



Assessment and Treatment of Adolescents With Chronic Medical Conditions

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Abstract

Chronic medical conditions persist for one year or more, require ongoing medical intervention, and impair functioning. Approximately 10–30% of youth are diagnosed with a chronic medical condition. Youth with chronic medical conditions are at heightened risk for psychiatric comorbidity and negative health outcomes across the lifespan. Managing a chronic medical condition becomes particularly difficult during the adolescent developmental period, which is marked by changes in biological, psychological, social, and cognitive development. Assessment and intervention with adolescents is often challenging, as this is a period of transition and risk. Given increasing rates of chronic medical conditions, health service psychologists are likely to encounter youth with medical conditions in their clinical practice. In this paper, an overview of chronic medical conditions and adolescent development is provided and fundamental assessment and treatment components, including multicultural considerations, are explored.

Keywords Chronic medical conditions · adolescence · cognitive behavioral therapy · multicultural considerations

Clinical Vignette

Mia, a 14-year-old Mexican American cisgender female, presents to you with her mother and father for health and behavioral intervention at the recommendation of her pediatric endocrinologist. Mia was diagnosed with Type 1 Diabetes Mellitus (T1DM) at age four. Mia's diabetes treatment regimen consists of basal (long-acting) and bolus (short-acting) insulin therapy, maintenance of a healthy diet, carbohydrate/fat/protein counting, frequent blood sugar monitoring, regular exercise, and attendance at regular follow-up appointments with her pediatric endocrinologist. At the most recent follow-up appointment, Mia's hemoglobin A1C (i.e., average blood glucose) was 9%, which indicated poorly controlled blood sugar. Mia has experienced insulin resistance secondary to puberty. Mia's endocrinologist has had to make several insulin dose adjustments. Mia has experienced episodes of both hyperglycemia (i.e., high blood sugar) and hypoglycemia (i.e., low blood sugar).

As you meet with Mia and her family, you learn Mia recently transitioned from a small middle school to a large public high school. Mia's parents describe Mia as a

quiet and reserved teenager who tends to exhibit anxiety and worry in novel and social situations. This transition in schools also occurred during the COVID-19 pandemic, which exacerbated symptoms of anxiety for Mia. During the assessment, Mia describes daily worry, fears of being perceived negatively by peers, fears regarding contracting coronavirus, difficulty concentrating, feelings of restlessness, and insomnia. Mia does not want to stand out or appear "different" than peers, so she often avoids dosing insulin at school. Mia has difficulty adjusting insulin doses to account for exercise and activity level, which has led to fluctuations in blood sugar. Fluctuations in blood sugar impair Mia's ability to focus at school and her grades have declined. Mia has become increasingly dependent on her parents to help manage diabetes and monitor school assignments. Mia also describes fear and anxiety related to the coronavirus pandemic. She worries she could contract coronavirus at school and bring the virus back home to family members, several who also have T1DM. As the clinician meeting with Mia for therapy, how should you approach the complexity of providing treatment to an adolescent with psychiatric and medical comorbidity?

Key Background Information

Chronic medical conditions often present in childhood or adolescence and are associated with psychosocial consequences across the lifespan. Adolescence is a developmental period marked by biopsychosocial and identity changes. Managing a chronic medical condition during the adolescent developmental period presents unique challenges for teenagers, families, and clinicians. The goal of this paper is to guide clinicians on how to provide psychological assessment and intervention to youth with chronic medical conditions to improve health behaviors, improve quality of life, and promote optimal functioning. This paper provides a brief review of the literature on chronic medical conditions and adolescent development, practical recommendations for providing assessment and intervention to this population, including multicultural considerations, and guidance on managing clinical challenges.

Defining Chronic Medical Conditions

Chronic medical conditions, as defined by the Centers for Disease Control and Prevention (CDC; 2021a), are conditions that persist for one year or more and require ongoing medical attention or limit activities of daily living. Chronic medical conditions that present in youth include but are not limited to asthma, diabetes, epilepsy/seizures, obesity, cystic fibrosis, allergies, sickle cell anemia, irritable bowel diseases (e.g., ulcerative colitis, Crohn's disease), migraines/headaches, juvenile arthritis, congenital heart defect, traumatic brain injury/spinal injury, and organ transplant (Roberts & Steele, 2017). It is estimated that 10–30% of youth have a chronic health condition. Rates of chronic medical conditions in youth are increasing, which is theorized to be the result of advances in pediatric medicine, which have increased survival rates of conditions that were once fatal in childhood (e.g., cystic fibrosis). Youth from communities of color are 1.5 to 2 times more likely to be diagnosed with a chronic medical condition (Price et al., 2013) and often have poorer health outcomes. Implicit racial and ethnic biases among health care professionals, in addition to social determinants of health such as food insecurity, inadequate insurance coverage, and inadequate access to medical care, are factors related to racial and ethnic health disparities.

Chronic medical conditions in youth are associated with a number of negative sequelae including psychiatric comorbidity, chronic pain, sleep disturbance, disordered eating and/or distorted body image, discrimination, social difficulties, missed school days, and academic impairment. With regard to psychiatric comorbidity, having a chronic medical condition in adolescence is related to increased

risk for depression, suicide, anxiety, and behavioral disorders. In turn, youth with chronic medical conditions who have a comorbid psychiatric disorder have more difficulty managing their health, which often results in higher rates of non-adherence to medical treatment regimens and poorer health outcomes (Suris et al., 2004). Managing comorbid physiologic, cognitive, and emotional symptoms can be challenging for many teenagers and families.

Type I Diabetes

T1DM is one of the most common chronic medical conditions of childhood and adolescence. T1DM is an autoimmune disease that occurs when the pancreas produces little or no insulin, a hormone that regulates the amount of glucose (sugar) in the bloodstream. As a result, glucose builds up in the bloodstream, which can cause dangerous consequences such as high blood sugar, diabetic ketoacidosis (i.e., high levels of ketones), neuropathy, retinopathy, stroke, and mortality. There is no cure for T1DM; rather, it requires constant management. Individuals with T1DM must adhere to daily basal (long-acting) and bolus (short-acting) insulin therapy while monitoring food intake (e.g., counting carbohydrates/fat/protein), performing frequent blood sugar checks, and incorporating regular exercise. Assistive technologies such as continuous glucose monitors, which monitor glucose on a continuous basis, and insulin pumps, which are small, computerized devices that deliver insulin on a pre-programmed schedule, are often recommended.

Rates of T1DM among youth are increasing. For youth 19 years or younger, the estimated prevalence of T1DM per 1,000 youths increased from 1.48 in 2001 to 2.15 in 2017 (Lawrence et al., 2021). T1DM accounts for nearly 98% of diabetes cases in children under and 10 and 87% of diabetes cases in youth ages 10–19 (Imperatore et al., 2021). Although T1DM can be diagnosed at any age, the peak age of onset typically occurs around puberty (Atkinson et al., 2014). There are a number of developmental changes that occur in puberty and adolescence that may complicate diabetes self-management. T1DM was selected as the chronic medical condition for the vignette in this article because (a) it is one of the more common chronic medical conditions that present in youth and (b) it requires a complex treatment regimen, which becomes challenging during the adolescent developmental period. Many of the assessment and intervention components discussed throughout this article can be applied when providing care for youth with other chronic medical conditions such as epilepsy and seizure conditions, inflammatory bowel conditions or gastrointestinal conditions, pulmonary conditions, and headache/migraine conditions.

Considerations in Adolescence

Adolescence is a period marked by a number of unique developmental changes including primary changes in biological, psychological, and cognitive development, in addition to social redefinition (i.e., biopsychosocial changes; Williams et al., 2002). The biopsychosocial model of health provides a framework for understanding the dynamic role of biological, psychological, and social factors (i.e., interpersonal and contextual factors) in shaping health trajectories across the lifespan (Lehman et al., 2017). Adolescence is a developmental period when attitudes and beliefs about health form, which impact health behaviors across the lifespan. Thus, adolescence is both one of the most challenging and critical time periods for the management of a chronic health condition. Understanding the impact of adolescent biopsychosocial changes on the disease process is a critical task of clinicians who work with adolescents with chronic medical conditions.

There are a number of changes that occur during the adolescent developmental period. Pubertal hormones are released, which results in changes in growth and metabolic rate, fat and muscle growth or redistribution, and breast and genital development (Vijayakumar et al., 2018). Youth with chronic medical conditions may experience delayed growth and puberty or early puberty. Delayed growth and puberty is most common in chronic inflammatory conditions or conditions that involve malnutrition, such as bowel disorders (Turkel & Pao, 2007). Early puberty has been demonstrated to increase risk for obesity, which may increase risk for conditions such as Type 2 Diabetes. Additionally, obesity may complicate disease management, particularly for conditions such as diabetes that require youth to carefully monitor diet and sugar intake.

There is a large body of research linking pubertal timing to psychosocial outcomes (Hoyt et al., 2020). Youth experiencing delayed or “off-time” puberty are often perceived and treated differently by adults and same-aged peers. Delayed puberty in adolescents, particularly cisgender adolescent boys, is associated with greater risk for teasing and bullying, low self-esteem, and internalizing symptoms (Kaplowitz, 2010). Early puberty is also a risk factor for depression, and this relationship is most robust in cisgender females (Alloy et al., 2016). For transgender youth, puberty is often perceived as a significant stressor, which may exacerbate depressive and anxiety symptoms. More research is needed specifically on the impact of pubertal changes on growth in transgender or gender nonconforming youth. Additionally, hormonal changes can impact the disease process. For instance, due to changes in growth hormones during puberty, adolescents with diabetes often experience insulin resistance and subsequent chronic hyperglycemia. Research suggests there are no sex differences in hemoglobin A1C in children

and adolescents with T1DM; however, cisgender males are more likely to exhibit suboptimal adherence (Naar-King et al., 2006). It is evident that puberty onset can complicate disease management and affect social development.

Adolescence is marked by changes in cognitive and psychosocial development including the adolescent drive to seek autonomy and develop a self-identity. Teenagers are increasingly motivated to pursue peer relationships; however, youth with chronic medical conditions often feel different than peers and may be excluded from peer groups. Additionally, teenagers with chronic medical conditions are often reliant on family to assist with medical care at a time when autonomy should be increasing and dependence on family members should be decreasing. Having a teenager with a chronic medical condition can place many demands on family members and disrupt the adolescent individuation process (Suris et al., 2004). Adolescents with chronic medical conditions often need to take on greater responsibility for their medical care in preparation for the transition to adulthood, but this can prove challenging.

Biopsychosocial factors can complicate adherence to medical treatment regimens. Adolescents who strive to fit in socially with peers may fail to engage in medical treatment behaviors (e.g., administering insulin) in social environments to avoid standing out in front of peers. Teenagers may prioritize friends, school, or extracurricular activities over their medical treatment regimens, which can result in suboptimal management of chronic medical conditions. Although the adolescent developmental period is marked by brain maturation, abstract reasoning, emotion regulation, and ability to set realistic goals are not yet fully developed. Thus, adolescents have difficulty with executive functioning tasks such as planning and reasoning, which may serve as a barrier to medical treatment adherence. Additionally, the prevention of long-term consequences may not be a strong motivator for treatment adherence (Suris et al., 2004).

Sociocultural and contextual factors influence disease outcomes. Chronic stress has been shown to contribute to persistent inflammation in the body, which is linked to poorer health outcomes (Hansel et al., 2010; Liu et al., 2017). Acute inflammation is an important mechanism in the body that triggers the immune system to fight disease; however, chronic inflammation is often problematic and can result in tissue damage and pathologies (Hansel et al., 2010). Many chronic medical conditions including diabetes, heart disease, irritable bowel diseases, and arthritis are inflammatory conditions. For youth with chronic medical conditions, persistent inflammation secondary to prolonged stress may lead to worsened health outcomes. Adverse childhood experiences such as child abuse and neglect, poverty, systemic racism, and exposure to pollution are all examples of chronic stressors that are detrimental to both youth mental and physical health. For a more thorough review of the

effect of adverse childhood experiences on both mental and physical health, please see the meta-analysis conducted by Hughes et al. (2017).

Youth from communities of color are particularly vulnerable as research suggests the association between chronic stress and inflammation is greatest in this population (Schmeer & Tarrence, 2018). This is reflective of racial and ethnic health disparities. A large study analyzing data from more than 1,300 youth presenting to pediatric tertiary care diabetes centers in the United States in 2018–2019 revealed that Non-Hispanic Black children compared to Non-Hispanic White children had higher hemoglobin A1C levels, more emergency department visits and hospitalizations, and had less access to medical technologies such as continuous glucose monitors and insulin pumps (Lipman et al., 2021). Social determinants of health (SDOH), defined as the conditions and environments in which individuals live and interact, have been found to impact health and wellness (CDC, 2021b). The CDC website provides a comprehensive overview of SDOH and includes programs addressing SDOH, policy resources to support SDOH, and tools for putting SDOH into action (CDC, 2021b). SDOH include factors such as racism, socioeconomic status, ableism, access to education, job status, family structure and support, access to clean water and nutritious foods, and health literacy. Both access to health care (e.g., access to transportation, physical distance to clinic, access to telehealth technology and reliable internet) and quality of health care (e.g., suboptimal insurance coverage, gaps in coverage) influence health outcomes. Communities of color, particularly Hispanic and Latino youth, have more gaps in insurance coverage (Bethell et al., 2011). Publicly insured youth compared to privately insured youth are more likely to rate their health care coverage as inadequate (Bethell et al., 2011). Having a child with a chronic medical condition is a huge financial burden for many families, and may be particularly burdensome for communities of color who more often report suboptimal insurance coverage (Bethell et al., 2011). Health services psychologists, often trained in the biopsychosocial model of health and the intersection of physical and mental health, are in a unique position to provide care to youth with comorbid medical and psychiatric conditions

Practice Considerations

Assessment of Adolescents With Chronic Medical Conditions

Health service psychologists providing intervention to youth with chronic medical conditions should conduct a thorough evaluation to assess biopsychosocial factors affecting disease management. The importance of a culturally responsive

approach to evaluation and treatment planning cannot be overstated. Communities of color are disproportionately affected by chronic medical conditions. A large body of research has indicated youth from communities of color compared to White youth are less likely to present for treatment and have an increased risk of dropping out of treatment, particularly in the early stages of treatment (de Haan et al., 2018). Predictors of premature treatment termination may include lack of a culturally sensitive and responsive approach to evaluation, discrepancies in therapist and patient explanations for symptoms, perceived racism, preference for informal therapy outside of the medical system, and weak therapist and youth/family alliance (de Haan et al., 2018).

Culturally responsive cognitive behavioral therapy as outlined by Hays (2009) should include an assessment of the person and family needs in a manner that is culturally respectful. Use of a strengths-based approach that emphasizes collaboration between the family and clinician is also critical. Motivational interviewing—a person-centered, therapeutic intervention that involves partnering with patients (i.e., meeting patients/families where they are at), assessing readiness and motivation to change, validating ambivalence, identifying patient’s goals and values, and eliciting change talk—is integral in both the assessment process and throughout treatment as patients are working toward behavior change. When discussing presenting problems, clinicians should clarify which part of the problem is environmental/external versus cognitive/internal while attending to cultural influences (Hays, 2009). Clinicians should validate reported experiences of oppression and should be careful not to challenge core cultural beliefs (Hays, 2009). Either during the assessment process or early in treatment, clinicians should emphasize their role as part of the medical care team. Clinicians should collaborate with all providers of the patient’s care team to communicate the importance of an integrated approach to health care and well-being.

The American Psychiatric Association (APA) (2013) now includes a supplementary cultural formulation interview (CFI) in the *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition (DSM-5), which is an evidence-based, culturally responsive, person-centered guide for clinicians to aid in the assessment process. There are several components of the CFI including the cultural definition of the problem; cultural perception of cause, context, and support (e.g., stressors and supports, role of cultural identity); cultural factors affecting self-coping and past help seeking; and cultural factors affecting current help seeking. When working with youth or with a teen with a chronic medical condition, it is important to listen and acknowledge the patient and family’s views and beliefs regarding the medical condition as well as family healing practices. Additionally, adolescent patients often benefit from creating an “identity wheel” either during the assessment process or

early in treatment to identify salient multicultural identity factors such as race, ethnicity, gender, sex, socioeconomic status, ability status, national origin, and language. Use of the CFI and use of a culturally responsive approach is critical to engage youth and families in treatment and to provide treatment that is respectful and responsive to the needs of all youth and families from diverse cultural backgrounds.

After a thorough evaluation with Mia and her parents, you identify several barriers to medical treatment adherence including fears of negative evaluation/desire to “fit in” with peer group, anxiety, lack of knowledge on dosing insulin to adjust for activity level, and parental overaccommodation (e.g., parents solely responsible for counting carbohydrates before meals). You also identify several problematic health behaviors including skipping meals/inconsistency in diet, insomnia and problematic sleep habits, high stress level, and limited coping strategies to manage distress. Mia shares about family values and several important identity factors including her identities as a first generation, bilingual, Mexican American woman who has a medical disability. Mia reports she is the first person in her family to attend therapy, and she shares feelings of hesitancy. Mia’s parents share one vehicle, and she does not always have access to consistent transportation.

Goal Setting

Collaborative goal setting with patients and families is a critical component of any intervention, but may be particularly important when working with youth with chronic medical conditions who are often referred by medical specialty providers—rather than self-referred—for health and behavior intervention or related services. These patients may perceive referral to psychology services as indicative that something is “wrong” with them. Additionally, clinicians should be mindful of the diversity of cultural beliefs regarding participation in behavioral intervention. Goal setting sessions should be focused on reducing stigma related to referral for mental health treatment, assessing treatment readiness and motivation, obtaining teen and family “buy in” for health and behavioral intervention, and collaboratively setting goals for treatment. Patients and families often benefit when clinicians acknowledge the burden of managing a lifelong chronic medical condition. Clinicians can utilize a dialectic approach to acknowledge patients and families are doing the best they can to manage a chronic condition, but there is also likely room for improvement. Goals for treatment may include helping adolescents learn to cope and manage disease-related stressors, improving adherence to medical treatment, teaching strategies to manage chronic pain, improving health behaviors, treating comorbid psychiatric conditions, improving assertiveness and communication skills, and increasing adolescent independence with

medical care to facilitate the transition into managing health in young adulthood.

Mia, her parents, and her psychologist collaborated to identify several targets for therapy. Goals for therapy included improving coping skills for managing diabetes, reducing anxiety, improving health behaviors including sleep and eating habits, improving adherence to diabetes treatment regimen, and improving assertiveness skills and teen independence with disease management. It was agreed upon that therapy sessions would occur via telemedicine to reduce transportation barriers and to reduce the risk of coronavirus infection.

Cognitive Behavioral Intervention

Cognitive behavioral therapy (CBT) and problem-solving interventions have been demonstrated as efficacious and effective for the treatment of youth with chronic medical conditions (Bennett et al., 2015; Lau et al., 2021). One recently published intervention, the *Children’s Health and Illness Recovery Program* (CHIRP; Carter et al., 2020), is a 12-session manualized intervention for teens with chronic medical conditions and their families. This intervention utilizes cognitive behavioral and family systems approaches to improve adjustment and independent functioning in teens with chronic medical conditions. CHIRP aims to increase coping and functioning in four areas including physical functioning (exercise, activity, sleep, nutrition), school functioning (attendance, academic accommodations), social functioning (peer relationships, interpersonal functioning, family communication), and coping skills (coping, stress management, lifestyle management; Carter et al., 2020). This is just one example of an evidence-based program for youth with chronic medical conditions. Many treatment programs for youth with chronic medical conditions incorporate similar treatment components and rely on a cognitive behavioral or integrative approach to improve adjustment and overall functioning.

The treatment of youth with chronic medical conditions may at times feel daunting for clinicians for several reasons. For youth managing a condition that is chronic, there may be many targets for intervention. It is important for clinicians to remember the goal of treatment is not to teach patients to manage a chronic medical condition “perfectly,” but instead, the goals are to reduce barriers to managing illness, facilitate coping with illness, and improve functioning. Given the variability across chronic medical condition presentations, there is not one evidence-based protocol that should be utilized in treatment. Rather, a cognitive behavioral, individualized approach that considers the needs of the patient and family is often most useful. There are several core treatment components that are integral in the treatment of many youth with chronic medical conditions including psychoeducation,

activity scheduling and pacing, sleep intervention, adherence, coping and cognitive behavioral skills, assertiveness and communication skills, and defining child and family roles to promote teen independence.

Core Treatment Components

Psychoeducation on the chronic medical condition and any comorbid psychiatric conditions is important early in treatment. The clinician should address any gaps in understanding as lack of knowledge regarding a chronic medical condition that may impair coping and serve as a barrier to treatment adherence. When delivering psychoeducation to adolescents, it is often helpful to deliver content in a format that is more engaging to teens by creating a psychoeducation game (e.g., “Diabetes Jeopardy”) or collaborating with the teen to create a visual chart, handout, or presentation. In the case of Mia, Mia’s psychologist learned Mia was unaware of the relationship between physical activity and fluctuations in blood sugar. This became a target of intervention. Mia’s psychologist provided psychoeducation on factors that affect blood sugar in youth with diabetes such as carbohydrate intake, exercise/activity level, sleep, stress, and menstruation. Psychoeducation was also provided on the importance of regular, daily activity for both general health and diabetes management. Mia, who enjoys art, chose to create a visual chart, which depicted the factors that affect blood sugar. The clinician worked with Mia to design an activity plan and discussed how to schedule exercise into Mia’s routine. Mia and the clinician discussed the importance of scheduling an appointment with her endocrinologist to review how to adjust insulin levels to account for activity level. Mia described feelings of nervousness regarding speaking with her doctor. Assertiveness skills training and communication skills became an important component of treatment. Mia and the clinician often engaged in role-play exercises in which she practiced asking questions about her medical treatment regimen.

Activity plans are often an important component of treatment for youth with chronic medical conditions. Regular exercise is recommended for all youth; however, for youth with chronic medical conditions, and particularly youth with chronic, painful medical conditions (e.g., juvenile arthritis, irritable bowel diseases), this may prove challenging. Youth who experience chronic pain may become fearful of overexertion and subsequent pain; thus, they may avoid regular activity, which can lead to physical deconditioning, increased pain, and reduced functioning over time. Even youth with chronic pain will benefit from some level of activity. When creating an activity plan with a teen with a chronic medical condition, it is important to first consult with the youth’s medical team to ensure you are providing appropriate and safe physical activity guidance. Youth with

chronic medical conditions should be instructed on activity pacing, which is a strategy for learning to modify activity (e.g., slower pace or rate, more frequent breaks) according to needs. Youth learn to listen to their bodies, reduce chances of overexertion, and push themselves when warranted.

Addressing sleep is important in the treatment of all youth with chronic medical conditions as poor sleep is related to reduced immune functioning, poor concentration, and increased anxiety, depression, and behavioral symptoms. Adolescents benefit from psychoeducation and monitoring of sleep habits such as consistent sleep/wake schedules, reducing screen use and bright lights at bedtime, avoidance of naps and late caffeine use, and regular bedtime routines to prepare the body for sleep. Adolescents who exhibit insomnia may require cognitive behavioral therapy for insomnia (CBT-I) or more targeted sleep intervention such as use of sleep diaries to track sleep, stimulus control intervention (i.e., bed only for sleep), sleep restriction therapy (i.e., provide limit for time spent in bed to improve sleep drive and reduce prolonged nighttime awakenings), cognitive therapy (i.e., challenging maladaptive beliefs about sleep), and relaxation training. For a more thorough review of CBT-I for adolescents please see Palermo et al. (2016). Adolescent usage of technology can be leveraged toward improved health behavior outcomes through smartphone apps and web programs, of which there are now many tailored to specific populations.

Instruction on coping skills for managing both typical teen stressors and illness-related stressors is an important component of treatment. Youth with chronic medical conditions encounter unique stressors often not experienced by peers without medical conditions. Stressors may include balancing school and medical appointments, adhering to medical treatment regimens at school or when out with friends, communicating with medical providers about illness, and managing chronic pain. Additionally, as youth are navigating the transition from adolescence to young adulthood, they will be faced with the challenge of learning to navigate the health care system and manage the expenses of a chronic medical condition. Youth with chronic medical conditions may benefit from learning problem-solving strategies and creating coping plans to address specific needs. Traditional CBT skills such as learning to identify, challenge, and restructure distorted or unhelpful thoughts, implement relaxation and coping strategies, and reduce avoidance or unhelpful behaviors is often needed. For youth with chronic medical conditions, cognitions and emotions regarding illness should be explored.

Many teens with chronic medical conditions have been isolated from peer groups, recurrently missed school due to illness, or have been reluctant to share about their chronic medical condition with others. These youth often exhibit anxiety regarding returning to school or engaging

with others. Anxiety intervention such as exposure-based CBT may be necessary to help youth gradually face fears and reintegrate into their communities. Teens may also need to review social skills. Additionally, connecting teens and families with group-based therapy (e.g., coping group for youth with T1DM), support groups or chronic illness camps, and community resources is integral to reduce stigma, validate patient experiences, and connect youth with other teens who may share similar experiences. This was helpful for Mia who was exhibiting anxiety regarding sharing about her diagnosis of diabetes and administering insulin at school or when with peers. Mia benefitted from creating a fear hierarchy (i.e., list of feared situations) and completing graduated exposure homework assignments (e.g., first sharing about diagnosis with one family friend, and then building to administering insulin in front of peers) to reduce anxiety and improve her ability to adhere to her treatment regimen. She also benefitted from joining a diabetes support group through Juvenile Diabetes Research Foundation.

Incorporating caregivers and families in treatment is essential as adolescents learn to take on more responsibility for caring for their health during transition into a young adult role. Many families struggle to identify parent and child roles in managing illness. Teens may become too reliant on family members for managing health or the opposite may occur, wherein teens may become overwhelmed by the responsibility of too much independence with managing health. Families benefit from psychoeducation on appropriate child and teen roles, reestablishing roles, and learning family problem-solving and communication strategies. Clinicians should be cognizant of individual and cultural differences in beliefs regarding family roles and responsibilities. In our current case, Mia's psychologist assessed family values and beliefs regarding parent and teen roles in the home environment. It was determined that Mia's parents would still take an active role in helping manage diabetes, but Mia would take on more responsibility. Mia's parents met with the psychologist to work on reducing parental overaccommodation behaviors that increased Mia's dependence on parents (e.g., parents packing diabetes supplies bag, parents counting carbohydrates at every meal). Over time, Mia learned to set medication alarms, count carbohydrates, administer insulin, and pack diabetes supplies. Organizational skills such as time management and planning were helpful for Mia as she took on more independence in her medical care. All of the aforementioned interventions helped improve Mia's adherence to her medical regimen. She also benefitted from creating a behavior adherence plan, which consisted of a checklist of diabetes management behaviors and a calendar schedule.

Additional Challenges and Considerations

Ethical Considerations

There are a number of unique ethical challenges that emerge when providing treatment to youth with chronic medical conditions. Health services psychologists who assess and treat youth with chronic medical conditions may be embedded within hospital settings, medical specialty clinics or practices, integrated primary care settings, or may operate independently in community mental health, private practice, or school settings. As part of a patient's care team, it is essential to collaborate with other medical providers but issues of confidentiality should be carefully considered. Appropriate releases of information should be obtained before communicating with medical providers and educators (i.e., schools) external to one's practice. Even with appropriate signed releases and patient/guardian permission for communication, psychologists should be mindful of content when sharing patient information with others. Information obtained during behavioral intervention is often sensitive and requires an extra layer of protection. Psychologists are advised to only share sensitive information that is pertinent to the patient's medical care and only after permission has been obtained from the legal guardian. When operating and completing documentation within integrated settings, psychologists should also be mindful of who has access to the patient's medical records.

One of the more complex ethical challenges that may arise when providing treatment to youth with chronic medical conditions are concerns related to medical neglect. Medical neglect occurs when a parent/guardian does not provide adequate medical care to their minor aged child. For youth with certain chronic medical conditions such as T1DM, inability to access required treatment such as insulin therapy presents an imminent risk for harm. There may be a number of reasons why a teen may not receive adequate medical care such as financial barriers, teen attitude/behavior, lack of awareness/knowledge/skills, cultural/religious practices or beliefs, and provider misunderstanding (e.g., provider misunderstanding of patient's cultural practices or patient's knowledge or skill level) or miscommunication. When there is imminent risk of harm (e.g., patient at risk for medical complications), clinicians, as mandated reporters, are required to report concerns to their local Department of Social/Child Services. These cases are often complex; thus, when there is a concern for possible medical neglect or imminent danger, psychologists are encouraged to consult with colleagues or other members of the medical team. It is also often beneficial to connect youth and families to other resources such as a case manager to assess the need for additional supports.

Considerations for the Coronavirus Pandemic

The global COVID-19 pandemic has furthered challenges for all youth, including disruption in routines, missed academic and learning opportunities, social isolation, changes in peer and family relationships, fear and uncertainty regarding the future, and increased psychiatric symptoms (Lau et al., 2021). Adolescents with chronic medical conditions are particularly vulnerable to psychiatric comorbidity and this risk may be heightened during the COVID-19 pandemic. Additionally, adolescents with chronic medical conditions may experience greater anxiety than typically developing peers due to knowledge that they are at increased risk for medical complications if they do contract COVID-19. This creates a challenge for clinicians providing behavioral intervention to youth with chronic medical conditions. Typical cognitive behavioral therapeutic interventions teach youth to identify, challenge, and restructure distorted patterns of thinking and change maladaptive behaviors. For youth with chronic medical conditions, fears of becoming seriously ill from coronavirus may not be a distorted belief, and may in fact be a reality. Adolescents with chronic medical conditions may benefit from an acceptance based therapeutic approach that teaches youth to learn strategies to accept and cope with worries, fears, and feelings of uncertainty regarding their health. Acceptance and commitment therapy approaches are useful for most youth with chronic medical conditions, regardless of the pandemic status.

The COVID-19 pandemic has altered the provision of mental health services for youth. There has been a rapid shift in providing telehealth psychotherapy and health and behavioral intervention services despite limited research supporting the efficacy or effectiveness of interventions delivered using a virtual modality in adolescent populations. However, results presented in a recent review paper examining the initial feasibility and efficacy of telemental health for youth with chronic medical conditions provide preliminary support for the use of virtual cognitive behavioral and problem-solving interventions for this population (Lau et al., 2021). Clinicians should consider use of telehealth treatment modalities to increase access to care and reduce risk of transmission of COVID-19 to vulnerable children and families, which may occur during in-person appointments.

504-Plans

Chronic medical conditions can interfere with learning and school attendance. Most, if not all, youth with chronic medical conditions will require a 504-plan, which is a plan outlined by Section 504 of the Rehabilitation Act of 1973 to permit for academic accommodations at school. Many clinicians are familiar with 504-plans for youth with ADHD, internalizing, or behavioral disorders, but fewer clinicians may have experience with 504-plans for medical conditions. Early in treatment,

it is critical for clinicians to communicate and collaborate with the patient's school psychologist in the creation and adaptation of 504-plans. These plans should have been created at time of medical diagnosis or entry into the school system; however, clinicians should be knowledgeable of the child's plan, evaluate the effectiveness of the plan, and collaborate with the educational team to consider the need for additional academic accommodations. Clinicians may need to serve in the role of patient advocate to ensure patients are receiving adequate accommodations and care for their health at school. The American Diabetes Association (2022) provides information on 504-plans for youth with diabetes in addition to sample plans in both English and Spanish languages. Please see Hopkins and Hughes (2016) for guidance on individualized health care plans in the classroom for youth with chronic conditions.

In our case example, Mia requires a 504-plan at school to keep diabetes supplies with her at all times, eat whenever necessary, use the bathroom at any time, and to permit for blood sugar checks and insulin administration. Mia needs to check blood sugar and administer insulin before meals. Mia is also required to check blood sugar before exams because hypo- or hyperglycemia will affect her ability to focus and perform to the best of her abilities. All medical appointments are excused without penalty, and Mia is provided with appropriate time to make up missed assignments or exams. Mia's psychologist regularly communicates with Mia's school to update the plan as needed. Mia's psychologist assisted with adding the diagnosis of generalized anxiety disorder to the plan and recommended a number of accommodations, including the ability for Mia to check in or meet with a trusted adult at school and the flexibility to choose to administer insulin in the nurse's office or in the lunchroom.

Conclusion and Key Clinical Considerations

Adolescence is a critical developmental period in which psychologists can intervene to help alter the life course of illness progression. The treatment of adolescents with chronic medical conditions is often complex and requires a comprehensive evaluation and consideration of biological, psychological, and sociocultural factors. A culturally responsive evaluation should utilize a strength-based and person-centered approach and include an assessment of multicultural identity factors, social determinants of health, and patient and family beliefs regarding healing practices. The ultimate goals of cognitive behavioral intervention include facilitating coping with disease-related stressors, improving health behaviors and adherence, increasing teen independence, and improving quality of life. Health service psychologists play a vital role in partnering with patients and families to reduce the burden of managing chronic medical conditions.

Summary of Assessment and Treatment Considerations

- A comprehensive and culturally responsive evaluation of youth with chronic medical conditions should include an assessment of medical treatment regimens, biopsychosocial health factors, comorbid pain symptoms, health behaviors, social determinants of health, and multicultural identity factors.
- Early in treatment, goal setting sessions should aim to reduce stigma related to referral for mental health treatment, assess treatment readiness and motivation, and obtain teen and family “buy in” for health and behavior intervention.
- Key components of integrated cognitive behavioral and family systems treatment for youth with chronic medical conditions include psychoeducation, activity scheduling and pacing, sleep intervention, adherence, coping and cognitive behavioral skills, assertiveness and communication skills, and defining child and family roles to promote teen independence.
- Specific interventions such as cognitive behavioral therapy for insomnia or pain management intervention for youth with chronic pain may be implicated.
- Collaboration with schools and other health care providers is essential in the treatment of youth with chronic health conditions.

Declarations

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