	California
		Zika virus infection	Both

Carolina as of December 2016. In general, the lists of reportable occupational conditions are much shorter than those for infectious disease. For example, North Carolina requires reporting of only three occupational diseases: silicosis, asbestosis, and elevated blood lead levels. The Council of State and Territorial Epidemiologists (CSTE) maintains web sites where physicians can look up infectious (http://www.cste.org/?StateReportable) and occupational illness reporting requirements (http://www.cste.org/group/OHWebsites) for their state. Reporting of suspected environmental or occupational causes of illness to federal agencies is not required. Nonetheless, state health departments routinely report selected infectious diseases specified by CSTE and CDC as "notifiable" to CDC in order to support monitoring of national disease trends and to inform national public health policies.

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The Life Course

38

Timothy P. Daaleman and John S. Preisser

Introduction

Chronic diseases, such as heart disease, stroke, and cancer, are among the most prevalent and serious health conditions, accounting for 70% of all deaths in the United States [1]. These diseases disproportionately affect older adults, a growing population that in coming years will be living with impaired function, decreased quality of life, and utilizing healthcare services at high rates [1, 2]. The term "serious and eventually fatal chronic illness" has been introduced to describe a subset of chronic diseases that are comprised of organ system failures (e.g., heart, lung, kidney), cancers, and stroke which are marked by a progressive loss in health and functional status until death occurs [3]. As the number of older Americans continues to grow, more adults will face chronic illness than ever before, resulting in years of disability and functional decline and greatly affecting their quality of life [4].

In addition to the human cost, the anticipated financial costs to provide the necessary healthcare for chronically ill patients are equally staggering. In addition to the demographic challenges of funding the general needs of an aging population, healthcare costs are expected to rise faster than the wages paid per worker into Social Security and Medicare [5]. The long-range costs for Medicare and Medicaid are projected to increase dramatically due to increases in use and the healthcare costs associated with serving a chronically ill population [5]. A major challenge for the US healthcare system in coming years will be developing value-based models and systems of care for these older adults [2].

Understanding how individual and contextual factors shape the experience of chronic illness is a prerequisite to the development and implementation of any proposed care model or system [6, 7] since both sets of factors contribute to the wide variation in health outcomes, and in the healthcare experiences, of patients living with chronic illness. Individual-level social factors, such as race/ethnicity, exert a substantial influence on perceived health status [8, 9], in addition to healthcare utilization (e.g., hospitalization, hospice usage) [10, 11]. In contrast, contextual factors are features of the social and physical world [12], and many of these influences account for dissimilarities in the healthcare experience of adults who are living with chronic illness, due, in large part, to geographic location and the area distribution of healthcare resources [13, 14]. For example, patients who live in areas with greater healthcare resources are more likely to die in an acute hospital setting than those residing in regions with less capacity [15]. Although much prior work has studied the separate effects of individual-level and contextual determinants [16–18], a common framework and methodology to examine how these factors jointly influence the experience of chronic illness, and important health and health service outcomes salient to these patients, has been lacking.

The life course can provide the foundation to understand and integrate important contextual and individual factors influencing the health and healthcare of chronically ill patients. This perspective has already gained wide acceptance across multiple disciplines, such as gerontology, developmental psychology, and social epidemiology [19]. A life course approach to chronic disease epidemiology, for example, examines the biological, behavioral, and psychosocial pathways that operate across an individual's life span and contribute to the risk of developing chronic disease [20, 21]. Conceptual models within life course epidemiology emphasize the temporal ordering of exposure variables [20].

T.P. Daaleman (✉)
Department of Family Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA
e-mail: tim_daaleman@med.unc.edu

J.S. Preisser
Department of Biostatistics, UNC Gillings School of Global Public Health, Chapel Hill, NC, USA
e-mail: jpreisse@bios.unc.edu

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Life course sociology also highlights principles of time and timing; however, this framework is grounded in a more ecological perspective that views health and illness in light of the social and historical trajectories of individuals [22, 23].

Many physicians and other stakeholders lack a fundamental understanding of how social factors impact health. This chapter provides an introduction to the life course as an orientation to how social determinants influence the health and healthcare of chronically ill patients. The life course framework is grounded in a contextual perspective that views health and illness in light of the social and historical trajectories of individuals [23].

The Life Course Framework

The life course provides a way of understanding how social and behavioral factors impact health. Life course theory emerged from three intellectual traditions: social relations, age and temporality, and life span development [23]. From a social science perspective, roles are patterns of expected behaviors and attitudes that are commonly held and defined within groups or by social situations [24]. A foundation for framing such a social and relational dynamic dates back to the sociological relationship theories that surfaced in the 1960s and 1970s and continues with the life course theory of today [25–27].

Socialization describes how individuals move into and out of social roles, such as being a parent or student, and is accompanied with a set of proscriptive and prescriptive expectations [26]. Patients characteristically occupy a sick role which can release them from their usual obligations and responsibilities, such as work or parenting [28]. These social roles, however, are not isolated sets of expected behaviors and attitudes but are often characterized by a graded sequence and transitions across different periods of the life cycle [29]. For example, older adults rather than children and adolescents are more readily recognized and accepted by others in the sick role, although individual members within each group may be afflicted with the same serious illness, such as diabetes mellitus or cancer.

Role-theoretical perspectives, such as those described by social roles or life cycles, do not fully capture the range of influences since they are timeless and fail to locate individuals within their larger social or historical contexts. Life course theory fills this void by incorporating constructs of age and temporality, which are developed from social anthropology [30, 31]. These elements recognize the multiple chronological meanings of age (e.g., historical time, social time, biological time) and the remarkable individual variability in the timing and scheduling of events along a life course [31]. For example, the health effects of life events and transitions often depend on when they occur, such as whether bereavement and widowhood occur early or later in life [32].

A life span concept of development represents the final intellectual strand of the life course, drawing upon contributions from developmental psychology and life course sociology. Life span concepts such as life review and autobiographical memory emphasize the importance of narrative and memoir accounts within lived lives [33], while human agency views individuals as central actors and producers of their own development [34]. In the United States, patient-centered movements such as end-of-life care and complementary and alternative medicine can be viewed as attempts by patients to reclaim their own voice and individual human agency within a system of healthcare that is often depersonalized and grounded in technology [35].

The life course has been derived from these intellectual strands and can frame how both contextual and individual factors jointly influence the health and healthcare experience of chronically ill patients [23]. This approach is characterized by locating people longitudinally along trajectories and characterizing their social contexts and situations as pathways in which their lives progress [23]. A life course approach to chronic disease epidemiology, noted earlier, looks at how the temporal ordering of exposure variables, such as stress, factors into later life [20]. Overall, the life course framework highlights the importance of time and timing and is grounded in a more ecological perspective that views health and illness in light of the geographic and social-historical trajectories of individuals [22, 23].

Principles of the Life Course

Life course principles promote an awareness of larger social and historical contexts and foster an understanding of the timing of events and the various roles that change over a lifetime [36]. These principles also frame human lives as embedded in relationships with significant others and consider a holistic understanding of lives over time and across changing social contexts [23]. As a whole, the principles are (1) *human development and aging as lifelong processes*, (2) *human agency*, (3) *historical time and place*, (4) *timing*, and (5) *linked lives* [22] (Table 38.1).

The principle of *lifelong development and aging* embraces a longitudinal, often intergenerational, perspective that links earlier life influences with events and outcomes in subsequent years. Life course epidemiology is representative of this principle and examines the long-term effects of physical, environmental, or social exposures during childhood on subsequent health or disease risk in later life [20]. This approach highlights the behavioral, biological, and psychological processes that are active across an individual's lifetime, or across generations, and that may contribute to the risk of developing disease or that can help maintain health and functional status [20].

Table 38.1 Organizing concepts and principles in the life course

Term	Definition
Trajectory	Sequences or long-term patterns within a focal area (e.g., health, family, or work situations) which are embedded in social pathways and defined by social institutions and interpersonal relationships
Transition	Changes in state that are discrete, acquire meaning within trajectories, and have an identifiable beginning and end
Turning point	Individual or institutional sentinel moments that result in a change of direction along one's life course
Linked lives	The interdependence and network of shared relationships that surround individual lives
Social convoy	A grouping of significant others (e.g., important family members, longtime friends) across different life periods
Timing	The developmental antecedents and consequences of behavior patterns, life events, and transitions that vary according to their chronological location in a person's life
Human agency	Views individuals as active participants who construct their own life course through the choices and actions they take, given the opportunities and constraints of history and social circumstances

Ideally, life course epidemiology integrates the contributions of well-established risk factors for disease, such as smoking and hypertension, with the social and environmental processes (e.g., lower socioeconomic status) that may be contributory factors. For example, the prevalence of heart disease peaked in the 1960s for a cohort of men born around the turn of the twentieth century. After this decade, there was a marked, progressive decline in heart disease that continues to this day, and this reflects both the reduction in smoking and advances in blood pressure management in the general US population [37]. However, the drop-off in heart disease in subsequent years was not uniform across all populations, illustrating the differences across subsequent birth cohorts in how early and later life exposures to smoking and hypertension – as well as to other social and psychological factors – predispose to developing heart disease [37].

A life course epidemiologic approach looks at how socially developed and patterned exposures to risk factors in early life may account for marked differences and inequalities – which may not solely be attributable to genetic or biological factors – in later life mortality, disease, and health [20]. In this way of thinking, socioeconomic factors at different periods of the life course can function through an accumulation of risk or via a chain of risk [20]. The accumulation of risk describes the gradual accrual of multiple behavioral risk factors (e.g., smoking, limited physical activity), adverse environmental conditions (e.g., limited green space and walkable areas), and repeated illness or injury episodes that cumulatively cause physiological damage and subsequently increase the risk of disease and mortality [20]. A chain of risk model, in contrast, is a sequence of linked exposures that raise the risk of disease; different types of social, biological, or psychological chains may mediate or moderate an increased or decreased risk of disease [20]. In either risk model, there can be a critical period, which is a limited window of time in which an exposure can have a hazardous or protective effect on subsequent outcomes [20].

Agency is the second principle in the life course, and this characterizes the sense of control that people seek to gain over the events in their lives [38]. Human agency views individuals as active participants who construct their own life course through the choices and actions they take, given the opportunities and constraints of their personal history and social circumstances [38]. Human behaviors, particularly health behaviors, are governed by a myriad of factors, and individuals contribute to – rather than being the sole influencers of – what they do or what happens to them [38]. Agency is tied to individual actions that are done intentionally, and these actions are driven and guided by a person's personal efficacy.

Self-efficacy beliefs are key in personal agency; if people do not believe that they have the power to change or produce a planned outcome, they will not initiate an activity or try to make things happen [38]. These beliefs can be drawn and developed from several sources: enactive mastery experiences that reinforce capability, vicarious experiences that promote efficacy beliefs through comparison with others, verbal and other types of social persuasion, and physiological and affective states through which people gauge their readiness and potential for change [38]. Personal agency does not operate autonomously and individually but works within a network of social structures that have both constraints and opportunities for personal growth and development [38].

Personal agency and efficacy beliefs have provided the theoretical foundation for many health behavior interventions around self-management of chronic disease. These beliefs – that people can motivate themselves and regulate their health behaviors – impact each phase of the personal change process, the contemplation and consideration of changing health behaviors, garnering the motivation and resources that are needed to be successful, and sustaining the desired change and dealing with setbacks [38]. One effective strategy that draws upon human agency is peer support or peer coaching. Peer supporters tap into the efficacy beliefs of people who live with comorbid disease by sharing a personal knowledge and an illness experience in authentic ways that provide the needed practical and emotional support of behavior change [39]. There is a substantial evidence base – from patients living with chronic conditions such as diabetes, cancer, cardiovascular disease, mental illness, and HIV/AIDS – that has demonstrated the effectiveness of peer support in sustaining health behavior change [39].

Peer support strategies offer emotional, social, and practical assistance on how to achieve and sustain complex behaviors that are essential for managing conditions and staying active and healthy [39]. In addition, this approach often complements and adds value to existing healthcare services that help people adhere to care management plans in daily life, to stay motivated and cope with the stressors of chronic illness, and to maintain continuity with their healthcare providers, often in a cost-effective manner [39].

Individual lives are located in a specific *historical time and place*, another core life course principle. The individual life course is embedded in and shaped by the places that a person experiences over a lifetime [22]. Consider the social and economic effects of how AIDS has impacted the lives of children in the African continent. Homelessness, migration, malnutrition, and reduced access to healthcare and education are staggering problems which have greatly increased the probability of illiteracy, poverty, and chronic illness in subsequent adulthood for this population. Place effects can be viewed as historical and ecologic constraints that limit the range of potential opportunities and choices along the life course.

Although there has been long-standing interest in the geographic variations found in health and healthcare services, there is wider recognition that many social determinants of health may operate at a more local level through neighborhoods and communities [40]. A number of health problems, such as low birth weight and infant mortality, tend to be aggregated and studied at the neighborhood level (i.e., census tract or block) and are tied to the cumulative disadvantage and geographic isolation of many African American populations. It is important to clearly define the characteristics of geographic boundaries or areas in ways that are applicable to specific health outcomes. The terms neighborhood, area, and community have frequently been interchangeably used, often referring to an individual's immediate residential environment [40]. Administrative boundaries (e.g., zip code or census block) have also been traditionally used in many studies to operationally define neighborhoods and communities that are situated in a specific geographic location [40].

An important contribution to this field has been the Dartmouth Atlas of Health Care [15]. The atlas has used Medicare claims data to analyze and report about health services in geographically different catchment areas, such as hospital service areas, and has informed how policymakers and healthcare providers understand the contribution of health services to health outcomes and contribute to many of the current national initiatives to improve health systems [15]. A geocoding methodology, known as small area analysis, is a population-based strategy and uses data collected by the Centers for Medicare and Medicaid Services to map out the healthcare services that are provided to Medicare beneficiaries in a defined geographic area [15].

Studies that have used data from the atlas have found that the supply of healthcare resources, such as hospital beds and specialist physicians, markedly and predictably drives utilization of these services [15]. For example, more people with the same diagnosis and comorbidities will be admitted to acute hospitals in regions with a large number of hospital beds per capita, when compared to areas where there are fewer beds per capita. Comparably, in areas that have greater numbers of specialty physicians per capita, there are more office visits. Unfortunately and surprisingly, studies have consistently shown that a higher volume or greater intensity of healthcare does not result in better outcomes for patients [15].

Over the last decade, geographic information systems have been increasingly employed as tools that have been more discretely used to define the social and physical environment of individuals, as well as a way to capture the distribution of healthcare resources (e.g., physicians, hospitals) in a spatial context [41]. Geographic software programs can now generate precise area coordinates that reflect more meaningful regions of human activity – rather than by administratively set boundaries – that are marked by commerce (e.g., markets and shopping centers), work locations, places of worship, and the sites of healthcare services, such as hospitals and physician practices [41].

The life course principle of *timing* acknowledges that the concept of age has several meanings and interpretations [23]. Healthcare providers commonly limit an understanding of time to strictly biological terms that are marked by developmental or physiological changes, such as childhood language acquisition, puberty, and menopause. However, the life course broadens this view to include other ways of thinking about time. For example, social time looks at how chronologic age (i.e., age in years since birth) distinguishes and differentiates role expectations among individuals, an understanding that is illustrated by ongoing discussions regarding the appropriate age for older adults to receive Social Security and Medicare benefits. Subjective time, in contrast, is a person's self-perception of how old they are or how old they wish to be [23].

Timing focuses on the assumptions and expectations that accompany when life events should occur and are normative in areas such as childbearing and family life. Timing gains greater importance for patients and family members around the beginning and end of life. The principle of timing takes into account the developmental antecedents and consequences of life events and transitions which may vary according to their emergence in a person's life [22]. This principle recognizes that the same events or experiences may impact individuals in different ways, depending on when they occur

in an individual's life course. For example, the very early transition to adult responsibilities – getting married or becoming a parent – at a relatively young age has been found to negatively impact subsequent mental health [23].

The principle of timing also takes into account that individuals may view themselves as synchronous ("on-time") or asynchronous ("off-time") with their expectations regarding their social time (i.e., is the life event concordant with their age) or subjective time (i.e., is the life event concordant with how old they see themselves) [22]. This principle is illustrated by variations in the timing of a terminal illness, whether early or later in life. For example, a 35-year-old woman who is unexpectedly diagnosed with breast cancer would be considered in a "too early" age group and asynchronous according to the timetable of her birth cohort.

The last principle in the life course, that of *linked lives*, refers to the interdependence and network of shared, social relationships that surround individual lives. Social relationships can be thought of as the relational ties between individuals (i.e., interindividual) or changes in these connections that take place within one individual over time (i.e., intraindividual) [22]. There are basic characteristics of social relationships, including the size of the personal network and the varying strengths of the social ties between network members. These ties and networks serve multiple functions, such as emotional and instrumental support, and often provide resources in the areas of caregiving and personal care services [42].

The convoy model is one organizing framework of social relationships, particularly for adults. The model views relationships as a series of interactive sequences involving significant others (e.g., important family members, longtime friends) that aggregate and disassemble across different periods of the life course [22]. This way of thinking emphasizes the longitudinal character of relationships and conveys a fluid aspect that is often not captured by social support or family network concepts. Social convoys view an individual as moving through their lifetimes surrounded by different groups of people who are close and important to them, an alliance of others who have a critical influence (either positive or negative) on their life and well-being [22].

Social network is another conceptual approach and recognizes that individuals are embedded in a web of relationships and are influenced by the behaviors and activities of those around them [42]. In analyzing social networks, the concept of a node is used to describe people who may or may not be connected to others in the network; the connection between two nodes is termed a tie [42]. Social networks acknowledge the human tendency of individuals who choose relationships with others that have comparable attributes and behaviors, and the grouping of nodes – each of which is connected to at least another node – is called a cluster [42].

This principle is illustrated by a study that evaluated a social network of over 12,000 people who participated in the Framingham Heart Study, a landmark cohort study which identified risk factors for cardiovascular disease [42]. Over 30 years of longitudinal data were used to create a social network variable that depicted clusters of people with different degrees of relationships or ties and examined the associations between social networks and obesity. The study found that a person's risk of becoming obese increased by 57% if he or she had a friend who also became obese. In pairs of adult siblings, if one sibling became obese, the chance that the other would become obese increased by 40%. If one spouse became obese, the likelihood that the other spouse would become obese increased by 37%.

Trajectories and Transitions

Life course principles provide a comprehensive understanding of lives over time and in changing social contexts. The concepts of trajectory and transition are central, unifying themes, and they represent both the short- and long-term perspective of life course principles [22]. Lived lives, for example, take place over an extended span of time, a social trajectory of work or marriage, or a developmental trajectory of self-rated health. In contrast, a sense of agency or personal control may be developed within a short time span that is marked by the transition of specific life events, such as graduating from college and getting married. The life course framework emphasizes the importance of trajectories, as well as transitions and turning points, as core concepts in its framework [22].

Trajectories are sequences or long-term patterns within a given area (e.g., health, family, or work situations) and are formed by linking states (e.g., health status, poverty) and transitions across successive years [22]. Trajectories are not individual events in time, but are embedded in social pathways that are defined by social institutions and relationships that provide social support. Transitions are inflections and changes in direction of the trajectory [22]. In health, transitions acquire meaning within trajectories and the changes in state that are discrete and have an identifiable beginning and end.

Illness trajectories go beyond the physiological unfolding of disease to encompass the total organization of activities which are done over the course of the illness. This way of thinking takes into account the impact that this work has on those involved in the accompanying activities. Work here refers to the physical and emotional tasks and activities performed by patients and caregivers. When a trajectory and its transition place people in new environments and alter behavioral and social patterns, they are referred to as turning points [22]. Turning points are individual or institutional

sentinel moments that result in a change of direction along the life course [22]. For example, a chronically ill patient who declines aggressive medical care has reached a turning point. The probable subsequent decline in health and functional status and entry into long-term care or hospice would constitute both a trajectory and a turning point. Trajectories are influenced by and directly impact social relationships (e.g., family caregivers) and provide a way to understand and conceptualize the important factors that potentially affect a patient's experience of health, illness, and well-being [22].

Trajectories have been mapped out to depict the patient experience of serious chronic illness and are distinguished by variations in their duration and shape [43–45]. A report from the Institute of Medicine, for example, offered three plausible functional trajectories specific to serious illness and dying: (1) sudden death from an unexpected cause, (2) steady decline from a progressive disease with a "terminal" phase, and (3) advanced illness marked by a slow decline with periodic crises (Fig. 38.1) [43, 46]. A subsequent study of Medicare beneficiaries examined the degree to which these three trajectories accurately characterized seriously ill

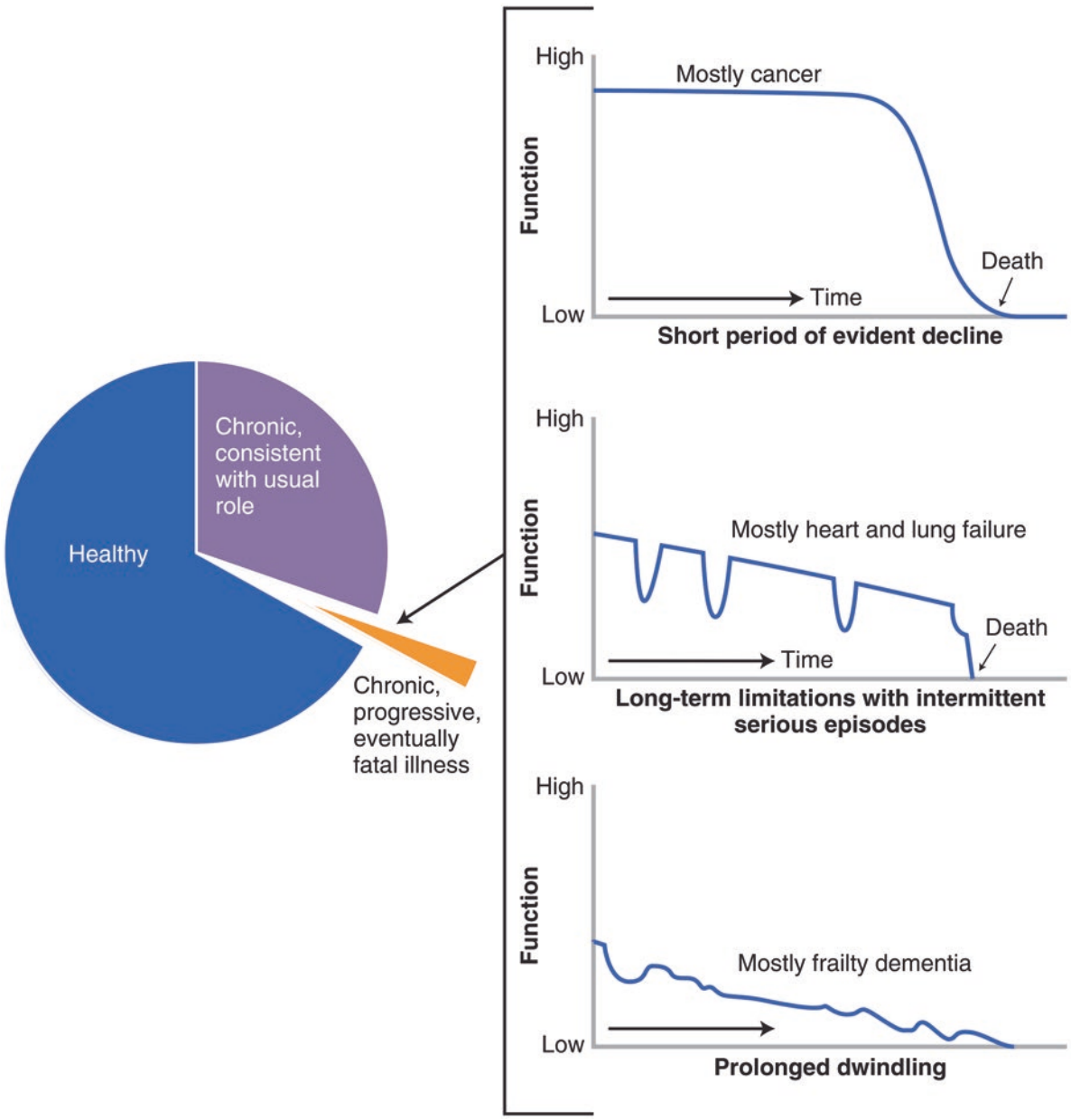

Fig. 38.1 Functional trajectories of serious chronic illness (Redrawn from [48, 49])

and dying patients and four trajectories were able to characterize 92% of individuals' pathways at the end of life: (1) sudden death, (2) terminal illness, (3) organ failure, and (4) frailty [47].

An Analytic Approach to Determining Trajectories

Statistical approaches that integrate repeated observations over time and identify different paths of progression are central to determining trajectories. This analytical method is different than simply using discrete observations at baseline and at one or more points in time. With trajectories, the focus is less on determining the outcome of interest as it is in describing the sequence of events that contribute to and sustain it. Since analytic strategies used in characterizing trajectories may not be commonly understood, this section describes one approach by illustrating the functional trajectories of older adults with serious chronic illness (i.e., a subset of chronic diseases which are marked by a progressive loss in health and functional status leading to death) [3].

The primary strategy assumes a continuous-scale outcome and relies on the use of hierarchical linear models (HLM) to account for repeated measures; these are also known as linear mixed models. When the outcome is categorical or discrete, generalized linear mixed models may be used. The methods include (1) equations for population-averaged trajectories and their corresponding residuals that are used to aggregate individuals into subgroups based on a specific outcome measure (e.g., older adults with a pattern of physical functioning over time), (2) explanatory models that identify factors associated with different outcome pathways, (3) estimating individual trajectories with prediction equations that include random individual-level effects to account for deviation of an individual's trajectory from the population-averaged trajectory for the group to which he/she belongs, and (4) validating the trajectories with respect to conceptually related measures.

Using this example, older adults with serious chronic illness (SCI) might be categorized into the following groups: (1) terminal illness (cancer, solid or hematologic malignancy, or malignant tumor of any type), (2) organ failure (ischemic heart disease, congestive heart failure, chronic kidney disease, chronic obstructive pulmonary disease), and (3) frailty (stroke, cerebrovascular accident). Life course principles, which were described earlier, can inform the selection of data elements to be used in modeling trajectories for specific patient populations. The following section illustrates how analyses might proceed in differentiating and then describing these three groups and the extent to which they provide a representation of the variety of pathways among those with serious chronic illness.

Identifying the Pathways: Population-Averaged Trajectories and Residuals to Identify Resilient or Vulnerable Functioning

For each of the three groups with serious chronic illness, an average trajectory can be estimated by adjusting the intercept for baseline severity (and comorbid conditions, such as depression) and then identifying individuals for whom the model does not have a good fit. For simplicity, an analysis for a single group can be considered, although models can be specified to analyze all three groups simultaneously as this provides improved precision when regression parameters are shared across the three groups. Specifically, a longitudinal data model may be fit with up to a cubic effect of time (i.e., an individual's age is used instead of calendar time (t) in order to address age cohort effects):

$$E\left[Y(t)\right] = b0 + b1 * t + b2 * t^2 + b3 * t^3$$

In conjunction with this model for the mean value of functional status where a higher value corresponds to higher function, an appropriate covariance model can be specified within the context of a hierarchical linear model [50] in the case of a continuous outcome or a generalized linear model (GLM) estimated by generalized estimating equations for a categorical outcome [51, 52]. Once the regression parameter estimates have been obtained, a set of residuals can be computed, one for each observation that an individual contributes to the analysis. An individual with a particularly large (i.e., positive) residual (e.g., about the estimated mean marginal regression curve) is one who has functional status better than expected at that particular age. An individual with a particularly small (i.e., negative) residual is one who has functional status poorer than expected at that particular age. In this way, so-called "resilient" (i.e., those who maintain their functioning) and "vulnerable" (i.e., those with declining functioning) older adults can be defined.

Practically, using longitudinal data from electronic health records can inform the categorization of an individual as resilient or vulnerable. This categorization will be time-dependent, as an individual who becomes vulnerable later in life may have better functioning than expected at a younger age and subsequently poorer functioning than expected at an older age. At each of several ages, which can be determined based upon the distribution of ages in the data, the upper quartile of residuals can be defined as the resilient older adults and the lower quartile of residuals as the vulnerable

older adults. Two logistic regression analyses can be conducted, the first assessing whether individual factors, such as linked lives and agency, predict resiliency and the second assessing whether these factors predict vulnerability. These analyses (i.e., one for resiliency and one for vulnerability) can provide an assessment of individuals' longitudinal indicators in order to summarize findings across the life course. For example, do stronger social network ties with others explain resiliency across all ages or only for some age groups? To address such questions, modeling approaches for longitudinal dichotomous outcomes such as generalized estimating equations can be used [51, 52], with extensions for ordered outcomes (e.g., resiliency vs. "typical" function vs. vulnerability) [53, 54].

Understanding Differences Among the Pathways: Explanatory Models that Identify Factors Associated with Different Functioning Pathways

This approach, which extends that of the previous section, assesses directly, within the context of an HLM (or GLM, in the case of a categorical outcome), whether or not trajectories of functional status differ by individual characteristics. For simplicity, consider a covariate, X, and the longitudinal data model for a single SCI group:

$$E\left[Y(t)\right] = (b0 + a0 * X) + (b1 + a1 * X) * t + (b2 + a2 * X) * t^2 + (b3 + a3 * X) * t^3$$

If X is equal to 0 or 1, then a test that the regression coefficients, $a0$, $a1$, $a2$, and $a3$, are simultaneously equal to 0 is a test of whether or not the trajectory of functional status is identical for the two groups determined by X. A fully saturated model including several categorical covariates, informed by life course principles, would estimate intercept, linear, quadratic, and cubic time effects for each group resulting from the cross-classification of the covariates. In accordance with the richness of the data, a sequence of regression models can be fit.

The first set of models can include severity factors retaining main effects in order to adjust the intercept $b0$ above but dropping nonsignificant polynomial time-effect interactions as more complex but parsimonious models are built to describe varying trajectories. In this regard, the second set of models can additionally include individual factors, and the third set of models can add potentially protective factors, such as social networks. For example, do protective factors alter the group trajectories of functional status after controlling for symptom severity and other individual factors? The focus here is on estimating functional status trajectories for the three SCI groups and determining whether subgroups within those three primary groups have different trajectories.

Identifying Individuals' Pathways: Estimating Individual Trajectories Using Prediction Equations

Hierarchical linear models, also known as random coefficient models in the context of repeated measures, can be used to estimate a trajectory of a continuous outcome for each individual; generalized linear mixed models (e.g., logistic models with random coefficients) [52] could be used for dichotomous or categorical outcomes. In the parlance of linear mixed models, the individual-level trajectories can be based upon best linear unbiased predictors of model random effects. It would be possible to estimate a trajectory for each individual using only person-specific data, for example, a cubic polynomial curve for an individual with at least four data points. However, these trajectories can be poorly estimated if there is little data. The strength of the HLM approach is that individual trajectories can be estimated by also using information from a comprehensive data set from electronic health records via the particular model that is used. Ideally, random coefficients would be fit for each of the four polynomial terms in the model above. However, this model is very complex and it may not be computationally feasible to test it. Therefore, a simpler model that specifies a random intercept and linear term may be employed. Considering one of the mean models above, the model for the i-th adult at the t-th time is:

$$Y(\mathrm{it}) = E\left[Y(t)\right] + \mathrm{bi0} + \mathrm{bi1} * t + e(\mathrm{it})$$

In the above equation, $Y(\mathrm{it})$ is the observed functional status for the i-th adult at the t-th time, $E[Y(t)]$ is the mean trajectory for a particular SCI group (or subgroups if individual-level factors are included), bi0 and bi1 are individual-level deviations from the overall group mean intercept and slope, and $e(\mathrm{it})$ is a random error term. With the usual zero-mean normality assumptions of these random deviations, empirical Bayes estimation is used to provide estimates of bi0 and bi1 for each individual. Plugging these estimates into the above equation (with zero for $e(\mathrm{it})$) gives a predicted trajectory for each individual. For each SCI group, the individual trajectories can then be plotted to reveal their variation about the overall group mean trajectory, allowing characterization of variability of trajectories within each SCI group.

Caring for Patients and Populations Through the Life Course

The US healthcare system is in the midst of a transformation to value-based care, which will emphasize and reimburse high-quality, cost-effective, patient-centered care at the individual patient and population level. In this emerging

system, healthcare providers and other stakeholders will be responsible for managing the care of chronically ill populations of patients. The life course can provide both the conceptual grounding and practical approaches for those who will be managing population in a system that seeks to optimize health and reduce disease burden, not just in the short term but over the life span [55]. This orientation will shift the focus away from discrete, unlinked episodes of care, such as office visits, hospitalizations, and treatments for episodic or time-limited problems to longitudinal trajectories of health and illness. In the foreseeable future, electronic health records and other sources will allow the measurement and creation of longitudinal data across the life course of patients, allowing the categorization of individual trajectories in specific health and wellness domains, such as overall health and functional status.

For healthcare providers and public health officials, life course health data will allow a more complete understanding of how health is maintained or how disease develops, throughout the course of patients' lives. Practically, this information will have the potential to transform the way health promotion and disease prevention programs are designed and implemented [55]. For example, predictive models using a life course approach may identify patients who are most likely to develop heart disease or diabetes, based on their cumulative individual (e.g., lack of exercise) and larger contextual (e.g., residence in a high-stress community) risk factors, facilitating the creation of targeted preemptive and preventive interventions [55]. At the same time, modeling pathways will support evaluation not in terms of "snapshots" of current status but of status and change in status over many years.

Health insurers and other payors will have greater incentives to promote health trajectories for patient populations, or segments, and to augment the longitudinal integration of healthcare services, such as extending coverage and benefits from years to decades, creating incentives to manage risk, and assuming accountability for specified health outcomes [55]. An effective and efficient healthcare system would ultimately require not only healthcare services that are vertically integrated across medical, educational, and social service sites (e.g., worksites, schools) but also the horizontal integration across the entirety of the life course [55, 56].

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Part VI

Health Policy and Chronic Illness Care

Medicare

39

Jonathan Oberlander

Introduction

Medicare plays a central role in American medical care. For over 50 years, it has provided health insurance to older Americans, ensuring their access to medical services and a measure of financial security during retirement. Since 1972, the program has additionally insured persons with permanent disabilities and end-stage renal disease. In 2016, Medicare covered over 57 million persons [1]. That number will climb substantially during the next decade as the baby boom generation retires.

Medicare also has an enormous role in shaping health-care payment and delivery. Medicare is the single largest purchaser of medical services in the United States and a major source of income for physicians, hospitals, and other medical providers. The decisions that Medicare makes about how to pay providers, and what types of medical care delivery to promote and experiment with, reverberate across American medicine. The future of payment and delivery reform depends in no small part on their fortunes in Medicare.

When Medicare was enacted in 1965, it emphasized coverage for acute episodes of illness, following the standard insurance model of that time. The needs of persons with chronic conditions received less attention. Sizable holes in Medicare's benefit package have left many enrollees who need ongoing care vulnerable to high costs and bereft of critical services. Over 50 years after its enactment, managing chronic disease remains a challenge for Medicare despite the fact that it "is in reality a program serving people with chronic conditions…" [2].

This chapter provides an overview of Medicare, its origins, populations served, benefits, and financing. It also covers major issues in Medicare reform, including efforts to control Medicare spending and to introduce innovations in medical care payment and delivery, and the impact of the Affordable Care Act.

J. Oberlander (✉)
Department of Social Medicine, School of Medicine, and Department of Health Policy & Management, Gillings School of Global Public Health, University of North Carolina-Chapel Hill, Chapel Hill, NC, USA
e-mail: oberland@med.unc.edu

Origins

The United States has a patchwork insurance system, with coverage varying by age, occupation, income, and even the condition of particular organ systems. That contrasts with the norm in other rich democracies like Canada that operate a single insurance system for all of their citizens. Why does the United States have a separate government health-care program for older Americans and younger persons with permanent disabilities? The answer lies in Medicare's roots in the twentieth-century debates over national health insurance in the United States. Efforts by reformers to advance national health insurance during the Progressive Era (1912–1920) and Franklin Delano Roosevelt's presidency (1933–1945) went nowhere. In 1945, President Harry Truman became the first US president to formally endorse a government health insurance program for all Americans. However, legislation creating such a program did not come close to passing Congress. It failed due to intense opposition from the American Medical Association (AMA), the power in Congress of a de facto conservative coalition comprising Republican and Southern Democratic lawmakers, and fears of socialized medicine that were magnified by rising anti-communist fears and Cold War anxieties [3, 4].

By 1951, Truman administration officials were seeking a new strategy to advance health-care reform. Instead of comprehensive universal health insurance for all Americans, they narrowed the goal to enacting a federal insurance program that would cover the costs of hospitalization for elderly Social Security beneficiaries [3]. The Medicare strategy was born. The strategy was one of incrementalism, shaped by political calculations and constraints. Medicare's architects

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decided to focus on covering the aged, as they were then called, because older Americans commanded public sympathy and could be seen as deserving of government aid. Moreover, the substantive case for government action was compelling. Before Medicare's enactment most seniors lacked meaningful health insurance, even though they used many more services than younger Americans. By connecting Medicare to and constructing it in the image of Social Security, reformers hoped to leverage that program's popularity as social insurance and an earned entitlement. And by narrowing coverage to hospital services, Medicare advocates hoped to diminish the AMA's opposition to federal health insurance [3, 5].

That latter goal was not realized—during the 1950s and early 1960s the AMA campaigned vigorously against Medicare. AMA President David Allman called the proposal to establish federal health insurance for the elderly "nine parts evil to one part sincerity" [5]. In 1961, the AMA hired Ronald Reagan, then an actor who subsequently became governor of California and president of the United States, to make a recording that warned of dire consequences if Medicare became law: "behind it will come other federal programs that will invade every area of freedom we have known in this country. Until one day…we will awake to find that we have socialism" [5]. Meanwhile, the influence of the conservative coalition in Congress—Southern Democrats and Republicans—blocked Medicare's legislative path. The 1964 elections, which President Lyndon Johnson won in a landslide and gave Democrats huge majorities in both the House and Senate, broke the impasse, leading to Medicare's enactment in 1965 (Medicaid, a program for certain categories of low-income Americans, was enacted as part of the same legislation as Medicare) [3].

Although Medicare was created as a program for the elderly, its advocates believed that was just the start. They saw Medicare as the cornerstone of a universal insurance system. After covering seniors, children were to be next in line for federal health insurance, and its architects envisioned that Medicare would eventually expand to cover all Americans. In 1972, Congress did extend Medicare eligibility to include younger Americans with permanent disabilities who were receiving Social Security Disability Insurance (SSDI) as well as persons with end-stage renal disease. Yet Medicare did not subsequently expand to add any more major populations. Instead it was Medicaid that followed an expansionary trajectory, including becoming the major government health-care program for children. The original vision of Medicare for All has never been realized [6].

Populations Served

Medicare is, like Social Security, an earned entitlement—eligibility is established through work—and a social insurance program that covers all eligible Americans regardless of their income, which is unlike welfare programs that are open only to those who earn below a specified income threshold. Medicare insures virtually all Americans age 65 and older, with 46 million older Americans enrolled in the program in 2015 [7]. Older Americans become eligible for Medicare through the Social Security system; persons who qualify for Social Security retirement benefits through either their own work or as dependents also qualify for Medicare. Medicare-eligible persons are automatically enrolled into the program when they turn 65 [8, 9]. Notably, Medicare has never charged elderly Americans who have pre-existing conditions higher premiums or refused to cover them, discriminatory practices that were common in the private insurance market before the 2010 Patient Protection and Affordable Care Act (ACA). Medicare has made insurance accessible and affordable for a population—older Americans—that otherwise would struggle to obtain private coverage [10].

Medicare insures two other populations with complex medical care needs: younger Americans with permanent disabilities and persons with end-stage renal disease (ESRD). While public attention often equates Medicare with seniors, these populations are a significant part of the program. In 2013, there were nearly 8.5 million persons with permanent disabilities under the age of 65 on Medicare, constituting 16% of all program enrollees [11]. Medicare insured 450,000 persons with ESRD (about half of those were younger than age 65; Medicare provides universal insurance for ESRD regardless of age, paying for dialysis and kidney transplants, as well as all Part A and B covered services, for persons with permanent kidney failure) [8, 9, 11]. Persons with permanent disabilities who receive Social Security Disability Insurance and are therefore eligible for Medicare must wait for 2 years before their Medicare coverage begins. However, persons with ESRD or amyotrophic lateral sclerosis (ALS) who are receiving SSDI do not face a waiting period to join Medicare [8].

The populations that Medicare covers—older Americans, persons with permanent disabilities, and those with end-stage renal disease—have substantial medical needs. Nearly two-thirds of Medicare enrollees have three or more chronic conditions, 31% have cognitive or mental impairments, and 27% report they are in fair or poor health [12]. A number of chronic conditions are prevalent in the Medicare population: 58% of beneficiaries in traditional Medicare have high blood pressure, 45% have high cholesterol, 31% have ischemic

heart disease, 29% have arthritis, and 28% have diabetes [13]. Many Medicare enrollees also have limited resources, with 50% having both incomes below $24,150 and savings below $63,350 in 2015 [7].

Benefits

Medicare beneficiaries can choose whether to join the traditional program operated by the federal government (sometimes called Original Medicare) where beneficiaries can generally go to any doctor or hospital that accepts Medicare patients or instead enroll in a private insurance plan that contracts with the government to provide Medicare benefits (i.e., Medicare Advantage plans) [7–9]. Private plans in Medicare at first were exclusively HMOs but now encompass a wider variety of options such as preferred provider organizations (PPOs). Such plans have gained a growing share of the Medicare population. In 2017, 33% of all program beneficiaries were enrolled in a Medicare Advantage plan, which often have restricted provider networks [14]. While Medicare is often called a single-payer program, it is in fact a hybrid, with a large government insurance plan operating alongside private insurers. Persons with specified chronic conditions such as diabetes or dementia are among the Medicare beneficiaries who are eligible to join Special Needs Plans (SNPs) [8].

Medicare benefits are divided into four components. Part A (hospital insurance) covers inpatient hospital care, as well as skilled nursing facility, hospice, and home health care. Part B (medical insurance) pays for physicians' services, as well as outpatient care, laboratory services, durable medical equipment, preventive services such as cancer and diabetes screenings, and home health care. Part C comprises the aforementioned Medicare Advantage program that offers Medicare beneficiaries the option to enroll in a private plan as an alternative to traditional Medicare (such plans must cover all Part A and B benefits). Part D provides voluntary coverage for outpatient prescription drugs through private plans that contract with Medicare [7–9].

The division of Medicare benefits dates back to the program's 1965 enactment, when insurance for hospital (Part A) and physician services (Part B) were established as separate components [3, 5]. The persistence of these arrangements attests to the enduring influence of decisions made over 50 years ago on contemporary Medicare. Yet this separation of service categories, which mirrored practices by some private insurers in 1965, makes little sense today when the aspiration is to integrate medical care across the spectrum of services—an aspiration that is particularly important for persons with chronic illnesses.

Beyond their administrative fragmentation, Medicare benefits are also limited in important ways [7–10]. Medicare does not have a general dental benefit and will not pay for routine dental services. Medicare does not cover hearing aids or routine eye exams. Coverage of skilled nursing care as part of Medicare's home health benefit is limited to part-time or intermittent care. Medicare will not pay for custodial care that provides help with the activities of daily living to persons with chronic illnesses or a disability. Nor does Medicare cover long-term stays in nursing homes, a responsibility that instead falls on Medicaid (though Medicare does cover stays up to 100 days in skilled nursing facilities, including rehabilitation services, after an inpatient hospitalization of at least 3 days). Medicare coverage for care in a psychiatric hospital is limited to 190 days total during a beneficiary's lifetime in the program.

Medicare coverage for hospital stays (Part A) requires a sizable deductible ($1316 in 2017) and copayments for prolonged stays (in 2017, $329 per day for days 61–90 and $658 for each lifetime reserve day, of which there are a total of 60 that beneficiaries can draw on during their time on Medicare) [8]. Medicare's coverage of hospital care is organized according to benefit periods ("spell of illness") that begin when a patient enters the hospital and end 60 days after a person leaves the hospital. As a result, some Medicare beneficiaries incur multiple deductibles for hospital insurance in 1 year, which imposes a substantial financial burden on them. There is a separate, more modest deductible ($183 in 2017) for Medicare Part B (which covers physician and outpatient services). Beneficiaries are also responsible for paying 20% of the Medicare-approved amount for physicians' bills and, in 2017, $164 a day for days 21–100 in a skilled nursing facility [8]. Medicare's coverage for outpatient prescription drugs requires substantial cost sharing—including a deductible ($400 for the standard plan in 2017) and coinsurance (25% up to an initial coverage limit of $3700). And traditional Medicare has no annual limit on the total amount that enrollees can pay out of their pocket for deductibles, copayments, and coinsurance (Medicare Advantage plans do have such a limit). Relative to typical health plans that large employers offer to their workers, Medicare coverage is somewhat less generous [15].

These limitations in Medicare benefits are longstanding. From its inception, Medicare never covered all of its beneficiaries' medical care costs. Medicare's architects sought to protect older Americans against the most devastating expenses from illness—hospitalization. While physicians' services were included in the 1965 legislation that established Medicare, the program still focused on insuring beneficiaries for acute illness episodes. Policymakers in effect presumed that older Americans' medical care needs were similar to those of younger populations and did not recognize the greater burden of chronic illness among the elderly [16]. While Medicare benefits have expanded in important ways over time—including the addition of outpatient prescription drug coverage in 2003—they still have major

limitations that leave program enrollees responsible for paying a substantial portion of their medical bills [17].

As a consequence of the holes in its benefit package, most Medicare beneficiaries carry additional insurance [7, 12]. About 20% of program beneficiaries are so-called dual eligibles who receive Medicaid as well as Medicare. Such persons may qualify for Medicare on the basis of age and for Medicaid on the basis of income. For these beneficiaries, Medicaid provides extra benefits and pays the cost sharing that Medicare requires. Another 39% of Medicare beneficiaries have supplemental coverage plans sponsored by their former employer, which commonly cover extra benefits like prescription drugs. About 20% of Medicare beneficiaries purchase their own supplemental insurance policies called Medigap plans that help pay for Medicare cost sharing including deductibles and copayments [7, 12]. And the 33% of beneficiaries who receive their Medicare coverage through private Medicare Advantage plans typically receive extra benefits (such as vision and hearing coverage) from those plans, which also usually cover prescription drugs [14].

Even with these supplemental sources of coverage, Medicare beneficiaries still pay substantial amounts for medical care. In 2011, the Kaiser Family Foundation reports, "Medicare beneficiaries spent $5,368 out of their pockets for health care spending, on average" [12]. Those financial liabilities are roughly equally split between insurance premiums (encompassing both Medicare and private supplemental plans) and payments for medical services, constituting a substantial burden for low-income enrollees. Out-of-pocket spending rises with age, with Medicare beneficiaries age 85 and older spending $8276 on average compared to about $4000 for those between ages 65 and 74. Such costs are also much higher for beneficiaries in poor self-reported health. In total, medical care accounted for 14% of all household spending by Medicare beneficiaries in 2012 [8, 12, 17].

Expenditures and Financing

Medicare spending totaled $646 billion in 2015, accounting for 20% of all US health-care spending and 14% of the federal budget [18]. Medicare is financed by a combination of taxes and beneficiary payments. Medicare hospitalization insurance (Part A) is funded predominantly through payroll taxes that all American workers pay. In 2017, the standard hospitalization insurance payroll tax was 1.45%, with higher-income Americans paying more. Beneficiaries become eligible for Medicare hospital insurance as a result of previously having paid (or their spouses paying) compulsory payroll taxes while they are employed. There is no Part A premium for persons who are eligible because they already contributed taxes to Medicare (10 years of contributions are required). Older Americans who aren't eligible through the Social Security system can pay premiums to join Part A [7–9].

Medicare Part B—medical insurance—is a voluntary program though persons who don't sign up for the program when first eligible must pay late penalties if they subsequently enroll [8, 9]. It is funded mostly through general revenues, which encompass all the money the federal government collects from individual and corporate income taxes, excise taxes (e.g., tobacco taxes), and other sources. While general revenues fund 75% of Part B spending, the other 25% comes from beneficiary premiums. In 2017, the standard Part B monthly premium was $134 for persons with $85,000 of income or less [7–9, 12]. Higher-income beneficiaries receive a lower subsidy from the federal government and thus pay higher premiums. In 2017, for example, Medicare enrollees making between $85,000 and $107,000 paid monthly Part B premiums of $187, with persons with annual incomes between $160,000 and $214,000 paying $348 a month. The funding of Part D prescription drug coverage mirrors the arrangements for Part B, with funding from general revenues and income-related beneficiary premiums (monthly premiums averaged about $36 in 2017). Lower-income Medicare beneficiaries are eligible for savings programs that help pay for their premiums for medical (Part B) and prescription drug (Part D) coverage. Beneficiaries who enroll in a Medicare Advantage private plan may pay additional premiums on top of the standard Medicare rates.

Medicare's finances are the subject of much political debate and controversy. The program is frequently said to be on the verge of bankruptcy. That rhetoric is a direct reflection of Medicare's financing arrangements [5]. Medicare's finances are organized into government trust funds, which are essentially accounting mechanisms to record program revenues and expenditures. Medicare's trust fund for hospital insurance is funded almost entirely from payroll taxes that are specifically earmarked for Medicare. Social Security financing works in a similar fashion. When those payroll taxes aren't sufficient to meet costs, Medicare appears to be running out of money and is therefore said to be going bankrupt. Trust fund revenues can drop for reasons having nothing to do with Medicare costs, such as a recession that increases unemployment and thereby reduces the amount of taxes that the government collects.

In contrast, most federal programs are financed out of general government revenues; they don't have a specific funding source or earmarked tax that is credited to a trust fund. Federal spending for the military, education, Medicaid, and many other federal programs are paid for through general revenues [5, 10]. No matter how expensive these programs are or how much their costs rise, we usually do not speak of them as going bankrupt. In fact, Medicare's trust

fund for Part B (i.e., physicians' services) is similarly funded mostly from general revenues that automatically increase when program costs rise. As a result, it too is immune from bankruptcy talk.

When policymakers allege, then, that Medicare is "going bankrupt," they are actually referring to actuarial projections that in some future year the program will not have sufficient funds to pay the entire cost of Medicare hospital insurance. In 2016, for example, actuaries estimated that the Medicare Part A trust fund would become insolvent in 2028, when they said the program would have 87% of the money it needs to pay all costs [19]. Yet the notion that Medicare will ever literally go bankrupt and stop paying for beneficiaries' medical services is misleading [5, 11]. These are projections, and policymakers can alter Medicare's future financial circumstances by increasing revenues through higher payroll taxes or decreasing costs by limiting program payments and reforming how Medicare pays for medical services. That is in fact exactly what has happened over the past half century of Medicare's operations. Periodically there have been warnings of shortfalls in the hospital insurance trust fund, and each time policymakers have acted to improve Medicare's fiscal condition. There is no chance that politicians would ever let a program that serves nearly 50 million (and growing) older Americans ever stop operations. Medicare will never go bankrupt. Yet even though bankruptcy rhetoric is misleading, it is nonetheless an important feature of Medicare politics. It is used by reformers and critics alike to push proposals to change Medicare in the name of saving the program [5]. Consequently, major Medicare reforms often happen during periods where the projected date of insolvency for the hospital insurance trust fund is within a decade.

Medicare and the Affordable Care Act

The 2010 Affordable Care Act (ACA, aka Obamacare), which aimed to expand health insurance to America's uninsured population while moderating health-care spending growth and reforming medical care delivery, made a number of significant changes to Medicare [20]. The ACA expanded Medicare benefits, providing program beneficiaries with coverage of preventive services such as flu shots and cancer screenings at no cost, enhancing Medicare coverage of outpatient prescription drugs by closing the "doughnut hole" in Part D, and adding coverage for an annual wellness visit. And it raised Medicare taxes on higher-income Americans, including an increase in the hospital insurance payroll tax and a new tax on "unearned" investment income (from capital gains, dividends, and other sources) for persons making over $200,000 a year.

The ACA also contained substantial reductions in Medicare spending. The nonpartisan Congressional Budget Office projected at the ACA's enactment that the law would slow down the annual rate of increase in Medicare spending from 6.8% to 5.5% during 2010–2019 (producing over $400 billion in savings) [21]. The ACA's Medicare savings largely reflected reductions in program payments to hospitals and private Medicare Advantage plans. The ACA additionally sought to advance a series of payment and delivery reforms in Medicare, including Accountable Care Organizations (ACOs) and bundled payment and adopted other initiatives to promote value-based purchasing that reward higher-quality care. The ACA also contained measures that aimed to improve care for persons with chronic conditions, including a program that reduces payments to hospitals with high readmission rates for their Medicare patient, the Medicare Community-Based Care Transitions Program that funds partnerships between hospitals and community-based organizations to reduce readmissions, and establishment of a new office to improve care coordination for dual persons who are dually eligible for Medicare and Medicaid [20]. The ACA established a new institution—the Center for Medicare and Medicaid Innovation (CMMI)—that could develop, evaluate, and scale up experiments in medical care delivery and payment.

Finally, the ACA created the Independent Payment Advisory Board (IPAB). IPAB was envisioned as a failsafe to restrain Medicare spending if the aforementioned measures didn't work to curb program spending growth [20, 22]. If Medicare spending per beneficiary increased at rates faster than targets specified in the ACA, then IPAB, a nonelected board of experts and health system stakeholders, would make recommendations to reduce program expenditures. Congress has to consider Medicare reforms proposed by the board under special legislative rules designed to ensure speedy action. If Congress does not enact legislation containing those proposals or alternative policies that achieve the same savings, the Secretary of Health and Human Services is to implement IPAB's recommendations.

Since its 2010 enactment, Obamacare has been engulfed by controversy, and Republicans have sought to repeal and replace it. The 2016 election of Donald Trump to the presidency gave the GOP, which also maintained its Congressional majorities, an opportunity to fulfill that goal. However, the fate of the ACA and Republican repeal and replace efforts is uncertain at this writing. Regardless of what becomes of the ACA, some of its Medicare provisions, including cuts in provider payments and the Hospital Readmissions Reduction Program, are likely to remain law. Other measures, such as the increases in Medicare taxes on high-income earners and the IPAB, could be eliminated.

Controlling Medicare Spending

Controlling spending has long been the dominant issue in Medicare policy. When Medicare was enacted in 1965, health-care cost control was not a policy issue in the United States. Private insurers at that time often exerted little control over payments to physicians and hospitals. Medicare, which sought to give the elderly access to mainstream medicine, built on that permissive status quo rather than seeking to transform it [3–5]. The 1965 Medicare statute declared that "nothing in this title shall be construed to authorize any federal officer or employee to exercise any control over the practice of medicine or the manner in which medical services are provided" [5]. The political context of Medicare also shaped its payment policies. Program administrators wanted to ensure a smooth takeoff for Medicare and secure the medical profession's cooperation; the AMA had fiercely opposed Medicare's enactment and there were fears that doctors would boycott federal health insurance. Medicare's initial payment policies thus were designed to promote political conciliation rather than fiscal control [23].

Hospitals were reimbursed retrospectively for the services they provided to Medicare beneficiaries on the basis of "reasonable costs," a standard adapted from private plans like Blue Cross [3, 5, 23]. Hospitals received generous capital depreciation allowances and, initially, a 2% bonus on their Medicare charges. Medicare paid physicians retrospectively on a fee-for-service basis, according to their "reasonable charges." Reasonable charges meant that the federal government would pay physician fees for Medicare patients that reflected their customary charges for similar services to private insurers as well as the prevailing community rate for such services. Medicare did not establish a national fee schedule to limit payments. Instead, the "customary and prevailing" formula gave physicians a strong economic incentive to raise their charges so they could receive higher fees [3, 5, 24]. In sum, Medicare started operations in 1966 with no real limits on program payments to hospitals or physicians.

Medicare's original methods of paying medical care providers were inherently inflationary. Predictably, federal spending on Medicare quickly increased at rates far exceeding the projections that had been made at the time of its enactment. In 1969, only 3 years after the program's beginning, Russell Long, chair of the Senate Finance Committee, declared that Medicare had become a "run-away program" [5]. By 1971, President Richard Nixon was warning that medical care costs had "skyrocketed" [25]. Spending more on medical care, which in earlier decades had been presumed to be a worthwhile investment in the nation's health, was now seen as a fiscal threat [4, 5]. The advent of Medicare and Medicaid transformed the role of the federal government in medical care. Rising health-care costs exacted a growing claim on the federal budget, and Washington consequently had an interest in restraining Medicare spending.

Early efforts to control Medicare spending during the 1970s, including establishing professional standard review organizations to audit inpatient care for inappropriate and unnecessary services, proved largely ineffective [4, 5, 26]. Federal policymakers were reluctant to take on the medical care industry and impose strong payment limits. But as federal spending on Medicare continued to climb in the context of rising government budget deficits, policymakers became more willing to disrupt the status quo. During the 1980s, Congress enacted a major reform in both hospital and physician payment. The 1983 Prospective Payment System (PPS) for hospitals was followed in 1989 by the Medicare Fee Schedule (MFS) for physicians [5, 26].

The new arrangements for paying medical care providers amounted to a revolution in Medicare policy. Since the implementation of the PPS and MFS, Medicare has paid doctors and hospitals according to rates prospectively set by the federal government, rather than retrospectively reimbursing costs, as the program initially did. Hospitals are reimbursed on the basis of diagnosis-related groups (DRGs), with Medicare paying hospitals a fixed amount based on a patient's clinical condition and treatment. Physicians are paid according to a preset fee schedule, with the fee for each service calculated on the basis of relative value units (RVUs) that measure the time, effort, skill, intensity, complexity, stress, and practice expenses associated with different medical services. In 1997, Congress extended prospective payment to post-acute care, including home health, skilled nursing facility, and hospital outpatient services. Over time, then, administered pricing has come to play a dominant role in Medicare [26].

The federal government adopted these prospective payment systems to help restrain Medicare spending growth. Have they worked? During 1975–1983, before the implementation of Medicare's hospital PPS, the annual rate of excess growth ("defined as growth beyond that attributable to general economic growth and changes in beneficiaries' age composition") was 5.6% [27]. During 1983–1997, as Medicare implemented prospective payment systems, that rate fell to 2.1% and then to 0.5% during 1997–2005 [26]. Federal policymakers have repeatedly used prospective payment systems to generate Medicare savings. The 2005 Deficit Reduction Act reduced Medicare payments for imaging, durable medical equipment, and home health services [28]. The 2010 Affordable Care Act cut the growth in Medicare payments to an array of medical providers (physicians were exempted), with especially large reductions for hospitals and private Medicare Advantage plans. Since the ACA's passage, there has been a pronounced slowdown in Medicare spending (the 2011 Budget Control Act led to additional cuts in

program payments) [28, 29]. In 2009 Medicare per beneficiary spending stood at $10,537; by 2014, it had risen only slightly to $10,809, $1200 lower than predicted in 2010 [29]. Medicare spending in 2014 totaled $580 billion, $126 billion lower than forecast in 2009, and the average annual growth rate in Medicare spending per beneficiary during 2010–2015 was 1.4% [29].

Medicare spending is sometimes portrayed as growing uncontrollably, with cost increases driven inexorably by medical technology and population aging. Those forces do increase Medicare spending. But the record of Medicare spending outlined above contradicts the notion that the program is uncontrollable [27]. In fact, Medicare spending growth slowed substantially after the federal government adopted prospective payment systems and used those systems to hold down expenditures. Medicare, in other words, is responsive to policy reform, and its spending is not simply the product of inexorable forces. That does not mean that Medicare's cost problems have been solved—some of Medicare's payment systems have been more effective than others, regulating prices has proven easier than controlling growth in volume and intensity of services, Medicare spending growth has varied across different time periods, and as noted later in this chapter, significant fiscal challenges loom in Medicare's future. It does mean, though, that Medicare's record on cost containment is better than often assumed and that federal policymakers have a proven ability to moderate program spending growth.

The impact of prospective payment in Medicare underscores the program's role as an innovator and reform leader in American medical care [30]. DRGs, after all, represented an early form of bundled payment that was designed to create incentives for hospitals to economize and control costs [26]. Other payers, including state Medicaid plans, private insurers, and health-care systems abroad, also use DRGs. Medicare's RVU-based physician fee schedule is commonly used by private insurers (though they typically do not have as much purchasing power as Medicare so pay higher rates). It also underscores the fact that Medicare's primary cost control strategy has been limiting payments to medical providers through price regulation. Price regulation is an imperfect tool. There is evidence that some services Medicare pays for are mispriced. Additionally, program payments have tilted toward specialists and proceduralists, creating an imbalance that contributes to the undervaluing of primary care in American medicine [24]. Price regulation is nonetheless an important tool, one has proven effective at slowing down Medicare spending growth.

Payment and Delivery Reform

During the program's first 50 years, Medicare reform focused on containing program spending. As noted above, cost containment in Medicare mostly meant limiting payments to medical providers. In recent years, though, there has been growing interest among the health policy community in changing how Medicare pays for services in order to create incentives that lead to improved quality and coordination of care, better patient outcomes, and stronger cost control. An array of payment and delivery reform initiatives are unfolding in Medicare, often under the labels of "value-based purchasing" or moving from "volume to value." Such measures are seen in part as a way to overcome the barriers in traditional Medicare to better management of chronic conditions: fragmentation of responsibility and lack of accountability for persons who receive medical services from multiple providers; the absence of financial incentives to encourage care coordination and discourage unnecessary, duplicative services across multiple settings; and the absence of policies to pay for or incentivize care management as well as interprovider communication and collaboration [2, 20, 31].

Value-based purchasing comes in many varieties. Under Medicare's Hospital Readmissions Reduction Program (HRRP), adopted in 2010 as part of the ACA, the federal government reduces payments to hospitals with excess admissions for targeted conditions such as heart failure, pneumonia, chronic obstructive pulmonary disease (COPD), and persons receiving coronary artery bypass graft surgery [32]. Enactment of HRRP reflected policymakers' concerns with high readmission rates in Medicare. During 2003–2004, about 20% of Medicare beneficiaries who had been discharged from a hospital were rehospitalized within 30 days, raising questions about the adequacy of discharge planning and follow-up care [33]. By penalizing hospitals financially—an example of so-called "pay for performance" arrangements—the aim is to reduce readmissions, improve care, and lower costs, though the costs of preventable rehospitalizations comprise a modest share of total Medicare spending.

Medicare is also experimenting with new forms of bundled payment (DRGs represented an early example of this strategy). Such arrangements pay a group of providers one aggregate, fixed amount for an episode of care or diagnosis rather than separate fees for each service delivered [34]. Bundled payment seeks to create incentives to limit medical spending and improve care coordination; providers who hold down the costs of care under bundled payment do better financially. Doctors and hospitals are at more financial risk in bundled payment than under arrangements where they are reimbursed for costs and services regardless of the volume and intensity of care [35]. Some bundled payment models include post-acute services in the episode of care, thereby incentivizing providers to pay attention to what happens to patients after a hospital stay. Medicare has implemented bundled payment for a number of medical care episodes, including stroke, chronic obstructive pulmonary disease, cardiac procedures, and joint replacement [36]. While participation in bundled payment was initially voluntary, in

2016 Medicare launched a mandatory bundled payment program for joint replacement.

Accountable Care Organizations (ACOs) embody another effort to transform how Medicare pays for and delivers medical care. ACOs are "networks of physicians and other providers that are held accountable for the cost and quality of the full continuum of care delivered to a group of patients" [37]. Patients typically don't actively enroll in an ACO, but instead are attributed to it based on where and from which providers they receive medical care. Persons generally can seek services outside of the ACO network, though the ACO is responsible financially for all of their medical care. ACOs operate under spending targets, based on historical spending patterns, for their patient populations. If they hold total costs below that target, they can keep some of the savings; if they exceed the target, they can lose money depending on the model [37]. As a result, ACOs have a financial stake in holding down spending, reversing the traditional incentives of fee-for-service payment that can lead to overutilization. Many ACOs actually pay providers fee-for-service and then reconcile those payments with the spending target.

ACOs' payments also depend on their ability to meet specified quality of care measures. They may not be eligible for bonuses based on containing spending if quality standards are not met. In Medicare ACOs, examples of these quality measures include patient ratings of providers; depression, colorectal cancer, and mammography screening; hemoglobin A1c control in diabetics; drug therapy to lower LDL cholesterol for patients with coronary artery disease; and unplanned admissions for patients with multiple chronic conditions [38]. ACOs thus aim to control spending, improve care coordination and service quality, and enhance population health. In these aims and by making a network of providers accountable for a defined population, ACOs recall the logic of HMOs that sought to integrate the financing and delivery of medical care within one organization. However, ACOs are looser, less restrictive, and ultimately less organized entities, allowing more beneficiary choice of provider and emphasizing a greater role for physicians and other providers in making care decisions. ACOs are, in effect, HMOs without the parts (like closed provider networks) that previously proved unpopular and controversial.

Medicare's new formula for updating physician fees also seeks to move beyond paying for the volume of services. Under the Merit-Based Incentive Payment System (MIPS), Medicare will pay physicians, starting in 2019, according to their performance on quality, resource use, reporting care information, and clinical practice improvement activities [39]. Physicians who receive a substantial portion of their payments from ACOs, patient-centered medical homes, and other innovative payment models can instead join the Advanced Alternative Payment Models (APM) program. Beginning in 2026, doctors who are in the APM program will receive higher annual fee updates than those participating in MIPS. Physicians consequently will face powerful new financial incentives to participate in such models [40].

In sum, Medicare's embrace of value-based purchasing through these and other initiatives marks a significant change in federal policy. In 2015, Secretary of Health and Human Services (HHS) Sylvia Burwell declared that "Our goal is to have 85% of all Medicare fee-for-service payments tied to quality or value by 2016, and 90% by 2018...[and] to have 30% of Medicare payments tied to quality or value through alternative payment models by the end of 2016, and 50% of payments by the end of 2018" [41]. In 2016, HHS announced that it had met the goal of having 30% of Medicare payments to alternative payment models like ACOs [42].

The appeal of value-based purchasing in Medicare, which promises to contain spending while rewarding high-quality care and promoting better patient outcomes, is understandable. Yet the results of such initiatives have been mixed. The introduction of the Hospital Readmissions Reduction Program has been associated with declines in readmission rates for Medicare patients [43]. The Independence at Home Program, which provides primary care services to chronically ill persons in their homes and enables providers to share in savings if spending and quality targets are met, has produced some savings as well as lower rates of hospital readmission and use [44]. However, other measures have not proven as successful. Medicare's Hospital Value-Based Purchasing Program (HVBP), which provides incentive payments to hospitals based on measures of the quality of inpatient care, "did not improve clinical process or patient experience performance in its first year" and a subsequent study found it "has also not reduced mortality" [45]. A demonstration of patient-centered medical homes in Medicare that paid fees to providers for care management, the Multi-Payer Advanced Primary Care Practice, did not produce savings. Separately, in 2015 Medicare implemented a new billing code that allows physicians to receive payment for non-face-to-face services that are part of chronic care management [44]. Meanwhile, Medicare's much-heralded ACO programs, after taking account of bonuses paid out by the government to high-performing networks, have not saved the program much money, though they have fared better in improving quality of care [46–48]. And despite the rhetoric of moving from volume to value, in reality most Medicare payments, as well as those in private insurance, still depend on the volume of services delivered [40]. The future of bundled payment in Medicare is also uncertain, despite some promising early results in joint replacement, as the Trump administration has delayed an expansion of a mandatory bundled payment initiative that was scheduled to begin in 2017 [49].

It is important to distinguish the aspirations of value-based purchasing models from their actual performance.

While the goals of such arrangements are laudable, that does not mean they will work in practice [50]. Indeed, much of the evidence to date regarding value-based purchasing strategies "suggests that incentives for providers do not improve value or lead to better outcomes for patients" [45]. Furthermore, based on experiences so far, value-based purchasing seems unlikely to emerge as a panacea for rising Medicare costs. In policymakers' and analysts' desire to find ways to "solve" the multiple challenges facing Medicare, there is, then, a danger of conflating rhetoric with reality and over-hyping the likely impact of emerging policy alternatives [51]. Much uncertainty remains regarding the ability of payment and delivery reforms to fulfill their promise.

There is also a strong tendency in US health-care policy, pervasive in discussions of Medicare reform, to presume the necessity of abandoning fee-for-service payment in order to control health-care spending. As noted by Bruce Vladeck, former head of CMS's predecessor, the Health Care Financing Administration, though such a view is "logically powerful," it is also "inconsistent with the facts" [52]. Nations like Canada and Japan that spend much less on medical care than the United States actually pay physicians fee-for-service [50–52]. Simply put, other rich democracies do not rely on value-based purchasing to control costs; they rely on price regulation and budgeting. There are good reasons, such as enhancing coordination and quality of care and curbing overtreatment, to modify or seek alternatives to fee-for-service payment. But international experience demonstrates that jettisoning fee-for-service is not the key to limiting medical care spending.

The Future of Medicare

In coming years, Medicare faces a series of major fiscal, political, and policy challenges. As the baby boom generation retires, program enrollment is growing substantially. During 2000–2030, the Medicare population is projected to increase from 40 million to 81 million [7]. While that demographic trend is often portrayed as a fearful prospect, the reality is that the real public policy crisis would be if we did not already have a program, Medicare, that guarantees health insurance to older Americans. Moreover, other rich democracies have older populations than the United States, yet those nations spend far less on medical care than we do [50]. Demography is not destiny.

Nonetheless, population aging will create financing pressures in Medicare and intensify debates over how to control program spending. As the stakes of Medicare reform grow, Washington will likely see renewed partisan conflict over how to change the program, including controversial proposals to transform Medicare into a modified voucher or "premium support" system that would limit the government's insurance subsidy for program enrollees. At the same time, the aging of the Medicare population will also draw attention to persistent limitations in program benefits, including the absence of long-term care coverage as well as to persistent challenges in caring for chronically ill persons and those with complex medical care needs. Payment and delivery reforms remain a work in progress and are unclear if Medicare can successfully rebalance its reimbursement arrangements to reward primary care. Medicare's fortunes are also tied to the volatile fate of health-care reform and the Affordable Care Act.

Medicare has been at the center of American medicine for over half a century. In future years, the importance of Medicare and its influence over US health care will only grow, as will its role in serving persons with chronic illnesses.

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Medicaid

40

Timothy P. Daaleman and Warren P. Newton

Introduction

Medicaid is the largest insurer in the United States and is the nation's public health insurance program for low-income adults, children, pregnant women, the elderly, and people with disabilities [1]. The program encompasses a wide scope of health services and covers patients who often have complex and chronic health-care needs, including long-term care. Medicaid provides a significant amount of financing – over 16% of all personal health-care spending – for physicians, hospitals, nursing homes, and community health centers [1]. The program is administered by states, according to federal requirements, and is funded jointly by the states and the federal government [2].

Medicaid has had a significant and positive impact on access to care and health-related outcomes, particularly for the most vulnerable Americans [1]. Participants in the program, for example, are more likely to get needed care when compared to the uninsured; both children and adults covered by Medicaid are comparable to those with private health insurance in areas of health-care access and utilization [1]. Medicaid coverage of low-income pregnant women and children has likely contributed to sustained declines in infant and child mortality, and a growing body of research indicates the program may also be associated with long-term improvements, such as lower rates of hospitalization and emergency department visits in later life [3].

This chapter provides an introduction to Medicaid. The first section describes the historical development of the program. The next section outlines the structure of the program, including Medicaid eligibility requirements and benefits that are covered. This content area is followed by an overview of Medicaid financing and reimbursement, as well as program costs. Next, several care innovations that were fostered by state Medicaid programs are highlighted before the chapter closes with opportunities and challenges going forward as the ACA is reformed.

Historical Developments

On July 30, 1965, President Johnson authorized Title XIX of the Social Security Act, which created Medicare and Medicaid. Medicaid was designed to provide health care for the poor, specifically "low-income children, caretaker relatives, the elderly, the blind, and individuals with disabilities" [4]. The initial bill covered 4 million people and cost $900 million [5] and the program has grown to cover almost 73 million [6] individuals, with costs exceeding $545 billion [7] over a 50-year timespan. Table 40.1 chronologically lists the major changes in Medicaid since its inception. There has been progressive growth in both covered benefits and in the groups of people entitled to benefits over that timeframe. In addition, there have been several noteworthy developments in the program. In 1967, Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services were mandated for children up to age 21, which defined a set of core benefits for children [4]. During the early 1970s, states were given the option to cover services for intermediate care facilities and for patients with mental retardation [4].

Arizona was the last state to join Medicaid in 1982 and throughout the 1980s, there was progressive expansion of benefits for pregnant women, in addition to targeted support of managed care, such as quality standards for certified nursing homes [4]. The Children's Health Insurance Program (CHIP) was enacted in 1997, a program that furnishes federal matching funds to states that provide health coverage to children in families with incomes that are too high to qualify for Medicaid, but who also can't afford private coverage [6].

T.P. Daaleman (✉) • W.P. Newton
Department of Family Medicine, University of North Carolina at Chapel Hill School of Medicine, Chapel Hill, NC, USA
e-mail: tim_daaleman@med.unc.edu; Warren_newton@med.unc.edu

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Table 40.1 Timeline of changes in Medicaid since 1965

1965	Social Security Amendments of 1965 passed (H.R. 6675)
1967	EPSDT services for children up to age 21 mandated
1971	States given option to cover services in ICFs and patients with MR
1972	SSI and Medicaid eligibility for the elderly and disabled are linked
1977	HCFA is created (ended in 2000)
1981	OBRA 81 allows states to make additional payments to DSH hospitals
1982	Arizona becomes last state to participate in Medicaid
1982	TEFRA expands states abilities to impose cost-sharing on certain Medicaid beneficiaries and allows states to extend coverage to disabled children living at home
1984	Deficit Reduction Act and Aid to Families with Dependent Children (AFDC)
1985	OBRA 85, Consolidated Omnibus Budget Reconciliation Act
1986	OBRA 86, requires states to provide Medicaid to immigrants and pregnant women and infants living 100% at or below the FPL
1987	OBRA 87, states granted option to extend coverage to pregnant women and infants living at or below 185% of FPL and quality of care standards for certified nursing homes
1989	OBRA 89, states required to cover services provided by FQHCs
1990	OBRA 90, Medicaid prescription drug rebate program
1995	Block grant veto
1997	CHIP is established
2000	States are given option to extend Medicaid coverage to uninsured women with breast or cervical cancer
2001	CMS is established
2003	Medicare Part D prescription program
2009	CHIPRA
2009	ARRA
2010	ACA, expand coverage, control health-care costs, and improve delivery
2013	First open enrollment for the health insurance marketplaces
2014	ACA coverage becomes effective

Adapted from source: Table 40.2: Key Core Medicaid Benefits (https://kaiserfamilyfoundation.files.wordpress.com/2013/01/8174.pdf)

Since that time, nearly every state has been providing coverage for children up to at least 200% of the Federal Poverty Level (FPL) [6]. Medicaid began to include drug coverage for classes of disease such as HIV in the 1990s and 2000s.

Concerns about the increased costs of care have led to multiple interventions in the Medicaid program. In the 1990s, states began to turn to managed care organizations (MCOs), of which there are two types: primary care case management (PCCM) and risk-based MCOs. In a PCCM system, the state pays for services on a fee-for-service basis as well as a monthly fee to a contracted primary care provider to coordinate care for the beneficiary. In a risk-based MCO, an insurance company assumes financial risk for the cost of health care in return for flexibility to manage care utilization and payment to providers. From the perspective of state governments, risk-based MCOs are attractive since they theoretically represent a predictable expense for state budgeting. As a result, managed Medicaid has spread rapidly, with 39 states and over 60% of Medicaid patients receiving coverage under this arrangement [8].

The Affordable Care Act (ACA) was passed in 2010 and created the capacity for states to expand Medicaid and cover nearly all low-income Americans under age 65 [6]. Since that time, Congress has enacted several laws designed to improve access to mental health care and substance use treatment under health insurance plans [6]. The Mental Health Parity and Addiction Equity Act, for example, affects millions of Medicaid beneficiaries participating in managed care organizations and the Children's Health Insurance Program [6]. There is ongoing debate around ACA reform with several of major policy proposals at play that will determine the future direction of the Medicaid program [9].

Medicaid Structure, Eligibility, and Benefits

Medicaid is a joint federal and state program in which states can design and administer their own individual program, subject to federal requirements [6]. The Centers for Medicare and Medicaid Services (CMS) is the federal agency responsible for Medicaid, which is governed by Title XIX of the Social Security Act and a large body of federal rules [6]. The agreement between each state and the federal government is known as a State Plan Amendment (SPA), which is an assurance that a state will abide by federal rules for Medicaid and may claim matching federal funds for its program activities [10]. When a state is planning to make a change to its program policies or operational approach, states send SPAs to CMS for review and approval. States can also submit SPAs to request permissible program changes, make corrections, or update their Medicaid or CHIP state plan with new information [10].

In order to participate in Medicaid, federal law requires states to cover certain groups of individuals, such as low-income families, qualified pregnant women and children, and individuals receiving Supplemental Security Income (SSI) [6]. There are additional options for coverage, and states may choose to cover other groups, such as individuals receiving home- and community-based services, and children in foster care who are not otherwise eligible [6]. States have great flexibility – within federal guidelines – to determine which populations will be covered, the scope of health-care services offered, and fiscal models for reimbursing physicians, hospitals, and other health-care providers [6]. States can also apply for waivers to test and implement innovative health-care delivery models that may not strictly fol-

low federal Medicaid rules, but that advance overall program objectives (i.e., improving care quality, lowering costs), as determined by the Secretary of the Department of Health and Human Services [6].

In 2010, the Affordable Care Act (ACA) created the capacity for states to expand Medicaid and cover nearly all low-income Americans under age 65 [11]. Eligibility for children was extended to at least 133% of the federal poverty level (FPL) and states were given the option to extend eligibility to adults with income at or below 133% of the FPL. The majority of states have chosen to expand coverage to adults and those that have not yet expanded may choose to do so [11]. In addition to Medicaid expansion, the ACA enacted the Basic Health Program, which provides states an option to establish a set of health benefits for low-income residents who would otherwise be eligible to purchase coverage through the health insurance marketplace [11]. The program's goal is to provide health insurance coverage and enhance continuity of care for people whose income fluctuates above and below Medicaid and CHIP levels [11].

The ACA also established a new approach for determining income eligibility for Medicaid, based on the modified adjusted gross income (MAGI) [11]. MAGI-based methodology considers taxable income and tax filing relationships to determine financial eligibility for Medicaid and has replaced an earlier process for calculating Medicaid eligibility, which was based on the Aid to Families with Dependent Children approach [11]. Some individuals are exempt from the MAGI-based income rules, including those whose eligibility is based on blindness, disability, or age (i.e., 65 and older). Medicaid eligibility for individuals 65 and older or those who have blindness or a disability is determined using methodologies from the Supplemental Security Income (SSI) program administered by the Social Security Administration [11]. Eligibility for the Medicare Savings Programs, through which Medicaid pays Medicare premiums, deductibles, and/or coinsurance costs for beneficiaries eligible for both programs (i.e., dual eligible), is also determined using SSI methodologies [11].

For citizens who have significant health needs and whose income is too high to otherwise qualify for Medicaid under other eligibility groups, states have the option to establish a "medically needy program" [11]. These individuals can become eligible by "spending down" expenses for medical care for which they do not have health insurance coverage. When an individual's incurred expenses exceed the difference between the individual's income and the state's medically needy income level (i.e., the "spenddown" amount), the person is eligible for Medicaid. The Medicaid program then pays the cost of services that exceed what the individual had to incur in the way of expenses in order to become eligible [11].

Medicaid benefits can vary across states since the program has evolved and serves diverse populations with a wide range of needs, including individuals who are very poor and very frail. States determine the type, amount, duration, and scope of services within broad federal guidelines, which provide certain mandatory benefits and allow states the choice of covering other optional benefits [12]. Mandatory benefits include services such as inpatient and ambulatory care services, physician services, laboratory and x-ray services, and home health services. Some optional benefits can include prescription drugs, case management, physical therapy, and occupational therapy [12]. Figure 40.1 lists mandatory and optional add-on benefit features that are mandated by the federal government [13].

In addition to hospital and physician services, Medicaid also covers some specialized services. The Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit provides comprehensive and preventive health-care services for children under age 21 [14]. The benefit seeks to ensure that children and adolescents receive appropriate preventive, dental, mental health, developmental, and specialty services [14]. States are required to provide comprehensive services needed to address health conditions, based on certain federal guidelines. EPSDT is comprised of the following screening, diagnostic, and treatment services: comprehensive health and developmental history, comprehensive physical exam, timely and appropriate immunizations, laboratory screening, health education, and vision, dental, and hearing services [14].

Medicaid is the single largest payer for mental health services in the United States and is increasingly playing a larger role in treatment services for substance use disorders [15]. States that have expanded Medicaid are preparing for a broader range of mental health and substance abuse services to the expansion population [16]. Under expansion, Medicaid beneficiaries must receive an Alternative Benefit Plan (ABP), covering categories of essential health benefits, including mental health and substance abuse services. By contrast, only certain substance abuse services comprise mandatory coverage categories for a non-ABP State Plan, such as physician services, inpatient services (including medically necessary inpatient detoxification), and Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services for children and adolescents 21 years of age and under. Coverage of most substance abuse services is optional [16]. Each state's approach to substance abuse services in managed care and the associated physical and mental health benefit will vary, depending upon the respective state's experience with funding, administration, and delivery of substance abuse services [16].

Minimun and Optional Medicaid Benefits

Minimum Benefits

- Physician services
- Laboratory and x-ray services
- Inpatient hosptial services
- Outpatient hospital services
- Early and periodic screening, diagnostic, and treatment (EPSDT) services for individuals under21
- Family planning
- Rural and federally-qualified health center (FQHC) services
- Nurse midwife services
- Nursing facility (NF) services for individuals 21 or over
- Home health care services for individuals entitled to nursing facility care
- Smoking cessation services for pregnant women
- Free-standing birth center services

Selected Optional Benefits

- Prescription drugs
- Clinic services
- Dental services
- Physical, occupational, and speech therapy
- Other diagnostic, screening, preventive, and rehabilitative services
- Prosthetic devices, dentures, eyeglasses
- Intermediate care facilities for intellectual and developmental disabilities (ICF/IDD) services
- Inpatient psychiatric care for individuals under 21
- Home health care services (for those not entitled for NF care)
- Personal care services with option to self direct
- Health home services to individuals with chronic conditions
- Community First Choice attendant care services
- Case management
- Hospice services

Fig. 40.1 Minimum and optional medicaid benefits (Adapted from: http://files.kff.org/attachment/Issue-Brief-Current-Flexibility-in-Medicaid-An-Overview-of-Federal-Standards-and-State-Options)

Medicaid Financing, Reimbursement, and Costs

Medicaid is financed jointly by the federal government and the states and there is currently guaranteed availability of federal Medicaid matching funding [17]. Federal matching funds provide a mechanism for state resources to cover low-income residents and also permit state Medicaid programs to respond to demographic and economic shifts, changing coverage needs, technological innovations, and public health emergencies such as the opioid addiction crisis, natural disasters, and other events beyond states' control [17]. The mechanism for providing matching funds from the federal government to the state governments is called the Federal Medical Assistance Program (FMAP). FMAPs are adjusted on a 3-year cycle for each state to account for economic fluctuations and are based on criteria such as per capita income [17]. This percentage varies across the United States and ranges between 50% and 82% [17]. Mississippi, for example, which has the lowest per capita income of all states, receives a 73% match through the FMAP [18].

Under their respective plan, states must ensure they can fund their portion of Medicaid expenditures for the care and services that will be provided. There are several funding sources for the state share of Medicaid including legislative appropriations to the single state agency, intergovernmental transfers, certified public expenditures, permissible taxes, and provider donations [17]. States must verify that state funding sources meet statutory and regulatory requirements before CMS approves a state plan amendment that authorizes federal participation for the services [17]. Regarding reimbursement, states can establish their own Medicaid provider payment rates within federal requirements and generally pay for services through fee-for-service or managed care arrangements [17].

Fee-for-service arrangements allow states to pay providers directly for services. Rates are generally based on the

costs of providing the service, a review of what commercial payers pay in the private market, and a percentage of what Medicare pays for equivalent services [17].

Approximately 70% of Medicaid enrollees receive care through managed care service arrangements, where providers are paid on a monthly capitation rate [17]. Under managed care, states contract with organizations to deliver care through networks and also pay providers [17]. These payment rates are updated and based on specific trending factors, such as the Medicare Economic Index or a Medicaid-specific trend factor that uses a state-determined inflation adjustment rate [17]. Medicaid limits the direct patient costs of care, which, unlike commercial insurance, usually includes substantial co-pays and coinsurance for visits, medications, and hospitalization. For some income levels, Medicaid allows co-pays up to 2% of patient income.

State Medicaid programs must make Disproportionate Share Hospital (DSH) payments to qualifying hospitals that serve a large number of Medicaid and uninsured individuals under federal law [17]. Figure 40.2 shows federal DSH payment allocations to states in 2015 [19]. An annual DSH allotment is established for each state, which limits the Federal Financial Participation (FFP) for total statewide DSH payments made to hospitals. In some states, only a limited number of safety net hospitals receive this support, while other states have mechanisms for distributing federal support across institutions. DSH requires a state contribution in order to get the federal match. In some states, funding is provided directly from the legislature, but in other states, there is a tax on health-care providers.

There is also a hospital-specific DSH limit in which FFP is not available for state DSH payments that are greater than the hospital's eligible uncompensated care cost [17]. This amount is the cost of providing inpatient hospital and outpatient hospital services to Medicaid patients and the uninsured, minus payments received by the hospital on or on the behalf of those patients [17]. Medicaid provided $18 billion in support to local hospitals in 2014 through Disproportionate Share payments [20]. Upper payment level (UPL) is another mechanism for providing selective support to safety net institutions. UPL provides flexibility for states to set the maximum rate to be paid [21]. The coverage and reimbursement requirements vary from state to state, but UPL allows some institutions to receive payment at a higher level for clinical services [21].

Medicaid provides supplemental payments to both federally qualified health centers (FQHCs) and rural health

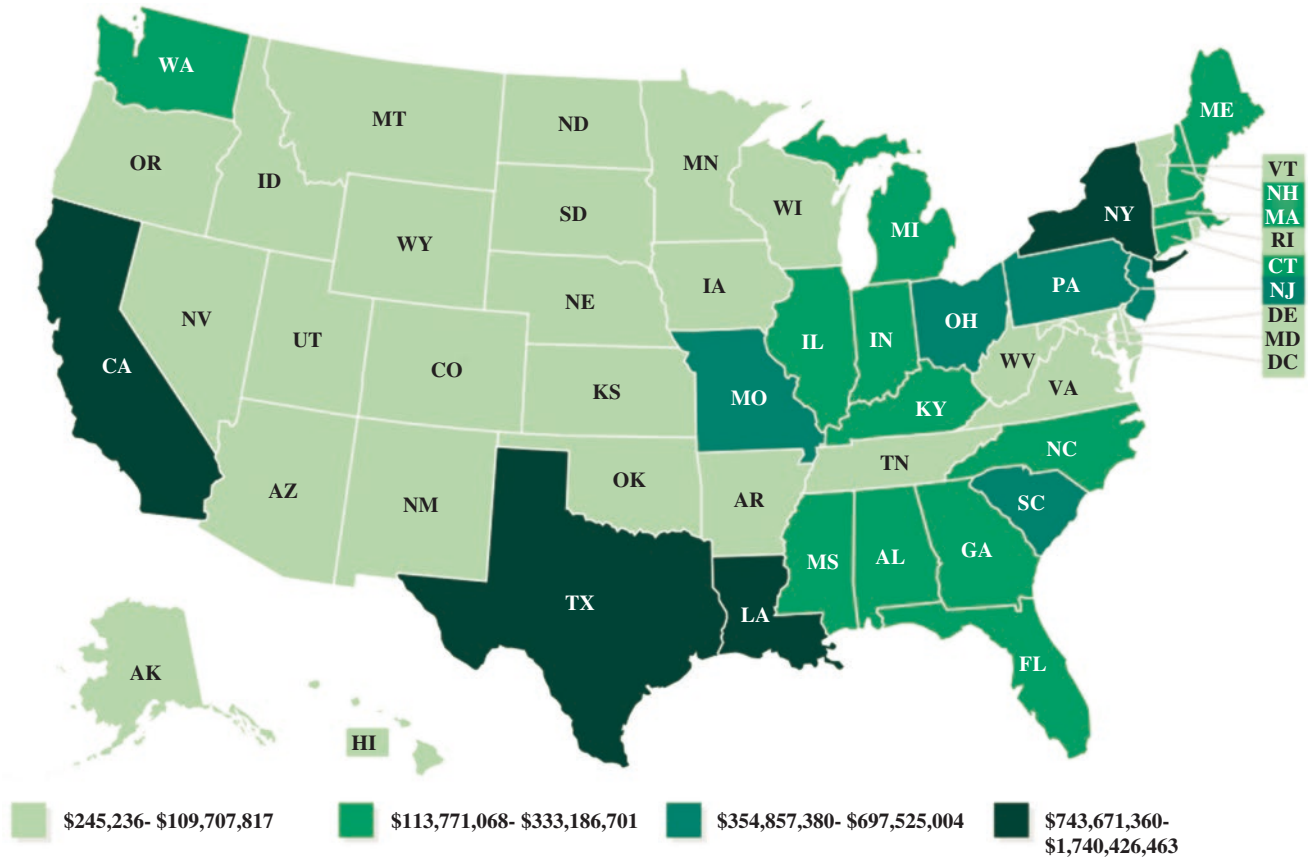

Fig. 40.2 DSH payment allocations to states (Adapted from source: http://kff.org/medicaid/state-indicator/federal-dsh-allotments/?currentTimeframe=0&selectedDistributions=dsh-allotment)

clinics (RHCs) under a prospective payment system (PPS) methodology or through an alternative payment methodology (APM) [22]. A PPS system establishes a provider's payment rate, which is not dependent on the provider's actual costs or the amount charged for the service, before the service is delivered [23]. APMs include a wide range of reimbursement mechanisms that include capitation, pay-for-performance, gain sharing, risk sharing, and global bundling [24]. One mechanism, called Delivery System Reform Incentive Payment (DSRIP), is part of Section 1115 demonstration waiver programs and provides states with funding to support hospitals and other providers in changing their approaches in caring for Medicaid recipients [24]. DSRIPs are performance-based incentive programs that focus on process metrics (e.g., infrastructure development or system redesign) in the early years of the waiver, before transitioning to outcome metrics (e.g., population health level outcomes) in later years of implementation [24].

Growth in Medicaid funding has provided key support for federally qualified health centers (FQHCs,) which receive enhanced Medicaid reimbursement to cover both the broader array of services, including medications, laboratory testing, and often dental and mental health services, and to compensate for a higher case mix of uninsured patients. In 2013, Medicaid provided 40% of health center operating revenues, making the program the single largest source of health center financing [25]. Operating grants that health centers receive through the federal annual appropriations process provide crucial support for care for uninsured patients and for services not covered by insurance [26]. The ACA augmented regular appropriations for health centers with a dedicated 5-year, $11 billion health center trust fund that has supported the establishment of new health centers and sites and initiatives to build service capacity in key areas.

The Medicaid program provides major support to develop the health-care workforce that is needed to care for Medicaid patients. Currently, most states provide some level of payment for Graduate Medicaid Education (GME) [27]. The specific financing mechanisms for GME vary from state to state, but the general approaches are comparable; states are able to invest funds (general revenues or other sources such as a tax on hospitals) and receive a federal match that is applied toward their respective state's GME. The state of North Carolina, for example, invested $30 million in GME in 2016 with a federal match, representing an investment of almost $90 million or approximately a quarter of the total public funding for GME in the state [28]. The funds flow for Medicaid is similar to Medicare; payments are directed to teaching hospitals and are used at their discretion [29]. There is no explicit social accountability or assessment of return on investment regarding funding that is applied to physician training. There are, however, increased calls led by the Institute of Medicine for more responsive and accountable use of public funds for training [28, 30].

The total costs of the Medicaid program are substantial, with federal and state spending at $532 billion in FY 2015 [1]. After Social Security and Medicare, Medicaid is the third largest domestic program in the federal budget and accounts for 9% of federal domestic spending. Table 40.2 presents Medicaid spending growth from FY 2000 to 2007. At the state level, Medicaid [1] is the second largest item in state budgets and accounts for approximately 19% of state general revenue spending and 28.2% of total state general revenue spending [1]. On a per enrollee basis, Medicaid is low-cost compared to private insurance, but total Medicaid costs are high because of the large number of people in the program and the high cost/high beneficiaries in the program (Fig. 40.3) [1].

Seniors and people with disabilities make up one in four beneficiaries but account for almost two-thirds of Medicaid spending, reflecting their high costs in both acute and long-term care (Fig. 40.3). Over half of Medicaid spending is attributable to the highest-cost 5% of enrollees. As the result of gradual expansion, Medicaid has grown larger than Medicare with an enrollment of 73 million. About 32 million low-income children [31] (approximately 43% of all children in the United States), nearly 50% of all obstetrical deliveries [32], and approximately 63% of all nursing home residents [33] are supported through Medicaid.

There are many factors that affect Medicaid spending such as the economy, state policy actions, and the overall health-care costs which include prescription drugs and new technology. Because Medicaid plays a large role in state budgets, states have an interest in cost containment and program integrity. A common strategy for mitigating costs is to reduce reimbursements to clinicians and hospitals. Since clinicians have the option to accept – or not accept – Medicaid patients, a reduction in reimbursement can limit the pool of clinicians who are available to care for Medicaid patients. In 2013, the acceptance rate of new Medicaid patients by physicians across the United States was 68.9% [34]. Another challenge for Medicaid beneficiaries can be at the hospital and health-care system level, since commercially insured patients and many Medicare patients are provided substantially with more reimbursement than Medicaid patients, and therefore Medicaid has an incentive to target higher-paying patients.

State Medicaid Plans as Laboratories for Policy Experiments

As noted earlier, Medicaid is a joint federal and state program in which states can design and administer their own individual program [2]. Because of this flexibility, Medicaid

Table 40.2 Federal medical assistance percentages and enhanced federal medical assistance percentages, effective October 1, 2016 to September 30, 2017 (Fiscal Year 2017)

State	Federal medical assistance percentages	Enhanced federal medical assistance percentages	Enhanced federal medical assistance percentages with ACA 23 Pt increase[a]
Alabama	70.16	79.11	100.00
Alaska	50.00	65.00	88.00
American Samoa[b]	55.00	68.50	91.50
Arizona	69.24	78.47	100.00
Arkansas	69.69	78.78	100.00
California	50.00	65.00	88.00
Colorado	50.02	65.01	88.01
Connecticut	50.00	65.00	88.00
Delaware	54.20	67.94	90.94
District of Columbia[c]	70.00	79.00	100.00
Florida	61.10	72.77	95.77
Georgia	67.89	77.52	100.00
Guam[b]	55.00	68.50	91.50
Hawaii	54.93	68.45	91.45
Idaho	71.51	80.06	100.00
Illinois	51.30	65.91	88.91
Indiana	66.74	76.72	99.72
Iowa	56.74	69.72	92.72
Kansas	56.21	69.35	92.35
Kentucky	70.46	79.32	100.00
Louisiana	62.28	73.60	96.60
Maine	64.38	75.07	98.07
Maryland	50.00	65.00	88.00
Massachusetts	50.00	65.00	88.00
Michigan	65.15	75.61	98.61
Minnesota	50.00	65.00	88.00
Mississippi	74.63	82.24	100.00
Missouri	63.21	74.25	97.25
Montana	65.56	75.89	98.89
Nebraska	51.85	66.30	89.30
Nevada	64.67	75.27	98.27
New Hampshire	50.00	65.00	88.00
New Jersey	50.00	65.00	88.00
New Mexico	71.13	79.79	100.00
New York	50.00	65.00	88.00
North Carolina	66.88	76.82	99.82
North Dakota	50.00	65.00	88.00
Northern Mariana Islands[b]	55.00	68.50	91.50
Ohio	62.32	73.62	96.62
Oklahoma	59.94	71.96	94.96
Oregon	64.47	75.13	98.13
Pennsylvania	51.78	66.25	89.25
Puerto Rico[b]	55.00	68.50	91.50
Rhode Island	51.02	65.71	88.71
South Carolina	71.30	79.91	100.00
South Dakota	54.94	68.46	91.46
Tennessee	64.96	75.47	98.47
Texas	56.18	69.33	92.33
Utah	69.90	78.93	100.00
Vermont	54.46	68.12	91.12
Virgin Islands[b]	55.00	68.50	91.50
Virginia	50.00	65.00	88.00
Washington	50.00	65.00	88.00
West Virginia	71.80	80.26	100.00
Wisconsin	58.51	70.96	93.96
Wyoming	50.00	65.00	88.00

Adapted from source: (https://aspe.hhs.gov/basic-report/fy2017-federal-medical-assistance-percentages)

[a]Section 2101(a) of the Affordable Care Act amended Section 2105(b) of the Social Security Act to increase the enhanced FMAP for states by 23 percentage points, but not to exceed 100%, for the period that begins on October 1, 2015 and ends on September 30, 2019 (fiscal years 2016 through 2019)

[b]For purposes of section 1118 of the Social Security Act, the percentage used under titles I, X, XIV, and XVI will be 75 per centum

[c]The values for the District of Columbia in the table were set for the state plan under titles XIX and XXI and for capitation payments and DSH allotments under those titles. For other purposes, the percentage for D.C is 50.00, unless otherwise specified by law

has provided an opportunity for states to develop and test innovative care delivery systems. In North Carolina, Community Care of North Carolina began in the 1990s as an alternative to commercial managed care, with a statewide community health network that managed Medicaid beneficiaries. Medical practices participated in CCNC, which also partnered with local hospitals, health departments, county health departments, and regional departments of social services. The fiscal model included a per member/per month payment, as well as a statewide informatics platform and care management system. This structure fostered innovation in many aspects of care, including behavioral health, dental services, and the use of community pharmacies to manage medications.

As part of the network, the practices were able to access a team of CCNC case managers who worked with patients in a defined geographic area [35]. Medicaid claims data were

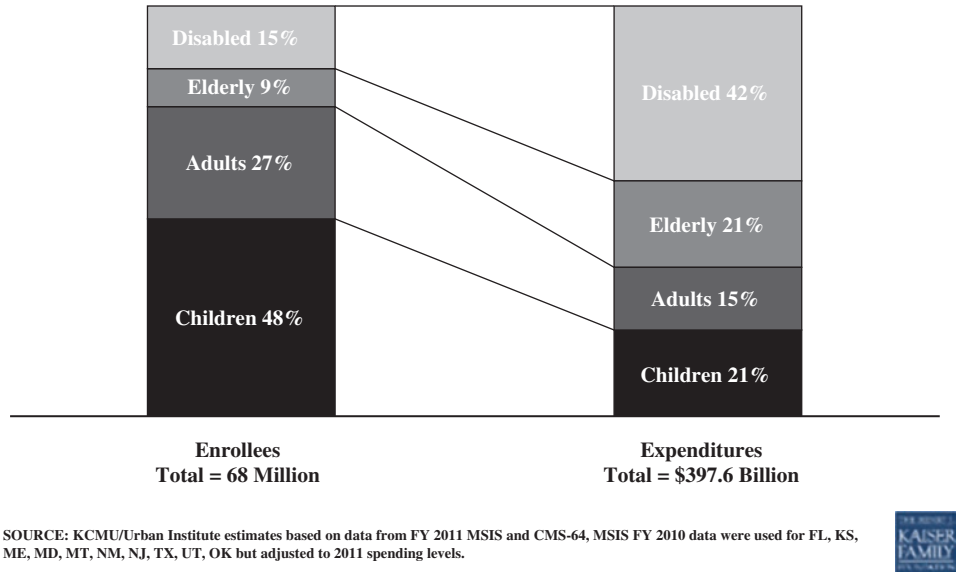

Fig. 40.3 Medicaid enrollees and expenditures, FY 2011 (Adapted from: http://www.kaiserfamilyfoundation.files.wordpress.com/2013/01/medicaid-an-overview-of-spending-on.pdf)

used to identify patients who were candidates for case management [35], such as those who had multiple emergency department visits, a high number of medication claims, or had diagnoses of asthma, diabetes, or congestive heart failure. An informatics system pulled Medicaid claims in a database that identified high-risk patients and provided capacity for care management and communication.

The CCNC model demonstrated impressive outcomes and saved North Carolina $60 million in fiscal year 2003; by 2006, savings had increased to $161 million annually [35]. The largest savings were achieved in emergency department utilization (23% less than projected), outpatient care (25% less than projected), and pharmacy (11% less than projected) [9]. In addition to cost savings, CCNC improved the quality of care for Medicaid beneficiaries. Since initiation of the program, there have been a 21% increase in asthma staging and a 112% increase in the number of asthma patients who received influenza vaccines over a defined time period [35]. Emergency department visits for CCNC children with asthma decreased by 8% during the first year of the program and hospitalization rates have decreased by 34%.

Building on a generation of Medicaid reform, Oregon has defined a statewide authority with responsibility for Medicaid, the Oregon Health Authority, expanded Medicaid again, promoted medical homes, and developed community care organizations (CCOs), which are partnerships of payers, providers, and community organizations that work at the regional level to provide coordinated health care for children and adult Oregon Health Plan enrollees [36]. Each CCO is provided with a fixed global budget, which gives CCOs flexibility to create alternative payment methodologies for providers and to explore innovative strategies to support transformation based on the needs within their specific communities. Early evaluations have demonstrated increased access to primary care, but mixed effects on health utilization, with a 66% reduction in hospitalizations in adults with COPD and asthma and a 77% increase in dental sealant, but a recent small increase in emergency department visits [37].

Health-care reform in Vermont was launched through the Blueprint for Health program [38]. In 2007, with the participation of Vermont's three largest commercial payers and Medicaid, the state legislature authorized pilots to test an integrated health services model, called the Blueprint Model. The model includes advanced primary care in the form of patient-centered medical homes (PCMHs), multidisciplinary support services through community health teams (CHTs) which support PCMHs, multi-insurer payment reforms that fund community health teams, and activities focused on continuous improvement using comparative valuation (learning health system). Medicare selected Vermont as a participant in its 2011 Multi-Payer Advanced Primary Care Practice Demonstration initiative. In 2013, Blueprint was expanded statewide and the initiative included 79 practice sites serving approximately 360,000 patients, more than half of the state's population. Unlike most states, Vermont is on a path toward an integrated health-care delivery system with a budget regulated by the new Green Mountain Care Board, an all-payer accountable care organization (ACO), a health insurance that is not linked to employment, and a unified system for administration of claims and payments to providers. Early outcomes suggest cost savings in both inpatient and outpatient care, with more savings among patients who receive primary care in a PCMH, and improvements in access to medication-assisted treatment and quality of care for opiate misuse [38].

Opportunities and Challenges with ACA Reform

Medicaid has demonstrated both programmatic and regional flexibility for over 50 years, evolving as the health-care landscape and health-care needs of Medicaid patients have changed in the United States. The federal requirements for eligibility and financing, the flexibility for states to determine its benefit design, and the significant growth and development of infrastructure support have contributed to the program's sustainability. Over the years, Medicaid has proved capable of adapting to new public health crises (e.g., AIDS), addressed cost growths through managed care, and supported major expansion under the Affordable Care Act (ACA).

Some foundational principles of the ACA included improvement in access, through better coverage of young adults, non-exclusion of pre-existing conditions, creation of statewide health insurance exchange, and Medicaid expansion. The original design assumption was that all states would expand Medicaid and that newly insured patients would provide financial buffering to hospitals whose reimbursement would be reduced by changes in Disproportionate Share Hospital (DSH) funding. ACA reform has been high on the political agenda, and it is unclear how a myriad of policy proposals will be crafted into legally binding legislation that will determine the future of Medicaid coverage for tens of millions of people [9].

There are two major aspects that have been under consideration with proposed ACA reform. The first is ending increased federal funding for the ACA's Medicaid expansion. Earlier, it was noted that there has variation in states that chose expansion versus those that did not expand under the ACA. If ACA expansion funding were to cease, non-expansion states would be seeking payments for funds that they would have received by expanding eligibility [9]. In expansion states, ending ACA Medicaid funding would significantly reduce the federal allocation by setting a lower match, leaving states with funding gaps. Medicaid beneficiaries frequently experience coverage breaks because of changes in employment, especially those who work at jobs where the hours fluctuate seasonally, and proposed legislation would make payments for beneficiaries who "do not have a break in eligibility for medical assistance" exceeding 1 month, which would further reduce funding [9].

A second, structural aspect of ACA reform is tied to Medicaid funding mechanisms. One approach is replace the current Medicaid funding system with [9] per capita cap payments that are linked to enrollment. This model would involve a block grant mechanism and would expose states to increased risk due to the financial fallout that could come from federal underpayments [9]. Under this arrangement, a prospective rate-setting system would be accompanied by an annual reconciliation process and states would receive payments based on the estimated number of beneficiaries and the per capita cost of children, or adults, or people with disabilities, or the elderly [9]. A key issue to be resolved is risk adjustment for patient severity of disease. Although the per capita payment would reflect a state's expenditures that "directly" result from spending on health care, the Secretary of Department of Health and Human Services (HHS) would have discretion to determine the permissible medical assistance payments [9].

Operationally, HHS would make interim payments without any recourse for states to negotiate those payments or a process by which the per capita payment formula would work in practice [9]. It would be unclear how real-time adjustments would be made if a priori federal estimates were inaccurate or if they fall below appropriately compensated medical care as the intensity of needed care increases [9]. A per capita approach has a conceptual appeal, but the effective implementation and measured impact would require multi-year pilots in select states [9].

Final Comments

Many of the challenges around the organization and cost of Medicaid – including its reform – are representative of larger problems in health care. For example, Medicare has rapidly moved financing from fee-for-service to value-based purchasing models. Responding to the changes in the health-care ecosystem, there have been substantial consolidation of hospitals and providers into clinically integrated networks and the initiation of pay-for-value contracts from commercial insurers. Unfortunately, the rise of health-care costs, slowed by the great recession of 2008, has returned, and the fundamental cost problems have not been fixed. Medicaid has been subject to these larger trends.

It is important to recognize that health-care cost is not an isolated issue. Despite huge investments in health care, the outcomes of care in the United States lag far behind other developed countries [39, 40]. For Medicaid, as for Medicare and commercial insurers, a larger goal should be achieving the Triple Aim in health care [41]: improving health, improving patient experience, and reducing cost. Reaching this goal will require (1) committed clinicians, investigators, policymakers, and stakeholders; (2) health-care delivery innovations, such as robust primary care models with integrated behavioral health, and "wraparound" informatics and care management, with attention to social determinants of health; and (3) effective patient and family engagement.

Medicaid represents a quintessential health-care safety net program. Jointly financed by the federal government and

states, it has been uniquely flexible over two generations, allowing states to set their own priorities and adapting to new patient populations and unanticipated social problems. How it evolves in the future – along with the clinical care delivery systems and associated financing infrastructure – will take 10–15 years to sort out.

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Value-Based Payment Models

41

Terri Menser and Ann Scheck McAlearney

Abbreviations

ACA	Affordable Care Act
ACE	Angiotensin-converting enzyme
ACO	Accountable Care Organization
ARB	Angiotensin receptor blocker
BMI	Body mass index
CAD	Coronary artery disease
CDC	Centers for Disease Control
CIN	Clinically integrated network
CMMI	Centers for Medicare and Medicaid Innovation
CMP	Civil Monetary Penalty
CMS	Centers for Medicare and Medicaid Services
CVD	Cardiovascular disease
DOJ	Department of Justice
EHR	Electronic health record
ESRD	End-stage renal disease
FFS	Fee-for-service
FTC	Federal Trade Commission
HbA1c	Glycated hemoglobin
HCAHPS	Hospital Consumer Assessment of Healthcare Providers and Systems
HF	Heart failure
HHS	Health and Human Services
IRS	Internal Revenue Service
IVD	Ischemic vascular disease
LDL-C	Low-density lipoprotein cholesterol
LVSD	Left ventricular systolic dysfunction
MSSP	Medicare Shared Savings Program
OIG	Office of Inspector General
PC	Primary care
PCMH	Patient-centered medical home
VBP	Value-based purchasing

T. Menser (✉)
Center for Outcomes Research, Houston Methodist Research Institute, Houston, TX, USA
e-mail: tmenser@houstonmethodist.org

A.S. McAlearney
Department of Family Medicine, The Ohio State University, Columbus, OH, USA
e-mail: ann.mcalearney@osumc.edu

Introduction

Managing chronic conditions is the primary business of health care today [1], and the burden of chronic illness is a looming challenge which steers America's flagship health insurance program, Medicare. Chronic illnesses, such as heart disease, diabetes, and cancer, now account for almost 93% of Medicare spending [2]. According to the Centers for Disease Control and Prevention (CDC), 70% of all deaths in the US are caused by a chronic disease, and nearly 50% of all Americans have at least one chronic condition [3]. Sixty-six percent of Medicare beneficiaries had multiple chronic conditions in 2010, while the number of baby boomers (i.e., individuals between the ages of 45 and 64) living with multiple chronic conditions is increasing [2].

These data forecast a threatened health-care environment and paint an ominous picture. Due to the escalation of chronic illnesses in the US, national health expenditures totaled $2.8 trillion in 2012 and are projected to increase nearly 6% per year; they are predicted to account for 19.9% of gross domestic product by 2022 [4]. Yet despite this higher level of health-care spending, the quality of care in the US is lacking. A recent study that compared the US health-care system to other developed countries found that, despite outspending the ten other comparator countries, the US ranked last in overall health outcomes [5].

The shift from focusing on volume of care to value is one step that has potential to reduce health-care costs and positively affect the quality of care and patient experience, particularly in chronic illness. This movement can be facilitated by using value-based purchasing models. Value-based purchasing (VBP) refers to performance-based

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payment strategies that link financial incentives to health-care provider performance, within a set of defined measures, in order to achieve better value by driving improvements in quality and by slowing the growth in health-care spending [6]. Examples of VBP include clinically integrated networks (CINs), Accountable Care Organizations (ACOs), hospital value-based purchasing programs, and bundled payment programs.

It is noteworthy that value-based purchasing may initially increase the reported prevalence of chronic illness, due to an emphasis on screening. Individuals identified with a chronic illness would likely benefit from early intervention (e.g., lifestyle and education interventions) since early identification may mitigate the complications associated with these illnesses [7]. For example, it is estimated that there are approximately 8.1 million Americans (28%) who are undiagnosed with diabetes [8]. Screening efforts may identify individuals who were unaware that they have diabetes and subsequently result in more individuals with diabetes within a defined population. However, a greater emphasis on screening will help identify early chronic illness that requires treatment, an approach that can help control the disease and reduce potential complications.

Chronic illness is tied to the complex care needs and associated health services of patients. "The typical Medicare beneficiary may see an average of two primary care physicians and five specialists each year, in addition to receiving diagnostic, pharmacy, and other health-care services" [9], p. 1064]. Such intensity of care from different providers can lead to duplication of services and unnecessary medical testing, increasing unnecessary care costs. The adoption of value-based purchasing models can encourage coordination of care and information sharing between providers to realize cost savings. This chapter describes several value-based purchasing models and provides an overview of how quality – specifically relating to chronic illnesses – is measured and incorporated in these models. In addition, the chapter provides recent research findings relevant to these models, focusing on associated benefits and/or drawbacks.

Background

The Patient Protection and Affordable Care Act (ACA) promoted changes to the structure of the US health-care delivery system through the creation of value-focused programs (e.g., ACOs), strategies that were intended to improve patient health outcomes while attempting to contain health-care costs. Historically, the US health-care system has been based on a fee-for-service (FFS) payment model, where payment is rendered on a per procedure basis, placing an incentive on maximizing the quantity of health services and procedures. Since the passage of the ACA in 2010, there has been a shift from FFS to population health, with new payment structures encouraging value over greater volume. Figure 41.1 displays the different categories of payment models, specifying the degree to which quality and efficiency are considered for models of value-based care.

The US Department of Health and Human Services (HHS) set a goal of having 50% of Medicare payments directly tied to cost and quality parameters by 2018, encouraging the transition of payment models from volume to value-based care. Health insurer Aetna followed this lead and established expectations for 75% of payments to be made through value-based contracts by 2020 [10]. The Pioneer ACO program, which is described later, was introduced to phase in value-based reimbursement models as well; by year 3 of the program, Pioneer ACOs were required to link payment with value. This model provides the capacity for a system-wide demonstration of value-based care in which organizations are not reimbursed for services provided but for the care of a defined population.

Quality Performance Measurement

Donabedian's quality of care framework (Fig. 41.2) was developed to map out the quality of medical care and includes three domains: structure, process, and outcomes. According to this framework, structure defines the system's capacity for care delivery, process defines the means of care delivery, and outcome defines the effect of care delivery [11]. Structural elements include facilities, equipment, personnel, as well as operational and financial processes supporting medical care (e.g., electronic health record (EHR)) [12]. The Donabedian model continues to provide the foundation for measurement of quality and performance in health care [12].

Quality in health care is often evaluated using a mix of process and outcome measures (see Table 41.2) which adds to the challenges of performance management in health care, a sector that is already more complex than others. Process measures capture the manner in which care is provided and are derived from evidence-based clinical guidelines. These process measures can often be directly linked to health outcomes when they outline best practices of care. In contrast, outcome measures capture objective, often biometric, assessments of disease states and health status (e.g., blood glucose level) and seek to focus on overall improvement in health as a result of the care that is provided [14]. The Centers for Medicare and Medicaid Services (CMS) has added additional quality of care domains, such as patient experience/satisfaction measured by the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey, but process and outcome measures remain the dominant domains across the various value-based purchasing models.

	Payment Taxonomy Framework			
	Category 1: *Fee for Service-No Link to Quality*	**Category 2:** *Fee for Service-Link to Quality*	**Category 3:** *Alternative Payment Models Built on Fee-for-Service Architecture*	**Category 4:** *Population-Based Payment*
Description	*Payments are based on volume of services and not linked to quality or efficiency*	*At least a portion of payments vary based on the quality or efficiency of health care delivery*	*Some payment is linked to the effective management of a population or an episode of care. Payments still triggered by delivery of services, but opportunities for shared savings or 2-sided risk*	*Payment is not directly triggered by service delivery so volume is not linked to payment. Clinicians and organizations are paid and responsible for the care of a beneficiary for a long period (e.g. ≥1 yr)*
Medicare FFS	• Limited in Medicare fee-for-service • Majority of Medicare payments now are linked to quality	• Hospital value-based purchasing • Physician Value-Based Modifier • Readmissions/Hospital Acquired Condition Reduction Program	• Accountable care organizations • Medical homes • Bundled payments • Comprehensive primary care initiative • Comprehensive ESRD • Medicare-Medicaid Financial Alignment Initiative Fee-For-Service Model	• Eligible Pioneer accountable care organizations in years 3-5

Fig. 41.1 Health service payment taxonomy (Centers for Medicare and Medicaid's Payment Taxonomy Framework Reprinted with permission from: U.S. Department of Health & Human Services. Centers for Medicare & Medicaid Services. Better Care. Smarter Spending. Healthier People: Paying Providers for Value, Not Volume. 2015. Retrieved from https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2015-Fact-sheets-items/2015-01-26-3.html)

Accountable Care Organizations

Accountable Care Organizations (ACOs) are groups of physicians, hospitals, and other health-care service providers who are aligned with a purpose to integrate care and promote accountability for a defined patient population by coordinating services across multiple sites. ACOs encourage investment in infrastructure and seek to maximize care processes to promote high-quality and efficient service delivery [15]. An ACO must be a legal entity and can be formed in a variety of different ways including: professionals in group practice, individual practices, hospitals employing professionals, critical access hospitals, Federally Qualified Health Centers, and Rural Health Centers. The establishment and development of an ACO, however, involves oversight, transparency, fiduciary duty, conflict of interest policy, and specified leadership roles within the organizational entity [16].

ACOs assume accountability for the health of a defined population, an approach that should ideally reduce the dysfunction of a disjointed health-care system. Patient assignment to ACOs is determined by the payer, and, for public

Fig. 41.2 Donabedian's quality of care framework (Donabedian's Quality of Care Framework) [11]

Table 41.1 Types of Accountable Care Organizations

Type of Accountable Care Organization	2013	2014	2015
Medicare ACOs – e.g., Pioneer and Medicare Shared Savings Program; see ACO initiatives section	134	368	426
Non-CMS ACOs – any provider organization with at least one shared-savings or shared-risk arrangement with at least one commercial payer but not with CMS	124	154	159

The total number of Accountable Care Organizations in 2015 has more than doubled in 2 years.
Adapted from [13]

ACOs, this is commonly attributed to where patients receive primary care services [17]. Medicare, Medicaid, and commercial payers offer different types of ACOs; approximately 11% (i.e., 5.6 million) of Medicare beneficiaries were covered by ACOs in 2015 [18]. Since their introduction, the number of ACOs across the country has grown dramatically, reaching nearly 600 in 2015 (see Table 41.1).

To participate in Medicare ACO initiatives (i.e., initially the Pioneer program and, more recently, the Medicare Shared Savings Program), an ACO must be accountable for care for a minimum of 5000 Medicare beneficiaries [16].

Value-based purchasing models have resulted in an increased focus on performance measures that have specified by CMS [20]. Specifically, the outcomes of ACOs are determined by meeting defined performance criteria that are gauged by patient experience measures, process measures, and outcome measures, while being cost neutral or cost saving. ACOs must report these measures which are specific for a defined population. A denominator is determined (e.g., total population of patients with diabetes) as well as the targets required to meet that measure which is the numerator (e.g., number of diabetics who are below a set blood glucose level). These measures are reported to CMS, or other third-party payors, as proxies for the quality of care. There is a phased implementation of payments that are linked to performance measures; participating ACOs are initially paid for the reporting of all measures, and reimbursement is subsequently shifted to payment based on performance [21].

Medicare's ACO Initiatives

Medicare has sought to promote better care delivery guided by established quality and performance measures, many of which target the management of chronic illnesses. Only ACOs are eligible to participate in initiatives such as the Pioneer or Medicare Shared Savings Program (MSSP). The Pioneer ACO was an initiative that selected participants (e.g., physician groups, hospital systems) through an application process that concluded in 2011; 32 organizations were selected from 80 applications, and as of May 2016 there were 9 ACOs participating in the final performance year [22]. Medicare's Next Generation ACO launched in 2017, and participants in this model will assume greater risk and reward [23]. The overall goal for these Medicare's ACO initiatives is to improve population health while containing health-care costs through realized efficiencies and reduced duplication. The main difference between the two programs is the level of risk that the health-care organization assumes. There are several

Table 41.2 CMS ACO performance measures

Measure	2012	2013	2014	2015	2016	Type
1. HCAHPS: getting timely care, appointments, and information	X	X	X	X	X	PE
2. HCAHPS: how well your doctors communicate	X	X	X	X	X	PE
3. HCAHPS: patients' rating of doctor	X	X	X	X	X	PE
4. HCAHPS: access to specialists	X	X	X	X	X	PE
5. HCAHPS: health promotion and education	X	X	X	X	X	PE
6. HCAHPS: shared decision-making	X	X	X	X	X	PE
7. HCAHPS: health status/ functional status	X	X	X	X	X	PE
8. Risk standardized all condition readmission	X	X	X	X	X	O
9. Chronic obstructive pulmonary disease/asthma (older adults)	X	X	X	X	X	O
10. Ambulatory sensitive conditions admissions: heart failure	X	X	X	X	X	P
11. Percent of PC physicians qualified for EHR program incentive	X	X	X	X	X	P
12. Medication reconciliation after discharge (inpatient facility)	X	X	X			P
13. Falls: screening for fall risk	X	X	X	X	X	P
14. Influenza immunization	X	X	X	X	X	P
15. Pneumococcal vaccination	X	X	X	X	X	P
16. Adult weight screening and follow-up	X	X	X	X	X	P
17. Tobacco use assessment and tobacco cessation intervention	X	X	X	X	X	P
18. Depression screening	X	X	X	X	X	P
19. Colorectal cancer screening	X	X	X	X	X	P
20. Mammography screening	X	X	X	X	X	P
21. Screening for high blood pressure	X	X	X	X	X	P
22. Diabetes composite: hemoglobin A1c control (<8%)	X	X	X			O
23. Diabetes composite: low-density lipoprotein (<100)	X	X	X			O
24. Diabetes composite: blood pressure <140/90	X	X	X			O
25. Diabetes composite: tobacco nonuse	X	X	X			O
26. Diabetes composite: aspirin use	X	X	X			P
27. Diabetes mellitus: hemoglobin A1c poor control (>9%)	X	X	X	X	X	O

(continued)

Table 41.2 (continued)

Measure	2012	2013	2014	2015	2016	Type
28. Hypertension (HTN): controlling high blood pressure	X	X	X	X	X	O
29. IVD: complete lipid panel and LDL control (<100 mg/dL)	X	X	X			O
30. IVD: use of aspirin or another antithrombotic	X	X	X	X	X	P
31. Heart failure: beta-blocker therapy for LVSD	X	X	X	X	X	P
32. CAD composite: drug therapy for lowering LDL cholesterol	X	X	X			P
33. CAD composite: ACE inhibitor or ARBs for patients with CAD and diabetes and/or LVSD	X	X	X	X	X	P
34. HCAHPS: stewardship of patient resources				X	X	PE
35. Skilled nursing facility, 30-day all-cause readmission				X	X	O
36. All-cause unplanned admissions for patients with diabetes				X	X	O
37. All-cause unplanned admissions for patients with HF				X	X	O
38. All-cause unplanned admissions (multiple chronic conditions)				X	X	O
39. Documentation of current medications in the medical record				X	X	P
40. Depression remission at 12 months				X	X	O
41. Diabetes: eye exams				X	X	P
42. Statin therapy for the prevention and treatment of CVD					X	P
Total measures by year	33	33	33	33	34	

P process measure, *O* outcome measure, *PE* patient experience
A summary of the quality performance measures by year for Medicare's ACOs, compiled from annual documents on program analysis quality performance standard narrative measure specification documents. Adapted from [19]

factors that organizations consider in choosing among ACO models: (1) future reimbursement structures, (2) level of risk aversion, (3) access to capital, (4) administrative capability, (5) opportunity for cost reduction, (6) risk level of patient population, and (7) synergies with other payers [24].

Shared savings programs were established by the ACA under the direction of the Secretary of Health and Human Services. The Secretary had discretion in promoting programs that advanced accountability for a patient population, coordinated items and services under parts A and B, and encouraged investment in infrastructure and redesigned care processes for high-quality and efficient service delivery. Under these parameters:

A. "Groups of providers of services and suppliers meeting criteria specified by the Secretary may work together to manage and coordinate care for Medicare fee-for-service beneficiaries through an Accountable Care Organization.
B. ACOs that meet quality performance standards established by the Secretary are eligible to receive payments for shared savings under subsection (d) (2)" [15] p. 313.

CMS has defined several measures to help gauge the performance of ACOs. The measures linked to chronic illness fall into the Preventive Health and At-Risk Population domains. Many of the ACO performance measures focused on risk factors for common chronic conditions or focus specifically on subpopulations with identified chronic illnesses. For example, measure 16 (i.e., body mass index) is linked to obesity; measures 17 and 25 discourage tobacco use; measures 18 and 40 focus on depression; measures 19 and 20 are preventive cancer screenings; measures 21, 24, and 28 target blood pressure; measures 22 and 27 focus on blood glucose levels; measures 23, 29, and 32 look at low-density lipoprotein cholesterol (LDL-C); and measures 26, 33, and 41 are specific to diabetes. Table 41.2 summarizes applicable measures by year and classifies the measures by type, as process, outcome, or patient experience measure. For 2016, there were 34 total quality performance measures: 17 process measures, 9 outcome measures, and 8 patient experience measures.

The defined quality performance measures for CMS ACO initiatives target the top medical conditions among Medicare beneficiaries between 1987 and 2001, which accounted for 2/3 of the growth in spending. These conditions included heart disease, mental disorders, trauma, arthritis, hypertension, cancer, diabetes, pulmonary conditions, hyperlipidemia, and cerebrovascular disease (e.g., strokes) [25]. The identification and management of risk factors for these conditions overlap and include tobacco use, diet, high blood pressure, high cholesterol, obesity, physical inactivity, and stress (see http://www.mayoclinic.org/diseases-conditions/ (i.e., disease--> risk factors). In consequence, a focus of ACOs is on coordinating patients' health-care, guided by these risk factors, in order to reduce the incidence of chronic illness and to improve overall health status for a defined population.

Impact of ACOs

There are data which provide early results of the Pioneer ACO and private ACO models [17, 26–29], but the evidence is mixed regarding the impact of ACOs on health-care costs and quality. Table 41.3 summarizes cost and quality findings from a Kaiser Family Foundation report. In brief, the net savings often did not exceed earned bonuses, which resulted in a net cost to the ACO. For example, in 2015 the net cost for the MSSPs and Pioneer ACOs totaled approximately $215 million (i.e., the $216 million MSSP cost minus the $669,000 Pioneer savings) [30]. Much of the savings were also likely concentrated among higher-performing ACOs [31]. Another study analyzed changes in spending and quality performance of ACOs entering the MSSP and found annual spending decreased by $144 per beneficiary in 2012 but only by $3 per beneficiary in 2013. Some quality measures improved while other remained unchanged [27].

There are several challenges in forming an ACO. University Hospital Health System described barriers to improving ambulatory quality and population health that included (1) the fleeting nature of outpatient interactions, (2) the uncertainty of patient outcomes, (3) the difficulty of screening an entire outpatient population due to volume, and (4) the lack of control to ensure patient compliance [32]. A recent study of four ACOs serving Medicaid and private sector patients noted the particular challenge of engaging patients in the ACO model of care, especially since ACO patients do not know they are part of an ACO [29].

In addition to these operational barriers, there are several ethical challenges that cut across multiple domains: (1) resource allocation (organizations focusing on the good of the many, ignoring the good of the few), (2) protecting physicians ethical obligations (balancing set cost goals and providing appropriate patient care), (3) developing fair decision processes (developing transparent, clinician-guided processes), (4) professional autonomy (the influence of quality metrics on provider focus), (5) clinician dual responsibility (provider responsibilities to the patients and to the organization), (6) managing competition (managing competition in light of incentivized collaboration), (7) patient autonomy and choice (physician balance of in-network referral against patients' preferences), (8) patient privacy and confidentiality (patients' perception about data sharing), and (9) patient engagement (level of patient accountability) [33].

One study, which examined changes in chronic illness management in primary care settings, described some of these challenges. The study found an increased emphasis on medication management and suggested that pay-for-performance programs contributed to polypharmacy (i.e., the use of multiple medications to treat a single condition) as a possible unintended consequence of meeting clinical targets [34]. Similarly, an Australian study that examined the associated pharmacy costs of treatment to goal in the management of cardiovascular risk factors for patients with poorly controlled type 2 diabetes, found low levels of attainment for target levels (i.e., HbA1c, blood pressure, and lipids), despite substantial costs for medications [35]. A case management model may mitigate some of the challenges found in ACO development. Banner Health, for example, implemented this model and found that it reduced utilization and costs while improving patient satisfaction. Their approach used interdisciplinary team collaboration to track costs per case and length of stay, manage the discharge planning process, promote communication, and enhance documentation [36].

Table 41.3 Impact of Medicare Shared Savings Program and Pioneer ACO on cost and quality

	Medicare Shared Savings Program	Pioneer ACO
Net savings on beneficiary expenditures before bonuses	2012–2013: $234 million	2013: $96 million
	2014: $291 million	2014: $120 million
	2015: $429 million	2015: $37 million
Net savings after bonuses	2012–2013: −$78 million	2013: $41 million
	2014: −$50 million	2014: $47 million
	2015: −$216 million	2015: $669,000
[a]Quality, overall average composite score	2014: 83%	2014: 87%
	2015: 91%	2015: 92%
Participating organizations	2012–2013: 220	2012: 32
	2016: 433	2013: 23
		2014: 20
		2016: 9

Selected data presented on ACO models in Medicare (Active in 2015)
Source: http://files.kff.org/attachment/Report-Payment-and-Delivery-System-Reform-in-Medicare.pdf
[a]Percentage of overall average composite score (see Table 41.2)

Clinically Integrated Networks

The Federal Trade Commission (FTC) is the federal agency responsible for regulating anticompetitive activity in businesses and organizations and for enforcing laws and statutes that protect consumers, in order to promote fair competition. In doing so, the FTC seeks to ensure compliance with antitrust laws, defined as laws that regulate business conduct for the purpose of promoting competition [37]. In 1996, the Federal Trade Commission (FTC) and the Department of Justice (DOJ) provided guidance on legal creation of clinically integrated networks (CINs), widely defining physician affiliations that did not violate antitrust laws. Although

there is no standard legal definition of a CIN, it is generally considered as a network of providers who continuously evaluate and modify their clinical practices in accordance with agreed-upon protocols to control costs and improve quality. Further, the FTC requires physician responsibility, physician investment, physician accountability, outcome measurements, and non-exclusivity [38].

There are legal considerations when establishing a CIN and existing legislation (e.g., Antitrust, Stark, and Anti-kickback laws) can be seen as ambiguious in regards to forming a clinically integrated network. Figure 41.3 provides an overview to laws relevant to clinical integration, as well as potential unintended consequences [39].

Clinical integration can be achieved when a network of physicians and other health-care providers implement an active and ongoing program to evaluate and modify practice patterns. There are approximately 500 CINs in the US [40], including Vanderbilt University Medical Center [41], MetroHealth [42], and CHI Health [43]. Several network characteristics point to successful clinical integration: using clinical practice guidelines, using web-based technologies to track and measure care, evaluating network performance, and sharing data with third-party payors [44]. In addition, to create a high degree of interdependence and cooperation, programs may consider (1) establishing mechanisms to monitor and control the utilization of health-care services and assure quality of care, (2) selectively choosing network physicians who are likely to further these efficiency objectives, and (3) investing capital, both monetary and human, in the necessary infrastructure and capacity to realize efficiencies [45].

Creating a CIN may be a strategy to successfully managing care and costs across the care continuum [46], although there is uncertainty over the extent to which CINs and ACOs can generate cost savings [47]. CINs and patient-centered medical homes (PCMHs) have been referred to as the second side of the ACO coin [48, 49]. The American Hospital Association (AHA) has outlined the benefits of implementing a clinical integration program, including improving quality of care and efficiency through collaboration, enabling performance in pay-for-performance (P4P) initiatives, gaining experience in episodic and population-based care, encouraging closer relationships with medical staff, and potentially obtaining greater reimbursement [50].

There is emerging but sparse evidence that has definitively examined the cost and quality of care in CINs. Part of the challenge in evaluation lies in the variability of organizational structures and outcome metrics, as evidenced in the Long Island Health Network [51]. Determining the level of integration can be operationalized in a number of different ways and is often based on the degree/type of ownership (e.g., "fully integrated organizations" defined as hospitals owning physician practices [52]). In addition, the process of becoming a CIN prompts organizational change, and evaluating key components of the adoption process also impacts organizational performance and, indirectly, patient outcomes. The planning and implementation process itself may introduce new programs, interventions, and technologies, such as a comprehensive asthma management initiative or the tracking of diabetic performance indicators [40]. In each case, information technology (IT) has been recognized as the backbone of CINs, a critical tool that can be used to track quality through the use of disease registries, scorecards, and quality analytics, and promote the use of health information exchanges, clinical protocol compliance, and analytics [40, 53].

Hospital Value-Based Purchasing

Hospital Value-Based Purchasing (VBP) is another strategy that was promoted through the ACA and began to affect payments for inpatient hospitalizations in approximately 3000 hospitals in 2013. VBP is a health-care reimbursement mechanism that is based on hospital performance and improvement in three areas: quality of care, adherence to best clinical practices, and patient experience [54]. VBP domains include clinical care (e.g., process and outcome measures), safety, patient experience, care coordination, efficiency, and cost reduction. Figure 41.4 depicts the domains and weights for CMSs measures of the VBP program.

There is little overlap between the ACO and VBP measures. Process measures for VBP largely focus on specific medication guidelines for varying conditions, while outcome measures examine mortality rates; safety measures capture the incidence of different types of hospital-associated infections. Efficiency is measured by Medicare spending per beneficiary, which compares efficiency to that of a median hospital [56]. Measures of patient experience are captured through the HCAHPS survey.

In hospital-based VBP, approximately 1% to 2% of Medicare payments are withheld and, based on quality and other measures, redistributed back to hospitals that meet their performance targets, compared to a baseline measure. In 2015, $126 million were redistributed, and 1375 hospitals were penalized (approximately 45% of program participants) although total payment reductions were less than 1.5% of base operating costs [57].

Impact of VBP

The overall effect of VBP on health outcomes and health disparities has been mixed [58]. A study that compared the incentives distributed in 2014, when quality was the sole domain, to 2015, when cost was included as incentive crite-

Law	What Is Prohibited?	The Concern Behind the Law	Unintended Consequences	How to Address?
Antitrust (Sherman Act §1)	Joint negotiations by providers unless ancillary to financial or clinical integration; agreements that give health care provider market power	Providers will enter into agreements that either are nothing more than price-fixing, or which give them market power so they can raise prices above competitive levels	Deters providers from entering into procompetitive, innovative arrangements because they are uncertain about antitrust consequences	Guidance from antitrust enforcers to clarify when arrangements will raise serious issues. DOJ indicated it will begin a review of guidance in Feb. 2010.
Ethics in Patient Referral Act ("Stark Law")	Referrals of Medicare patients by physicians for certain designated health services to entities with which the physician has a financial relationship (ownership or compensation)	Physicians will have financial incentive to refer patients for unnecessary services or to choose providers based on financial reward and not the patient's best interest	Arrangements to improve patient care are banned when payments tied to achievements in quality and efficiency vary based on services ordered instead of resting only on hours worked	Congress should remove compensation arrangements from the definition of "financial relationships" subject to the law. They would continue to be regulated by other laws.
Anti-kickback Law	Payments to induce Medicare or Medicaid patient referrals or ordering covered goods or services	Physicians will have financial incentive to refer patients for unnecessary services or to choose providers based on financial reward and not the patient's best interest	Creates uncertainty concerning arrangements where physicians are rewarded for treating patients using evidence-based clinical protocols	Congress should create a safe harbor for clinical integration programs
Civil Monetary Penalty	Payments from a hospital that directly or indirectly induce physician to reduce or limit services to Medicare or Medicaid patients	Physicians will have incentive to reduce the provision of necessary medical services	As interpreted by the Office of Inspector General (OIG), the law prohibits any incentive that may result in a reduction in care (including less expensive products)...even if the result is an improvement in the quality of care	The CMP law should be changed to make clear it applies only to the reduction or withholding of medically necessary services
IRS Tax-exempt Laws	Use of charitable assets for the private benefit of any individual or entity	Assets that are intended for the public benefit are used to benefit any private individual (e.g., a physician)	Uncertainty about how IRS will view payments to physicians in a clinical integration program is a significant deterrent to the teamwork needed for clinical integration	IRS should issue guidance providing explicit examples of how it would apply the rules to physician payments in clinical integration programs
State Corporate Practice of Medicine	Employment of physicians by corporations	Physician's professional judgment would be inappropriately constrained by corporate entity	May require cumbersome organizational structures that add unnecessary cost and decrease flexibility to achieve clinical integration	State laws should allow employment in clinical integration programs
State Insurance Regulation	Entities taking on role of insurers without adequate capitalization and regulatory supervision	Ensure adequate capital to meet obligations to insured, including payment to providers, and establish consumer protections	Bundled payment or similar approaches with one payment shared among providers may inappropriately be treated as subject to solvency requirements for insurers	State insurance regulation should clearly distinguish between the risk carried by insurers and the non-insurance risk of a shared or partial risk payment arrangement
Medical Liability	Health care that falls below the standard of care and causes patient harm	Provide compensation to injured patients and deter unsafe practices	Liability concerns result in defensive medicine and can impede adoption of evidence-based clinical protocols	Establish administrative compensation system and protection for physicians and providers following clinical guidelines

Legal barriers to achieving clinical integration and proposed solutions [39].

Fig. 41.3 Legislation and CIN development (Used with permission of American Hospital Association)

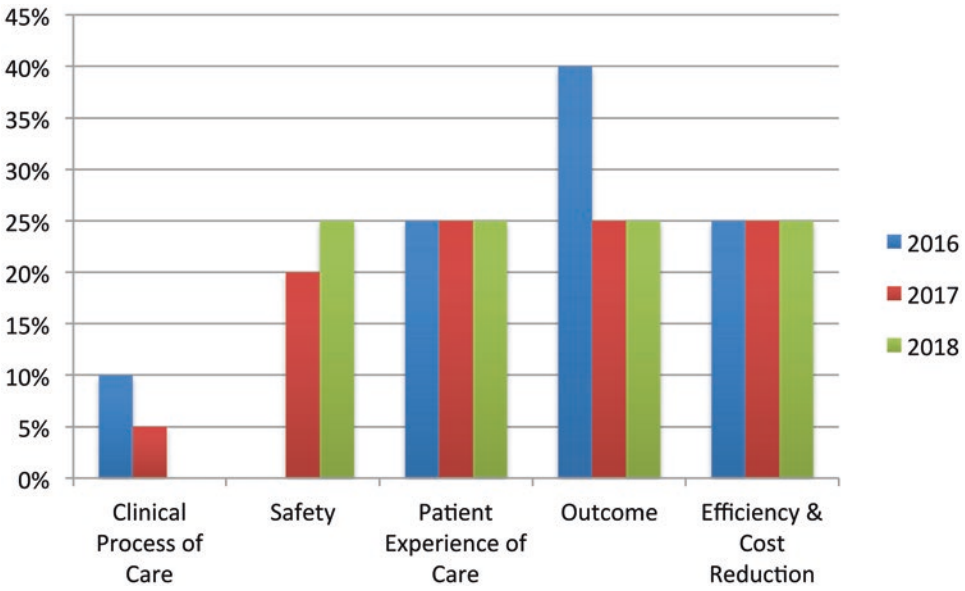

Fig. 41.4 Domains and weights for CMS hospital value-based purchasing. Domains and weights for measuring hospital performance by year in CMS' VBP program [55] (Data source: Centers for Medicare and Medicaid Services)

ria, reported that that the cost incentive resulted in bonuses to 17% of lower-quality hospitals [59]. The impact of VBP also varies across different types of hospitals. Safety net hospitals were found to score lower on all measures of patient experience when compared to non-safety net hospitals, and this has fiscal and operational implications for organizations that operate on small margins [60] and provide care to a population of patients who are uninsured and have lower socioeconomic status. Another study that examined the association between hospital efficiency and VBP performance found lower patient satisfaction scores in less efficient hospitals [61]. Since nursing care has been identified as being the most significant factor affecting the HCAHPS overall rating, many hospitals have subsequently invested in nurse staffing and training. Other factors, such as the state of the hospital room, the care received by providers, and the meal quality have also been shown to be significant predictors of patient satisfaction [62].

Bundled Payment Programs

The Centers for Medicare and Medicaid Innovation (CMMI) was established by the ACA and introduced bundled payments in 2013 as an approach that would assign a fixed cost to an entire episode of care across the care continuum. The episode is defined as all care related to a certain medical event or procedure within a set time frame, mitigating the incentives and risks of over-utilization that were common in a fee-for-service reimbursement model [63]. Bundled payments are an alternative payment approach where a single payment is made for an episode of care. This mechanism moves away from payment for each discrete service that is provided, and the intent is to enhance coordination of care and, ultimately, improve quality. The involvement of both specialists and primary care providers is necessary to determine payment schemes for episodes of care.

Payment models that bundle episodes of care encourage providers to eliminate inefficiencies, but episodic payment does not take into account other conditions that a patient may have, such as comorbidities from chronic illnesses. There are four different models for bundled payments and 48 different clinical episodes of care defined by CMS. Model 1 involves discounted hospital payment with no changes to physician payment; models 2 and 3 are retrospective payment models where the difference between what is billed (using FFS) and the set episode price is settled after the fact; model 4 is a prospective payment model that makes a single set payment for a care episode [63]. Figure 41.5 shows the adoption of the different bundled payment models across the US in 2016.

Impact of Bundled Payment Programs

Bundled payment programs are still in development, and it is too early to weigh in on how they affect care quality and cost of care. A report by the Kaiser Family Foundation summarized the early results of bundled payment in Medicare and reported variation between and within the four models including lower spending growth, no significant differences in spending growth, declines in average overall episode payments for orthopedic surgery episodes, increases in average overall episode payments for spinal surgery episodes, and limited significant differences in quality [30]. Another study that examined the relationship between comorbidities and the total cost for hip fracture care found an association between comorbidities and an increased length of stay, with greater costs illuminating the complexity that exists in pro-

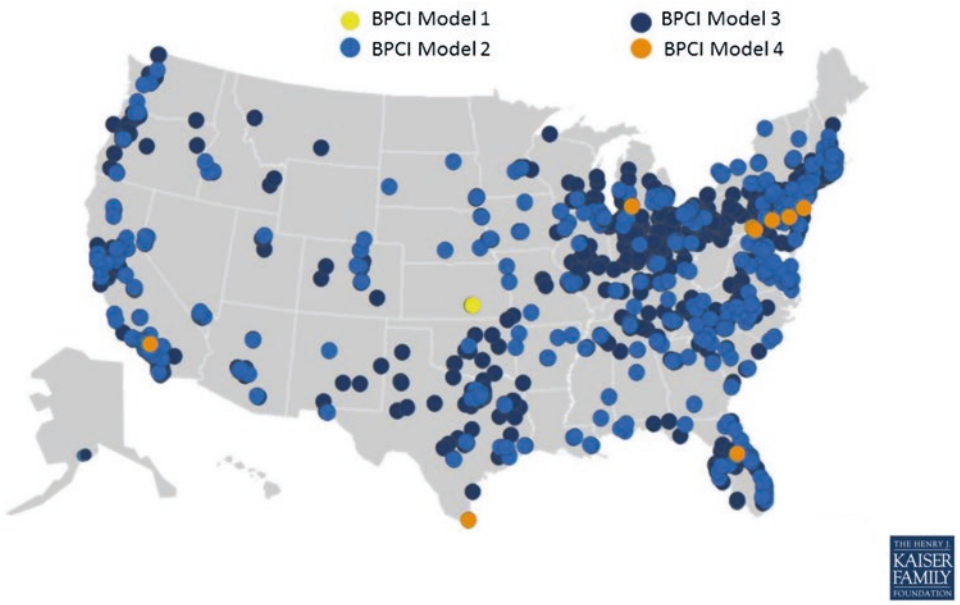

Fig. 41.5 Bundled payment care improvement (BPCI) models in the US (Reprinted with permission from The Henry J. Kaiser Family Foundation: Map data downloaded October 7, 2016 from CMS: https://innovation.cms.gov/initiatives/ map/index.html). Participant counts in this dataset are updated periodically. See Table 4 [30] for official counts in most recently available CMS documents and webpages

viding care for patients with concurrent diagnoses [64]. The Netherlands has adopted bundled payments for chronic illnesses, such as diabetes, chronic obstructive pulmonary disease, and vascular risk management. Several elements of their implementation process have been described including specified minimum care requirements, availability of electronic health records, and optimizing clinical expertise [65]. In contrast, bundled payments implemented in the US focus primarily on inpatient and post-acute care [66].

Future Directions

Policy changes that have shifted payment models from volume to value are intended to promote the quality of care and encourage a coordinated effort to manage chronic diseases. Efficient approaches to meaningful measurement are key to value-based payment models [67], and, as a result, measures of quality performance should be clinically meaningful, patient-centered, transparent, and evidence-based [68]. This will require a regular refresh of quality performance measures to ensure continued alignment with best practices.

Given the prevalence of and expense related to chronic illnesses, it is likely that chronic conditions will remain a focus of performance-based models. Changes in the delivery of care for chronic illnesses will include an increased focus on determining cost-effective, impactful means for improving the health status of the chronically ill population. Additionally, the use of electronic health records will continue to grow in order to document care that was provided and to track the health and illness course of chronically ill patients. These technologies will facilitate more timely identification of patients who may benefit from evidence-based interventions.

The joint emphasis on prevention and care coordination will be essential to decrease costs, given the increased prevalence of chronic illness and the associated cost of chronic disease management [69]. New approaches to adopt and sustain care coordination will be needed as a means of reducing the unnecessary burden to patients and can offset the challenges involved in health-care delivery [70]. This emphasis is consistent with the Institute of Medicine's recommendation for improved coordination and communication across patients' care teams to increase care continuity [71]. Further, the increased use of interdisciplinary treatment teams will provide team-based, patient-centered care to increase care continuity and ideally improve both the quality of care provided and patient-related satisfaction.

The responsibility of increasing population health will fall largely to the care team that is proximal to the patient and can be facilitated by increased understanding of the social determinants of health. There will be an array of care delivery and workflow redesigns for organizations that can help them better navigate a value-focused structure in realizing the quality improvements and cost savings that Medicare is seeking. However, without proper organizational support, these new demands for value will increase providers' burden and may have unintended consequences related to increased burnout and/or decreased provider satisfaction.

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Population Health

42

Deborah S. Porterfield

Introduction

Population health, which examines the health outcomes of a group of individuals and the distribution of defined outcomes within the group [1], has become a focal area of interest in clinical practice at a time of value-based health care. Measuring and ultimately improving population health have particular relevance to chronic disease care. Although population principles of health measurement and management can be applied to all patient populations, the potential for improving health outcomes and cost savings in chronically ill patients is considerable and timely. This chapter provides an overview of population health and population health management and will introduce applications of population health management principles to clinical practice, with a focus on chronic disease care.

The first section introduces the concepts and principles of population health and the historical development of these concepts. The subsequent section will illustrate population health concepts, with attention to measurement and applications to chronic illness care. Content will focus on the areas that are most relevant to health-care systems and health plans that are considering or adopting a population health improvement approach. Finally, an appraisal of the state of the science of population health and future directions in the field will be provided.

Defining Population Health

Population health is best understood as an outcome, rather than in terms of structure or process, which may help to distinguish it from other related concepts in the field [1]. In this way of thinking, population health can be conceptualized of as the sum of specific health outcomes, in domains such as mortality rates, disease burden, and health behaviors, that collectively provide a measure of the health of a defined group of individuals. A more refined understanding of population health would not only examine the health outcomes of a group of individuals but also the distribution of such outcomes within that group [2]. Specific measures of population health include infant mortality rates, prevalence of diabetes, and prevalence of smoking in a given population.

A related concept is population health management, which is the collective systems and policies that affect health-care quality, access, and outcomes for a defined population, with an ultimate goal of improving the health of that group [3]. Population health management focuses on the strategies that improve or promote population health. When the population of interest is a clinical or health-care-based population rather than a general population, the concept of population medicine may be used. This associated term is sometimes synonymous with population health management and has been defined by the Institute of Healthcare Improvement as the design, delivery, coordination, and payment of high-quality health-care services to manage the Triple Aim for a population, using the resources available within a health-care system [4].

There are several strategies that may be designed and implemented in a population management or population medicine approach, such as the use of data registries to identify persons in need of specific clinical preventive service and the use of care managers. For clarity, the term population medicine may be used when clinical populations are being considered and population health for more geographically based populations [5]. However, the term population health can be applied in both situations.

A consistent and rigorous method for determining the numerator and denominator of the defined group is critical in measuring population health. However, clearly delineating the denominator for a clinical population (e.g., health system, health plan, or practice) in particular can be challenging.

D.S. Porterfield (✉)
Department of Family Medicine, UNC School of Medicine, Chapel Hill, NC, USA

RTI International, RTP, NC, USA
e-mail: dport@med.unc.edu

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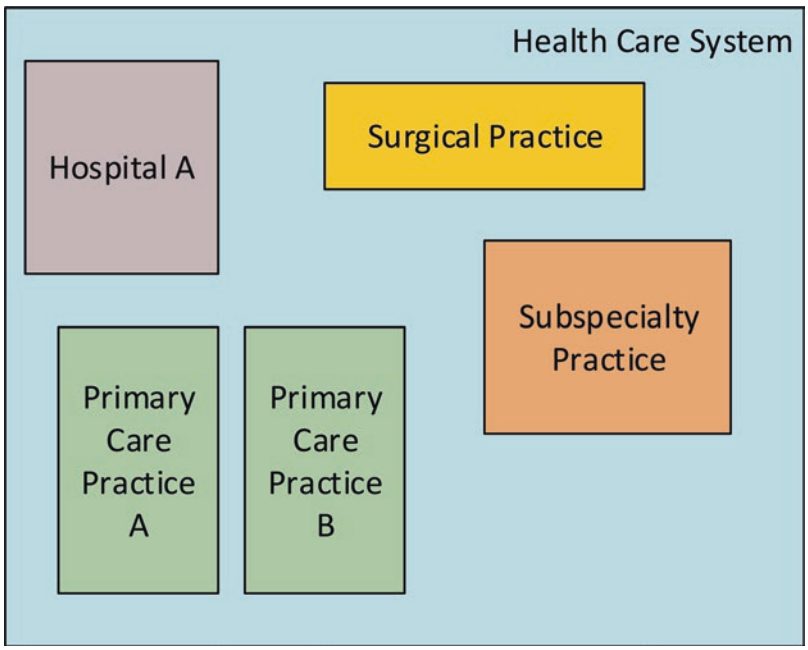

Fig. 42.1 Ideal integrated health service system

For example, at the health system level, hospital service areas overlap in geographic regions and may share patient populations, and patients may receive primary and specialty care in more than one practice. In an ideal and well-integrated health service ecosystem, (see Fig. 42.1) patient populations would easily be identified and attributed and their health outcomes readily measured longitudinally across practice settings. However, health service systems vary considerably in their level of integration and patient attribution (see Fig. 42.2).

One additional clarification is needed to distinguish between public health and population health. These two concepts have sometimes been used interchangeably, for example, to describe the impact of an intervention (e.g., smoking cessation) for a specific population's health (e.g., smokers with emphysema), as well as the public's health (e.g., non-smokers who benefit from reduction in secondhand smoke). In addition, the term public health is most often used to describe an approach to protecting and improving the health of a geographic population, such as a city, county, or state, which is often tied to government or other regulatory agencies (e.g., health departments) with jurisdiction over that population [6].

Intellectual Developments in Population Health

When compared to the long history of public health, the evolution of key ideas in population health is relatively recent [5]. In 1994, members of the Population Health Program of the Canadian Institute for Advanced Research published the text, *Why Are Some People Healthy and Others Not? The Determinants of Health of Populations* [7]. Although this source did not use or define population health, it provided an important early articulation of the concept and, in particular, the need to understand the underlying determinants of population health. A seminal definition came 3 years later with the publication of *Purchasing Population Health: Paying for Results*, in which population health was characterized as "the aggregate health outcome of health-adjusted life expectancy (quantity and quality) of a group of individuals, in an economic framework that balances the relative marginal returns from the multiple determinants of health" [8]. In 2003, this definition was sharpened yet notably broadened the range of health outcomes to include the health outcomes of a group of individuals, including the distribution of such outcomes within the group [2].

A subsequent milestone in the development and application of population health came when the Institute of Healthcare Improvement (IHI) first defined and promoted the notion of the Triple Aim to improve the health of populations in 2008 [9]. The Triple Aim is focused on improving the patient experience of care, improving the health of populations, and reducing the per capita cost of health care [9]. Although population health is not defined or operationalized in the earliest references to the Triple Aim, the IHI has devoted attention to measurement of population health in a recent measurement guide [10].

The concept of population health was operationalized in the Affordable Care Act (ACA) of 2010, which included the phrase "accountability for a patient population" in section 3022, and created the Medicare Shared Savings Program and Accountable Care Organizations (ACOs). The Centers for

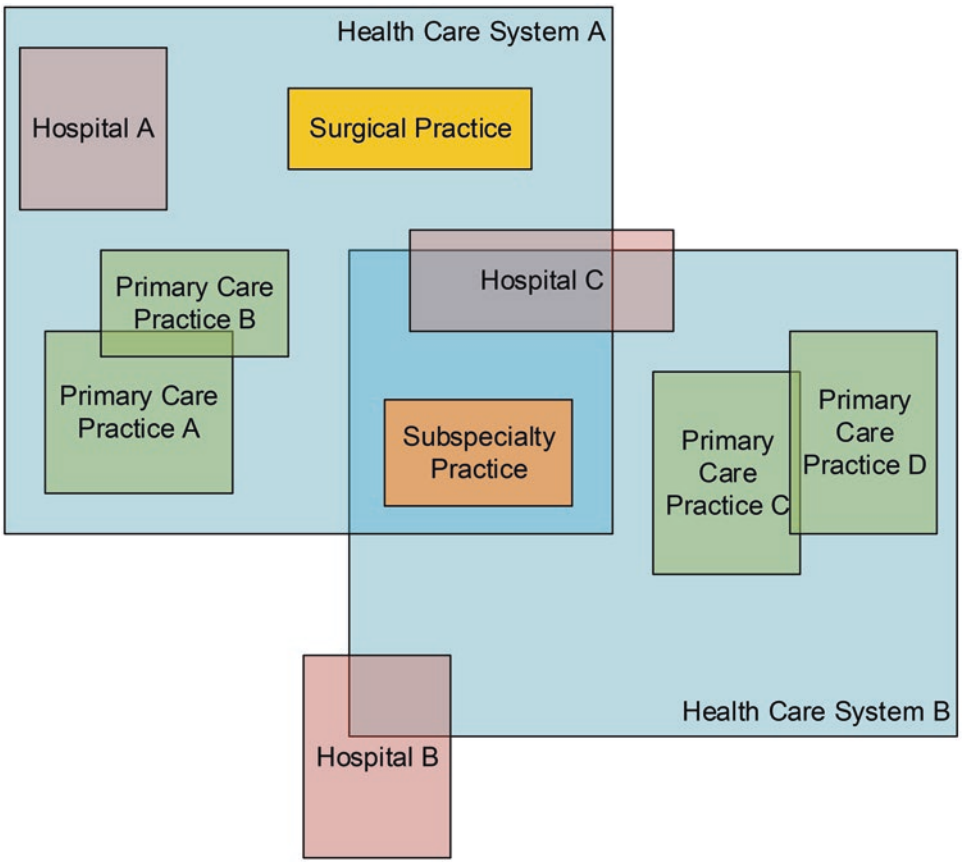

Fig. 42.2 Real-world health service systems

Medicare and Medicaid Services (CMS) defines Shared Savings Program ACOs as groups of doctors and other health-care providers who voluntarily work together with Medicare to give high-quality service to Medicare fee-for-service beneficiaries [11]. ACOs in this way of thinking are accountable for the quality, cost, and overall care of the Medicare beneficiaries assigned to it and must have a formal legal structure that allows the organization to receive and distribute shared savings [12]. The ACA helped direct the focus of health-care delivery systems from improving quality of care for a clinical population to improving its overall health. However, the use of the term population health raised questions and some confusion about the scope of accountability in an ACO, particularly around improving the health of a wider geographic population [13].

A white paper commissioned for the National Quality Forum (NQF) in 2012 helped to further an understanding of population health by providing an environmental scan of population health programs and models and by articulating a rationale for a consistent use in terminology [14]. The report recommended using "total population health" to describe geographic populations, reserving use of the term population health for clinical subpopulations [14]. This recommendation has not been widely adopted, and, as noted earlier, a standard practice has been to clearly define the denominator when using the term population health [14].

A final milestone in the history of population health, and specifically in chronic disease care, came with the development and dissemination of the Chronic Care Model (CCM) in the 1990s [15]. Although this organizational framework to chronic disease care did not specifically use the term population health, the model is an early articulation of population health management principles. For example, the six domains of the CCM overlap with current thinking in population health management strategies (as shown in Table 42.1, below). Specific interventions that are central to the CCM model are also key to current population health management paradigms (Table 42.1) and include measurement of quality of care using information systems and proactive population management strategies based on data [16].

The CCM and the development of quality improvement collaboratives (QICs) had widespread impact on promoting population health thinking and practices in health-care systems, particularly in federally qualified health centers [17]. QICs are structured, multi-organizational learning initiatives in which multidisciplinary teams from each organization focus on a specific health-care quality issue, design and implement a quality improvement plan, measure and report

Table 42.1 Population health management and Chronic Care Model

Population identification	Clinical knowledge of determinants of health
Registry/data warehouse	**Integration with public health/ community systems**
Risk stratification modeling	Utilization of evidence-based guidelines **and embedded decision support**
Use of registry/electronic medical record for: identification of subpopulations for tailored interventions; tracking of referrals to specialists and other providers in the medical neighborhood	Providing of culturally and linguistically appropriate care
Personalized patient-centered care that includes **self-management,** health promotion, disease management, case management	Ongoing evaluation of outcomes with feedback loops
Medical home	Interoperable cross sector health information technology
Interdisciplinary health-care team	*Ongoing quality improvement efforts addressing prioritized health and health-care areas*

Adapted from Siderov and Romney [16]
Bold, also named in the Chronic Care Model; *italicized*, added by the authors

on care processes or outcomes, and engage in organized learning activities [18, 19]. The CCM model was disseminated via national and regional QICs to over 1000 health-care systems [20]. The model also arguably influenced health policy, such as current payment models developed and implemented the by Centers for Medicare and Medicaid Services for chronic care management [21]. The practice and system-level changes envisioned by the CCM promoted widespread adoption of population improvement approach, as well as policies to support it.

Measuring Population Health

Measurement is an essential component to population health, and candidate measures need to have rigor in areas such as validity, reliability, responsiveness, functionality, credibility, and feasibility [22, 23]. Amidst a plethora of measurement sets – from nongovernmental recommendation-making bodies to federal agencies and payors – end users (e.g., health systems, insurance plans) should weigh relevant criteria before choosing a source for general population health measures and for more discrete measures. A key consideration is whether the measurement sets have been developed for clinical populations, geographically based populations, or both.

There are several population health measurement sets that have potential applications to chronic illness. The Institute of Healthcare Improvement's white paper, *A Guide to Measuring the Triple Aim: Population Health, Experience of Care, and Per Capita Cost*, provides a set of population health measures in a menu format, including data sources and representative measures [10]. The paper organizes measurement categories for population health as follows; health outcomes, disease burden, behaviors, and physiological factors (e.g., HbA1c). Electronic health records and patient or health plan participant self-reported surveys are suggested data sources for the candidate measures [10]. For chronic disease, measures include categories of life expectancy, mortality rates, health and functional status, disease burden (e.g., the incidence and/or prevalence of chronic disease), and behavioral and physiological factors such as smoking, physical activity, diet, blood pressure, BMI, and cholesterol [10].

The National Quality Forum (NQF) is another source for validated measures of care and outcomes for clinical populations. The NQF has worked to strengthen a collaborative approach across clinical, public health, and other sectors in order to measure and improve population health [24]. In 2012 the NQF endorsed two specific sets of population health measures – a total of 24 measures – including items such as late HIV diagnosis, adult smoking prevalence, and BMI screening and follow-up [24, 25]. In a subsequent activity, the Health and Well-Being Project, the NQF focused on measures of health and well-being that were applicable across a subset of contexts including health-care settings and communities. The currently endorsed 22 indicators include cancer screenings, immunizations, HIV screening, and population-level HIV viral suppression [26]. The NQF also published a report entitled, *Improving Population Health by Working with Communities: Action Guide 3.0* [27], which, although is not a measurement set, does identify data sources for measuring population health and recommendations on how to select measures of population health to use in improvement efforts.

The Institute of Medicine (IOM) has led several initiatives relevant to population health, with key recommendations to promote population health measurement, and cautions about the proliferation of measurements and the need for alignment [28]. To account for the number of overlapping measurement sets, the IOM presented a streamlined core set of 15 measures of health and health care, with an additional 39 priority measures, designed to assess and monitor progress in the national's health and to be used across sectors [28]. Candidate population health measures from the IOM report include self-reported health status, life expectancy, body mass index, addiction death rate, teen pregnancy rate, and preventable hospitalizations [28]. The IOM also explored approaches to measurement capture since multiple initiatives to improve population health have provided a

landscape of population health metrics, as well real-world examples [29].

A number of health-care quality measurement sets may be considered as sources of population health measures, although health-care quality is usually not considered a domain of population health. There are several examples of health-care quality measurement, including the Medicaid Core Set of Adult Health Quality Measures [30], the Health Resources and Services Administration Uniform Data System [31], Agency for Healthcare Research and Quality's (AHRQ) Prevention Quality Indicators [32], and HEDIS Health Plan Measures [33]. These measurement sources of health-care quality may be relevant if there is a focus on process – in addition to outcome – measures for a specific condition that can enhance strategies to improve health outcomes.

Finally, an additional source for population health measurement may be found in AHRQ's National Healthcare Quality and Disparities Report Chartbooks [34]. The chartbooks are organized in a similar fashion to the IOM's domains of quality of care (e.g., safe, effective, patient-centered, timely, efficient, equitable); however, there are multiple health status measures (e.g., deaths from colorectal, breast, and lung cancer, HIV viral suppression, high blood pressure prevalence) in the dataset that reside in the population health measurement domain. The distribution of health outcomes in specific subpopulations (e.g., persons of color) is a specific and important aspect of population health.

Models and Applications of Population Health

It is critical to have a conceptual framework, theory, or an evidence-based model to guide the selection of measures and interventions when considering approaches to measuring, and ultimately improving, the health of populations. A model provides an organizing framework in terms of plausible interventions to improve health outcomes. Specificity is required when applying a model in order to gauge fidelity to the intervention and development of a measurement and analytic approach to determine the effect of the intervention. This is important when working with health-care systems and/or health insurance plans that may be less familiar with methods to identify and address more "upstream" factors, such as social determinants of health. A well-developed theory, which elucidates the important drivers of population health, can map out pathways to determine how health system-level factors influence those drivers of population health. A theoretical or empirically based model can also identify potential levers to those upstream drivers, pointing out ways to synergistically work with clinical care interventions to improve health.

There have been several models of population health, and two have particular relevance to chronic illness care [10, 15]. The Chronic Care Model (CCM) is a foundational framework for chronic disease population health improvement (Fig. 42.3). As noted earlier, the CCM does not specifically use the term population health but instead describes "health outcomes" [15]. The CCM focuses on clinical service delivery and is comprised of several domains; organization of health care, decision support, delivery system design, clinical information systems, and self-management support. The sixth domain included in the model – community resources and policies – is the most underdeveloped of the domains.

The CCM has been evaluated in systematic reviews, most recently in a review that included 77 original studies of implementation of the CCM for patients with chronic disease [36]. All but two studies reported improvements in health-care practice or health outcomes, and the review described specific elements of the CCM that were included in the interventions. Self-management support and delivery

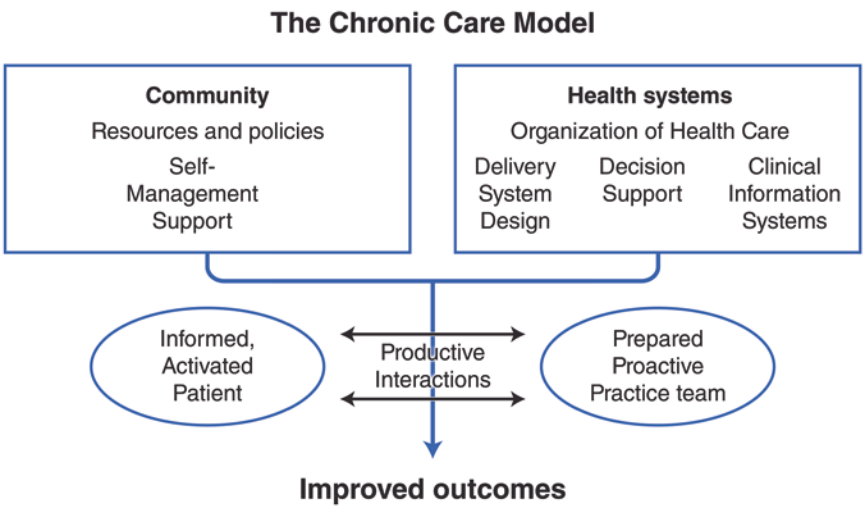

Fig. 42.3 Adapted from the Chronic Care Model developed by the MacColl Institute [35]

system design were the most commonly used approaches; however, it was unclear which combinations of interventions were most effective.

The CCM has had broad influence in clinical practice and policy [20]. An "Expanded Chronic Care Model" of the CCM includes elements of chronic disease prevention, social determinants of health, and the role of community supports to positively impact population health for patients with chronic disease [37]. These targeted areas enriched the original CCM, which had a primary focus on care delivery for chronic disease, by expanding the scope beyond clinical settings as well as highlighting the importance of primary and secondary prevention. An "eHealth Enhanced Chronic Care Model" potentiated each of the CCM elements by applying health and communication technologies, as well as adding a new element of "eHealth Education," or the promotion of skills for persons with chronic disease in areas such as texting, websites, and mobile phone applications [38, 16].

The Institute of Healthcare Improvement's guide to measurement of the Triple Aim A is a second model of population health that is relevant to chronic disease care [10] (Fig. 42.4). This framework organizes a menu of measures for the Triple Aim components and is comparable to the Expanded Chronic Care Model in its depiction of how health-care delivery systems can work with preventive services to promote population health [10]. In the model, prevention and health promotion efforts influence upstream factors, such as the social determinants of health, and individual factors, such as health behaviors. In contrast, health care is depicted as influencing disease burden, health and function, and mortality.

Two IHI model features of population health measurement are noteworthy. First, the IHI model does not include health-care delivery measures within its population health aim but collapses these in the experience of care aim. Second, the model does not include social determinants of health in the measure set, although health equity is featured prominently in the model.

Information Technology

Information technology (IT) is a prerequisite and a key component in population health management. The federal Office of the National Coordinator defines health information technology as the "array of technologies to store, share, and analyze health information [39]," including EHRs, personal health records (PHRs), and e-prescribing. Well-integrated and high-functioning IT systems can potentially facilitate population health management in multiple ways: through the identification of a population at risk, either by health outcomes or lack of preventive or clinical services, by tailoring clinical services to subpopulation identified through queries or risk modeling, and by ongoing evaluation of outcomes and quality improvement efforts. One framework of health IT in ACOs describes a set of tools needed to accomplish the functions of IT and population health management: electronic health records, clinical data warehouses, registries, predictive modeling/risk stratification abilities, decision support tools, patient portals, and data analytics tools [40]. An Agency for Healthcare Research and Quality report specified requirements and functions for IT systems in order to support population health management [41]. These requirements

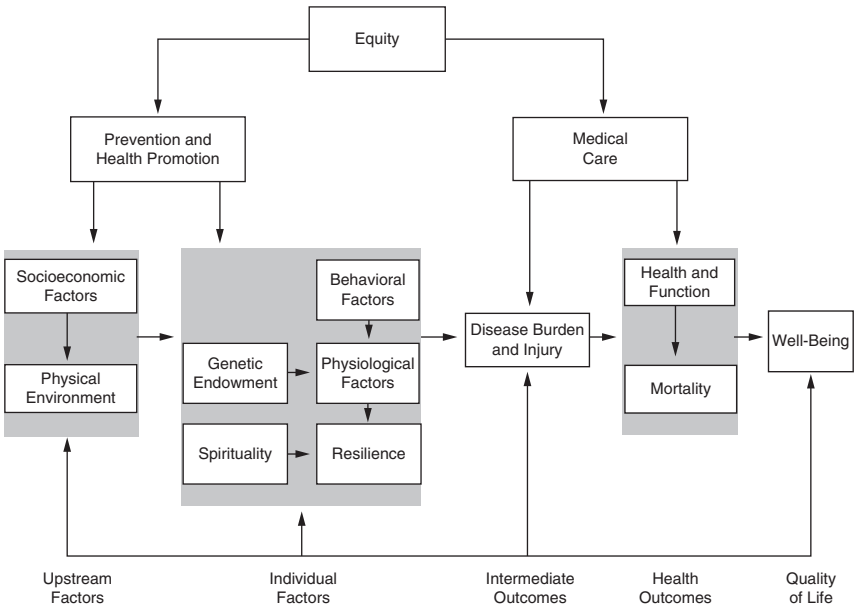

Fig. 42.4 The Institute of Healthcare Improvement's model of population health. (Adapted from [10])

include technical functionalities to identify subpopulations of patients, examine detailed characteristics of identified subpopulations, create reminders for patients and providers, track performance measures, and make data available in multiple forms [41].

The applications of IT are being adopted into organizational levels, as evidenced by the formation of Accountable Care Organizations (ACOs) and several other national initiatives such as recognition of clinical practices as patient-centered medical homes (PCMH) and the spread of meaningful use. The PCMH Recognition Program of the NCQA [42] includes a specific standard of "Population Health Management" with elements such as clinical data and use of data for population management. Meaningful use of certified electronic health record technology, a term developed and promoted by the federal government, promotes the use of EHRs to improve care delivery, population health, and health data security [43]. The sustained adoption of the meaningful use of EHRs will be incentivized through payment programs of Medicare and Medicaid.

Table 42.2 displays the domains and features of IT systems that are required to support respective functions. Of note, the second and third domains support population health management [44].

A survey of early ACOs found that about half reported complete or near complete capability for the most common IT functions [40]. Only 36% of ACOs were able to integrate outpatient and inpatient data from providers within the organization, and only 34% had the IT capability for primary care physicians to bidirectionally share referral information with specialists.

Table 42.2 Domains of information technology systems for provider organizations

Domain	System features	Purpose
Transaction systems	Patient registration and scheduling	Care of the individual patient
	Electronic health record, including orders, e-prescribing, and patient portal	
	Patient billing and collection	
	General financial systems	
Population management	Patient registries; care coordination and case management	Population-level view
	Risk stratification: predictive analytics, protocols for intervention	
	Task tracking and documentation	
Data warehouse and analytics	Analytical models	To develop knowledge
	Cost accounting	
	Comparative data, benchmarking	
	Exploratory analyses	
	Practice profiles for clinicians	
	External reporting	

Adapted from [44]

Social Determinants of Health

Another focus in population heath management is increasing the awareness of individual providers and health-care organizations to address the social determinants of health (SDOH), which are key drivers of health of populations [45]. The World Health Organization defines SDOH as "conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life" [46]. Some proponents of population health improvement have advocated for measurement and intervention in the SDOH, including a recent call for including SDOH and behavioral factors as part of the medical record, a key first step toward clinicians to identify and address these factors [4]. In addition, the Centers for Medicare and Medicaid Services has promoted the Accountable Health Communities initiative, a program to promote screening approaches for adverse SDOH in clinical care settings as a central part of managing of the health of the populations [47]. This initiative has drawn some criticism since criteria for an effective SDOH screening are underdeveloped [48].

Independent of the Accountable Health Communities program, there has been interest in promoting collaborations between health-care systems and public health or community-based organizations, in order to address behavioral and social determinants of health [49]. Early work in this area was led by the Agency for Healthcare Research and Quality, specifically for the delivery of preventive services [50], but other sources of resources to promote these collaborations, in addition to AHRQ, are now available, such as the Practical Playbook [51]. However, evidence for these collaborations is early, and emerging research will need to elucidate efficacy for chronic disease states and effectiveness in health-care organizational contexts [52, 53].

Future Directions

Population health is best understood as a set of outcomes that describe the health status of a defined population. As such, the state of the science of population health is tied to the measurement science of key outcomes. To further this science, more robust measures and data collection strategies will be needed in chronic disease population health. Although there is not a paucity of measures of chronic disease population health, evidence mapping, which includes the synthesis, consensus, and identification of measurement gaps, will be needed from the patient, the health-care system, the health

payor, and larger social perspectives. Collaborative activities and neutral convening bodies, such as IOM and NQF, can guide approaches to promote alignment among various stakeholders and achieve consensus in measurement priorities. Payors will continue to heavily influence measurement priorities; however, public health agencies (e.g., health departments, CDC) will also provide important input, even in clinical population health measurement.

The development of new data sources and acquisition methods is another gap area, especially as IT systems and connectivity mature. For example, collecting quality of care data (e.g., delivery of preventive services) at a geographic level is possible from patient self-reported surveys, but the capacity to systematically gather and synthesize this data from electronic medical records (EMRs) is uneven and made possible only by shared data systems, data warehouses, and health information exchanges. IT compatibility to facilitate measurement for both the clinical and geographic populations must be prioritized, developed, and implemented to decrease fragmentation of efforts. The area of population health informatics needs further development to facilitate measurement [54].

The evidence base is evolving in the science of population health management. The toolkit for population health management has included interventions such as the patient-centered medical home (PCMH) model, patient registries through electronic health records, and a plethora of quality improvement activities. Given the wide range of interventions, it is unclear which of these strategies are effective – in combination with others or as stand-alone interventions – and highlight the challenges of evaluating population health management strategies as a single package or toolkit. For example, the Chronic Care Model (CCM) has been evaluated in systematic reviews, and all but two studies reported improvements to health-care practice or health outcomes; however, the wide variation among interventions that were implemented precluded the identification of the most effective interventions [36].

These prior evaluations of the CCM can inform the future of evaluating population health management strategies. Standardized evaluation, research, and quality improvement can evaluate and promote the evidence base for targeted population health management interventions and the practice level. One intervention, for example, would link facilitated communication through an electronic health record between a physician and a midlevel provider, with a care management model that allows the midlevel to implement a care management protocol.

Population health management is becoming an integrated part of clinical practice, and there is a growing need to include population health and population health management in the curriculum of undergraduate, graduate, and postgraduate education [55]. The American Association of Medical Colleges and the Centers for Disease Control and Prevention have spearheaded efforts to develop curriculum and competencies in population health [55, 56], but dissemination efforts are limited, and adoption is unknown. Current postgraduate opportunities are growing in number, and there are online and in-person degrees in public health, population health, preventive medicine, and health-care administration or business. For example, there are 73 residencies in Preventive Medicine, which provide 2-year training in population health, including a Master's in Public Health Degree. In addition, the American Board of Preventive Medicine has recently developed board certification in Clinical Informatics. These advancements begin to address the gap in population health in medical education; however, incorporating population health into undergraduate and graduate education will be a high priority to ensure that the health-care workforce of the future has acquired basic competencies in this critical area.

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Health-Care Workforce

43

Erin Fraher and Bruce J. Fried

Introduction

Ensuring that the health workforce is equipped to care for patients with chronic conditions is increasingly important to employers struggling to keep pace with the growing demands placed on the United States (US) health-care system by an aging population. Labor costs are a significant expenditure for employers; approximately 50% of a hospital's bottom line is spent on wages [1]. US health-care spending is rising, growing 5.8% in 2015 alone, reaching $3.2 trillion or nearly 18% of gross domestic product [2]. Eighty-six percent of health-care spending in the United States is for patients with one or more chronic conditions [3]. With the costs of caring for patients with chronic illness consuming an ever-increasing percentage of state and federal budgets, policy makers are seeking ways to bend the cost curve, including implementing new payment models that shift from rewarding volume to incentivizing value. New payment models will require transforming the workforce from one predominantly trained to treat episodic illnesses to one prepared to manage chronic disease and improve population health. Such a transformation will require recruiting, retaining, and managing a workforce that is properly trained in the care of people with chronic disease and distributed into needed geographies and specialties.

E. Fraher (✉)
Department of Family Medicine School of Medicine, Program on Health and Workforce Research and Policy, Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA
e-mail: erin_fraher@unc.edu

B.J. Fried
Health Policy & Management, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA
e-mail: Bruce_Fried@unc.edu

Defining the Chronic Care Workforce

The workforce of the future needs to care for patients with the most common chronic diseases including hypertension, hyperlipidemia, arthritis, mood disorders, diabetes, asthma, coronary artery disease, dementia, and chronic obstructive pulmonary disease (COPD) [3]. Characterizing the chronic care workforce is challenging because it consists of a wide range of licensed and unlicensed providers who work in inpatient, outpatient, long-term, community, and home-based settings. Table 43.1 shows the numbers of workers in what are considered traditional health-care occupations.

Nurses

The largest licensed health professional group in the United States is nursing. There are over 2.7 million registered nurses (RNs) employed in health care, more than three times the number of physicians. The majority of nurses (64%) are employed in hospitals [4]. Licensed practical nurses (LPNs) make up the next largest licensed health professional group behind physicians. About half of LPNs work in long-term care with three out of four of these LPNs employed in skilled nursing facilities [5].

Therapists

Therapists make up the next largest group with nearly 611,000 occupational, physical, radiation, recreational, and respiratory therapists in practice in the United States. Therapists are sometimes overlooked in health workforce planning discussions despite the critical and increasingly important role they play in addressing the health-care needs of patients with chronic disease in acute and community-based settings. For example, as Medicare moves away from

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Table 43.1 Number of health-care workers, select occupations, United States, 2015

	Number
Physicians and surgeons[a]	860,939
Family physicians	111,295
General internists	114,089
Geriatricians	5227
Other specialties	630,328
Physician assistants	98,470
Nurse practitioners[b]	154,057
Registered nurses	2,745,910
Licensed practical nurses	697,250
Dentists	116,750
Pharmacists	295,620
Optometrists	35,300
Chiropractors	32,080
Podiatrists	9500
Therapists	
Occupational therapists	114,660
Physical therapists	209,690
Radiation therapists	16,930
Recreational therapists	17,880
Respiratory therapists	120,330
Speech-language pathologists	131,450
Audiologists	12,070

Source: Bureau of Labor Statistics, https://www.bls.gov/oes/current/oes_nat.htm#29-0000

[a]AAMC 2015 State Physician Workforce Data Book, https://www.aamc.org/data/workforce/reports/458480/1-1-chart.html

[b]NCHWA, National Sample Survey of Nurse Practitioners 2012, https://bhw.hrsa.gov/sites/default/files/bhw/nchwa/npsurveyhighlights.pdf

paying for individual procedures toward providing payments for episodes of care for conditions like hip fractures and joint replacement, health systems are increasingly focused on ways to deploy physical and occupational therapists to improve patients' functional status and reduce the risk of costly hospital readmissions.

Physicians

There are about 861,000 physicians in active clinical practice in the United States. Per capita physician supply has increased steadily over time, from 17 physicians per 10,000 population in 1980 to 25 physicians per 10,000 in 2013. However, growth among specialties has not been equal. Proceduralist specialties, such as vascular and interventional radiology and interventional cardiology, are growing rapidly, with the workforce expanding by 49% and 69%, respectively, between 2010 and 2015. By contrast, primary care specialties have grown more slowly. The number of internists increased by only 4.6%, and family physicians grew by just 4.5% over the same period. The Association of American Medical Colleges has projected that the United States will be short between 4900 and 35,600 primary care physicians by 2025 [6].

In addition to family physicians and internists, geriatricians play a critical role in caring for elderly patients with multiple chronic conditions. While Table 43.2 shows that the number of geriatricians in active practice in the United States increased 22% between 2010 and 2015, this growth rate is deceiving because the total number of geriatricians is small. In 2015, there were 5,227 geriatricians in practice, representing just 5% of the numbers of internists and family physicians. Despite increased demand and potential shortages, family medicine, general internal medicine, and geriatrics have not been popular career choices due to perceived low prestige and low remuneration compared to other specialties [7–9].

Chronic Care Workforce Planning

Ensuring an adequate supply of providers for patients with chronic disease is not the only challenge. The United States faces a persistent misdistribution of providers. Over 51 million Americans, representing 20% of the US population, live in rural areas where less than 11% of the nation's physicians practice. The Department of Health and Human Services uses a ratio of one primary care physician per 3,500 population as the standard for designating primary care health professional shortage areas (HPSAs). More than 20 million Americans live in an area with a shortage of primary care physicians [10]. In these geographic areas, patients with chronic disease have problems accessing care, which often means they do not receive the routine services needed to avoid hospitalization. The lack of access to outpatient services for people with ambulatory sensitive conditions such as asthma, diabetes, COPD, heart failure, and hypertension leads to higher hospitalization rates [11].

The United States needs a large and diverse health-care workforce to effectively care for patients with chronic disease. Between 2000 and 2002, the average Medicare beneficiary saw a median of two primary care physicians and five specialists and required a host of diagnostic, therapeutic, and pharmacy services [12]. There is an increasing demand not just for primary care physicians but also specialists including vascular surgeons, cardiologists, general surgeons, nephrologists, and pulmonologists to meet the needs of the growing number of patients with diabetes, heart failure, COPD, and asthma [13]. These workforce projections suggest that the future number and distribution of primary care and specialty physicians will not be adequate to meet the growing burden of chronic disease. Care will therefore need to be delivered by interdisciplinary teams of health-care providers who are working at the highest roles and functions allowed by their professional licenses [14].

Table 43.2 Percentage change in the number of active physicians by specialty, United States, 2010–2015

	2010	2015	% growth 2010–2015
Interventional cardiology	1923	3255	69.3
Vascular and interventional radiology	1990	2967	49.1
Critical care medicine	7101	10,159	43.1
Pain medicine and pain management	3224	4607	42.9
Neuroradiology	2345	3295	40.5
Pediatric hematology/oncology	1981	2545	28.5
Internal medicine/pediatrics	3844	4840	25.9
Pediatric cardiology	2012	2521	25.3
Geriatric medicine	4278	5227	22.2
Nephrology	8362	10,083	20.6
Infectious disease	7149	8515	19.1
Endocrinology, diabetes, and metabolism	5891	6968	18.3
Neonatal-perinatal medicine	4404	5196	18
Vascular surgery	2853	3358	17.7
Emergency medicine	33,984	39,579	16.5
Rheumatology	4917	5612	14.1
Hematology and oncology	12,743	14,476	13.6
Child and adolescent psychiatry	7706	8736	13.4
Gastroenterology	12,852	14,126	9.9
Radiation oncology	4459	4848	8.7
Dermatology	10,820	11,706	8.2
Physical medicine and rehabilitation	8502	9164	7.8
All specialties	*799,501*	*860,939*	*7.7*
Allergy and immunology	4325	4630	7.1
Neurological surgery	5047	5346	5.9
Internal medicine	109,048	114,089	4.6
Family medicine/general practice	106,549	111,295	4.5
Neurology	12,916	13,392	3.7
Pediatrics	55,509	57,543	3.7
Ophthalmology	17,943	18,593	3.6
Anesthesiology	40,123	41,351	3.1
Plastic surgery	6822	7020	2.9
Obstetrics and gynecology	40,377	41,481	2.7
Otolaryngology	9232	9411	1.9
Cardiovascular disease	21,819	22,058	1.1
Urology	9826	9808	−0.2
Psychiatry	38,289	37,736	−1.4
Radiology and diagnostic radiology	27,986	27,522	−1.7
Orthopedic surgery	19,822	19,145	−3.4
Preventive medicine	6824	6592	−3.4
General surgery	26,314	25,254	−4
Thoracic surgery	4682	4485	−4.2
Pulmonary disease	6077	5482	−9.8
Anatomic/clinical pathology	14,975	13,286	−11.3

Source: Association of American Medical Colleges, https://www.aamc.org/data/workforce/reports/458514/1-9-chart.html

Using three different scenarios regarding the amount of preventive and chronic care that could be delegated to non-physician providers (77%, 60%, and 50% of primary care and 47%, 30%, and 25% of primary care), it is estimated that a primary care team could effectively care for a panel of 1,947, 1,532, or 1,397 patients, respectively [15]. Team-based models that expand physician panels will sufficiently size the primary care workforce to serve the needs of the aging population. This change in the structure of primary care practice will require retraining of both physicians and other providers, remapping of workflows, standing orders that empower non-clinicians to share more responsibilities, educating patients, and primary care payment reform [15].

Individual states determine the scope of practice legally allowed for health professionals, and there is considerable variation between states. In most states in the western region of the United States, nurse practitioners (NPs) can evaluate and diagnose patients, order and interpret tests, and initiate and manage treatments, including prescribing medications. In other states including many states, in the American South, an NP's scope of practice is limited and she or he must be supervised by a physician. Health workforce experts warn that the current state-based system for health profession regulation is problematic and they have urged policy reforms to redesign scope-of-practice laws and regulations to better support the transformation of the workforce that will be necessary to effectively care for the population [16].

Team-Based Care

The standard 15-min visit with a physician is ill-suited for chronic disease management. Some practices have addressed this challenge by employing nurse practitioners, physician assistants, pharmacists, registered nurses, medical assistants, social workers, and other health professionals. A physician may pair with a non-physician team member who helps patients with tasks such as paperwork, authorizations, scheduling tests, and coordinating referrals to specialists [12].

Medical Assistants

The non-physician team member is often a medical assistant (MA). There are over 600,000 MAs in practice in the United States, and their numbers are expected to increase by 23% between 2014 and 2024 [17, 18]. MAs are not licensed, but certification is available through national organizations such as the American Association of Medical Assistants (AAMA) though this is often not required for employment. MA training is highly variable in length and rigor with programs ranging from 6 months to 2 years in length. Some MAs enter the workforce with only a high school degree and receive on-the-job training [19]. The legal requirements governing the types of services MAs can provide vary considerably between states.

As the population of patients with chronic disease has grown, the roles of many MAs have expanded beyond the traditional tasks of rooming patients and taking vital signs. In some primary care practices, MAs take patient histories, give immunizations, provide preventative care services, act as health coaches, and serve as scribes to document clinical encounters [19–21]. MAs follow standing orders and algorithm-based protocols that do not require the direct involvement of the physician or other providers [22]. MAs also manage patient panels by using patient registries or data from electronic health records to identify and contact patients who are overdue for services, visits, and other needs [23, 24].

Registered Nurses

Only one in four registered nurses works outside of acute care [25]. RNs have a significant and yet largely untapped potential to increase access to primary care by managing the needs of patients with a wide range of chronic medical and mental health conditions, including substance abuse. Many RNs who are employed in primary care spend much of their time triaging patients. While it is important and essential to determine which patients need immediate care, RNs who function in this capacity are limited from taking on a range of other direct patient care responsibilities. Innovative primary care practices are optimizing and reconfiguring the RN role to include care coordination, management of aging and chronically ill patients, enhancement of patients' self-management skills for chronic physical and behavioral health conditions, and provision of transitional care and wellness services [26]. Other high-functioning primary care practices use RNs for same-day appointments or group visits and deploy nurses to conduct health risk appraisals, depression screens, health promotion, and disease prevention services [22, 25].

Pharmacists

The common use of pharmaceuticals to manage chronic disease has broadened the role of the pharmacist. Traditionally, pharmacists were employed in retail pharmacies and mostly focused on dispensing medications. In recent years, pharmacists have taken on increasing patient care roles including coordinating drug therapies, developing medication management plans, educating patients, promoting medication compliance, and performing medication reconciliation to reduce medication interactions and duplication [27]. California, Montana, New Mexico, and North Carolina have created advanced practice pharmacy designations that expand pharmacists' scope of practice to include direct patient care, but because most pharmacists are employed in retail settings and paid based by dispensing fees, reimbursement for direct patient care services remains limited [28].

Evolving Reimbursement Practices

In January 2015, Medicare began paying $42 per month per enrolled patient for managing the care of patients with two or more chronic conditions including heart disease, diabetes, and depression [29]. This reimbursement stream has accelerated the use of care coordinators to reduce care fragmentation and address the service gaps often confronted by patients with chronic disease. Nurses generally fill this coordination role, arranging referrals between primary care and specialty physicians and acting as case managers for complex patients. This coordination role is critical for lowering costs and improving care quality because patients with multiple chronic conditions and complex therapeutic regimens are at particularly high risk for hospital readmission in the days and weeks following discharge. When done effectively, transitional care intervention after hospitalization can increase the length of time between the hospital discharge and readmission or death while also decreasing costs, particularly in vulnerable populations such as older adults hospitalized with heart failure [30].

Addressing Social Needs

To be effective, the health-care workforce must be trained to address the social determinants of health—those factors that affect patients in places where they live and work. The importance of considering the upstream factors affecting health is reflected in a story told by Irving Zola, a medical sociologist who recognized the need for preventive health. Zola relates the story of a physician trying to explain modern medical practice:

> "You know," he said, "sometimes it feels like this. There I am standing by the shore of a swiftly flowing river and I hear the cry of a drowning man. So I jump into the river, put my arms around him, pull him to shore and apply artificial respiration. Just when he begins to breathe, there is another cry for help. So I jump into the river, reach him, pull him to shore, apply artificial respiration, and then just as he begins to breathe, another cry for help. So back in the river again, reaching, pulling, applying, breathing and then another yell. Again and again, without end, goes the sequence. You know, I am so busy jumping in, pulling them to shore, applying artificial respiration, that I have no time to see who the hell is upstream pushing them all in." [31]

Expanding Care into the Community

In January 2016, the US Secretary of Health and Human Services, Sylvia Burwell, announced the creation of the Accountable Health Communities Model, a $157 million investment aimed at addressing the upstream factors that

affect population health. The model recognizes that keeping people healthy is about more than what happens inside a doctor's office and will test whether providing social services improves population health and reduces costs to taxpayers [32]. The program will address the gap between clinical care and community services in the current health-care system by systematically identifying and addressing the social needs of Medicare and Medicaid beneficiaries, such as housing, food, violence prevention, and transportation [33]. In early 2017, 32 communities were enrolled in the program. These 32 communities will be studied to determine if addressing unmet health-related social needs reduces the risk of developing chronic conditions, increases an individual's ability to manage these conditions, decreases health-care costs, and prevents avoidable health-care utilization [34].

The Accountable Health Communities Model and other newly implemented programs expand the boundaries of many traditional roles in the health-care system [35]. New roles focus on meeting patients' health-care needs across the continuum from home to community and between acute and long-term care settings. This approach requires that health system planners adopt a broader definition of who is in the workforce and shift from thinking of a "health workforce" to a "workforce for health" [36]. This broader definition will consider the roles that social workers, patient navigators, community health workers, paramedics, public health professionals, and other community-based workers play in keeping patients healthy in their homes and communities.

Social Workers

Social workers play an increasingly important role on interdisciplinary community-based teams. They work alongside nurses to provide in-home visits, psychosocial assessments, patient education, referral to community resources, and regular check-ins for chronically ill older adults. Team care that pairs geriatricians with social workers lowers costs and reduces hospital days in chronically ill older men who are frequent users of health services, due to social workers' help with financial resources, psychosocial problems, and improved discharge planning [37]. Social workers improve both the behavioral and physical health of patients without increasing overall costs for populations, including those with chronic illness and behavioral health needs [38]. Social workers integrate behavioral health into standard care by addressing mental health and substance abuse problems and coordinating referrals to community resources. They serve as care managers for patients with chronic conditions, monitor treatment plans and adherence, consult with primary care providers, and perform behavioral health interventions.

Community Paramedicine

Community paramedicine (CP) is a relatively new community-based model of health care that may fill gaps in the health-care infrastructure and decrease costs by reducing emergency transports and readmissions to the hospital [39]. There is growing interest in CP programs, particularly in rural communities where residents tend to have reduced access to health care and poorer health outcomes than their urban counterparts. Community paramedics can administer injections, care for wounds, manage medications, educate, and provide other in-home services to patients. CPs can also provide follow-up care after hospitalization and a range of other services to older adults with chronic conditions with the aim of reducing readmissions [40, 41].

Occupational Therapists, Nurses, and Handymen

The Community Aging in Place, Advancing Better Living for Elders (CAPABLE) program, funded by the US Department of Health and Human Services' Center for Medicare and Medicaid Innovation, is a community-based model of care that serves dually eligible older adults (low-income seniors on both Medicare and Medicaid). This innovative program addresses the daily health-care needs of enrollees by providing assistive devices and modifying the home to make ambulation and navigation easier and safer [42]. These services are delivered by an occupational therapist with support from nurses and handymen, who install equipment and make necessary home modifications. Improving the ability to perform the activities of daily living improves medication management and reduces depression in chronically ill patients.

Public Health Workers

In addition to the traditional roles of managing infectious disease outbreaks, promoting vaccines, and tracking community illness, the public health system must now address the challenges of caring for an aging public that has an increased prevalence of chronic disease. Public health measures that address obesity, tobacco use, poor nutrition, and inactivity can reduce the risk factors that contribute to chronic illness. While the potential role of public health in preventing and managing chronic disease is significant, health-care systems and public health services in the United States have largely operated in separate spheres. Coordinating these systems can address chronic illness and the fragmentation of care [43, 44].

Training Gaps for the Chronic Care Workforce

The health-care workforce needs to manage a growing population of patients with chronic diseases, yet many health professional students feel they lack key chronic care

competencies [45, 46]. They also lack exposure to the wide range of other health and community-based workers with whom they will come in contact as they manage patients' chronic health and psychosocial needs across a continuum of different settings. More interdisciplinary training opportunities are needed to bring together traditional health-care providers and nontraditional workforce members such as social workers, community health workers, public health professionals, and other community-based and social service workers. These interdisciplinary teamwork competencies must be taught to students but also to the workforce already employed. Certification bodies and education institutions need to ensure that health-care professionals who care for patients with chronic disease have the opportunity to access affordable, convenient, and evidence-based continuing education.

Training Mismatch

Health-care professionals' future practice patterns are influenced by the settings in which they train. Most chronic illness care takes place in primary care practices [14]. Yet most health profession students, including those training to be physicians, nurses, and therapists, receive most of their clinical training in acute care settings with little exposure to the treatment and management of patients with chronic diseases in ambulatory settings. More training in high-performing primary care practices that have redesigned workflows and reallocated tasks to efficiently and effectively deliver care to patients with chronic disease is appropriate and more fitting for the work world that most trainees will encounter after graduation.

The physician workforce is similarly not being appropriately prepared for the needs of an aging population with complex care needs. Obstacles to growing the needed physician workforce include the perceived low prestige of primary care, perceived futility of care to chronically ill people, and low remuneration [8]. Physicians in training report frustration regarding the lack of time available in a standard ambulatory care visit to address the complex health-care needs of patients with chronic illness, though they also identify rewards to this kind of practice [47]. Residents in training enjoy seeing patients when they feel empowered by knowledge, have continuity with patients, and have a sense of teamwork with MAs and nurses.

Though most primary care is provided by family physicians and general internists, more geriatricians are needed in teaching and practice settings. Yet the number of physicians newly board certified in geriatrics has decreased in the last 10 years, from about 300 new certifications in 2006 to 250 new certifications in 2015 (Fig. 43.1). About two-thirds of

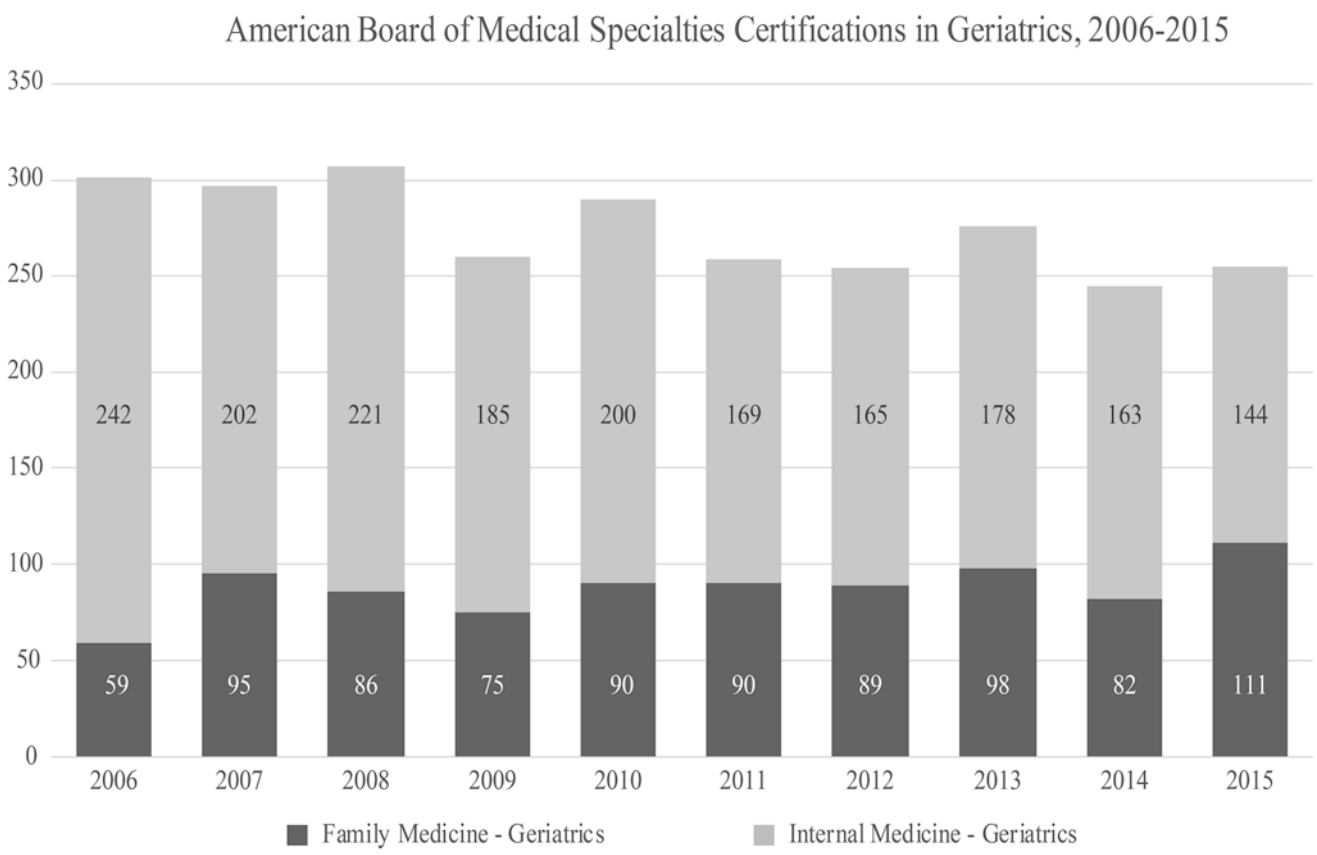

Fig. 43.1 American Board of Medical Specialties certifications in geriatrics, 2006–2015

board certified geriatricians are internists, and the remaining third are family physicians.

Recruitment, Management, and Retention of the Chronic Care Workforce

Health-care organizations struggle to provide the salaries, benefits, and work environment that recruits and retains people willing to work in chronic care. Provider salaries tend to be lower in primary care, and some find work with chronically ill people less professionally rewarding than work in acute care. Staffing challenges occur across the worker spectrum, from relatively low-skilled home aides to highly trained physicians, nurses, and therapists. The need for these workers is broad since chronic care is rendered in multiple settings, including long-term care, outpatient clinics, community health centers, public health departments, hospice settings, and the patient's home. Common themes in recruiting workers include attracting people who are culturally competent, are comfortable in interacting with patients who have cognitive and physical impairment, and find intrinsic rewards in working with patients with complex chronic illnesses.

The Role of Compensation

Salary is clearly an important factor in the recruitment and retention of health care workers, but other factors are also important, including autonomy, the ability to provide high-quality care, positive relationships with supervisors and peers, a supportive organization, good working conditions with reasonable workload, and the ability to maintain work/life balance [48]. Given the complex and important role of the primary care provider in providing continuous and longitudinal care to the growing population of chronically ill patients along with an increasing demand for such providers, one might expect that the law of supply and demand would place a high value on these professionals, resulting in substantial increases in compensation. However, this has not been the case so far, and there remains a gap in earnings between primary care physicians and specialists, which is shown in Table 43.3 [49, 50]. Noteworthy to the chronic care population, the median annual salary for geriatricians is estimated at $186,174 [50]. While there is a dire shortage of geriatricians, the number of trainees choosing this field has either decreased or been flat in recent years, causing some medical educators to give up on training geriatricians as primary care providers and prepare them to serve as consultants to generalist physicians who treat older patients [51].

In contrast to other workers, there is rapid growth in the supply of nurse practitioners with those practicing in primary care expected to increase by 84% between 2010 and 2025 amid a background of evidence that the quality of care and patient satisfaction provided by them equal or exceed that provided by physicians [52]. The cost of NPs providing primary care for Medicare beneficiaries is 29% lower than for patients assigned to physicians for similar care. Coupling this with the growing supply of NPs incentivizes the shift in chronic care from physicians to NPs [53]. The system in the future is increasingly likely to see NPs and physicians working in teams, with physicians using their more advanced training to oversee, consult, and advise on the management of the more medically complex patients.

Table 43.3 Average annual physician salaries

Primary care physicians		Specialty physicians	
Obstetrics/gynecology	$286,000	Orthopedics	$489,000
Internal medicine	$225,000	Cardiology	$410,000
Geriatrician (median)	$186,174	Gastroenterology	$391,000
Family medicine	$209,000	General surgery	$362,000
Pediatrics	$202,000	Nephrology	$280,000
Primary care physicians overall	$217,000	Specialty physicians overall	$316,000

Sources: Grisham [49]; "Physician—geriatrics salaries." Salary.com: http://www1.salary.com/Physician-Geriatrics-Salary.html

Market incentives are in place to attract NPs to the chronic care workforce. In contrast with the comparatively low salaries earned by geriatricians, NPs specializing in geriatrics earn more than the average NP salary, which ranges from $72,420 to $140,930 [54]. In 2017, the median salary for nonspecialized nurse practitioners was $90,600, while the salary for geriatric NPs and palliative care NPs was $92,000 and $96,126, respectively. Hence, unlike physicians, NPs are rewarded for working in chronic care [55].

High Staff Turnover in Chronic Care Organizations

The demand for workers in occupations that provide care to patients with chronic illness is projected to increase significantly between 2014 and 2024 (Table 43.4), likely outpacing the supply [54].

At the same time, places that provide chronic care such as long-term care facilities face consistently high rates of staff turnover, often to the point of negatively impacting the quality of care. Turnover rates for nurses and aides range from 55% to 75% and sometimes exceed 100% [56]. High rates of turnover are also found among registered nurses (50%), licensed practical nurses (36.4%), and certified nursing assistants (51.5%) [57]. Organizations look for strategies at every step in the employment process that can reduce this turnover problem.

Table 43.4 Estimated growth rates for health-care workers between 2014 and 2024 [54]

Personal care aides	26%
Home health aides	38%
Nursing assistants	18%
Medical assistants	24%
Licensed practical and licensed vocational nurses	16%
Registered nurses	16%

Adapted from [54]

Recruitment

The ability to be selective in hiring is dependent on the number of qualified applicants who apply. Hiring qualified people who fit the culture of the organization increases the probability that the employee will perform at a high level and stay with the organization. Employees already in the organization can have a positive effect on recruitment provided they exhibit high levels of job satisfaction. New recruits should have a clear understanding of what the job entails, understand reporting relationships, have the appropriate license, and have the ability to be flexible when the role changes. Recruiting can involve promoting the job in the local community or, for some positions, can involve a regional or national search.

Staffing requirements for working in chronic care include not only relevant education and skills but also less easily measured competencies such as empathy and communication skills and the ability to work effectively with patients and families, often in a relatively autonomous manner. Finding the right fit between an employee, the organization, and the patient population is an important predictor of job satisfaction and organizational commitment [58]. Evaluating candidates may involve cognitive tests, assessments of physical abilities that are relevant to the job, personality tests, reference checks, and interviews, though even the best processes may not accurately predict future performance or longevity with the organization. From the applicant's point of view, these steps will either encourage him or her to move forward or terminate the application process.

Organizations are often constrained by a limited pool of qualified candidates in which case they may prefer employees who show a willingness to learn. Attributes that predict success include a familiarity and understanding of team-based care, comfort with the organization's leadership style, and conflict management skills. An individual who is hired without having been thoroughly evaluated on key qualities is at risk of providing inadequate care, endangering patients, alienating co-workers, and leaving the organization.

Retention

Staff retention is a critical issue facing health-care organizations, especially those who provide chronic care where salaries can be suboptimal, workload is high, patients are challenging, and the quality of supervision is variable. With the increasing demand for health-care workers, mobility between jobs is often quite easy and sometimes the best way to increase one's pay. Long-term care workers leave their jobs at a rate that outpaces the rate of new employees entering the field [59]. Younger employees in nursing care and residential care facilities are more likely to leave their jobs than older employees. Organizations should monitor turnover trends including the types of employees who are leaving and where they are going and then design evidence-based retention strategies [60]. Exit interviews with departing employees often yield useful data. Since compensation is often an issue, organizations can institute reward systems that may include incentive pay. There is no shortage of suggestions to reduce turnover, and ongoing research will help establish the strategies that work [61, 62].

Challenges and Opportunities for the Chronic Care Workforce

The challenges facing the chronic care workforce are straightforward and include meeting the needs of an aging population that will require multiple types of chronic care services. The workforce must provide patients with medical care, rehabilitation, care coordination, discharge planning, community resources, homemaker and personal care services, nutritional services, and social and emotional support, as well as support for family members. These services will need to be provided in multiple settings including outpatient clinics, rehabilitation facilities, hospitals, assisted living and skilled nursing facilities, hospices, and patients' homes. Care transitions across these locations must be smooth with plans well communicated.

With these challenges come opportunities. Keeping patients at home rather than in institutions stimulates the development of electronic monitoring technologies that will be safe and effective and reduce the need for scarce and expensive human resources, possibly filling the worker gap with a virtual workforce. This will allow human workers to focus on areas where technology cannot offer a substitute.

Other strategies to stretch the workforce include the concept of plasticity where there are multiple configurations of professionals in a community that can meet the needs to the population [63]. For example, not every community will have access to a geriatrician, but through training and task shifting, others, even some with limited education, can be trained to effectively carry out particular geriatric care tasks. The World Health Organization recommends that task-shifting arrangements may be more efficient than traditional models but must also be safe, effective, equitable, and sustainable [64].

Health-care teams are likely to transform from the traditional form with relatively permanent members to ones where teams are organized as needed and may only exist for a limited period of time. Health-care teams may have relatively permanent disciplines represented, but the actual persons may vary by the day. Some members may never make a personal appearance and only participate virtually. Rather than the traditional slower method of team building, changes in patients' care needs will require specific disciplines to come and go quickly, so effective team performance will depend on strategies that do not require the luxury of time-dependent team-building techniques, a process called "teaming" [65]. "Scaffolding" is another mechanism organizations can use to enable teams to form and perform at a high level [66]. These ideas all allow greater flexibility and fluidity in the provision of team care that is required to meet the needs of the chronic care population.

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International Perspectives

44

Dana Sarnak, Arnav Shah, and Jamie Ryan

Introduction

This chapter provides an overview of the burden of chronic disease and describes health care policies and strategies implemented in four countries: Canada, France, the Netherlands, and the United Kingdom. We focus on these industrialized countries because they share similar demographic profiles and burden of chronic disease burden with each other, as well as with the United States. These four countries have addressed their growing chronic disease populations by implementing promising policies and delivery system innovations from which the United States can potentially learn.

The prevalence of chronic disease is increasing throughout the world [2]. Approximately 70% of deaths globally are caused by non-communicable diseases [3]. Canada, France, the Netherlands and the U.K. are facing the same four most prevalent chronic diseases--cardiovascular disease, cancer, chronic respiratory diseases, and diabetes. In Canada and France, 67% of deaths are caused by the four major chronic diseases, while in the Netherlands and the United Kingdom, the rates are 73% and 79%, respectively [5].

This chapter is organized into five sections. Section 1 describes demographic indicators, mortality rates from major chronic diseases, and risk factor prevalence in the four countries. Section 2 provies a brief background on the health-care systems, including relevant aspects to the management and prevention of chronic disease. Section 3 presents key data in each country related to self-management of chronic disease, coordination of care for patients with chronic disease, prevention and health promotion, and primary care infrastructure and capacity to care for patients with chronic disease. Section 4 highlights country-specific policies that have been implemented by governments at the federal level which address the identified chronic care challenges in each nation. Section 5 describes key innovations at the delivery system- and provider- level in each country that have been enacted and tested for chronically ill populations. Throughout, the chapter highlights best practices that may offer lessons of successful policies and innovations related to caring for a growing chronically ill population that the United States may consider or adopt.

Chronic Disease Burden

The four profiled countries (Canada, France, the Netherlands, the United Kingdom) vary in size, geography, and population density (Table 44.1). The populations of these countries range from approximately 65 million in France and the U.K., to 35.9 million in Canada, to 17 million in the Netherlands. [1]. The countries have similar age structures, with growing elderly populations (16–18% over age 65) [1]. Although older adults in all countries are healthier than previous generations, mostly due to improvements in health care and prevention, they are more likely to experience chronic conditions. Additionally, the prevalence of chronic disease among younger populations is rising in many of these countries, adding to the burden of chronic illness.

Risk factor reduction is key in mitigating the impact of chronic disease. Two of the most significant risk factors for chronic disease, smoking and obesity, are widely present in the four countries. In Canada and the United Kingdom, around one in five adults reports being daily smokers; in France and the Netherlands, this proportion approaches one in three [3]. One in five adults in the Netherlands, and one in four adults in Canada, France and the U.K. are considered obese [3].

D. Sarnak (✉)
The Commonwealth Fund, New York, NY, USA
e-mail: dsarnak1@jhu.edu

A. Shah
The Commonwealth Fund, Policy and Research, New York, NY, USA

J. Ryan
Pardee RAND Graduate School, Santa Monica, CA, USA

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Table 44.1 Chronic disease burden in four countries

	Canada	France	Netherlands	United Kingdom
Demographics				
Population in millions, 2015[a]	35.9	66.8	16.9	65.1
Percent of population over age 65, 2015[a]	16%	18%	18%	18%
Percent of population less than age 15, 2015[a]	16%	18%	17%	18%
Percent of population in urban regions, 2013[b]	82%	79%	89%	82%
Gini index, 2012[a]	33.7	33.1	28	32.6
Proportional mortality (% of total deaths, all ages, both sexes)[b]				
Cancers	30%	31%	33%	29%
Cardiovascular diseases	27%	28%	29%	31%
Chronic respiratory diseases	7%	4%	6%	8%
Diabetes	3%	2%	2%	1%
NCDs estimated to account for—of total deaths	88%	87%	89%	89%
Probability of dying between ages 30 and 70 from cardiovascular disease, cancer, diabetes or chronic respiratory disease, 2012	11%	11%	12%	12%
Mental health				
Prevalence of mental health problems among general population[c]	20%	15%	18%	25%
Mental and behavioral disorders—estimated DALYs ('000), 2012[d]	1246	2366	603	2440
Standardized death rate for mental and behavioral disorders, 2012[e]		33	68	71
Risk factors for chronic diseases[f]				
Prevalence of current tobacco smoking				
Population aged 15+ years, age standardized, 2012	17%	30%	29%	21%
Alcohol per capita consumption of pure alcohol (liters), crude adjusted projected estimates, 2012	10	12	10	11
Prevalence of insufficient physical activity, age standardized, 2010	23%	24%	16%	37%
Obesity (BMI > =30), age-standardized adjusted estimates, 2014	28%	24%	20%	28%
Raised blood pressure (SBP > =140 and/or DBP > =90), age-standardized adjusted estimates, 2014	17%	28%	24%	20%

Sources:
[a]DataIThe World Bank [Internet] [1]. Gini index of 0 represents perfect equality, while an index of 100 implies perfect inequality
[b]Country statistics [Internet] [4]
[c]Smetanin et al. [60], de Graaf et al. [61], and Norton et al. [62]
[d]WHO Department of Health Statistics and Information Systems, 2014
[e]Mental health and related issues statistics [Internet]. Eurostat Statistics Explained. Available from: http://ec.europa.eu/eurostat/statistics-explained/index.php/Mental_health_and_related_issues_statistics
[f]Global status report on noncommunicable diseases 2014 [Internet] [3]
[g]Noncommunicable diseases country profiles 2014 disease [Internet] [5]
[h]OECD Health Statistics, 2016

Mental health conditions contribute largely to disease burden worldwide. Evidence suggest that one fifth of the working age population in high-income countries is affected by a mental health condition, and data suggest that one in two will experience a mental health impairment at some point in their life [6]. Mental illness is responsible for up to one third of disability-adjusted life years (i.e., the sum of premature mortality and reduced quality of life), the largest single source of disability across countries, which is second only to cancer in France and the Netherlands [4]. Further, people with chronic conditions are more likely to experience mental health problems than those without; research shows that depression is two to three more times likely among people with cardiovascular disease, diabetes, COPD, and chronic musculoskeletal disorders [7]. Finally, the true prevalence and scope of mental health problems are considered to be conservative since many cases go un- or underreported.

The economies of all four countries have associated burdens due to chronic disease though direct health-care costs such as utilization and treatment, as well as indirect costs inccured from productivity loss, disability, workforce absenteeism, and informal caregivers. Treatment of chronic disease consumes 67% of all direct health-care expenditures and costs the Canadian economy $190 CAN billion annually [8]. The health care of 15.4 million people in England who had at least one long-term condition took up 70% of the NHS £110 billion budget and £10.9 of the £15.5 billion spent on social care in England in 2014 [7].

In the Netherlands, the largest costs are due to the treatment and care of working patients with cardiovascular

disease and mental illness (approximately €16 billion). The national financial burden due to work absence that was associated with chronic musculoskeletal disorders amounted to €1.3 billion annually [9, 10]. It is important to note that an increase in health care spending may not directly map out to more efficient or better service delivery, although greater investments in care have resulted in decreases in overall mortality and avoidable mortality in most western European countries [11]. This trend may level off as investments in chronic care are realized [10].

The impact of the major chronic illnesses is magnified in all countries by social and economic disparities. Poverty predisposes individuals to develop chronic diseases by potentiating risk factors [12]. Chronic diseases can also contribute to poverty through the increased risk of disability and premature death, increased out of pocket health-care costs and productivity losses. For example, people with severe mental health conditions are six to seven times more likely to be unemployed than those with no mental health condition, and those with a mild to moderate condition are two to three times more likely to be unemployed [6]. More complex social determinants of health in these countries impact disparities in differential effects related prevalence and prevention of chronic disease. While access to care (through insurance) is often cited in the United States as a contributing factor to health-care disparities, universal coverage is provided in all of these countries. The relationships between social determinants and ill-health are complex and go beyond poverty, race, or gender and include measures of autonomy, control, empowerment, and social participation [12].

Finally, cultural norms influence the prevention, diagnosis, and treatment of chronic disease. Lifestyles and behaviors related to risk factors such as diet, exercise, tobacco, and alcohol use vary across countries. Stigma in society and self-stigmatization around mental health problems is ubiquitous and contributes greatly to the "treatment gap"—the gap between the true prevalence of a disorder in the population and the proposition of affected individuals who are receiving treatment—in all countries [6].

Health-Care System Organization in Canada, France, the Netherlands, and the United Kingdom

The health-care systems in Canada, France, the Netherlands, and the United Kingdom are organized and financed differently. Table 44.2 presents a snapshot of the health-care systems in Canada, France, the Netherlands, and the United Kingdom, describing the role of government and public and private insurance schemes and the role of primary care. The U.S. system differs from these countries in the way the health-care system is funded, how the public and private insurance markets are run, and the role of primary care [13].

The health-care systems in Canada, France, and the Netherlands are mixed public-private systems that provide universal coverage though statutory health insurance systems which offer public health insurance through the government and/or private insurers [13]. The systems in France and the Netherlands have been traditionally run and controlled mainly from a federal level. France is moving toward a mixed centralized state/public health insurance regulation, with the emergence of regional health agencies in 2009 (i.e., Autorités de Santé Regionales) [13]. In Canada, provincial and territorial governments receive substantial federal transfer payments but ultimately bear almost all responsibility for organizing and delivered health services and supervising providers [13]. Canadian provinces administer insurance plans, and each one is slightly different.

The level of competition in the public health insurance markets in these three countries varies. For example, in France coverage is universal and compulsory, provided to all residents by noncompetitive statutory health insurance, and covers approximately 75% of total health expenditure [14]. In the Netherlands, adults are mandated to purchase statutory health insurance for a flat rate premium from competing private insurers. The systems are funded through general tax revenues, earmarked taxes, and payroll taxes [13]. The essential services—those categories of services that health insurance plans must cover—vary by country.

The United Kingdom has a national health system (National Health Service or NHS) which covers 100% of the population for most care and is largely free at the point of service [13]. There are some services—for example, dentistry, optometry, and prescriptions—that are covered but with copays for patients. The NHS is funded through general tax revenue.

Additional private insurance in all four countries is intended to cover services not included as a public benefit and often includes dental care, alternative medicine, and rehabilitation services. It also often covers cost-sharing under the public system or certain private providers. The percentage of the population that has private insurance varies greatly, from 11% in the United Kingdom [15] to 66% of Canadians, 85% of Dutch, and 95% of French residents [13].

The role of primary care is central to these health-care systems. Private, not for profit, group practices are common in the Netherlands, while primary care physicians in the United Kingdom are self-employed with a contract from NHS England, and the majority work in group practices. In France, private individual practices are still very common. In Canada, models of primary care include solo doctor practices, family health teams, and community health centers. Gatekeeping—where patients need a primary care physician

Table 44.2 Snapshot of health-care systems in four countries

Country	Principles of health-care system and government role	Public system financing	What are the insurance schemes?		Primary care		
			Public	Private	Gatekeeping	Models of care	Primary care physicians payment
Canada	Provinces and territory governments have the main responsibility for organizing and delivered health services and supervising providers. They also administer insurance plans, each one is slightly different Federal government oversees adherence to Canada Health Act, yet really only play advisory role	Provincial/ federal general tax revenue	Regionally administered universal public insurance program that plans and funds (mainly private) provision Insurance covers primary care, hospitals, dental surgery, most diagnostics	Private insurance, held by about 2/3 of Canadians, covers services excluded by public benefit including vision and dental care, RX, rehabilitation services, and home care and private rooms in hospitals	Yes, mainly through financial incentives varying across provinces, e.g., in most provinces, specialists receive lower fees for patients not referred	Solo doctor practices, family health teams, community health centers	Mostly fee-for-service, but some alternatives (e.g., capitation) for group practices
France	Provision of health care in France national responsibly through a mixed public-private system Statutory health insurance (SHI) system, with all SHI insurers incorporated into a single national exchange	Employer/ employee earmarked income and payroll tax; general tax revenue, earmarked taxes	Coverage is universal and compulsory, provided to all residents by noncompetitive statutory health insurance Insurance covers hospital care, treatment in rehabilitation, outpatient care, specialists, dentists, and midwives. Preventive services are limited but full reimbursement for screening and targeted populations	95% of the French population is covered by private supplementary insurance which covers mainly cost-sharing and some non-covered benefits	Voluntary but incentivized: higher cost-sharing for visits and prescriptions without a referral from the physician with which patients registered	Self-employed or private group practices staffed by physicians only	Mix fee-for-service/pay for performance/flat EUR40 bonus per year per patient with chronic disease and regional agreements for salaried GPs
The Nether-lands	Dutch philosophy emphasizes solidarity—all medical care is covered by health insurance, medication included Statutory health insurance system, with universally-mandated private insurance (national exchange); government regulates and subsidizes insurance	Earmarked payroll tax; community-rated insurance premiums; general tax revenue	Residents mandated to purchase statutory health insurance from private insurers, who are private, set prices and bargain with providers—managed competition Private plans provide statutory benefits; 84% buy complementary coverage for benefits excluded from statutory package such as dental care, alternative medicine, physiotherapy, eyeglasses, contraceptives and copayments Insurers cannot refuse applicants or differentiate the premium—all citizens pay about 100 euro a month—own risk is 375 euros and then the insurer kicks in (deductible) There is an income-dependent reimbursement system by the government		Yes, except in case of emergency	Private group practices staffed by physicians and other health professionals (e.g., nurses)	Capitation, fee-for-service, pay for performance
United Kingdom	National Health Service (NHS)	General tax revenue (includes employment-related insurance contributions)	100% coverage under NHS, largely free at the point of use	Only 11% have private insurance, and these are typically complementary rather than duplicate insurance products	Yes	Public primary care clinics staffed by physicians and other health professionals (e.g., nurses)	Mix capitation/ FFS/pay for performance/ salary payments

Source: Reproduced with permission from Mossialos et al. [13]

referral to access most types of specialist care—is required in the Netherlands and the United Kingdom. While gatekeeping is not required in Canada and France, it is part of some capitation models in Canada, while France has financial incentives for patients to obtain a primary care referral to specialists.

Mental health care for common mental disorders (e.g., depression, anxiety) are often treated by GP offices in the Netherlands and the United Kingdom, where the integration of primary and mental health is a developed care model [13, 16]. In Canada, universal coverage for mental health care is provided by physicians and complimented by allied providers. Although there is no formal integration of primary and mental health care, there are increasing efforts to promote this approach at the provincial level. France provides mental health care though the public and private sectors. Statutory health insurance covers care provided by GPs and psychiatrists, and those with long-term mental illnesses are exempt from cost-sharing.

Chronic Care: Self-Management, Coordination of Care, and Health Promotion

Several domains are key to the management and prevention of chronic illness including disease self-management, coordination of care, prevention, and health promotion. A robust primary care infrastructure and capacity to treat chronically ill patients are the foundation to these domains, and (Table 44.3) the Commonwealth Fund International Health Policy Survey of Primary Care Physicians and Adults provides comparative data [17]. To begin, chronic disease self-management and a supportive care team that helps manage and monitor a patient's condition have been demonstrated to improve health outcomes [18]. Close to two thirds of adults with a chronic condition [19] in Canada, France, the Netherlands, and the United Kingdom reported having discussed their main goals, care priorities, and treatment options with a health professional. However, 10–15% of patients in Canada, France, and the United Kingdom did not feel they had the support they needed from health-care providers to manage their health problems. On the other hand, 95% of adults with a chronic illness in the Netherlands felt they definitely had the support they needed to manage their condition.

Patients with chronic illness often see multiple providers and are prescribed many medications, increasing the need for efficient and effective care coordination. Over half of French adults with at least one chronic condition reported experiencing a coordination problem in the past 2 years [20]. In contrast, close to one in three chronically ill adults in Canada, the Netherlands, and the United Kingdom reported a problem in care coordination. Failure to coordinate health care delivered over time and across different providers can compromise patient safety and leads to inefficiency and waste [21].

A growing elderly population and the associated burden of chronic disease in these countries have focused attention on managing health-care costs. Secondary prevention and health promotion are seen as important strategies, yet not all patients report discussing issues such as healthy diet, exercise, smoking cessation, and alcohol use with their primary care doctor. Only half of adults in France, the Netherlands, and the United Kingdom reported having such a conversation in the past 2 years. Slightly more Canadian adults reported having had these conversations (59%). Of equal concern are the disappointing rates of smoking cessation counseling in France (49%), the Netherlands (53%), and the United Kingdom (57%). The United States reports a higher level of this health promotion than its European and Canadian counterparts.

On the delivery system level, there is variation in the primary care practice infrastructure for the care and management of patients with chronic illness. The Netherlands and the United Kingdom are leaders in how they deploy nurses in leading multidisciplinary teams to provide care for chronically ill populations. Over 90% of primary care physicians in the Netherlands and the United Kingdom report their practices used nurses or case managers to monitor and manage care for patients with chronic conditions. These two countries also have most primary care practices reporting that their practice staff makes home visits (84% in both countries in contrast to 6% reported among US doctors). Unsurprisingly, a large number of Dutch and British doctors report that their practice was well-prepared to manage patients with multiple chronic illnesses (88% and 79%, respectively), compared with 45% in France and 70% in Canada. Dutch and British doctors were also more likely to report feeling that their practice was well-prepared to serve patients with severe mental illness (44% and 43%, respectively) than their Canadian and French counterparts (24% and 14%), possibly due to the formal integration of primary and mental health in those two countries.

International Perspectives on Chronic Care Policies

Many policy options have been explored and tested to reduce the burden (e.g., cost, mortality, morbidity, etc.) of chronic illness, predominantly by improving the quality and accessibility of chronic care services. This section introduces a few select examples of programs and policies that the governments of Canada, France, the Netherlands, and the United Kingdom have tested and/or implemented.

Table 44.3 Policy issues facing the system relevant to chronic care

	Canada	France	The Netherlands	United Kingdom	United States
Self-management for chronic care[a]					
Percent of adults with a chronic condition who:[b]					
In the past year, discussed with a health professional their main goals and priorities in caring for their condition	56	66	59	61	63
In the past year, discussed with a health professional their treatment options, including side effects	57	61	57	54	60
Did not feel they had the support they needed from health professionals to manage their health problems	14	13	5	10	15
Coordination problems					
Experienced any coordination problem in past 2 years[c]	36	53	34	30	42
Prevention and promotion					
Percent of adults who, during the past 2 years, talked with doctor or other clinical staff at regular place about:					
A healthy diet and exercise and physical activity	41	16	24	33	59
Smoking and ways to quit[d]	71	49	53	57	74
Things in life that cause worry or stress, among those with a history of mental illness[e]	63	n/a	62	58	64
Primary care infrastructure and capacity[f]					
Percent of primary care physicians who:					
Reported their practice used nurses or case managers to monitor and manage care for patients with chronic conditions	64	96	92	96	66
Reported their practice staff frequently make home visits	19	55	88	84	6
Reported their practice was well-prepared to serve patients with multiple chronic conditions	70	45	88	79	76
Reported their practice was well-prepared to serve patients with severe mental illness	24	14	44	43	16

Source: 2015 and 2016 Commonwealth Fund International Health Policy Survey
[a]2016 Commonwealth Fund International Health Policy Survey
[b]Had ever been diagnosed with asthma or chronic lung disease, diabetes, heart disease, or hypertension
[c]Any coordination problem include one of more of the following: Test results/records not being available at appointment or duplicate tests ordered; specialist lacked medical history or regular doctor not informed about specialist care; and/or received conflicting information from different doctors or health care professionals in the past two years
[d]Base: smokers
[e]Base: had ever been diagnosed with depression, anxiety, or other mental health problem
[f]2015 Commonwealth Fund International Health Policy Survey

Canada

Integrated Strategy on Healthy Living and Chronic Disease

Canada's federalized system—made up of ten provinces—has traditionally had little national coordination in health care. However, since 2005 Canada's Public Health Agency has implemented the Integrated Strategy on Healthy Living and Chronic Disease in order to address the country's prevalence of chronic disease. The Integrated Strategy created a policy framework for the Canadian government to fund partnerships across different sectors to promote healthy living and reduce the impact of chronic disease. The three pillars of the framework are promoting health, preventing chronic disease, and supporting the early detection of chronic disease [22]. Canada has used this strategy to guide investments in reducing chronic disease.

The Integrated Strategy was announced in the federal budget in 2005, with an initial allocation of $300 million over 5 years and $66.7 million in ongoing annual funding [23]. The goal of the strategy was to ensure that Canada had a cohesive approach to addressing chronic disease across its provinces and at the national level, by targeting risk factors and increasing disease prevention and health promotion. For example, under this policy framework, Canada has provided funding for a diabetes risk assessment tool (CANRISK) that is used in pharmacies to help Canadians better understand their risk and provide diabetes prevention support [24].

Canadian Chronic Disease Surveillance System

The Canadian Chronic Disease Surveillance System (CCDSS) is an example of how government can use disease surveillance initiatives to reduce the impact of chronic disease at the population level. The Canadian government uses this approach to provide relevant information and analyses

for informing public health interventions and filling information gaps related to chronic diseases. The overall goal of the program is to facilitate the collection of surveillance data in a timely, consistent, and comparable way across jurisdictions, allowing for the planning and evaluation of chronic disease policies and programs [25]. The CCDSS uses linked administrative data sources from each Canadian province and territory to estimate the prevalence of chronic conditions, related risk factors, use of health services, and health outcomes. The Canadian government has also invested in closing data gaps related specifically to cardiovascular disease (CVD) by improving CVD surveillance, with a goal of creating a national CVD surveillance system. National surveillance activities like the CCDSS are dependent upon provincial cooperation.

France

Financial Incentives to Improve Chronic Care Coordination

France offers general practitioners (GPs) a yearly per-patient bonus (€40/US$47) for coordinating care for patients with chronic conditions [13]. This policy approach was created in 2004, and payment bonuses are tied to a primary care initiative aimed at improving quality of care, increasing patient monitoring, promoting effective communication of care guidelines to providers, and strengthening the role of primary care in the French health-care system [26].

Exemptions in Cost-Sharing for Patients with Chronic Diseases

French patients who have one of 30 chronic diseases, such as diabetes, cancer, or psychiatric illness, may receive cost-sharing waivers for related chronic disease care. Patients with medical conditions that are not on the list can be exempted from cost-sharing if the condition requires 6 months or more of treatment or if the costs of care are expensive. To qualify for the cost-sharing exemption, people with chronic diseases must follow a care protocol that is developed with their doctor and a consulting physician from the insurance fund [27]. The cost-sharing is waived for expenditures related to their chronic illness if the care plan is adhered to.

Netherlands

Chronic Care Model

In 2008, the Netherlands launched a national program of chronic disease management to improve the quality of chronic care delivery based on the Chronic Care Model (CCM) [28]. The CCM offers a framework for shifting the focus of care from treating acute problems to a more proactive, organized, and planned approach, utilizing effective teams in a patient-centered manner [48]. The initiative included the use of nationally developed, evidence-based care standards and quality indicators, multidisciplinary care teams, and self-management activities [29]. In the Dutch version of the CCM, disease management programs (DMPs) redesigned existing care practices to increase care coordination and communication between providers and care teams. The incorporation of nurse practitioners with chronic care expertise into primary care practices has resulted in improved process and outcome measures for patients in the Netherlands and appears likely to have contributed to the success of the Dutch CCM [30]. Analyses of the CCM program point to the contribution of care coordination and communication as key improvement domains in chronic care delivery, which in turn, improved the quality of communication and task integration among multiple providers [30].

Bundled Payments for Integrated Chronic Care

The adoption of bundled payments, or episode-based payments, was a fiscal policy designed to incent coordinated care among providers. In a bundled payment arrangement, a single fee is paid for an episode of care; however, episodes of care can be defined in different ways. In 2007 the Netherlands introduced an experimental bundled payment system for diabetes, a strategy that was subsequently approved for nationwide implementation for diabetes, COPD, and vascular risk management in 2010, although participation was voluntary [31]. Since then, efforts to implement bundled payments have been expanded to chronic health failure and depression [32]. Under the system, insurers pay a single annual fee to a contracted "care group," which in turn covers all of a patient's care services related to a specific chronic disease. For example, insurers pay a group of providers a fee to cover all diabetes-related care for a patient in a given year [33]. Early evaluations of the nationwide bundled payment system have indicated that care for patients with diabetes and some heart conditions has been more integrated, multidisciplinary, and collaborative [34].

United Kingdom

Pay-for-Performance Contract

A pay-for-performance (P4P) contract called the Quality and Outcomes Framework (QOF) was introduced in 2004 for general practitioners (GPs) in the National Health Service (NHS). The contract initially offered financial incentives to physicians who improved the quality of care for 10 chronic conditions, based on nearly 150 performance indicators [35]. The average GP increased their gross income by £23,000 ($40,200) in the first year of the contract [36], and incentives

currently amount to approximately £1 billion of the health-care budget per year and up to 20% of a practitioner's income [37]. The chronic conditions in the initial contract include coronary heart disease, hypertension, diabetes, and asthma; this was expanded in 2006 to include chronic kidney disease and indicators related to mental health conditions.

The impact that the QOF has had on quality, costs, and other outcomes has been mixed [38]. The clinical effectiveness has been questioned with research showing that the initiative contributed to improved outcomes in some areas after initiation, but then regressed to pre-intervention levels. Data also suggest the development of disparities in conditions which have not been incentivized as part of the QOF scheme [39]. The focus of the QOF has mainly been on secondary prevention, and there is attention to link contract's measures to primary prevention and health promotion. Evaluative data indicates that the QOF strengthened team-based care and allowed for greater roles for nurses in care delivery, which may have reduced GP workload and potentially freeing up time to focus on more complex patients and their needs [38].

Chronic Disease Self-Management

The United Kingdom has taken several different policy approaches to addressing chronic care. For example, the NHS has emphasized the Expert Patient Programme (EPP) as a way to help patients with chronic diseases manage their conditions, using strategies that may be more effective than traditional patient education approaches. For example, the EPP is a program that utilizes trained peer supporters who provide self-management skills to patients [35]. Evaluations of the program have reported higher rates of self-efficacy among participants compared to a control group, as well as cost-effectiveness, but no statistically significant reductions in use of health services [35]. The impact of the EPP has been limited due to relatively low levels of funding for its implementation, but is an example of a patient-centered policy approach to dealing with chronic disease care.

Innovative Care Delivery Strategies

This section describes innovative delivery system reforms and strategies designed to improve chronic care in each of the four selected countries. These innovative models have not been formalized in national policy, but provide examples of demonstration projects for broader policymaking.

Canada: Community Health Links

Health-care costs are concentrated among a small number of patients [40] who have multiple complex chronic conditions [41]. In response, Community Health Links was established in Ontario in 2012 and serves complex patients who see multiple providers, use multiple services, and have frequent inpatient hospital visits. These complex patients generally have multiple comorbidities, including mental health issues, and they may have inadequate community social supports. The Health Links model is a "low rules" initiative that allows for flexibility in funding based on local needs. Health Links are established by a coordinating geographical partner, such as a hospital, community health center, or home care agency, that engages and collaborates with other providers and community supports to achieve better access and care for their complex patients. Each patient cared for by Health Link providers will have a personalized coordinated care plan, providers committed to following the care plan, medication adherence support, and a "team lead" provider they can call who is familiar with their situation [42].

To participate in the program, a Health Link coordinating partner must demonstrate existing collaboration with other community providers as well as the ability to improve coordinated care for complex patients, such as those with multiple chronic conditions. The coordinator must also submit a business plan detailing how the Health Link partnership will achieve identified short- and long-term goals in order to be eligible for up to $1 million CAD in funding.
By the end of 2015, over 80 approved Health Links had teamed up with nearly 1000 partner organizations. Preliminary analyses indicate that the Health Link programs had an increase in the number of patients attributed to a primary care provider and an increase in the number of coordinated care plans developed with patients [43]. Ideally, patients should have greater access to services; however, no evaluative data that have reported on these health service outcomes or on the long-term sustainability of the model.

France: Action de Santé Libérale en Equipe (ASALEE)

Most physicians in France practice in solo or small group practices on a fee-for-service basis. There is also limited regulation of professional practices and ambulatory care, which has led to inefficiencies in care delivery, particularly for chronically ill patients [44].

To improve quality, several demonstration projects have been launched to test team-based approaches to chronic illness care. As part of an array of national pilot models tested from 2004 to 2008, the Action de Santé Libérale en Equipe (ASALEE) experiment aimed to improve primary care for patients with chronic illnesses by better coordinating care provided by general practitioners and nursing services.

The ASALEE model targets rural patients with diabetes, hypertension, chronic obstructive pulmonary disease, those

with high risk of cardiovascular complications, and elderly patients (>75 years of age) with cognitive problems and loss of memory. Level 1 of the intervention includes reassignment of defined preventive care services, diagnostic evaluation, and chronic care management from general practitioners to nurses who work in consultation with GPs. Level 2 of the intervention includes having nurses, rather than general practitioners, assume responsibility for patient education [45].

The ASALEE model also includes creation of an electronic registry of patients with type 2 diabetes. This registry integrates with the electronic health record system to activate care reminders during a patient visit, prompting the GP to offer preventive service screenings and examinations in accordance with national guidelines. Additionally, GPs are prompted to refer patients to nurses with specialized training for nutritional and disease management counseling.

A case-control study of diabetic patients has shown that patients in the intervention group (i.e., a nurse provided supplementary education and counseling that was prompted by an electronic reminder to the GP) were more likely to have achieved better glycemic control when compared to the control group [44]. According to this analysis, the ASALEE team-based care approach appears to effectively improve care quality and health outcomes [46].

Netherlands: ParkinsonNet

Many patients with debilitating and progressive chronic diseases, such as Parkinson's, have difficulty accessing a wide range of needed health-care services. Coordinating these services can be challenging even in the Netherlands, which has universal insurance coverage, since physicians and other providers may lack expertise in caring for Parkinson's patients. In addition, there is no access to a shared electronic medical record, and care coordination is not a billable service in the Netherlands and thus is not routinely provided. Since no single provider is responsible for outcomes [49], fragmentation can lead to confused and dissatisfied patients, who do not feel involved in their treatment decisions.

The Dutch ParkinsonNet model was created in 2004 and targets these vulnerable Parkinson's patients. This model features 69 regional multidisciplinary networks, including approximately 3000 allied health professionals who are committed to Parkinson's care using evidence-based guidelines, with an emphasis on home- and community-based care [50]. The networks include neurologists, rehabilitation specialists, psychiatrists and psychologists, pharmacists, and social workers. Nurses and physical therapists serve as local coordinators and team leads, maintaining the network and organizing local educational programs.

To join a regional network, health providers must have specific training in caring for Parkinson's patients and be willing to adhere to ParkinsonNet's practice guidelines. Additionally, providers commit to collaborating with the professionals, patients, and families in the ParkinsonNet community. In addition to discipline-specific training in the use of practice guidelines and skill development, ParkinsonNet providers receive multidisciplinary training covering general information about Parkinson's disease, the patient's perspective, types of services patients may need, and interdisciplinary communication and collaboration.

The model also includes a dedicated online community for patients and families to identify providers with Parkinson's-specific expertise located near them and communicate with these professionals and other patients. In addition to using these online resources to obtain disease and treatment information, patients can use a decision support tool to help them make informed decisions about their treatment options. Patients can also build their own virtual "network" to encourage information exchange and collaboration among their providers [51].

In 2015, ParkinsonNet launched a national quality registry so that all providers can contribute information to their patient's record. For example, neurologists are required to enter information about patients' health status, outcome indicators such as hip fractures, and organizational structure indicators, such as the involvement of a Parkinson's specialty nurse, on an annual basis for each patient [50]. Building this registry enables teams to identify and learn from best practices by providing feedback about the cost, quality, and outcomes of care [50].

ParkinsonNet is available nationwide, and most Parkinson's patients use providers from a ParkinsonNet network. ParkinsonNet has also served as a platform for testing innovative approaches to occupational therapy and multidisciplinary care through randomized trials. Patients report satisfaction with the reorganization, noting that ParkinsonNet is responsive to patients' concerns and suggestions. Costs per patient in the ParkinsonNet model is also significantly lower than usual care, which total about $150 per patient per year. However, the services that ParkinsonNet provides are not reimbursable since there is no billing code for "care coordination" in the Netherlands. As a result, ParkinsonNet has required grant funding to remain sustainable; more recently, ParkinsonNet has been able to negotiate with insurers directly to recoup some of the operating expenses.

Regarding health and cost outcomes, a study reported that ParkinsonNet patients are 55% less likely to suffer a hip fracture, which is a proxy for falls [52]. Another study, comparing patients in hospitals using the ParkinsonNet model to patients receiving usual care, found that the costs for the ParkinsonNet patients were substantially lower than for patients receiving

usual care, although there were no differences in disability and quality of life over the study period [53].

United Kingdom: Reconfiguring Stroke Care

Stroke is a major cause of long-term disability, and poor initial management can increase mortality and the severity of disability. Each person who experiences a stroke in the United Kingdom costs the NHS £29,000, including informal care costs [54]. Timely treatment with thrombolysis can significantly reduce the likelihood and severity of disability [55]. In 2005, it was estimated that 1500 patients per year could fully recover from ischemic strokes if given rapid thrombolysis [55]. In London, access to timely care was historically dependent on where the patient lived; acute stroke care varied across the 32 different hospital units that treated stroke, including large specialized teaching hospitals and smaller district general hospitals.

Patients who receive rapid and standardized stroke care, provided by teams of multidisciplinary providers working together in a dedicated stroke unit, are more likely to be living independently at home one year after a stroke than those who receive usual care [56]. In 2009, commissioners across London came together to reorganize stroke care using a systems-based approach. The scale of the problem at the citywide level required collaboration in a clinical advisory group of clinicians, consultants, nurses, therapists, and members of the London Ambulance Service.

As a result of this work, acute stroke services were centralized in London in 2010. Several dedicated hyper-acute stroke units (HASUs) were designated to provide rapid access to evidence-based care, including assessment by specialist stroke clinicians; rapid brain imaging to determine the type of stroke; thrombolysis where appropriate for clot-based strokes; and continuous specialist care during the first 72 h. All patients with suspected stroke are eligible for treatment in one of the eight HASUs, available 24 h a day. The HASUs were established in specific locations to ensure that all Londoners would have the ability to receive timely and standardized stroke care within 30 min of presentation.

A larger number of local stroke units were also established to provide high-quality inpatient rehabilitation in local hospitals, as well as multi-therapy rehabilitation and ongoing medical supervision. In effect, the reorganization created a hub-and-spoke model with the eight HASUs as the hubs and the 24 local stroke units serving as spokes to provide a clinically optimal solution in an achievably deliverable way.

Independent evaluations of this initiative have shown reduced mortality and length of stay and increased provision of evidence-based clinical processes. For example, a study comparing mortality and length of hospital stay before and after the reconfiguration found a significant decline in risk-adjusted mortality at three, 30, and 90 days after admission for stroke post-reconfiguration [57]. A cost-effectiveness analysis found that the new HASU model results in cost savings of $1307 per patient over the first 90 days after admission and $6233 per patient over 10 years [58]. It is estimated that much of these savings is due to reductions in admissions to long-term nursing home care and reductions in need for social support in the community. To encourage system transformation, local stroke units in hospitals were financially incentivized if they met defined standards of care. These quality standards were promoted across London and required significant design changes to many of the previously poorly performing hospitals. After reconfiguration, the rate of indicated thrombolysis rose from 3.8% to 19% [59].

Although London is geographically and demographically more centralized than much of the United States, this type of model has potential for adoption in urban areas such as New York or Chicago. Self-designated centers of excellence for designated conditions (e.g., trauma) in the United States may be comparable to the UK's stroke care redesign, but a comprehensive citywide restructuring on this scale is still in the developmental phase in the United States. The comprehensive strategic planning process undertaken by the London commissioners was effective and can be considered for other services for which centralization and standardization could increase access to appropriate care.

Conclusion

The burden of chronic disease in Canada, France, the Netherlands, and the United Kingdom is increasing, as it is in the United States. Despite fundamental differences in health-care organization at a system level, there are opportunities for cross-national dialogue and idea exchange on the policy and delivery system levels, since all countries are facing similar challenges with respect to treating and preventing chronic illness. This chapter highlighted some promising international policy approaches and delivery models that policymakers and delivery system leaders may be able to adopt as they try to address this ongoing issue.

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Future Directions in Chronic Illness Care

45

Shana P. Ratner and Darren A. DeWalt

We always overestimate the change that will occur in the next two years and underestimate the change that will occur in the next ten. Don't let yourself be lulled into inaction. Bill Gates

Envisioning the Future State of Chronic Illness Care

The demographic trends of an aging population are ongoing, and a greater burden of chronic illness will continue to be part of the patient experience and the ways in which we care for them. People are living longer with diseases and conditions that, in previous times, would have limited life expectancy and function [1, 2]. The average number of illnesses per person is increasing [3], but a growing array of medical treatments and technologies will promote better functional status and prolong life. Multimorbidity will be the common denominator in this future state, and integration of care across multiple diseases will become more complex. Unfortunately, competing economic demands and global inequity will lead to more constrained resources [4], effects that will create a demand for clearer articulation of trade-offs between treatment benefit and burden.

In such a future state, chronic care delivery will evolve toward goal-directed care and underscore the need for clear and ongoing communication about patient values and goals, directly contributing to more nuanced decision-making about what it means to have "optimal therapy [5, 6]." Patients and clinical care teams will focus on goals and discuss known evidence about how each treatment helps or hinders those goals and what resource constraints may limit choices. These are predominantly cognitive skills and services that will require empathetic providers who can communicate effectively with patients and synthesize the anticipated effects of multiple treatments across a range of outcomes.

There are generally multiple treatment options for specific chronic diseases, and those range of options will continue to expand [7]. To facilitate a higher order of chronic illness care, cognitive specialties – particularly primary care – will need to have usable, clear decision support that integrates the outcomes and consequences of treatment and illness across multiple morbidities [8]. In this way of thinking, single disease guidelines will become secondary sources of information, and integrated approaches to treatment decisions will become primary. Patients will be able to connect their selected treatments and behaviors with their desired health outcomes. As a result, treatments and therapies (e.g., exercise, nutrition, mindfulness) that can simultaneously address multiple illnesses will become predominant [9, 10].

The sites of chronic illness care will move outside of the medical exam room. Because of the inconvenience and time inefficiencies of clinical encounter-based care, patients will have scheduled, focused visits with care team members that can occur over video conference or telephone. Non-urgent and other minor patient concerns will be addressed through asynchronous electronic communication. As a result, the business model of ambulatory care will shift further toward personnel and away from capital costs (e.g., infrastructure, bricks, and mortar) [11, 12]. Chronic illness care reimbursement will no longer be transaction based since fee-for-service does not align with a philosophy of care that is ongoing, relational, spontaneous, and routine.

Practices will care for patients through population-based payments that are risk adjusted, based on the complexity and comprehensiveness of care needed [13, 14]. Both government and commercial payers will streamline their reimbursement strategies in order to reduce the administrative complexity of managing multiple fee-for-service arrangements. Payment will be tied to the evaluation of the quality of care delivered, aligning evidence-based, cost-effective care with the patient care experience, away from fixed targets set by individual disease group guidelines [13]. However,

S.P. Ratner (✉) • D.A. DeWalt
Division of General Medicine and Epidemiology,
University of North Carolina-Chapel Hill School of Medicine,
Chapel Hill, NC, USA
e-mail: shana_ratner@med.unc.edu

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this framework will substantially challenge data collection strategies for performance measurement in real-world practice settings, potentially impacting both patient and provider sensibilities about optimal care delivery.

Patients will continue to struggle with the complexity of health-care delivery and behavior change, and integrated health-care systems will need to focus on reducing the complexity of navigating health services and promoting access to care. Community-based organizations will also be a part of the landscape and will provide a larger perspective to help understand the patient's goals and provide complimentary support for navigating complexity and promoting behavior change. Ideally, community-based organizations will be able to communicate directly with health-care systems and have access to patients' overall care plans in the health record.

Bridging the Gap and Getting to the Future State

There are several key areas of development that are necessary to achieve this vision of chronic illness care: workforce, attention to social and behavioral determinants of health, care redesign, patient and family engagement, evaluation and research, and business models.

Workforce

The current health-care workforce is not prepared for the knowledge and skills which will be necessary to care for an aging, chronically ill population [12]. These gaps cut across nurses, physicians, social workers, and other health-care professionals. Current training programs need to better reflect the anticipated needs in managing an aging population, and there may be a need to create new health-care professions altogether. It will be important to view workforce redesign through the lens of a team, with the patient as the captain. If the patient is the most important member of the team, training in disease self-management skills will be needed. Although health-care systems such as the Veterans Administration (VA) have promoted disease self-management skills in their patients, a majority of patients do not have ready access to this type of training from their health-care system or community-based organizations [15].

Team-based care is another skill set that the workforce will need in order to meet the needs of patients [16]. Team members will need to have clear and defined roles and expectations for their performance and communication. Clearly defined policies and buy-in from team members will allow each person on the team to do the tasks they are best equipped to do and communicate to others the tasks that they cannot carry out. The lack of role definition and buy-in can create uncertainty and frustration among team members and impede patient care. The colocation of team members is one approach that can help facilitate communication among members [17].

Within the team-based domain, identified and selected team members will need training in behavior change techniques, such as motivational interviewing, to help modify risks of substance use, depression, smoking, and poor dietary habits. In addition to medication management (e.g., drug-drug interactions and drug-disease interactions), clinical pharmacists can be tapped to provide chronic disease management across more conditions [18]. Both medical assistants and social work-prepared personnel must be encouraged to practice to the full scope of their license and have capacity to facilitate behavior change and address social determinants of health, such as trauma, and poverty, which impact chronic disease management and outcomes [19]. Trauma-informed care, for example, is an emerging competency, since childhood trauma is associated with the risk of multiple chronic illnesses later in life [20–27].

Physicians will need an enhanced educational framework and targeted training in order to treat patients with multiple complex chronic illnesses. Undergraduate medical education will need to move beyond paradigms that focus on acute disease states and chronic conditions, to a more integrated approach, such as the health system science framework that is emerging in some schools [28]. Both medical students and residents will need skill sets to function as effective members on interprofessional teams, including the capacity to listen and learn from the expertise of related disciplines [29]. Other competencies will include the recognition and management of polypharmacy, goal setting, group visits, and team communication. Clinical teaching sites and educators will need to be highly functional so that students, residents, and other learners are exposed to care models and mentors in practice.

A population health specialist may be representative of the new type of provider in the emerging health-care ecosystem [30]. This person may have skills in epidemiology, as well data management and analysis, and would primarily manage and analyze clinical data at the individual patient, practice, and population level. Data from multiple sources, such as claims, wearable devices that record biomarkers (e.g., pulse, blood pressure), patient-reported outcomes, and clinical encounters, will be integral to managing the health of chronically ill patients. The population health specialist can assist the care team to plan the highest yield interventions for their population at the individual or community level.

Attention to Social and Behavioral Determinants of Health

There has been increased interest in addressing social and behavioral determinants of health. Providers feel ill equipped,

and health-care systems have largely not been accountable for these factors [31]. As a result, it is challenging to develop and implement care plans in chronically ill patients without fully tackling the underlying social and behavioral factors that impact their lives [19]. The health-care system, for example, will need to improve social support to meaningfully see improvement in chronic disease management.

Many health-care systems utilize social workers in clinical settings to better assess and manage social and behavioral barriers to care [32]. Complex chronic diseases require a high degree of engagement, coordination, travel, and communication, and clinics and hospitals are finding that social workers are effective at addressing several barriers that can impede high-quality care, including the ability to pay for medications, travel to appointments or pharmacies, and linkages with providers [32]. Transportation is a key barrier for many patients, and new models are focusing on ways to provide home-based care [33]. Pharmacies are also recognizing the need to bring the care to the patients. Care systems will need creative strategies to help patients maximize the care they need when they need to visit clinics.

Coordinating with behavioral health resources is critical in helping patients manage chronic disease. More primary care practices are seeing the value of colocated social workers or psychologists in meeting the behavioral health needs of their patients [34]. Clinics that are small or in rural locations may collaborate to share these resources or bridge with community-based behavioral health organizations to streamline and facilitate transitions of care to the community [35]. Adding services for substance use disorders, such as specialists in tobacco control, alcohol, and medication-assisted treatment for opioid use, can also mitigate the future risks for chronic disease in vulnerable patient populations. These key drivers of poor health, health-care utilization, and poor chronic disease control are modifiable, and an understanding of substance abuse as a chronic disease will greatly improve the health of the individuals with these conditions [36, 37]. Finally, telemedicine is another model that has potential to help expand the reach of behavioral health care. In general, policy and reimbursement changes are needed to support the increased integration of physical and mental health [38].

Health-care policy and reimbursement are starting to shift toward supporting behavioral health improvements [39, 40]. In 2017, Medicare expanded payment for collaborative care for depressive disorders between specialty and primary care [39]. This new payment structure allows payment for care coordination between specialties and outreach and follow-up for enrolled patients. While the structure of the payment program does reinforce an evidence-based collaborative care model [41], the specific requirements for payment may not allow clinics to be nimble in meeting the behavioral needs of their patients.

Care Redesign

The redesign of chronic illness care begins by recognizing that current ambulatory approaches are marked by multiple sites of care (i.e., primary and specialty care) that frequently result in dislocating patients out of their communities and their jobs to spend time in clinical settings. Patients with multiple chronic illnesses will need to receive care that is seamless between home, community-based locations, and clinical settings. Clinical teams will need to move out of their practice silos into the communities they serve to better learn about and meet the needs of patients and families.

In some aspects of care redesign, there has been great movement to the chronic illness care paradigm of the future; in others, there is lot of work to do. For example, most clinicians appreciate the complexity of multiple chronic illnesses, but usually lack evidence-based information on the best therapies and interventions for comorbid conditions [42]. The majority of chronic illness care is provided through office-based visits with little focus directed to non-transactional care [43]. There has been an increase in disease management and case management programs, which have demonstrated modest improvements in outcomes by filling some care gaps between traditional visits. More advanced practices often provide embedded care management but can have difficulty finding fiscal models that support the costs involved [44, 45].

Better guidelines are another component to care redesign. Unfortunately, guidelines are predominantly developed for disease states, not patients, which have resulted in conflicting recommendations that often do not promote optimal care in preventive services, diagnostic testing, and therapeutic interventions [46]. For example, individual disease guidelines generally focus on process or intermediate outcomes, such as blood pressure, hemoglobin A1C levels, or specific medication therapies [47]. In chronically ill patients with comorbid conditions, it is unclear how to adjudicate these intermediate outcomes, or the additional burdens created with competing guidelines, or the strategies to help patients reach their goals.

Clinical guidelines and decision support need to be applicable across comorbid diseases. For example, an analysis of drug-disease interactions and drug-drug interactions for common chronic diseases in the National Institute for Health and Care Excellence (NICE) clinical guidelines found that many potential drug-disease interactions and drug-drug interactions were not highlighted in UK national guidelines [48]. Future guidelines should seek to incorporate common conditions, such as arthritis, chronic kidney disease, and hearing or vision impairments in chronically ill patients, and highlight approaches to navigate comorbidities.

Health information technology (HIT) and electronic health records (EHR) that incorporate decision support tools

have the potential to assist with guideline implementation [49]. A recent systematic review, for example, noted the under-investigation of decision support tools for multimorbidity [8]. Patients and providers need better information to inform the highest priorities for an individual's care and should have the ability to modify EHR reminders for a particular patient to meet that patient's needs and priorities. In addition to decision support, EHRs can also identify important drug-drug interaction and drug-disease interaction concerns for chronically ill patients [50, 51].

In addition to EHR's, HIT applications can further facilitate chronic disease management by making the work easier, more streamlined, and less duplicative. Software applications and devices can interface with clinical care to allow information exchanges between patients and the care team [52]. There will be a great need to expand the capacity of smartphones and other devices to connect the patient and team by video, email, and text. Existing communication processes that include sending and receiving faxes, paging and returning pages, and telephone messaging will continue to limit the capacity for effective care redesign. Patient-centered communication approaches will be multi-model and driven by their preferences, which will require building a more robust HIT infrastructure.

As practice settings move into team-based care designs, the overall structure of care provision must be reconsidered, and a culture of shared responsibility will be the hallmark. The alignment of inpatient, outpatient, and community-based care has the potential to bring the right care to the patient, in the most convenient location, at the right time. New care redesign models will need to move from health centers that are medically based to centers of health which are community-based. Although acute hospital care is a key component in care redesign, these settings will need to also manage multiple chronic illnesses, sustain the care plans set in the communities and clinics, and communicate with the outpatient care team.

Finally, care redesign will need to rebalance primary and specialty care. This will require recruiting and training the next generation of clinicians into primary care. Primary care will need to work with specialty care partners to build out medical neighborhoods, where care pathways clearly delineate primary care responsibilities and the contributions of specialists in care plans. Emerging integrated models, such as robust eConsult services from the University of California, San Francisco, can provide technical information and assist in decision support for issues that come up in primary care without requiring the patient to see a different provider [53]. New care models of integrated care delivery will require a rethinking of payment models that can reimburse and incent primary care for high-quality, cost-effective, patient-centered care.

Patient and Family Engagement

To make chronic illness care truly patient-centered, patients and their families must be engaged in decision-making about their care, integrated into quality improvement in the practice, and engaged in policy and research about their conditions [54]. Patient and family members need to be included in all levels of health-care delivery. The Southcentral Foundation's Nuka System of Care in Anchorage, Alaska, is an example of a care delivery system that was transformed by changing to a patient engagement model [55]. Nuka had been a bureaucratic health system centrally controlled by the Indian Health Service with low performance in health-care outcomes [55]. Several regulatory changes allowed the Alaskan Native people to become the operators, owners, employees, and patients, effectively driving a complete care redesign of the Nuka system. They were able to change the health-care system to meet their needs: focusing on physical, mental, emotional, and spiritual wellness. The patient owners changed the health-care system from an example of bureaucratic low-quality care to the current state of a Nuka that is viewed as a model of patient and community engagement, population health, quality improvement, and clinical quality [55].

Quality improvement teams in clinical settings will need to shift their engagement strategies from consulting with patients and families to approaches where patients are at the forefront of driving the quality improvement [56]. The work of health-care improvement often occurs in silos, without understanding how service lines interface and impact patient care. At the health-care leadership and administrative levels, patient and family voices can richly inform quality improvement. For example, the Medical College of Georgia Health System in Augusta has invited and placed patient and family advisors on system and practice-level councils and committees. During this time, clinical quality has improved and litigation has gone down [57].

Evaluation and Research

Chronic illness care of the future will be informed by data and dependent upon robust evaluation strategies. Unfortunately, existing quality metrics and initiatives do not often reflect real-world patient care. Improvement efforts are often indexed to care that is demarcated by single biomarkers, such as blood pressure and hemoglobin A1c, or process compliance measures [46]. Promoting the uptake of beta-blocker usage in heart disease or retinopathy screening in diabetes are valid quality improvement targets, but they may not be focused on what patients value most. Alternate patient-centered measures may include a functional status that

allows full-time work or the number of work hours that are missed for doctor visits or diagnostic testing. Patients, policy makers, and clinicians will need to work together to identify new metrics that determine the degree of care that is aligned with a patient's values and takes into account the benefits and risks of the treatment options across chronic illness.

Some have argued that the growing climate of measurement and quality improvement has contributed to provider burnout [58]. Physicians and other providers still value autonomy, mastery, and purpose, attributes that can be threatened by attempts to measure and incent well-developed outcomes [59]. Some health-care organizations have used an alternative approach through the use of "true north metrics," which define global, practice-wide goals, and encourage providers and care staff to provide input about how they will achieve these goals [60]. Figuring out the balance of incenting quality care without burning out the workforce will be critical in coming years.

Research in chronic disease management will need to become more applied and implementation and dissemination activities more nimble and timely. Currently it takes many years between the development of a research idea to reach practice implementation, which leads to research findings that can be outdated or unable to be adapted due to shifting practice. This type of research will need to be conducted across disciplines and disease states, with a focus on patients with multimorbidity who are often on multiple medications [61]. In the rapidly changing world of chronic disease management, the research to application pipeline must become quicker. In addition, traditional health services and clinical trial research, with its narrow inclusion and exclusion criteria, are often not applicable to real-world practice. Chronic illness care will benefit from an increase in pragmatic trials that can better inform care in clinical settings.

Finally, research priorities need to emphasize new models of care for patients with chronic disease. For example, eConsult is increasingly being piloted to see its impact on helping primary care providers manage patients without face-to-face visits by multiple different specialists [53, 62, 63]. Emerging care delivery models will need to determine risks and benefits versus usual care, and the growing disciplines of implementation science, health systems science, and data analytics will be foundation fields in chronic care research and evaluation. A workforce of well-trained researchers, specializing in studying health delivery models, will be critical to help produce the evidence base for new care models [64].

Business Models

The current fee-for-service payment structure creates disincentives for the effective integration of care that is required for patients with chronic illness. Health-care payment reform is moving toward bundled payments and population-based payments, strategies that will help to incentivize coordinated care across the continuum. For example, the Medicare Access and CHIP Reauthorization Act (MACRA) set forth strong incentives for providers to enter into alternative payment models – beyond fee-for-service – that reward quality and efficiency. These new payment models are designed to support care that has the highest value, limiting incentives to perform as many procedures as possible.

New payment models will also expand the accountability for the health of populations. For example, the Center for Medicare and Medicaid Services is testing the Accountable Health Communities model, an initiative that broadens an understanding of care to include social determinants, and encourages health-care system-community partnerships that would be accountable for health outcomes in a defined population of patients [65]. Health systems must now begin to consider social factors of care that contribute to patient outcomes, such as providing housing for a homeless patient.

As we pursue the system of the future, incentives will need to be used wisely. Quality metrics will need to encourage value-based change while not threatening providers' motivations for care. This will involve organizations looking inward at how they use quality metrics and incentives to reward high-quality care. Many health-care systems introduce fiscal incentives for physicians and other health-care workers that are based on these metrics and/or productivity [66]. Although attractive, a body of evidence now suggests that this approach may decrease intrinsic motivation to improve and provide high-quality care [59, 67].

Final Comments

There are rapid changes ongoing in health care, and we will arrive at the future state before we know it. Communities and health-care systems that have invested in rapid improvement and change will be poised to lead this change. Health-care systems that include patients in meaningful ways in their improvement efforts will be able to more easily design the improvements that patients want and need. By training a new workforce of health-care providers with needed skills, the culture of health care has the potential to shift to one that is patient-centered, accountable, and value-driven. It will take a tremendous investment of time and capital by many stakeholders to reach the care system of the future that is responsive to the needs of chronically ill patients. This is a social movement, and our best chance of success lies in focusing on the patient, simplifying the payment system, and designing care systems for multimorbidity.

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