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8.28 Child Health and Illness

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8.28.1 Introduction

Improving the health of children is a worldwide priority, with concerted efforts resulting in reductions in mortality in children five years and younger (The Global Burden of Disease Child and Adolescent Health Collaboration et al., 2017). The global trends for both mortality and nonfatal health outcomes among children and adolescents from 1990 to 2015 were explored in 195 countries and territories (The Global Burden of Disease Child and Adolescent Health Collaboration et al., 2017). Results demonstrated that child and adolescent mortality decreased globally by 50%, with 14.18 million deaths in 1990 and 7.26 million deaths in 2015. However, reductions have not been evenly distributed. A larger proportion of mortality burden was observed in countries with a lower socio-demographic index score (SDI; i.e., identifies where countries or other geographic areas sit on the spectrum of development). Specifically, the majority of child and adolescent deaths in 2015 occurred in South Asia and sub-Saharan Africa. With respect to nonfatal outcomes, disability was found to be associated with long-term consequences of congenital conditions and complications of infections and malnutrition. Further, a key cause of disease burden in adolescent females in low SDI countries was maternal and reproductive health. Mortality was the primary contributor to health loss for children and adolescents in low SDI locations, yet disability was the primary contributor in higher-SDI locations.

It is evident that there has been substantial worldwide progress toward reducing mortality rates in younger children, however Patton et al. (2016) draw attention to the limited focus on understanding and reducing the mortality burden among older children and adolescents. Patton et al. (2016) explain that the health profiles of adolescents differ, typically as a function of a country’s “epidemiological transition” (p. 2) whereby mortality and fertility reductions alter structures within a population and disease patterns. Government priorities as it applies to adolescents may be directed by the predominant types of health problems. For example, Patton and colleagues explain that for countries who are characterized by multiple burdens [e.g., including diseases of poverty (HIV and other infectious diseases, undernutrition, and poor sexual and reproductive health), injury and violence, and non-communicable diseases], the priority would be on addressing diseases of poverty, while implementing methods to curb increases in...
the other risk areas. Whereas countries that are characterized by high unintentional injury or violence coupled with high adolescent birth rates, efforts need to be doubled to reduce injury, violence, and adolescent births as well curb increases in the other risk areas such as mental health disorders and noncommunicable diseases.

A great deal of work is required to facilitate equitable, global improvements in child and adolescent health. In order to fully understand and address the general health and wellness of children and adolescents, consideration of chronic health conditions is required as these conditions have widespread impact children and adolescents, and society as a whole.

8.28.1.1 Chronic Health Conditions

Approximately 27% of children and adolescents in the United States have a chronic health condition, with prevalence rates increasing over the last two decades (Van Cleave et al., 2010). Chronic health conditions can be defined as “any physical, emotional, or mental condition that prevented a person from attending school regularly, doing regular school work, or doing usual childhood activities or that required frequent attention or treatment from a doctor or other health professional, regular use of any medication, or use of special equipment” (Mokkink et al., 2008, p. 1441). The prevalence of chronic health conditions is now greater than acute illnesses in some developed countries (Halfon and Newacheck, 2010). The most common types of pediatric chronic health conditions are asthma and obesity, with rates increasing over time (Perrin et al., 2007). Less common chronic conditions include chronic pain, cystic fibrosis (CF), and congenital heart disease (CHD). While the latter conditions may be less common, these conditions are associated with significant health care utilization, costs, and functional impact and therefore deserves a more detailed examination.

In the next sections, pediatric chronic pain, CF, and CHD will be discussed. In particular, prevalence rates, health care utilization, costs, functional impact, and intervention will be explored. Specific attention will be to paid to unique features of the particular chronic health condition. The chapter will wrap up with a discussion of future directions and clinical implications.

8.28.2 Pediatric Chronic Pain

Chronic pain is a leading cause of disability and morbidity across the lifespan (Rice et al., 2016). However, it was not until 2018 that chronic pain was recognized as its own disease through the creation of diagnostic codes for chronic pain in the International Classification of Diseases, 11th revision (ICD-11; World Health Organization, 2019). According to the ICD-11, chronic pain is defined as pain that persists or recurs for longer than three months. It is further classified as primary (i.e., diagnosed independent of identified biological or psychological contributing factors) or secondary to an established, underlying etiology (e.g., disease, injury or lesion) or their treatment (e.g., surgery, chemotherapy, radiotherapy).

As recent as 40 years ago, children were thought to be less sensitive to pain, and provided minimal analgesic management (McGrath, 2011). McGrath (2011) notes that today’s understanding and approach to pediatric pain was “born out of a marriage of science and public concern” (p. 2457). An internationally informed Commission of experts in pediatric pain recently completed a comprehensive review of the current state of knowledge in pediatric pain with the goal of directing transformative action in this area (Eccleston et al., 2021). Eccleston et al. (2021) suggest that while there has been growth in the area of pediatric pain in terms of amassed data and changes in practices over the last 40 years, pain “remains poorly understood in infants, children, and adolescents, and has made few leaps since Jill Lawson’ advocacy in 1986 led to use of anesthesia in infants” (pp. 48). As such, in an effort to improve the lives of children and adolescents with pain and their families, the Commission outlined four transformative goals (and clinical and research related priorities): (1) make pain matter, (2) make pain understood, (3) make pain visible, and (4) make pain better. It is anticipated that these goals and priorities will make significant contributions to both research and practice over the next 10 years. However, Eccleston and colleagues highlight that in order to achieve timely advancement of these goals, a coordinated approach between researchers, clinicians, policy makers, funders, and those with lived-experience (i.e., patients and parents) must be embraced.

Embedded within the latter is the importance of engagement of and partnership with those with lived experience with pediatric pain, as this collaboration provides an opportunity to reduce the division between empirical research findings and patient priorities (Banner et al., 2019). The pivot to utilizing a patient-oriented lens for pediatric pain research (and health research in general) sets the stage for innovation and translation of evidence into health care policy in the years to come. In the next sections, we will explore what we know about the prevalence, functional impact, and intervention directions for pediatric chronic pain.

8.28.2.1 Prevalence, and Health Care Utilization and Costs

Significant variability in estimates for pediatric chronic pain exist, due in part to the adoption of various definitions for chronic pain (King et al., 2011). Overall, available estimates extend up to 30% (King et al., 2011), with severe chronic pain with high impairment occurring in approximately 3%–5% of children (Huguet and Miró, 2008). The estimates for the specific types of pediatric chronic pain is even more disparate. King et al. (2011) findings demonstrated prevalence rates ranging from 8% to 82.9% for headache, 3.8% to 53.4% for abdominal pain, 13.5% to 24% for back pain, 3.9% to 40% for musculoskeletal/limb pain, 3.6% to 48.8% for multiple pains, and 5% to 88% for other/general pain. Epidemiologic national data is suggested as a better estimate of the population prevalence of pediatric chronic pain. Tumin et al. (2018) employed the 2016 National Survey of Children’s Health (NSCH) to explore the prevalence of chronic pain in 43,712 children ages 0–17 years in the United States. Results estimated the US
population prevalence of pediatric chronic pain to be 6%, with higher prevalence among older children, children from low-income families, children using public insurance, and children whose parents did not complete higher education.

Pediatric chronic pain contributes to high rates of health care utilization. Those with pediatric chronic pain access a variety of health care services including primary care physicians, radiological examinations, and visits to the emergency department (Ho et al., 2008). The estimated annual burden in the United States is $19 billion in health care costs and loss of productivity for caregivers of children and adolescents with moderate to severe chronic pain (Groenewald et al., 2014). Incremental health care costs for adolescent chronic pain in Canada was explored and results demonstrated mean annual total costs per adolescent with chronic pain to be $1663 versus $706 in a matched healthy control group (Hogan et al., 2016). The annual incremental cost to manage chronic pain for the matched group was $956 per person, with the largest contributors to the incremental cost being physician care and hospitalizations. Overall, the estimated total annual burden for adolescents with chronic pain in Canada was $144 million. Sleed et al. (2005) estimated the mean annual cost per adolescent with chronic pain for the United Kingdom’s National Health System at approximately $16,400 (value in 2012) in a small cohort of youths with both inflammatory-type (arthritis) and noninflammatory-type chronic pain. It is evident that there is a significant economic burden associated with pediatric chronic pain; albeit the adverse consequences equally impactful.

8.28.2.2 Functional Impact
Pediatric chronic pain is associated with a myriad of negative outcomes. Negative sequelae include disability, impairments in sleep, and social functioning (Liossi and Howard, 2016). Chronic pain and accompanying disability are also observed in terms of missed school days, in fact recent data demonstrated that chronic pain was associated with 22 million days of missed school (Groenewald et al., 2019). Not surprisingly, pediatric chronic pain is also associated with impairments in academic achievement (Groenewald et al., 2020).

8.28.2.2.1 Impact on Family
Families with children and adolescents with chronic pain have demonstrated poorer family functioning, with pain-related disability more consistently associated with family functioning than pain intensity (Lewandowski et al., 2010). With respect to healthy siblings, research has demonstrated that siblings of children with chronic pain are at increased risk of experiencing pain themselves, as compared to peers (Guite et al., 2007).

8.28.2.2.2 Role of Parents
Researchers have paid particular attention to the role parents play in the pediatric chronic pain experience. A number of parental factors individually have demonstrated associations with child pain and functioning, including parental responses to child pain (e.g., increasing attention to pain symptoms, excusing child from responsibilities), psychological functioning (e.g., depression, anxiety), cognitions (e.g., catastrophizing about child pain), and chronic pain history (Poppert Cordts et al., 2019). The interrelationship between many of these factors has been explored by a number of researchers; however, the aforementioned studies have not considered the complex interplay of these factors in a holistic manner.

Poppert Cordts et al. (2019) proposed and tested a multifactorial model of parent factors in pediatric chronic pain which included chronic pain features (i.e., chronic pain status, number of pain locations, pain frequency, pain intensity), physical function as proxy for parental modeling (i.e., pain interference, physical function), psychological factors (i.e., anxiety, depressive symptoms, catastrophizing about child’s pain), and behavioral responses to child pain (i.e., protectiveness, monitoring). Model was tested in 146 children with chronic pain, and one of their parents from a multidisciplinary pain assessment clinic within an outpatient pediatric pain program at a tertiary-level children’s hospital. The initial model was supported with the exception of the parent behavioral responses to pain, suggesting that parental responses (i.e., protectiveness and monitoring) were unrelated to child pain. Results demonstrated that other parental factors (i.e., parents emotional distress and physical health and functioning) require attention within comprehensive pediatric chronic pain assessment and, in extension, incorporated within family-centered interventions.

8.28.2.2.3 Mental Health
In addition to high health care utilization and functional impairment, pediatric chronic pain is often comorbid with mental health disorders (Soltani et al., 2019). In particular, rates of pediatric chronic pain and depressive comorbidity exceeds rates in typically functioning youth (Tegethoff et al., 2015). Pediatric populations with chronic pain are also at increased risk for anxiety (Anderson Khan et al., 2015). Youth with chronic abdominal pain have been found to be at greater risk of psychiatric disorders as compared to youth without chronic pain (Fearon and Hotopf, 2001). It is postulated that a complex interplay of youth neurobiology (i.e., genes, hormones, brain networks, inflammation) and parental variables (e.g., chronic pain status, mental health) influence the co-occurrence of chronic pain and mental health conditions in youth (Vinall et al., 2016). Vinall et al. (2016) suggest that future research endeavors in this area should be developmentally sensitive with a focus on the integration of biological, behavioral, and social perspectives. Given the widespread prevalence, significant impact on health care utilization, and deleterious effects on individual and family functioning, it is prudent to have appropriate, evidence-based, accessible interventions for those with pediatric chronic pain and their families.
8.28.2.3 Intervention

8.28.2.3.1 Pharmacological Approaches
Management of pediatric chronic pain typically involves multidisciplinary and biopsychosocial approaches (World Health Organization, 2020b). The initial approach to pain management is often pharmacological, including (but not exclusively) opioids, paracetamol, antidepressants, anti-epileptic drugs, and NSAIDs (Eccleston et al., 2019). However, there has been limited expansion in the exploration of the efficacy and harm of pharmacological interventions in those with pediatric chronic pain since 2003 (Eccleston et al., 2019). In fact, in Eccleston and colleagues recently completed a comprehensive systematic review of the pharmacological interventions for pediatric pain and they found only six trials involving the pharmacological intervention in those with pediatric chronic pain, all of which were identified as low quality. Battell and Hathway (2019) stress that the latter review not only highlights the lack of systematic, controlled examination of the pharmacological interventions for pediatric chronic pain, but also speaks to the common use of off-label prescribing by means of extrapolating evidence established in adults to children. The latter persists despite warnings of the dangers of using such evidence to guide prescribing practices as it applies to pediatric populations (Schechter and Walco, 2016).

8.28.2.3.2 Nonpharmacological Approaches
Nonpharmacological approaches include exercise, acupuncture, manipulation, and psychological interventions [i.e., cognitive behavioral therapy (CBT), mindfulness; Skelly et al., 2018]. Psychological interventions that have been explored to address pediatric chronic pain primarily employ CBT and behavioral approaches (Fisher et al., 2018). In general, the objectives of psychological interventions for pediatric populations include prevention of periodic pain, management of severe or inescapable pain, and mitigation of the negative consequences of pain (Eccleston et al., 2021). Recently, Fisher et al. (2018) explored the efficacy of face-to-face psychological treatments (including telephone and at home via a written instruction booklet) for the clinical outcomes of pain intensity and disability in children with pediatric chronic and recurrent pain in 47 studies. Secondary outcomes included children’s depressive and anxiety symptoms, and adverse events. Results demonstrated that psychological therapies reduced pain frequency immediately following treatment for children and adolescents with chronic headache and reduced pain intensity for children and adolescents with mixed chronic pain conditions. Disability was also reduced in children and adolescents with mixed chronic pain conditions immediately following treatment and up to 12 months later, and for children with headache conditions up to 12 months later. However, authors noted that all outcomes were viewed as low or very low-quality. Results point to the need of well-designed, methodologically robust studies going forward to appropriately understand the efficacy of face-to-face psychological interventions to address pediatric chronic pain.

While the aforementioned evidence does suggest that traditional face-to-face psychological interventions reduce pain intensity and improve physical functioning in children and adolescents with chronic pain, traditional face-to-face approaches are time and resource intensive and may be geographically limiting for clients (Palermo and Jamison, 2015). In turn, evidence demonstrates lengthy wait times for chronic pain clinic appointments, with waits extending up to 197.5 days (Palermo et al., 2019). As such, remote or ehealth (i.e., those delivered digitally via computers, smart phones, tablets) programming may be preferable for some. The use of technology as a health care service delivery platform has expanded at an exponential rate in response to the COVID-19 pandemic (Fritz et al., 2021), however ehealth as a platform for psychological interventions for pediatric populations in general, and more specifically for pediatric chronic pain, is not new (Fisher et al., 2019). Thabrew et al. (2018) reviewed the effectiveness of ehealth interventions for anxiety, depression, and quality of life in children and adolescents with chronic health conditions [i.e., chronic headache (migraine, tension headache, and others), chronic pain conditions (abdominal, musculoskeletal, and others), chronic respiratory illness (asthma, cystic fibrosis, and others)]. Five trials of three interventions [i.e., Breathe Easier Online, Web-based Management of Adolescent Pain (Web-MAP), and multimodal CBT] were included. Thabrew and colleagues indicated that their findings did not clearly demonstrate that current ehealth interventions significantly reduced anxiety or depressive symptoms more than comparison groups (i.e., attention placebos, psychological placebos, treatment as usual, wait-list controls, or non-psychological treatments). Further, researchers noted that the evidence was of very low quality.

With respect to pediatric chronic pain specifically, Fisher et al. (2019) explored the efficacy of ehealth psychological interventions compared to waitlist, treatment as usual, or active control treatments, for primary (i.e., pain severity/intensity, disability, depression, anxiety, and adverse events) and secondary (i.e., satisfaction) clinical outcomes in the management of chronic pain in children and adolescents. The review was comprised of 10 studies and included the following programs: Internet CBT, Headstrong, Help Yourself Online, Web-MAP, Web-based Management of Adolescent Pain-2 (Web-MAP2), CBT Coping Skills Training, Teens Taking Charge: Managing Arthritis, and Internet-based Self-Help Training. Results demonstrated that these programs did not reduce pain intensity/severity, or other symptoms associated with chronic pain. Albeit, preliminary evidence suggested that these program may reduce pain severity immediately following treatment for those with headache, but these reductions were not maintained at three months. Positive participant satisfaction was observed. However, as whole, researchers indicated that the overall quality of the evidence was very low.

While the above findings are not overly encouraging; they should not be viewed as definitive as to the utility of ehealth interventions for pediatric chronic pain given the small pool of existing studies. eHealth interventions provide opportunities for individuals who may want to access services but live in a geographically isolated area (i.e., rural area) and for those who may be reluctant to access traditional face-to-face care (e.g., adolescents). eHealth interventions may also provide interim care for those who have a significant wait for specialized services (Fisher et al., 2019). Fritz et al. (2021) outlined additional considerations, that are not
Child development in the context of living with CF can result in unique psychosocial challenges (Jamieson et al., 2014; Prieur et al., 2020). Moreover, the infection prevention and control guidelines that necessarily specify the importance of social distancing, which can contribute to social challenges such as having difficulty relating to peers (Jamieson et al., 2014). Children with CF may feel self-conscious about their health status and fear bullying or rejection from peers based on their illness (Jamieson et al., 2014; Prieur et al., 2020). Moreover, the infection prevention and control guidelines that prevent face-to-face contact between individuals with CF limits the ability for children with CF to obtain disease-related social support from other children with CF (Saiman et al., 2013).

8.28.3 Cystic Fibrosis

Cystic fibrosis (CF) is a rare and progressive autosomal recessive condition that occurs when a person inherits one abnormal gene from each parent (Antoniou and Elston, 2016). CF results from a genetic mutation in the cystic fibrosis transmembrane conductance regulator (CFTR) protein (Antoniou and Elston, 2016). More than 2000 CFTR mutations have been identified and produce varying degrees of CF presentations and severities (Cystic Fibrosis Canada, 2018). The result of a CFTR mutation is a complex disease that impacts multiple body systems, with its greatest effects on the lungs and digestive system, creating a thick mucus, persistent cough, and recurrent lung issues (Antoniou and Elston, 2016). While the type and severity of symptoms of CF differ from person-to-person, symptoms may include shortness of breath, wheezing, persistent cough, frequent chest infections, bowel problems, weight loss or failure to gain weight, pancreatic insufficiency, and decreased fertility in women and infertility in men (Antoniou and Elston, 2016).

At present, there is no cure for CF. Due to medical advances, the life expectancy of people living with CF has increased and the large majority survive into adulthood (Stephenson et al., 2017). Americans living with CF are living to a median age of 46 years, while Canadians living with CF are living to a median age of 52.3 years (Stephenson et al., 2017). Treating CF involves the coordination of multidisciplinary care and daily treatment regimens for CF are complex and time-consuming (Antoniou and Elston, 2016). As the experience of CF is variable, individualized and age-specific treatment programs are required. The basis of treatment management for CF involves treatments that help clear mucus from the lungs and treat consequence lung infections, optimization of nutritional status, and management of CF-related complications (Antoniou and Elston, 2016). Preventative approaches have also been suggested to manage CF including restrictions of person-to-person contact among people with CF to reduce cross-infection (Saiman et al., 2013). In the next sections, we will explore what we know about the prevalence, functional impact, and intervention directions for CF.

8.28.3.1 Prevalence, and Health Care Utilization and Costs

The prevalence estimates for CF range from 70,000 to 100,000 patients worldwide (Sawicki and Tiddens, 2012). Of those, approximately half are children under the age of 18. In many countries most CF diagnoses are made in infancy via newborn screening (NBS; Gonska and Ratjen, 2015) NBS facilitates early diagnosis of and initiation of interventions for CF prior to significant morbidity and malnutrition occurring (Southern et al., 2009).

Although CF is relatively rare, there is significant health care utilization and cost burden required to manage CF (Perkins et al., 2021). Average annual CF care costs across literature and nationality range from $8148 to $131,000 (Perkins et al., 2021). Health care costs appear to be increasing as a retrospective evaluation of a claims database for a cohort of the United States privately insured patients from 2010 to 2016 found the mean annual expenditures related to CF care nearly doubled from $67,000 in 2010 to $131,000 annually (Grosse et al., 2018). Similar cost increases have been observed across the industrial nations (i.e., England, Australia, Canada, Germany, France, and The Netherlands; Perkins et al., 2021). Most recently Perkins et al. (2021) sought to explore health care utilization patterns and costs at a large pediatric-adult CF center in the era where patients may be prescribed CFTR modulators [i.e., medications designed to address underlying CFTR dysfunction including Kalydeco® (ivacaftor), Orkambi® (lumacaftor/ivacaftor), Symdeko® (tezacaftor/ivacaftor), Trikafta® (elecaftor/tezacaftor/ivacaftor). Results demonstrated that 38% of patients utilized the emergency department, required hospitalization, or both. Further, mean clinical charges were $28,755. When controlling for age and modulator indication in the 18 and older subgroup, the total charges in patients using Kalydeco remains lower than other modulator types or patients not using a modulator.

8.28.3.2 Functional Impact

Child development in the context of living with CF can result in unique psychosocial challenges (Jamieson et al., 2014; Prieur et al., 2020). Socially, children with CF may experience feelings of isolation from peers and difficulty establishing friendships as a result of frequent absences from school due to hospitalizations and illness (Jamieson et al., 2014). Lifestyle restrictions such as avoiding activities that may increase risk of infection may also contribute to social challenges such as having difficulty relating to peers (Jamieson et al., 2014). Children with CF may feel self-conscious about their health status and fear bullying or rejection from peers based on their illness (Jamieson et al., 2014; Prieur et al., 2020). Moreover, the infection prevention and control guidelines that prevent face-to-face contact between individuals with CF limits the ability for children with CF to obtain disease-related social support from other children with CF (Saiman et al., 2013).
Other functional impacts include difficulties in academic achievement and independence at school (Grieve et al., 2011). Parent caregivers may decide to delay or avoid enrollment in daycare, preschool, and school settings due to concerns about infection risk for their children. In turn, children with CF experience increased school absences due to illness, hospitalizations, or clinic appointments. Grieve et al. (2011) found that adolescents with CF missed an average of 23.6 days of a 180-day school year. Thus, children with CF may have decreased exposure to academic teaching and socializing with peers affecting their social-emotional development (Prieur et al., 2020). Psychosocial difficulties in children with CF have been reported to contribute to lower quality of life and reduction in treatment adherence and as a result have an impact on health outcomes (Prieur et al., 2020).

8.28.3.2.1 Impact on Family
Psychosocial challenges for family members of children with CF have also been documented. CF is a challenging pediatric illness to manage and the burden of managing treatments may impact family well-being and functioning (Gillespie et al., 2020). Along with navigating the routine roles of parenting, parent caregivers of children with CF carry a heavy treatment burden in helping their child manage their disease (Gillespie et al., 2020). Parent caregivers may experience feelings of fatigue and guilt associated with spending more time engaging in medical activities and less time in recreation and play with family members (Prieur et al., 2020).

Siblings of children with CF also experience various psychosocial challenges. Siblings of children with CF may have to cope with their parents giving preferential attention to children with CF as a result of their complex medical needs (Milo et al., 2021). Moreover, siblings may participate in fewer extracurricular activities than their peers as a result of medical appointments and time-consuming treatment regimens. Siblings of children with CF are at high risk of internalizing (e.g., anxiety, low mood) and externalizing (e.g., behavioral difficulties, anger) symptoms (O’Haver et al., 2010). Despite these challenges, some studies have demonstrated adaptive coping in siblings (Haver et al., 2011). Quality of life in siblings of children with CF may vary on several factors such as sibling age, illness severity of the child with CF, level of parental stress, socioeconomic status, and amount of social support (O’Haver et al., 2010).

8.28.3.2.2 Mental Health
Beyond high health care utilization and functional impairment, individuals living with CF and their parent caregivers have been demonstrated to experience elevated psychopathology (e.g., depression, anxiety). The International Depression Epidemiological Study (TIDES) assessed the prevalence of depression and anxiety in 6088 adolescents and adults with CF and 4102 parent caregivers across nine countries (Quittner et al., 2014). The results showed elevations in depressive symptoms in 10% of the adolescents with CF, 19% of the adults with CF, 37% of their mothers, and 31% of their fathers. Elevated anxiety symptoms were reported in 22% of adolescents with CF, 32% of adults with CF, 48% of their mothers, and 36% of their fathers. The elevations in depression and anxiety symptoms found in this study were two to three times higher when compared with community samples. The findings of TIDES have been bolstered by other studies and the psychological challenges among adolescents and young adults living with CF have been well-established (Prieur et al., 2020).

More recently, researchers have begun to investigate the psychological challenges of younger children with CF (i.e., below age 12 years) and there is evidence to suggest that mental health symptoms may be presenting in early childhood (e.g., Gundogdu et al., 2019). Psychological disorders that have been found to be prominent in younger children with CF include depression, social anxiety disorder, separation anxiety disorder, specific phobia, and attention-deficit/hyperactivity disorder (Georgiopoulou et al., 2021). In particular, diagnoses of specific phobia in children with CF have been largely related to fears of medical procedures and by definition result in significant functional impairment (Gundogdu et al., 2019). Other psychological constructs that may be prominent in children with CF, but have yet to be explored, include health anxiety, anxiety sensitivity, and intolerance of uncertainty. As children with other chronic health conditions (e.g., congenital heart disease) demonstrate elevated levels of these psychological constructs when compared to healthy peers, it is possible that children with CF may share a similar experience of these symptoms (Oliver et al., 2018).

Psychological symptoms among children and adolescents with CF and their parent caregivers have a deleterious impact on health outcomes including worse adherence, decreased lung function, more frequent hospitalizations and health care outcomes (Quittner et al., 2014). Additionally, experiencing anxiety and depressive symptoms has been associated with reduced quality of life in children and adolescents with CF (Tomaszek et al., 2019). Given the functional impact of increased psychopathology in this population, addressing the mental health symptoms potentially faced by children and adolescents with CF is critical.

8.28.3.3 Intervention
Over the past ten years, significant advances have been made in systematically promoting the mental health of people with CF and their families (Quittner et al., 2016). International recommendations for CF clinics include incorporating an annual mental health screening for patients, as well as offering education, preventative and supportive interventions to develop effective coping and disease-management skills during all routine care for people with CF and their families (Quittner et al., 2016). Thus far, studies that have assessed the feasibility and effectiveness of implementing an annual mental health screening for CF patients at pediatric and adult CF clinics have demonstrated success in identifying child, sibling, parent, and family risk and protective factors that may need to be addressed by the CF clinic team (e.g., Prieur et al., 2020).

In terms of mental health programs, several modalities of psychotherapeutic interventions have been studied for children with CF including supportive, cognitive behavioral, family systems, and psychodynamic approaches (Goldbeck et al., 2014). Due to the
heterogeneity of studies, more research with each type of intervention is needed to support the preliminary evidence (Goldbeck et al., 2014). In the cases of other chronic illnesses, support groups and group psychological interventions are the traditional method of treatment (e.g., Tomczak et al., 2019). For children and adolescents with CF, infection prevention and control guidelines prevent participation in face-to-face disease-related support groups (Saiman et al., 2013). In Canada, researchers are addressing this barrier by developing an Internet-delivered mental health prevention program for use in the pediatric CF population. The Internet-delivered Mental Health Cystic Fibrosis Prevention, Wellness, and Resource (iCF-PWR) program is in the final stages of creation with the goal to provide a consistent and comprehensive approach to mental health prevention for children and adolescents with CF and their siblings (Wright et al., 2020). Based on the CBT model, the iCF-PWR is comprised of (1) illness education, (2) treatment education, (3) education about the impact of CF, (4) CBT psychoeducation, and (5) coping skill training. It is anticipated that the integration of this program into existing CF clinic care models will work to prevent the development of psychological symptoms and improve the quality of life of this population.

### 8.28.4 Congenital Heart Disease (CHD)

Congenital heart disease (CHD), also known as a congenital heart defects, refers to a diverse group of diseases characterized by defects or structural abnormalities of the heart and intrathoracic great vessels (e.g., aorta, pulmonary artery) that are present at birth (Karsdorp et al., 2007). The severity of CHD is typically classified as “simple” or “complex” where these terms refer to the severity of lesions present in each case (Warnes et al., 2001). Further diagnostic distinction is made between cyanotic CHD (i.e., in which the individual has a bluish tint to the skin due to low oxygen saturation) and non-cyanotic CHD (i.e., the individual maintains normal oxygen saturation and normal skin coloring; Cassidy et al., 2018). Due to the different types of heart defects and their severity, symptoms can vary depending on the individual. Symptoms may include shortness of breath, poor feeding, rapid heartbeat, cyanosis, and fatigue during exercise in older children (Sun et al., 2015). Mild forms of CHD may present with no obvious symptoms. In the next sections, we will explore what we know about the prevalence, functional impact, and intervention directions for CHD.

#### 8.28.4.1 Prevalence, Health Care Utilization and Costs

CHD is the most common congenital anomaly affecting 1.35 million newborns worldwide every year (van der Linde et al., 2011). Several genetic and prenatal environmental risk factors have been identified for the disease including family history of CHD, chromosomal abnormalities (e.g., trisomy 21 which causes Down Syndrome), pregestational diabetes, maternal smoking during pregnancy, and use of certain medications (Fung et al., 2013). Recent advances in medicine have significantly increased the survival rates for the disease, with the majority of children with CHD surviving into adulthood (van der Linde et al., 2011). Due to the improved survival rates, the prevalence of CHD has increased by 11% in children and 57% in adults from 2000 to 2010 (Marelli et al., 2014).

Health care costs associated with caring for a child with CHD are significant, in particular for those with severe presentations. For example, in the United States out-of-pocket costs during the first twelve months of an infant’s life with can cost up to $11,000 (Elhoff et al., 2016). If a child is admitted to the emergency room, a multi-day stay can cost a total of up to $59,975 (Chan et al., 2018). In a longitudinal retrospective cohort study of infants with severe CHD presentations, the average inpatient costs was ~$137,000 over the first 10 years of life (Pinto et al., 2018).

As survival rates improve, research efforts have been directed toward understanding the growing health concerns of this population including long-term health trajectory and overall quality of life. Studies have demonstrated that children with more complex forms of the disease have a lower health-related quality of life than the general population, comparable to populations of other chronic health conditions (Mellion et al., 2014). Most children with CHD require lifelong monitoring and palliative or corrective surgery, with some cases requiring a heart transplantation (Warnes et al., 2001). In addition, children and adolescents with CHD are less physically active and have higher rates of obesity compared to healthy peers (Ray et al., 2011). Although physiological functioning and disease severity have been attributed to this association, contributing factors may include worries regarding the negative impact of exercise on physical health, parental overprotection, and uncertainty about how to monitor for overexertion and symptom exacerbation (Chong et al., 2018). Individuals with CHD may therefore represent a growing clinical population with significant health care exposure early in life which may precipitate disruptions in psychological and psychosocial functioning.

#### 8.28.4.2 Functional Impact

Current empirical evidence suggests that compared to healthy peers, 20% of children and adolescents with CHD face challenges that significantly impact their psychosocial functioning (Uzark et al., 2008). Changes in physical appearance and lifestyle restrictions may act as unavoidable reminders of the illness and imbue a sense of abnormality compared to healthy peers (Chong et al., 2018). Body image issues can occur in children and adolescents with CHD in situations when physical indications of the disease or surgical scars become visible. For example, undergoing cardiac surgery may leave a substantial surgical scar in the middle of the chest and possibly a chest wall deformity. Research has shown that adolescents and adults with CHD report having difficulties with distorted body image, negative self-esteem, and symptoms of depression (Masi and Brovedani, 1999). Females with CHD attempt
to conceal the physical indications of their disease with makeup and clothing (Chong et al., 2018). Children and adolescents with CHD may experience elevations in social anxiety and social avoidance in situations when surgical scares become visible to peers (e.g., changing into gym clothing, swimming; Oliver et al., 2018).

Challenges associated with the development of peer relationships also impact the psychosocial adjustment of children and adolescents with CHD. Due to their medical condition, children and adolescents with CHD experience higher rates of school absences that prevent social engagement with siblings and peers and lead to feelings of social awkwardness and isolation (Horner et al., 2000). In addition, parents may view their child as “vulnerable” to symptom exacerbation and engage in protective behaviors that limit extracurricular activities and social interaction with peers (Ong et al., 2011). This reduction in social opportunities for children and adolescents with CHD may hinder the development of age-appropriate social skills, independence, and self-efficacy with peers (Masi and Brovedani, 1999). In particular, children and adolescents with CHD that are highly engaged in organized sports report losing a sense of personal identity and social network when advised against participating in rigorous physical activity (Chong et al., 2018). Older adolescents also have more difficulty accepting the diagnosis when they perceive themselves as physically healthy and have reported concerns regarding the impact of CHD on potential career and family opportunities (Chong et al., 2018). These psychosocial challenges may partially account for the findings that children and adolescents with CHD report higher levels of separation anxiety, physical injury fears, and social anxiety (Oliver et al., 2018).

8.28.4.2.1 Family Impact
A growing body of literature has shown that living with CHD is a burden for children and adolescents with CHD as well as their healthy family members (McClung et al., 2018). Research has demonstrated that CHD has an impact on caregiver and family quality of life including overall psychological distress and poorer mental health (Dennis et al., 2019). Families may encounter anxiety and uncertainty about their child’s health condition, relationship stress, and strain on healthy siblings (Connor et al., 2010). As CHD severity varies, so do the lived experiences of children with CHD and their family members (Rempel et al., 2012). The risk of psychological distress experienced by those caring for a child with CHD increases during critical periods of care such as diagnosis and surgery (McClung et al., 2018). Caregivers may also encounter financial difficulties related to having a child with CHD including substantial costs of medical expenses, increased caregiver time, and income reduction and strain (McClung et al., 2018). Children with CHD have been shown to feel guilty about the emotional and financial burden their disease places on the family and hide their feelings to protect family members from additional stress (Moola et al., 2008). Research suggests that caregivers might be overprotective and restrict opportunities to develop employment and independence skills, leading to dependence on parents and lack of personal responsibility over their health (Kovacs et al., 2005). Associations between caregiver and child anxiety in families of those with CHD further suggests that parents may perceive physical anxiety symptoms as dangerous cardiac signs and model maladaptive internalizing behaviors to their children with CHD (Drake and Kearney, 2008).

8.28.4.2.2 Mental Health
In addition to high health care utilization and functional impairment, research has shown that children and adolescents with CHD experience psychological challenges. Children and adolescents with CHD have been shown to be at an increased risk for developing mental health conditions (Uzark et al., 2008; Warnes et al., 2001); albeit findings are limited and not entirely consistent. For example, Oliver et al. (2018) demonstrated that compared to healthy peers, children and adolescents with CHD experienced higher levels of health anxiety and associated constructs (i.e., intolerance of uncertainty, anxiety sensitivity, anxiety-related symptoms). Many children and adolescents with CHD who require a cardiac transplant display internalizing behavior problems post-surgery (Wray and Radley-Smith, 2006). In fact, behavioral and quality of life challenges may persist for years after the heart defect has been repaired and physiological symptoms have improved (Knight, 2016). Whereas, other studies have reported mixed findings as to whether adolescents with CHD are at greater risk of developing internalizing disorders (e.g., anxiety and social withdrawal) or externalizing disorders (e.g., aggression and hyperactivity) compared to healthy children (e.g., Karsdorp et al., 2007).

8.28.4.2.3 Neurodevelopmental Deficits and CHD
The neurodevelopmental functioning of children with CHD is of particular interest to clinicians and researchers alike. Research studies have demonstrated that children with heart defects have a higher rate of neurodevelopmental problems than healthy peers their age. Children with CHD are shown to have particular impairments in the areas of motor function, working memory, attention, and language skills (Hövels-Gürich et al., 2006). Included within this categorization is an increased risk of learning disabilities and attention deficit-hyperactivity disorder. For instance, high-risk scores for inattention and hyperactivity in children with CHD have been shown to be three to four times higher than the general population (Shillingford et al., 2008). Altered blood flow and impaired oxygen delivery (hypoxia) may be experienced in utero, prior to surgical repair of the anomaly, and even post-surgery in certain children, impacting brain growth and development (Kaltman et al., 2005). A greater frequency of neurodevelopmental problems is consistent with reports that children with CHD have significantly lower academic functioning. Despite these concerns, Uzark et al. (2008) reported that only 1 in 3 children with CHD and low academic functioning were receiving special educational services. Researchers have indicated that academic problems and lack of educational supports are associated with poor psychosocial functioning and fewer social relations with peers (Dunbar-Masterson et al., 2001).
8.28.4.3 Interventions

To mitigate the challenges of CHD, it is recommended that caregivers and clinicians monitor children and adolescents with CHD for indications of distress and psychological difficulties (Knight, 2016). In 2012, the American Heart Association (AHA) published guidelines and recommendations for the evaluation of children with CHD to enhance identification of deficits and implementation of interventions for improved behavioral, academic, and psychosocial functioning (Marino et al., 2012). Given that elevated anxiety is associated with lower adherence to cardiac rehabilitation in those with CHD, it is essential for this population to receive mental health intervention (Harris et al., 2019). Research has demonstrated benefits for interventions involving patient education, physical activity promotion and advice regarding symptom monitoring. However, no comprehensive pediatric chronic disease management programs for CHD has existed to-date. The Children’s Healthy Heart Activity Monitoring Program in Saskatchewan (CHAMPS) is a chronic disease management intervention program for children and adolescents with CHD that was developed to address this intervention gap (Tomczak et al., 2019). The program promotes involvement in physical activities, disease knowledge, and psych-education aimed at enhancing well-being and health-related self-care. Preliminary evidence has suggested maintenance of psychological functioning of children and adolescents with CHD (Shivak et al., 2019). Further exploration of the effectiveness and efficacy of the CHAMPS program is required going forward. Overall, early detection of mental health concerns and subsequent application of tailored, evidence-based, comprehensive interventions such as CHAMPS may help to mitigate the impact of CHD on the mental health and quality of life of children and adolescents with CHD.

8.28.5 COVID-19

In December 2019, an outbreak of pneumonia with unknown origins emerged in Wuhan, Hubei Province, China (Xu, 2020). This outbreak increased global health concerns due to the ease of transmission (Chan et al., 2020). In fact, as early as February 8, 2020 there were already 34,800 confirmed cases and 724 deaths reported in China and 24 other countries (World Health Organization, 2020a). Initial research identified a novel coronavirus, named Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) as the cause of the coronavirus disease-19 (COVID-19). COVID-19 symptom presentation ranged from asymptomatic/mild to severe illness and death (Lovato et al., 2020). Symptoms included cough, fever, shortness of breath, weakness, malaise, respiratory distress, muscle pain, sore throat, loss of taste and/or smell. To date (June 15, 2021), worldwide reported cases exceed 175 million with 3,793,230 deaths (World Health Organization, 2021a). The vast majority of COVID-related deaths have been adults, with child deaths (0–17 years) in the United States, United Kingdom, Italy, Germany, Spain, France, and South Korea remaining fairly rare (as of February 2021) at 0.17 per 100,000 population (comprising 0.48% of the estimated total mortality from all causes in a typical year; Bhopal et al., 2021).

Research suggests that children and adolescents (including infants) have a low risk for infection (Gotzinger et al., 2020). A multicentre cohort study involving 82 health-care institutions across 25 European countries explored key data from 582 children and adolescents (18 years and under) with confirmed COVID-19 (Gotzinger et al., 2020). Results demonstrated that a small proportion developed severe symptoms requiring ICU admission (8%) and prolonged ventilation (4%). Four individuals (all older than 10 years) had a fatal outcome. Further, COVID-related sequelae in children and adolescents was rare (80% resolved without incident), whereas 4% remained symptomatic at study close. However, a COVID-19-associated multisystem inflammatory syndrome in children and adolescents (MIS-C) has since surfaced (Riphagen et al., 2020). MIS-C has been demonstrated to have a wide spectrum of signs and symptoms and disease severity, ranging from fever and inflammation to myocardial injury, shock, and development of coronary artery aneurysms (Jiang et al., 2020). Although the prevalence of MIS-C is unknown, >600 cases have been reported in the literature (Alsaied et al., 2021). Extant research suggests that most recovery within days to a couple of weeks and mortality is rare, although sequelae is not fully understood (Alsaied et al., 2021).

While the rate of infection and negative sequelae are rare in children, the consequences of the COVID-19 pandemic are far reaching. The pandemic represents global all-encompassing disruption. Both essential health care services and education systems were significantly altered (World Health Organization, 2021b). For example, the second round of the WHO Pulse survey (2021b) reported that 94% of countries experienced disruptions to essential health services, including 45% reporting disruptions across mental health services (including prevention and promotion services, diagnosis, treatment and life-saving emergency care). Further, school closures impacted over 91% of the student population globally (Lee, 2020). It is anticipated that the effects will be more evident for those who were more negatively affected by the pandemic, and for those who entered the pandemic in pre-existing vulnerable circumstances (Graves et al., 2021). We have yet to see the long-term mental health consequences of COVID-19 but research exploring the impact of previous pandemics demonstrated increased levels of stress, worry, helplessness, and social and risky behavioral problems among children and adolescents (e.g., substance abuse, suicide, relationship problems, academic issues, and absenteeism from work; Meherali et al., 2021).

8.28.6 Future Research Directions and Clinical Implications

Overall, it is encouraging that the general health and mortality rates for children and adolescents globally are improving; however this does not overshadow the inequities and widening gap between the health of children and adolescents in higher- and lower-SDI
countries. Looking forward, continued surveillance and education, international government attention, policy development and implementation, and advocacy for the health of children and adolescents, particularly for lower-SDI countries but also for other vulnerable and marginalized people in all walks of life, is crucial. More concentrated global focus and research on adolescent health and outcomes is also warranted, as this population has been neglected thus far in international government policy and practice.

Pediatric chronic health conditions have significant health care costs and disease burden, functional impact, and mental health implications—factors that are strongly interrelated. The mental health implications are far reaching for the individuals with chronic health conditions and their family members. Historically, much attention and financial support has been directed to the management of the physical symptoms of these conditions, and rightly so as some conditions are life-limiting (e.g., CF). The association between mental health and disease and symptom presentation has garnered more attention recently. The available literature highlights that it is critical for health care providers who provide care to children and adolescents with chronic physical conditions to become educated about, assess for, and provide intervention for and/or make appropriate referrals to mental health professionals for the mental health challenges experienced by their patients and family members. This evidence-based approach can be initiated by updating curriculum for training programs across allied health care professionals as to the mental health impacts of pediatric chronic illness on the patient as well as the family and education about appropriate, evidence-based intervention options and referral sources. The latter should be paired with ongoing continuing education opportunities for practicing health care professionals. In terms of appropriate referral sources, psychologists (in this case those who provide care to pediatric populations) represent those mental health specialists who have specialized, advanced assessment, diagnostic, and intervention training and skills sets to help support those with pediatric chronic illness. Early and expedient referral to a psychologist can be most helpful not only at the intervention stage for identified mental health concerns but also in a preventative manner.

Given the trend of providing evidence-based, accessible, cost-effective, interventions via ehealth platforms, attention needs to be paid to important variables (e.g., clinician guide and contact) while employing an iterative, user-centered or patient-oriented design approach (McCurdie et al., 2012) in the development of such programs. Not only is strategic, informed program design required, but thought needs to paid to the ability to upscale and integrate developed programs into existing health care systems. With respect to pediatric pain ehealth assessment and intervention applications, less than 30% of applications became accessible to the public, which was associated with an average of $300,000 of grant funds per application (Higgins et al., 2018). As such, issues such as scalability and sustainability should be at the forefront of application or program development. Using a patient oriented lens allows for the amalgamation of research objectives and patient priorities (Banner et al., 2019); with the goal of innovation and translation of evidence into practice and health care policy. Overall, well-designed, methodologically robust intervention development and efficacy studies are required in order to contribute meaningfully to the improved mental health, quality of life, and overall health of children and adolescents with chronic health conditions.

COVID-19 represents an unprecedented, global health crisis, one that has required expedient and innovative action. We have yet to understand the full impact of the pandemic (in so far as economic, health, or social impacts). Global research efforts related to COVID-19 has also been unprecedented (Cai et al., 2021). By the start of October 2020, 87,515 COVID-19 articles had been published, with the United States identified as the single largest contributor to global publication productivity. It will be essential to continue this research trajectory, not necessarily at the same pace, in order expand and deepen our understanding of how the pandemic has impacted our children and adolescents, in particular for those in vulnerable and comprised groups. Garnered information should be used to inform clinical practice and social reform to address the needs of people globally, children and adolescents in particular. Further, it will also be important to not lose sight of potential positive outcomes yielded (e.g., resilience, self-efficacy, coping and problem-solving) and explore those elements accordingly. Working to synthesize the collective knowledge base that we will have amassed during the pandemic and utilizing this knowledge to be prepared for a future life-altering situation is vital.

**8.28.7 Conclusions**

Great strides have been made in improving child and adolescent health and outcomes, albeit much work remains. In particular, inequities persist in the prevalence, disease progression and outcomes, health service access, and mortality rates. Global attention, research, and action toward addressing these inequities remains fundamental. Research, clinical application, and policy reform regarding pediatric chronic illness (not limited to those reviewed here) requires strategic study development and collaboration between researchers, clinicians, policy makers, funders, and those with lived-experience (i.e., patients and parents).

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