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## Chronic Illness Care

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Timothy P. Daaleman • Margaret R. Helton  
Editors

# Chronic Illness Care

Principles and Practice

 Springer

*Editors*

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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.*

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## 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.

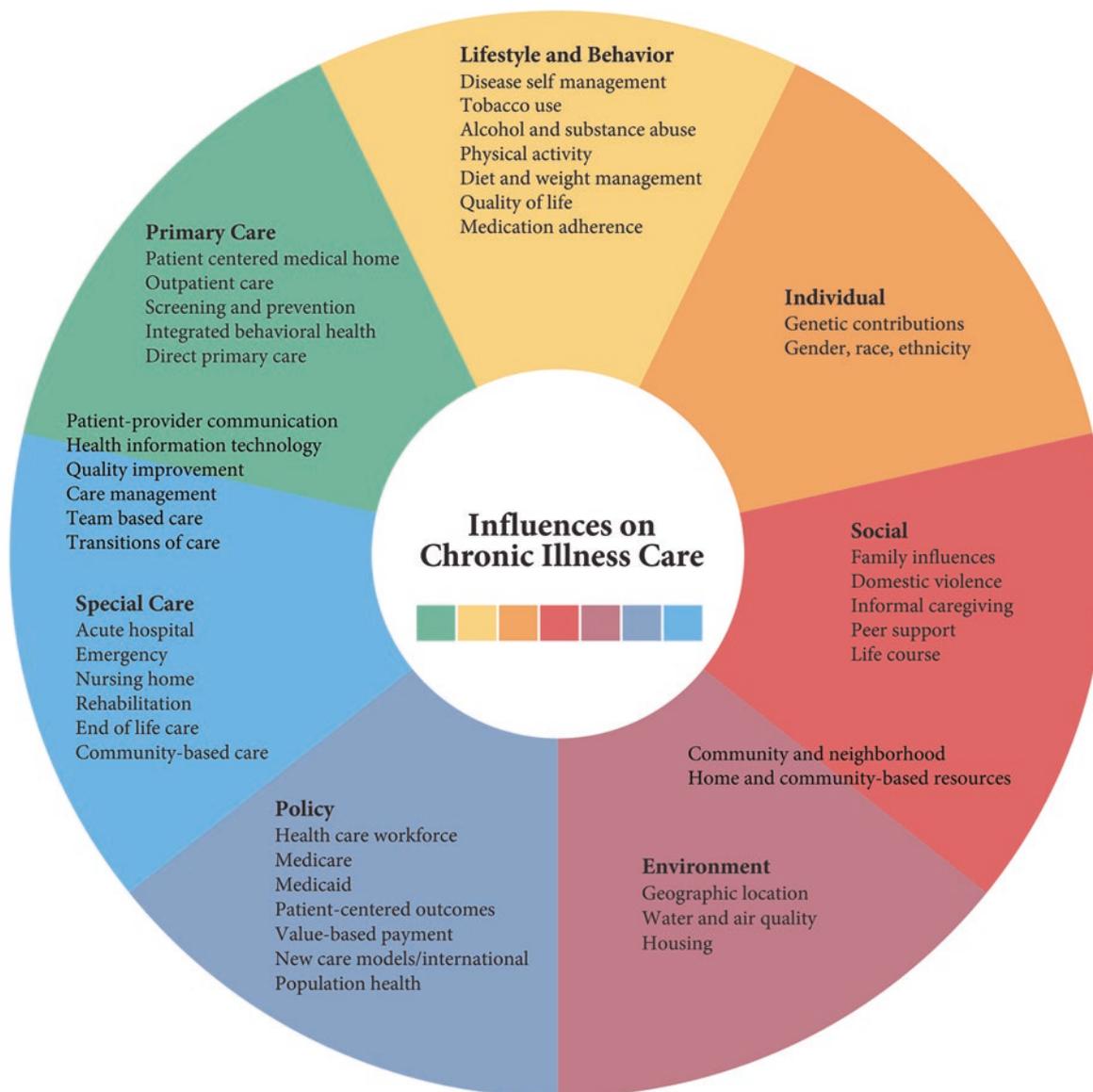
Chronic disease is generally defined as a condition that lasts for more than 3 months, is not prevented by vaccines or cured by medication, does not spontaneously resolve, and has long-lasting and significant effects on an individual's quality of life [3]. In contrast to acute illness, chronic disease 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.

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# Contents

## Part I Individual Influences on Chronic Disease

<b>1 Genetic Contributions and Personalized Medicine</b> .....	3
J. Kevin Hicks and Henry M. Dunnenberger	
<b>2 Race, Ethnicity, and Cultural Influences</b> .....	17
Lori Carter-Edwards, Jada L. Brooks, Sylvia Willie Burgess, and Forrest Toms	
<b>3 Chronic Disease Self-Management</b> .....	29
Hazel Tapp, Michael Dulin, and Marcus Plescia	
<b>4 Tobacco Use and Dependence</b> .....	41
Carol E. Ripley-Moffitt and Adam O. Goldstein	
<b>5 Promoting Physical Activity</b> .....	55
Lauren Porras, Harry Stafford, and Nailah Safiya Adams	
<b>6 Diet and Weight Management</b> .....	71
Leah Elizabeth Chapman, Ramine Alexander, Thomas C. Keyserling, and Alice S. Ammerman	
<b>7 Alcohol and Drug Use Disorders</b> .....	83
Sarah E. Wakeman and Richard Saitz	
<b>8 Quality of Life and Patient-Centered Outcomes</b> .....	95
Margaret C. Wang and Jim Bellows	

## Part II Family and Social Support

<b>9 Family and Other Caregivers</b> .....	111
Megan Gately and Keren Ladin	
<b>10 Domestic Violence, Abuse, and Neglect</b> .....	121
Samantha Schilling and Adam J. Zolotor	
<b>11 Peer Support</b> .....	133
Edwin B. Fisher, Patrick Y. Tang, Maggy Muchieh Coufal, Yuexing Liu, and Weiping Jia	
<b>12 Government Agencies and Community-Based Organizations</b> .....	147
Sherry S. Hay	

## Part III Providing Chronic Illness Care

<b>13 Screening for Chronic Disease</b> .....	163
Alexander Kaysin and Margaret L. Gourlay	

<b>14 Medication Management and Treatment Adherence .....</b>	<b>175</b>
Emily M. Hawes	
<b>15 Patient-Provider Communication and Interactions .....</b>	<b>187</b>
Jennifer Martini	
<b>16 Ambulatory Care .....</b>	<b>199</b>
Nicholas P. Shungu	
<b>17 Emergency Care.....</b>	<b>213</b>
Mary R. Mulcare	
<b>18 Acute Hospital Care.....</b>	<b>221</b>
Amir H. Barzin	
<b>19 Acute Rehabilitation Care.....</b>	<b>233</b>
Karen D. Halpert	
<b>20 Nursing Home Care .....</b>	<b>245</b>
Maureen C. Dale and Margaret R. Helton	
<b>21 Community Care Alternatives for Older Adults .....</b>	<b>259</b>
Amy C. Denham	
<b>22 Home Care .....</b>	<b>271</b>
Christine E. Kistler and Margaret A. Drickamer	
<b>23 End-of-Life Care .....</b>	<b>281</b>
Margaret R. Helton and Jenny T. van der Steen	
<b>24 Special Population: Children and Adolescents.....</b>	<b>297</b>
Morgan A. McEachern and Cristen Page	
<b>25 Special Population: Older Adults .....</b>	<b>305</b>
Gregg A. Warshaw	
<b>26 Special Population: Adults with Intellectual and Developmental Disabilities .....</b>	<b>319</b>
Timothy P. Daaleman	
<b>27 Vulnerable Populations.....</b>	<b>331</b>
Evan Arthur Ashkin	
 <b>Part IV Organizational Frameworks for Chronic Illness Care</b>	
<b>28 Patient-Centered Medical Home .....</b>	<b>345</b>
Mark D. Gwynne and Timothy P. Daaleman	
<b>29 Integrated Behavioral Health Care.....</b>	<b>357</b>
Linda Myerholtz	
<b>30 Transitions of Care.....</b>	<b>369</b>
Mallory McClester Brown	
<b>31 Care Management.....</b>	<b>375</b>
Amy N. Prentice, Rayhaan Adams, and Timothy P. Daaleman	
<b>32 Team-Based Care .....</b>	<b>385</b>
Yee Lam	
<b>33 Direct Primary Care and Concierge Practice .....</b>	<b>391</b>
James O. Breen	

---

<b>34 Health Information Technology</b> .....	401
Carlton R. Moore	
<b>35 Quality Improvement</b> .....	419
Dana M. Neutze and Lindsay Stortz	
<b>Part V Social and Environmental Determinants of Chronic Disease</b>	
<b>36 Social Determinants of Health</b> .....	435
Robert L. Ferrer	
<b>37 Environmental Determinants of Health</b> .....	451
Jacqueline MacDonald Gibson	
<b>38 The Life Course</b> .....	469
Timothy P. Daaleman and John S. Preisser	
<b>Part VI Health Policy and Chronic Illness Care</b>	
<b>39 Medicare</b> .....	481
Jonathan Oberlander	
<b>40 Medicaid</b> .....	493
Timothy P. Daaleman and Warren P. Newton	
<b>41 Value-Based Payment Models</b> .....	505
Terri Menser and Ann Scheck McAlearney	
<b>42 Population Health</b> .....	517
Deborah S. Porterfield	
<b>43 Health-Care Workforce</b> .....	527
Erin Fraher and Bruce J. Fried	
<b>44 International Perspectives</b> .....	537
Dana Sarnak, Arnav Shah, and Jamie Ryan	
<b>45 Future Directions in Chronic Illness Care</b> .....	549
Shana P. Ratner and Darren A. DeWalt	
<b>Index</b> .....	557

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