Behavioral Approaches to Chronic Disease in Adolescence
Behavioral Approaches to Chronic Disease in Adolescence

A Guide to Integrative Care

Editors

William T. O’Donohue
University of Nevada, Reno, NV, USA

Lauren Woodward Tolle
University of Nevada, Reno, NV, USA

Springer
Preface

This book fills a gap in the literature on evidence-based approaches for treating adolescents with chronic illness in an integrated care setting. It is comprehensive in accurately addressing specific considerations inherent in adolescent psychology (therapist burnout, ethical considerations, bringing in the family, cultural considerations, etc.) and in outlining evidence-based practice guidelines for common chronic conditions in adolescence (type I diabetes, asthma, juvenile rheumatoid arthritis, chronic pain, etc.). There are very difficult problems that need to be sorted out and we hope this book, while reflecting the current state of knowledge, will encourage research and intellectual work in this area.

We owe deep gratitude to all our contributing authors who took part in making this a high-quality, integrated resource. We greatly appreciate Ian Marvinney and Janice Stern, our editors at Springer, for their assistance and patience in completing this project. We would also like to thank the wonderful individuals who helped us finish this book, especially Linda Goddard. Finally, we thank our family members Jane Fisher, Katie and Anna, Dennis and Barbara Woodward and Nate Tolle for their unyielding support.

William T. O’Donohue
Lauren Woodward Tolle
Reno, Nevada
Contents

Part I  Basic Issues

Introduction: Adolescents with Chronic Illnesses: Issues and Answers . . . . . . 3
William O’Donohue and Lauren Woodward Tolle

An Introduction to Adolescent Development .......................... 7
Angela J. Huebner

Unique Considerations when Treating Adolescents with Chronic Illness .......................... 15
Dorothy E. Warner and Stuart T. Hauser

Adolescent Physiology ...................................................... 29
Kathryn L. Eckert, Vincent A. Loffredo, and Kathleen O’Connor

Family Influence on Adolescent Treatment Outcomes ......................... 47
Clint Field and Rachel Duchoslav

Ethics and the Teen Patients .............................................. 55
Michael Lavin

Overextending the Overextended: Burnout Potential in Health-Care Professionals, Psychologists, Patients, and Family Members ........ 65
Lauren Woodward Tolle and Steve Graybar

Part II  Integrated Care Practice Guidelines

Type 1 Diabetes Mellitus ................................................ 85
Annette M. La Greca and Eleanor R. Mackey

Type 2 Diabetes in Youth .................................................. 101
Alan M. Delamater, Farrah Jacquez, and Anna Maria Patino-Fernandez

Integrated Care Practice Guidelines for Adolescents with Asthma ........ 111
Anthony R. Cordaro, Jr. and Marianne Z. Wamboldt

Juvenile Rheumatoid Arthritis ........................................ 129
Michael A. Rapoff and Carol B. Lindsley
Epilepsy .................................................... 143
Deirdre A. Caplin, Joan K. Austin, and David Dunn

Migraines/Chronic Headaches ................................... 155
Joyce Engel

The Assessment and Management of Chronic and Recurrent Pain in Adolescents ........................................ 163
Gary A. Walco, Helen Rozelman, and David Aaron Maroof

Adolescent Depression ........................................ 177
Brandyn M. Street and Judy Garber

Cancer .................................................................. 197
Lisa A. Schwartz, Anne E. Kazak, and Ifigenia Mougianis

Cystic Fibrosis in Adolescents ................................... 219
Anthony A. Hains, W. Hobart Davies, Diana Quintero, and Julie A. Biller

Chronic and End-Stage Renal Disease ......................... 233
Michelle A. Meade, Sarah Tornichio, and John D. Mahan

Sickle Cell Disease ................................................ 253
Lamia P. Barakat, D. Colette Nicolaou, Emily A. O’Hara, and Sarah Levin Allen

Inflammatory Bowel Disease .................................. 269
Carin Cunningham and Rachel Neff Greenley

Chronic Fatigue Syndrome ..................................... 285
M. Elena Garralda

Adolescents Living with HIV/AIDS ................................. 297
Maureen E. Lyon and Lawrence J. D’Angelo

Health-Related Quality of Life Instruments for Adolescents with Chronic Diseases ........................................ 311
Alexandra L. Quittner, Ivette Cruz, Avani C. Modi, and Kristen K. Marciel

Index ..................................................................... 329
Contributors

Sarah Levin Allen  Clinical Psychology Program, Drexel University, Philadelphia, PA, USA

Joan Austin, DNS, RN, FAAN  Center for Enhancing Quality of Life in Chronic Illness, Indiana University School of Nursing, Indianapolis, IN, USA

Lamia P. Barakat, Ph.D.  Children’s Hospital of Philadelphia and University of Pennsylvania School of Medicine, Drexel University, Philadelphia, PA, USA

Julie A. Biller, M.D.  Medical College of Wisconsin, Milwaukee, WI, USA

Dedee Caplin, Ph.D.  Department of Pediatrics, University of Utah Health Sciences Center, Salt Lake City, UT, USA

Anthony R. Cordaro, Jr., M.D.  Department of Psychiatry, The Children’s Hospital, University of Colorado at Denver and Health Sciences Center, Aurora, CO, USA

Ivette Cruz, M.S.  Department of Psychology, University of Miami, Miami, FL, USA

Carin Cunningham, Ph.D.  Case Western Reserve School of Medicine, Cleveland, OH, USA

Lawrence J. D’Angelo, M.D., MPH  Division of Adolescent and Young, Adult Medicine, Children’s National Medical Center, Washington, DC, USA

W. Hobart Davies, Ph.D.  Department of Psychology, University of Wisconsin – Milwaukee, Milwaukee, WI, USA

Alan Delamater, Ph.D.  Department of Pediatrics, University of Miami Leonard M. Miller School of Medicine, Miami, FL, USA

Rachel Duchoslav, Ph.D.  Department of Psychology, Utah State University, Logan, UT, USA

David W. Dunn, M.D.  Department of Psychiatry, Indiana University School of Medicine, Indianapolis, IN, USA

Kathryn Eckert, M.D.  Department of Pediatrics, University of Nevada School of Medicine, Reno, NV, USA
Joyce Engel, Ph.D., O.T.  Department of Rehabilitation Medicine, University of Washington School of Medicine, Seattle, WA, USA

Clint Field, Ph.D.  Department of Psychology, Utah State University, Logan, UT, USA

Judy Garber, Ph.D.  Department of Psychology and Human Development, Vanderbilt University, Nashville, TN, USA

M. Elena Garralda, M.D.  Division of Neurosciences and Mental Health, Imperial College London, London, UK

Steve Graybar, Ph.D.  University of Nevada School of Medicine, Reno, NV, USA

Anthony Hains, Ph.D.  Department of Educational Psychology, University of Wisconsin – Milwaukee, Milwaukee, WI, USA

Stuart Hauser, M.D., Ph.D.  Harvard Medical School, Judge Baker Children’s Center, Boston, MA, USA

Angela Huebner, Ph.D.  Department of Human Development, Virginia Tech University, Falls Church, VA, USA

Anne E. Kazak, Ph.D., ABPP  Department of Psychology; Department of Pediatrics, University of Pennsylvania School of Medicine, Children’s Hospital of Philadelphia, Philadelphia, PA, USA

Annette La Greca, Ph.D.  Psychology Department, University of Miami, Coral Gables, FL, USA

Michael Lavin, Ph.D.  Psychologist – private practice, Washington, DC, USA

Carol B. Lindsley, M.D.  Department of Pediatrics, University of Kansas Medical Center, Kansas City, KS, USA

Vincent A. Loffredo, M.D.  Department of Pediatrics, University of Nevada School of Medicine, Reno, NV, USA

Maureen Lyon, Ph.D.  Children’s National Medical Center, Washington, DC, USA

Eleanor Mackey, Ph.D.  Children’s National Medical Center, Washington, DC, USA

John D. Mahan, M.D.  Nationwide Children’s Hospital, The Ohio State University, Columbus, OH, USA

Kristin K. Marcie, Ph.D.  Psychology Department, University of Miami, Miami, FL, USA

David A. Marrof, M.A.  Ferkauf Graduate School of Psychology, Yeshiva University, Bronx, NY, USA

Michelle A. Meade, Ph.D.  Department of Physical Medicine and Rehabilitation, University of Michigan, Ann Arbor, MI, USA
Avani C. Modi, Ph.D.  Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children’s Hospital, Cincinnati, OH, USA

Ifigenia Mougianis, B.A.   Children’s Hospital of Philadelphia, Philadelphia, PA, USA

D. Colette Nicolaou, Ph.D.  Children’s Hospital Los Angeles, Los Angeles, CA, USA

Kathleen O’Connor M.D.  Department of Pediatrics, University of Nevada School of Medicine, Reno, NV, USA

William T. O’Donohue, Ph.D.  Department of Psychology, University of Nevada, Reno, Reno, NV, USA

Emily A. O’Hara  Psychology Department, Drexel University, Philadelphia, PA, USA

Diana Quintero, M.D.  Medical College of Wisconsin, Milwaukee, WI, USA

Alexandra L. Quittner, Ph.D.  Department of Psychology & Pediatrics, University of Miami, Miami, FL, USA

Michael A. Rapoff, Ph.D.  Department of Pediatrics, University of Kansas Medical Center, Kansas City, KS, USA

Helen Rozelman, Ph.D., LMSW  Stern College for Women, Yeshiva University, New York, NY, USA; Department of Pediatrics, New York University, School of Medicine, New York, NY, USA

Lisa Schwartz, Ph.D.  Children’s Hospital of Philadelphia, Philadelphia, PA, USA

Brandyn M. Street  Department of Psychology and Human Development, Vanderbilt University, Nashville, TN, USA

Lauren Woodward Tolle, M.A.  Department of Psychology, University of Nevada, Reno, NV, USA

Sarah Tornichio MSW, LSW  Nationwide Children’s Hospital, Columbus, OH, USA

Gary A. Walco, Ph.D.  The David Center for Children’s Pain and Palliative Care, Hackensack University Medical Center, Hackensack, NJ, USA; Department of Pediatrics, University of Medicine and Dentistry of New Jersey, New Jersey Medical School, Newark, NJ, USA

Marianne Z. Wamboldt, M.D.  University of Colorado at Denver and Health Sciences Center, Aurora, CO, USA

Dorothy Warner, Ph.D.  Harvard Medical School, Judge Baker Children’s Center, Boston, MA, USA
Introduction

Adolescents with Chronic Illnesses: Issues and Answers

William O’Donohue and Lauren Woodward Tolle

Adolescence is a difficult period in life, regardless of whether or not there is a chronic illness involved. This period is often marked with distress, strained relationships, and difficulty in navigating new social roles. When individuals enter this developmental stage with a chronic illness, it can be especially trying. Despite how difficult this can be, little research has critically examined optimal, evidence-based ways of treating adolescents with chronic illness within an integrated care setting. Given the long-lasting impact of problems that can arise during this developmental stage (transitioning into adulthood, developing autonomy, creating an identity, creating long-lasting relationships, family functioning, etc.) along with problems that can arise from having a chronic illness (i.e., problems with treatment adherence, social stigma, school functioning, depression, lack of social support, poor coping skills, poor adherence to proper diet/exercise) it seems appropriate and necessary to look at these issues holistically. In addition, adolescence is frequently the time when both positive (i.e., regular exercise, healthful diet, treatment adherence) and negative health behaviors (i.e., poor treatment adherence, smoking, overeating) are initiated and set the tone for future health behaviors (Chesney & Antoni, 2002). This makes this developmental stage an all the more important period to intervene early and implement skills training early to prevent the likelihood of poorer health outcomes later in adulthood.

Adolescents display a huge amount of variability. If one says “13-year-old girl,” one can gain a rough idea of what that person would be like physically, socially, cognitively, emotionally but still there is wide variability. We want to caution against stereotyping. Each adolescent needs to be viewed ideographically. Nothing in this book implies that easy generalizations can be made about adolescents.

Some of this variability comes from the usual sources: genetics (which also turn on genes at different times, hence different ages for puberty), previous history (an adolescent has already had a decade or so of childhood experiences that produce variability), different current circumstances (family status, economic status, unique cohort effects), and different prospects and goals (family history of attendance of Ivy League schools vs. family history of imprisonment).

A key point is that adolescence is generally the time where the individual needs to take more responsibility for managing their chronic disease. However, this is often not very straightforward. Chronic disease management can require cognitive and behavioral skills (such as self-control, planning, problem solving, empathy) that can be beyond the grasp of adolescence (and all too often key family members). It also can be a time where the individual engages in a lot of risky behaviors, seemingly with little appreciation of the magnitude of these risks. It can also be a time of increased reactivity and counterpianlce. Attempts by parents to move in one direction seem to be keys for the adolescent to move in the opposite direction. It is also a time when the child more keenly discerns and responds to the parents’ or family’s own problems. With the

W. O’Donohue (✉)
Department of Psychology, University of Nevada, Reno, NV, USA

exception of clear abuse and neglect, the infant is relatively oblivious to their parents’ deficits, but the adolescent is much more keenly aware (and may even become somewhat of a connoisseur of these). These factors present increased challenges and increased costs of failure for professionals engaged in attempting to help these individuals and their families. Again, we don’t wish to stereotype; many adolescents are healthy individuals with good support networks and this often means a more straightforward response to their chronic disease and its management. In general more research is needed in understanding developmental progressions and factors that account for variability in these. The state of the science is itself in its infancy: we have very little nomothetic information to rely on.

But there is a rough developmental progression: infancy to childhood to adolescence, to adulthood, to old age; we believe this “third stage” presents its unique and very challenging problems for the adolescent themselves, for the families of these individuals, and for helpers involved with them. This book attempts to delineate these and to offer some tools for addressing the problems of chronic disease management.

The importance of the book is that it will help equip practitioners with tools necessary to treat psychosocial problems inherently found in adolescents with chronic illness. This book is divided into two parts, the first part outlines the special considerations of adolescent and family psychotherapy within the context of chronic illness. The second part provides detailed descriptions of evidence-based practice guidelines for the major chronic conditions that adolescents face. It is our hope that this book is comprehensive in its ability to accurately address specific considerations inherent in adolescent psychology (therapist burnout, ethical considerations, bringing in the family, cultural considerations, etc.) and to specifically outline evidence-based practice guidelines for common chronic conditions in adolescence (type 1 diabetes, asthma, juvenile rheumatoid arthritis, chronic pain, etc.) such that a clinician can clearly comprehend them and easily use them in an integrated care setting. The strength of this book is the quality and expertise of the contributing authors.

In the second chapter, Huebner sets the scene for this book by providing the reader with an overview of normative adolescent development. He addresses the various aspects of adolescent development by way of an ecological model, focusing on physical development, cognitive development, and psychosocial development. This important chapter highlights how these normative stages might be exacerbated in a case of an adolescent with a chronic illness (i.e., the “it can’t happen to me” syndrome or a heightened level of self-consciousness).

The chapter by Warner and Hauser expands off of the second chapter by explicitly discussing how normative adolescent development may be disrupted by the presence of a chronic illness. The chapter follows disease progression from diagnosis and initial adjustment to adherence and living with the illness, the desire for autonomy, and complications in the context of chronic illness, as well as adaptive and maladaptive coping strategies. Warner and Hauser provide empirical evidence for adolescent-focused interventions, family-focused interventions, and finally community and school interventions.

Eckert, Loffredo, and O’Connor, in their chapter, provide detailed information of the important physiological changes occurring in adolescence. Specifically, the chapter first addresses normative physiological changes that occur in adolescence and then addresses specific pediatric conditions (i.e., asthma, type 1 diabetes, cancer, eating disorders, and cystic fibrosis) and how these normative pubertal processes are disrupted and can lead to permanent changes in the adolescent (i.e., short stature or poor bone mineral accretion). This chapter also addresses adolescent brain physiology, the effects of alcohol and antidepressants on the developing brain, and how the developing brain is relevant to issues inherent in chronically ill adolescents (e.g., assisting adolescents in preventing hospitalization by making the connection between cause and effect – the use of preventative inhalers in the case of asthma in preventing hospitalization). Finally, three case examples are provided to illuminate important physiological processes involved in three pediatric illnesses (i.e., lymphocytic leukemia, type 1 diabetes, and asthma).

Field and Duchoslav address the importance of the family and familial influences in adolescents with chronic illness in their chapter. Specifically, they report empirical literature related to family conflict, family cohesion, family relationships, and
expressiveness within the family as it relates to adolescent adjustment to chronic illness. The chapter also provides empirical literature concerning family responses to treatment including appraisal of the illness and coping strategies found to be adaptive or maladaptive. Finally, the authors provide findings from literature concerning specific parental factors including maternal maladjustment to the illness and distress as well as overprotection of the adolescent. The chapter concludes with implications for future research and clinical work in providing the best family environment to predict adolescent success in managing their illness.

The next chapter by Lavin provides a thoughtful and interesting perspective on ethical issues that are inherent in treating adolescent patients and provides an example from Shaffer’s 1977 play, Equus. Lavin follows this play and includes relevant ethical issues that abound with adolescents and the additional complications when that adolescent has a chronic illness.

Tolle and Graybar, in the seventh chapter, address the inherent problem of burnout in all individuals involved in treating chronic illnesses in adolescents, from the adolescent patient themselves to the family of the adolescent and the medical professionals involved. They provide empirically supported treatment guidelines to treat burnout in the adolescent and family members, as well as structural strategies to prevent burnout and treat compassion fatigue in the mental health care professionals working with this population. A case study is also provided to illuminate the process of working through burnout in a family with an adolescent with type 1 diabetes.

Part II (from the eighth to the twenty-second chapter) of the book provides evidence-based treatment guidelines for specific chronic illnesses commonly found in adolescents. Chapter twenty three is unique in that Quittner, Cruz, Modi, and Marciel provide a review of available assessment tools used in determining quality of life and other health-related constructs in adolescents with chronic health conditions. The contributing authors in Part II are experts in their respective fields and provide cutting-edge information to assist the clinician in an integrated care setting. The chapters follow a consistent outline to provide optimally efficient information. This outline is as follows.

---

**Chapter Outline**

1) Description of the chronic condition with adolescents including
   - Epidemiology
     i. Typical age of onset
     ii. Progression
     iii. Percentage of population afflicted with this disease
     iv. Prognosis
   - Symptomatology
     i. Frequency (do they occur all day/every day?)
     ii. Severity (life interference? visible? pain associated?)
     iii. Duration (Does it go away? lifelong?)
     iv. Lethality (Is it or can it be life threatening? If so, how and when?)
     v. Complications
   - Treatment regimen for adolescents (and families where indicated)
     i. Necessary frequency of adherence (what, when, how often)
     ii. Side effects (of medication, etc.)
     iii. Treatment options
     iv. Cost
     v. Insurance coverage
     vi. Frequency of necessary medical attention (checkups, etc.)

2) Common comorbid psychosocial problems:
   - Stigma (how does this affect the given disease, treatment, etc.)
   - Comorbidity (depression, anxiety, substance abuse, body image problems, poor diet, poor physical activity, etc.)
   - Social support
   - Family conflict
   - Treatment adherence issues
   - Cultural considerations

3) How a behavioral health specialist, working within an integrated team, can most effectively target these adolescents:
   - What are the best practices for assessment and treatment?
   - What is the behavioral health clinician’s role in most effectively helping this individual?
Effective psychosocial/psychological interventions and necessary collaboration with primary care physicians, nurses, dietitians, specialty care practitioners, etc.

4) Methodological considerations if conducting research with this population

5) Research agenda

This important book provides the multidimensional context and resulting difficulties of treating adolescents with chronic illnesses. As medical treatments for various chronic conditions improve, thus reducing mortality rates, and advanced technologies are developed to assist those with chronic conditions, psychologists are presented with a unique opportunity to advance research agendas in a medical setting. Also, behavioral health interventions implemented in pediatric populations can potentially assist in saving billions of dollars in health care spending by using evidence-based approaches to prevent long-term medical complications in a significant number of individuals. Through a succinct presentation of issues surrounding the adolescent (i.e., family considerations, developmental changes, cultural considerations, potential for burnout), a clear review of empirical data on adolescents with a number of common chronic illness, and finally evidence-based guidelines to assist the practitioner in working within a medical setting, this book assists in this process by providing practitioners with the knowledge and the tools to continue to make significant contributions in improving the quality of life of adolescents with chronic illnesses.

Reference

An Introduction to Adolescent Development

Angela J. Huebner

Although this quote was not intended to describe the period of adolescence, it does bear some striking truths to the "revolution" that is occurring during this time. Adolescence is a particularly exciting and uniquely vulnerable period of development. Not since infancy has the individual undergone so many changes at such a high rate of speed (Carnegie Council on Adolescent Development, 1996). These changes are occurring across multiple developmental systems—physiological, cognitive, and psychosocial. Additionally, these changes are occurring in part in reaction to the individual's environment. That’s right. While development in infancy could be considered "generic" such that the organism is at that time primed to adapt to any environment (e.g., aboriginal tribe or middle-class American—they all begin the same), development during adolescence is designed to fit the organism more efficiently into his or her environment or context. Thus, development during the period of adolescence reflects an active interplay between the organism and his or her context. Such contexts include the individual, family, friends, community, and culture.

The purpose of this chapter is to provide the reader with an overview of what most agree to be "normative" development among adolescents. Such a basic understanding is necessary before one can begin to consider the unique burden that chronic health conditions (CHC) adds to an already stressed system. To this end, the reader is first presented with a framework for organizing considerations about development. Second, descriptions of normative development are presented, followed by unique considerations that must be addressed given the additional condition of CHC. Finally, special treatment considerations for working with adolescents will be provided.

Ecological Model of Development

Because of its usefulness as a framework for mapping the contexts of adolescents, the ecological model of development (Bronfenbrenner, 1979) will be used to organize this discussion of normative adolescent development. Briefly, the ecological model of development assumes that development occurs in context and that in each context a unique “transaction” between the individual and others occurs. In other words, development is considered to be a joint function of the individual and his or her environment (Bronfenbrenner, 1992). The ecological model is intended to describe development over the entire life course. However, for purposes of this chapter, its scope has been narrowed to focus only on adolescent development. In the following section, each ecological “level” will be described and the associated contextual issues of adolescent development highlighted.
Let’s begin in the innermost circle, with the individual organism: the “youth.” This circle represents what the individual organism brings to the context. This includes issues of temperament, physical health, capacity for learning, skills, and the like. These characteristics influence the types of interaction the young person will have with those in the second circle. In the ecological model, the second circle is called the “microsystem” and refers to those contexts or immediate settings in which the individual interacts as a direct participant. This includes, for example, the family, the peer group, youth groups, sports teams, religious groups, and even health care professionals. For adolescents, these microsystems are a crucial influence on development. They provide the context in which the adolescent is trying to fit his or her behavior, ideals, and identity; similarly the adolescent is shaping the context through what they bring to the interactions. Development results from the interaction of the two.

The third level maps the potential connections among those individuals who interact with the adolescent. These connections are referred to as the “mesosystem.” Because each microsystem may include different expectations or norms, it is important to consider how much cross-communication is occurring between them. The double-headed arrows in Figure 1 suggest that mesosystems influence each other, such that what happens in one mesosystem informs what happens in another. The adolescent is not a direct participant in these interactions; rather, he or she is the focus of the connection. For example, does the parent communicate directly with the adolescent’s teachers? Do the adolescent’s teachers talk with the youth group leaders? Do parents talk with youth’s friends? Does the health care team talk with the parent? Does the physician talk with the adolescent’s siblings?

Level four, known as the “exosystem,” includes more indirect influences on adolescents. The exosystem includes those systems, policies, or decisions that impact adolescents, even though there is not necessarily a direct relationship with the adolescent. For example, does mom’s place of work allow her to use her sick leave if her son is ill? Do parents have family health insurance benefits? Did the school board vote to hire a full-time nurse for the school? Did citizens vote to raise taxes in order to open their own hospital?

Finally, level five is called the “macrosystem.” The macrosystem refers to the broad patterns of a culture and society. These tend to be reflected in the norms and values supported (directly or indirectly) by those in the community. For example, how do people treat those who are different? Is there discrimination? Is bullying or violence tolerated? Do people genuinely look out for each other?

Development is enhanced when there is goodness of fit between the individual and his or her environment. This model suggests a way of thinking about that fit and the implications it has for supporting youth with chronic health

---

**Fig. 1** Five levels of youth development
conditions. The next section focuses on issues of normative development at the individual (innermost circle) level.

**Normative Adolescent Development**

As part of this overview of “normative” adolescent development, physical development, cognitive development, and psychosocial development will all be briefly explored. As you read the following information, keep in mind that while adolescents develop in each of these areas, they do not all necessarily follow the same time line.

**Physical Development**

During the teen years, adolescents experience changes in their physical development at a rate of speed unparalleled since infancy. Physical development includes rapid gains in height and weight, development of secondary sex characteristics, and continued brain development (Archibald, Graber, & Brooks-Gunn, 2006). With respect to physical development, during a 1-year growth spurt, boys and girls can gain an average of 4.1 and 3.5 inches in height, respectively (Steinberg, 2007). This spurt typically occurs 2 years earlier for girls than for boys. Weight gain results from increased muscle development in boys and body fat in girls. During puberty, changing hormonal levels play a role in activating the development of secondary sex characteristics. These include (1) growth of pubic hair; (2) menarche (first period for girls) or penis growth (for boys); (3) voice changes (for boys); (4) growth of underarm hair; (5) facial hair growth (for boys); and (6) increased production of oil, increased sweat gland activity, and the beginning of acne.

Additionally, recent research suggests that regions of the adolescent brain are not completely developed or integrated. Of specific interest is the frontal cortex region of the brain. This region of the brain is responsible for impulse control, decision-making skills, and affect regulation. Research suggests that while neuron proliferation is expanding during the 0- to 3-year-old time frame, a process of “synaptic pruning” is occurring during adolescence, the suspected effect of which is to more efficiently “fit” the organism to his or her environment (Blakemore & Choudhury, 2006). Such “pruning” actually increases the speed of information processing. The individual is becoming specialized or refined to respond more efficiently to the type of stimuli presented in his or her particular context. It is important to note, however, the behaviors that occur during this pruning process (i.e., learning about impulse control, affect regulation, decision making) will most likely be inconsistent or spotty at best. It has been compared to the period of early development when a toddler is first learning to walk (Baird, 2008). For toddlers, walking doesn’t happen right away, instead it occurs in steps with many starts and stops and much falling down in between. Adults are much better able to allow for this development in children (i.e., not punishing them for falling down) than they are in adolescents, probably in part because toddlers don’t look as much like adults as do adolescents. This yet unfinished process of “pruning” and rewiring is thought to explain why some adolescents seem to be inconsistent in controlling their emotions, impulses, and judgments (Dahl, 2004).

How do these physical changes affect adolescents and their interactions with others?

**Adolescents frequently sleep longer.** Research suggests that adolescents’ actually need more sleep to allow their bodies to conduct the internal work required for such rapid growth. On average, adolescents need about 9 ½ hours of sleep a night (Steinberg, 2007). This increased need for sleep is often at odds with conventional school day schedules and may become a source of conflict between parents and teens. It is important to recognize that medications involved in the treatment of CHC may interfere with sleep—either reducing or increasing the need impacting the adolescent’s readiness and ability to interact with others or to perform well in school.

**Adolescents may be more clumsy or overly sensitive about weight.** Words like “gangly,” awkward,” and “gawky” are all great descriptions of the condition of the adolescent body. During this phase of development, body parts don’t all grow at the same rate. Previous bodily mastery may have to be relearned as adolescents try to cope with limbs that seem to have grown overnight. This new awkwardness may contribute to teens becoming more sensitive about their looks and their physical abilities (Archibald et al., 2006). Previously active youth
may hesitate to become involved in sports. Additionally, teenage girls may become overly sensitive about their weight. This concern arises because of the rapid weight gain associated with puberty. In a recent national survey, 62% of adolescent girls reported that they were trying to lose weight (Center for Disease Control, 2005). A small percentage of adolescent girls (1–3%) become so obsessed with their weight that they develop severe eating disorders such as anorexia nervosa or bulimia. These concerns about weight may influence their mealtime and activity choices. Again, the use of medications to control CHC may contribute to inflammation or "puffiness" that further increases self-consciousness about weight and appearance.

Adolescents may be concerned because they are not physically developing at the same rate as their peers. Adolescents may be more developed ("early maturers") or less developed ("late maturers") than their peers. Being out of developmental "step" with peers is concerning to adolescents because most just want to fit in. Early maturation affects boys and girls differently (for review see Archibald et al., 2006). Research suggests that early-maturing boys tend to be more popular with peers and hold more leadership positions. Adults often assume that early-maturing boys are cognitively mature as well. This assumption can lead to false expectations about a young person’s ability to take on increased responsibility. Because of their physical appearance, early-maturing girls are more likely to experience pressure to become involved in dating relationships with older boys before they are emotionally ready. Early-maturing girls tend to suffer more from depression, eating disorders, and anxiety (Ge, Conger, & Elder, 2001). Medications or treatments related to CHC or the CHC itself may interfere with pubertal development, exacerbating off-time development with an adolescent and his or her peer group.

Cognitive Development

Most adults recognize that adolescents have better thinking skills than do younger youth. These advances in thinking skills tend to center around advanced reasoning skills, ability to abstract, and meta-cognitions (Byrnes, 2006). Advanced reasoning skills include the ability to think about multiple options and possibilities. It includes a more logical thought process and the ability to think about things hypothetically. It involves asking and answering the question of "what if...?" For example, What if I don’t take my medicine on time? or What if I decide to skip this meal? or What if I decide to eat this cake? Advanced reasoning also includes the concept of abstract thinking. Abstract thinking means thinking about things that cannot be seen, heard, or touched. Examples include things like faith, trust, beliefs, and spirituality. Adolescents may begin to challenge parents or adults about what they believe, all in an effort to develop their own system of beliefs. Topics like faith and spirituality may take on new meaning for a young person with CHC, as they may have to come to terms with the possibility of a diminished quality of life or life span.

Finally, adolescents are developing the ability to think about thinking in a process known as "meta-cognition." Meta-cognition allows individuals to think about how they feel and what they are thinking. It involves being able to think about how one is perceived by others. It can be used to develop strategies for improving learning. The ability to think about one’s thoughts also has implications for managing stress or for pain management (e.g., mindfulness meditation).

How do these cognitive changes affect adolescents and their interactions with others?

Adolescents demonstrate a heightened level of self-consciousness. Adolescents tend to believe that everyone is as concerned with their thoughts and behaviors as they are. This leads the teen to believe that they have an "imaginary audience" of people that are always watching them (Elkind, 1967). This may be especially true if they have an illness that is physically apparent (e.g., hair loss due to chemotherapy). Adolescents tend to believe that no one else has ever experienced similar feelings and emotions (Elkind, 1967). They may become overly dramatic in describing things that are upsetting to them. They may say things like “You’ll never understand,” or “My life is ruined!” These feelings may be exacerbated for young people experiencing a chronic health condition. In some cases, their experience is truly unique as others really may not have experienced the same pain, frustrations, or stresses that they have.

Adolescents tend to exhibit the “it can’t happen to me” syndrome, also known as a "personal fable" (Elkind, 1967). This belief may cause adolescents to
take unnecessary risks like drinking and driving (“I won’t crash this car”), having unprotected sex (“I can’t possibly get pregnant”), or smoking (“I can’t possibly get cancer”) (Greene, Krcmar, Walters, Rubin, & Hale, 2000). Translated to the adolescent with CHC, this “personal fable” may facilitate lack of treatment adherence with respect to diet or behavioral restrictions—especially if the consequences of treatment non-compliance aren’t immediate.

Adolescents tend to become very cause oriented. Their activism is related to the ability to think about abstract concepts. After reading about cruelty to animals a teen may become a vegetarian and a member of “People for the Ethical Treatment of Animals” (PETA). Another teen may become active in “Green Peace” or “Save the Whales” campaign. Similarly, they may begin to exhibit very strong opinions about the medications, treatments, or diets to which they are willing to adhere.

Adolescents tend to exhibit a “justice” orientation (Kohlberg, 1984). They are quick to point out inconsistencies between adults’ words and their actions. They have difficulty seeing shades of gray. They see little room for error. They may ask questions like “What did I do to deserve this?” or believe that life is not fair. They may also have difficulty accepting non-definitive answers to questions related to their condition.

**Psychosocial Development**

There are five recognized psychosocial issues that adolescents deal with during their adolescent years. Essentially these issues all center around the interaction between self and others. “Who am I?” and “How am I perceived by others?” Specific tasks include establishing an identity, autonomy, intimacy, comfort with one’s sexuality, and achievement.

Establishing an identity. This has been called one of the most important tasks of adolescents [see Kroger (2006) for review]. The question of “who am I” is not one that adolescents think about at a conscious level. Instead, over the course of the adolescent years, adolescents begin to integrate the opinions of influential others (e.g., parents, friends, other caring adults) into their own likes and dislikes. The eventual outcome is people who have a clear sense of their values and beliefs, occupational goals, and relationship expectations. People with secure identities know where they fit (or where they don’t want to fit) in their world. CHC add another layer to the quest of identity development. Do I define myself as my illness? (e.g., “I am a diabetic”) or do I define myself as a person with an illness (“I am Katie and I have diabetes”). How do others define me?

Establishing autonomy. Some people assume that autonomy refers to becoming completely independent from others. They equate it with teen “rebellion.” Rather than severing relationships, however, establishing autonomy during the teen years really means becoming an independent and self-governing person within relationships (Allen & Land, 1999). Autonomous adolescents have gained the ability to make and follow through with their own decisions, live by their own set of principles of right and wrong, and have become less emotionally dependent on parents (Zimmer-Gembeck & Collins, 2006). Autonomy is a necessary achievement if the teen is to become self-sufficient in society. The experience of the CHC may complicate the task of establishing identity. Depending on the condition, parents or other adults may hesitate to allow the young person to be responsible for treatment adherence; similarly, young people may not be willing to give up support in this area.

Achievement. Our society tends to foster and value attitudes of competition and success. Because of cognitive advances, the teen years are a time when young people can begin to see the relationship between their current abilities and plans and their future vocational aspirations. They need to figure out what their achievement preferences are—what they are currently good at and areas in which they are willing to strive for success. CHC may limit the development or exploration of some skills and abilities. Such youth may need additional guidance and support in figuring out how to match their interests with their abilities.

Establishing intimacy. Many people, including adolescents, equate intimacy with sex. In fact intimacy and sex are not the same. Intimacy is usually first learned within the context of same-sex friendships and then utilized in romantic relationships. Intimacy refers to close relationships in which people are open, honest, caring, and trusting. Friendships provide the first setting in which young people can practice their social skills with those who are their equals. It is with friends that adolescents learn how to
begin, maintain, and terminate relationships, practice social skills, and to become intimate. Adolescents with CHC may be hesitant to explore intimacy with their peers, in part because they may not feel as though they are really “equal.” How do these psychosocial changes affect adolescents and their interactions with others?

Adolescents begin to spend more time with their friends than their families. It is within friendship groups that adolescents can develop and practice social skills (Brown & Klute, 2006). Adolescents are quick to point out to each other which behaviors are acceptable and which are not. It is important to remember that even though adolescents are spending increased amounts of time with their friends, they still tend to conform to parental ideals when it comes to decisions about values, education, and long-term plans.

Adolescents may become elusive about where they are going or with whom. When asked what they’ll be doing for the evening, adolescents typically reply with “nothing” or “hanging out.” When asked whom they’ll be with, adolescents reply “just some friends.” They are spending increasing amounts of time in context with peers rather than with adults (Brown & Klute, 2006).

Adolescents may begin to interact with parents and other adults as people. Even though they may not want to be seen with parents in public, adolescents may begin to view parents more as people. They may ask more questions about how a parent was when he or she was a teen. They may attempt to interact with adults more as equals (Granic, Dishion, & Hollenstein, 2006). Along with this newfound “equality” adults may find that adolescents become more argumentative (Granic et al., 2006). Adolescents may question adults’ values and judgments. When adolescents don’t get their way, they may say “you just don’t understand.” This inconsistency in responses (i.e., sometimes acting as a adult, sometimes acting as a child) is a normal part of development.

Special Considerations

The previous discussion highlighted the major normative developmental tasks of adolescents and how this development changes or influences their interaction with others. It also highlighted the additional issues and complexity that arises when one adds a chronic health condition to this already highly transitional time. This section highlights issues unique to those with CHC. These include the therapeutic alliance and issues of treatment compliance as well as the recognition of the comorbidity of mental health issues with CHC.

Therapeutic Alliance and Treatment Compliance

Therapeutic alliance refers to the relationship between the health care team and the adolescent. The notion of therapeutic alliance has traditionally been relegated to the psychotherapy arena but its relational aspects are an important consideration in other health care contexts. A “good” therapeutic alliance suggests that the patient and health care provider(s) have a mutual understanding and agreement upon the treatment goals and tasks required to meet the goals (Bordin, 1979). Much research has demonstrated a positive relationship between therapeutic alliance and treatment compliance among adults (e.g., Martin, Garske, & Davies, 2000); that is, the more positive the therapeutic relationship, the more likely it is that compliance with treatment will occur.

Less empirical research has explored the therapeutic relationship for adolescents. This is unfortunate given the finding that about half of adolescents with chronic health conditions do not adhere to treatment recommendations (Kyngas, Kroll, & Duffy, 2000). Related research on communication between physicians and their adolescent patients is informative. For example, in their study of doctor–adolescent communication, Beresford and Sloper’s (2003) findings suggest that three areas were important for facilitating effective physician–patient communication: adolescent choice about who they are engaging with; a sense of equality, or being treated as an individual rather than a “condition”; and continuity of contact with the same treating physician. Other researchers suggested that adolescents with CHC rated physician honesty, attention to pain, and physician expertise with their respective chronic illness as the most important aspects of care (Britto et al., 2007).