Preface

Who Are Adults with Chronic Childhood Conditions?

Adults with chronic childhood-onset conditions are a special population with unique needs. As children, they are often termed children or youth with “special health care needs” (CYSHCN). CYSHCN are defined by the U.S. Health Resources and Services Administration (HRSA)’s Maternal and Child Health Bureau (MCHB) as “children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require more than routine health and related services” [1]. Each year nearly half a million children with chronic conditions become adults [2]. Moreover, roughly 20% of young adults have a chronic childhood-onset condition [1].

A Note on Terminology

Many terms have been used to describe the population we are covering in this book. Variations to the MCHB term CYSHCN exist, such as “adolescents and young adults with special health care needs (AYASHCN)” or “young adults with special health care needs (YASHCN).” Some prefer to refer to “chronic conditions” or “chronic medical conditions.” Also, the terms “youth”, “emerging adults” and “young adults” often overlap.

Because of the collaborative nature of this book and the contributions of dozens of authors, we chose to respect the individual author’s preferences for terminology. We have tried to streamline and stay consistent in places where it did not seem to matter as much. For the most part, “adolescents” refer to individuals age 14–18 years, “emerging adults” to individuals age 19–25 years, and “young adults” to individuals age 26–30 years.

Audience

This book is for the practicing adult healthcare provider—either generalist or specialist. For primary care physicians, this book provides a new framework for thinking about care of young adults and identifying opportunities to impact patient health outcomes over a life trajectory. For others, this book serves as a reference with approaches for caring for young adults with
specific conditions acquired in childhood. While we understand that we have not presented every chronic childhood condition, we chose the most common conditions based on data on CYSHCN from the U.S. Department of Health and Human Services needs or conditions that are illustrative of broader approaches.

This book also discusses the challenges facing this special population of patients as they transition from the pediatric healthcare system to the adult health care system and highlights why this period is often associated with poor outcomes. Ultimately, we provide some strategies to improve health outcomes for CYSHCN and assist adult health providers in better understanding the challenges they face.

In a recent publication, the following questions were articulated regarding healthcare transitions: “Who most needs a deliberate transition plan, at what age should transition planning begin, how should the transfer of medical care occur, what preparation is required, and in what manner should the actual transfer of care take place?” Also, one of the most basic questions remains: What are the effective strategies to engage the adult healthcare system in the care of these young people? Targeting this book to adult healthcare providers will hopefully help bridge the gap that exists between the pediatric and adult healthcare systems.

Understanding and Responding to Emerging Adulthood

This book is grounded in several guiding principles: patients live in the context of their families and communities, social determinants of health influence health outcomes and quality of life, and preventive measures and interventions applied in young adulthood can have a tremendous impact on an individual’s life trajectory. The practice of internal medicine has been to date very medically focused, particularly in approaching chronic diseases of middle age and geriatrics. In order to take advantage of the opportunities to change the health trajectories of adults, both without and with chronic childhood conditions, the practice of internal medicine needs to shift towards a preventive paradigm in which the primary care physician provides anticipatory guidance to help patients change health behaviors that could be detrimental.

In this book, we present a model of primary and secondary prevention for emerging adulthood—primary prevention in which all young adults are screened for high-risk behaviors and health needs and secondary prevention in which young adults with chronic childhood conditions are optimized through coordinated care, connections to community resources, and social/family support. The second part of this book details the new developmental period of emerging adulthood and the opportunities for primary care physicians to optimize health during this time.
Transition from Pediatric to Adult Health Care as a Major Determinant of Adult Health Outcomes

Although the importance of transitional care and excellent health care for this population is widely recognized, research regarding the effectiveness of such programs is lacking. A 2012 review of transition program research found no randomized controlled trials or similar strong study designs. It found that introduction to adult care providers or the use of care coordinators may be effective, but the level of evidence was weak [3]. Some have said there is an urgent need for research to evaluate current transitional care practices for youth with SHCN. In general, the needs of young adults and the challenges they face do not receive widespread attention in research or in policy making, although many are starting to pay attention as this is a generation of individuals who may have the worst health outcomes to date.

A recent publication showed some promise, finding that practices that implemented the Center for Health Care Transition’s Six Core Elements and utilized their resources were able to conduct transition readiness assessments for more than 70% of patients [4]. Still, comprehensive transition plans were developed for only about 30% of patients, demonstrating that much work remains to be done. Therefore, we hope more adult healthcare practices are able to adopt these steps and achieve the triple aim of better healthcare individual outcomes, better population health, and reduced costs [5].

In order to implement these steps for the excellent care of adults with childhood-onset chronic conditions, there is also the requirement that physicians and other healthcare professionals develop the knowledge and skills required to provide high quality, developmentally appropriate health care to this population. Young adults with childhood-onset chronic conditions are very different than typical adult patients, and therefore adult providers may need specialized training to care for them [3]. Adult providers have cited concerns about their ability to provide needed care coordination and social supports (e.g., social workers) that are thought to be more available in pediatric settings and about financial constraints from payers that may prevent them from spending sufficient time with newly transitioned youth. Training and education, as well as structural reforms, may be needed to overcome this problem. There are several health professional education resources on the “Got Transition?” program website, including links to CME courses, webinars, and online course modules that we encourage all health care professionals working with this population to investigate (www.gottransition.org).

Structure of This Book

This book is organized in five parts. Part I provides a detailed overview of the healthcare transition from pediatrics to adult medicine from both a policy and practice perspective. We review the literature on healthcare transition
and describe the efforts of the Maternal and Child Health Bureau (MCHB)-funded Center for Health Care Transition Improvement (Got Transition). In the second part, we introduce the concept of emerging adulthood as a developmental period and provide strategies to the adult primary care provider for providing improved comprehensive care for this age group. Part III is divided into condition-specific chapters, each of which details a specific chronic childhood condition, starting with a clinical case and ending with summary reports that can be used as a quick guide. The fourth part ties very closely to the third and reviews additional clinical considerations that are not necessarily condition-specific, but are highly relevant to the care of many young adults with chronic childhood conditions. Finally, Part V describes certain socio-legal issues adult providers should be aware of when caring for this population.

There are several simple steps that adult primary care providers and their practices can implement immediately [6]:

1. Meet with colleagues, ideally in their practice and in practices from which patients often transition, to create a healthcare policy statement that can be distributed to young adults and their families.
2. Use a transition readiness assessment tool to track readiness for adult health care for young adults entering their practice, especially those with childhood-onset chronic conditions.
3. Ensure direct contact with the childhood primary care provider and other childhood providers prior to or at the beginning of the transfer of care, and obtain all relevant medical records.
4. Start every relationship with a transitioning young adult patient, in particular those with childhood-onset chronic conditions, with goal-setting and the creation of a comprehensive written healthcare plan.

Most of what is recommended in this book is based on pediatric literature and the care of children or youth who have the disease. Much of the information is derived from consensus statements among experts who have cared for young adults but not from randomized treatment control trials or blinded studies for this specific population of patients. Some inroads are being made to identify the appropriate care for young adults surviving with childhood conditions, but much more needs to be done.

Much more discussion needs to take place on how we care for a generation of individuals who are just recently having their healthcare needs recognized as a national issue. For more information and to use as a resource, we recommend Investing in the Health and Well-Being of Young Adults, authored by the Committee on Improving the Health, Safety and Well-Being of Young Adults; Board on Children, Youth, and Families with the Institute of Medicine and the National Research Council [7]. Arguably, this is a
population in whom the U.S. healthcare system needs to invest as the returns to this nation could be not only a healthy workforce but also a much healthier economy.

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