

## Chapter 4

# Promoting Resilience During the Transition to Adolescence in Chronically Ill Children and Their Families

Jaelyn M. Lennon, Alexandra M. Psihogios, Caitlin B. Murray,  
Christina E. Holbein, and Grayson N. Holmbeck

The number of children and adolescents diagnosed with a chronic illness has steadily increased over the past two decades (Van Cleave, Gortmaker, & Perrin, 2010). Prevalence rates of childhood chronic conditions vary based on region, and based on the diverse methods used to measure prevalence in epidemiologic studies (van der Lee et al., 2007). Still, current research suggests rates have been steadily increasing, with some studies suggesting that as many as 1 out of 4 children in the United States aged 14 years and younger suffer from a chronic health problem, defined as lasting at least 12 months (e.g., Van Cleave et al., 2010). This increase is primarily attributed to higher prevalence rates of certain chronic illnesses such as obesity (Ogden, Carroll, Curtin, Lamb, & Flegal, 2010; Van Cleave et al., 2010), diabetes (Dabelea et al., 2014), and asthma (Weiss, Sullivan, & Lyttle, 2006). In addition, advancements in medical care and treatments have led to increased survival rates for certain illness groups such as those with cancer (Ward, De Santis, Robbins, Kohler, & Jemal, 2014), cystic fibrosis (CFR, 2010), kidney transplants (Smith, Martz, & Blydt-Hansen, 2013), and spina bifida (Parker et al., 2010). Conditions once seen only in young children are now being seen into adolescence and beyond, with as many as 85% of children with congenital or chronic illnesses now surviving into adolescence (Halfon & Newacheck, 2010; Yeo & Sawyer, 2005).

As chronic illness rates in children and adolescents continue to increase, so does the associated burden. A chronic illness creates numerous challenges and stressors that can be unexpected, uncontrollable, and functionally impairing for families (Compas, Jaser, Dunn, & Rodriguez, 2012). Children and parents respond differently to chronic illness, as each family is confronted with unique challenges and possesses certain strengths. Responses to pediatric chronic illnesses are therefore

---

J.M. Lennon, M.A. (✉) • A.M. Psihogios, M.A. • C.B. Murray, M.A.  
C.E. Holbein, M.A. • G.N. Holmbeck, Ph.D.  
Department of Psychology, Loyola University Chicago,  
1032 W. Sheridan Rd., Chicago 60660, IL, USA  
e-mail: [jlenco2@luc.edu](mailto:jlenco2@luc.edu); [gholmbe@luc.edu](mailto:gholmbe@luc.edu)

best understood from a developmental perspective that recognizes both individual experiences and the shared experiences of child and adolescent development. The transition from childhood to adolescence may be a particularly challenging time for families of children with a chronic illness, as this developmental period is marked by rapid changes related to biological, cognitive, social, and emotional functioning (Susman & Rogel, 2004). Indeed, the manner in which the transition from childhood to adolescence is managed has important implications for disease outcomes throughout the remainder of the life span (Williams, Holmbeck, & Greenly, 2002).

Managing a chronic illness, while maneuvering the developmental challenges of adolescence, can prove taxing for families. Attention is needed to how medical practitioners can assist families in responding to the challenges of this transitional period. Promoting resilience in these families can produce optimal responses to the daily stressors of chronic illness, by building upon the strengths of each family. Resilience has been defined in many ways but, in this context, it refers to the attainment of desirable social and emotional adjustment, despite adversity due to chronic illness (Rutter, 1985). A social-ecological model conceptualizes resilience as the notion that an individual or group can adapt to and overcome challenges by utilizing psychological, social, cultural, and physical resources (Ungar, Ghazinour, & Richter, 2013). This model is based on social-ecological theory insofar as human development is best studied by considering the dynamic interplay among the social and environmental contexts in which the individual is imbedded over time (Bronfenbrenner & Morris, 2006). This understanding of resilience provides a comprehensive framework for understanding how families respond to challenges presented by childhood chronic illness. Indeed, research in the area of pediatric psychology supports a disruption-resilience model, which suggests that while the presence of a child with a chronic illness may disrupt normative family functioning in certain ways, these families are able to adapt and demonstrate considerable resilience. In other words, families of children with chronic illness display both resilience and disruption, compared to families of healthy children (Costigan, Floyd, Harter, & McClintock, 1997; Lennon, Murray, Bechtel, & Holmbeck, 2015). Therefore, medical practitioners working with families of children with chronic illness may promote better outcomes if they adopt a strength-based approach that will help such families capitalize on their own strengths and resources to solve problems.

The present chapter aims to identify potential resilience factors and how medical practitioners can target these factors as a way to promote an optimal response to pediatric chronic illness during the transition to adolescence. These issues are examined from the perspective of pediatric psychology, “a multifaceted and integrated field of both scientific research and clinical practice that focuses on addressing a wide range of physical and psychological issues related to promoting the health and development of children, adolescents, and their families, with an emphasis on evidence-based methods” (Aylward, Bender, Graves, & Roberts, 2009). First, we will review the impact of pediatric chronic illness on children and families during the transition to adolescence, including its impact on children’s biological, cognitive, psychological, and social functioning, as well as its impact on parenting and

family functioning. Next, we will identify potential individual, family, and community resilience factors that can serve as targets for interventions. We will conclude with suggestions for medical practitioners, as well as areas for future research.

## **The Impact of Chronic Illness During the Transition to Adolescence**

To promote resilience from a developmental perspective, it is useful to have an understanding of typical development during this period, including children's individual abilities and functioning as well as parent functioning and family processes. Adolescence is characterized by rapid biological, cognitive, and social maturation in which the adolescent begins to assume new roles within the family (Hill, Bromell, Tyson, & Flint, 2007). The biopsychosocial changes that occur as children transition into adolescence can increase youths' physical and emotional distress and risk behaviors, but it can also strengthen relationships and foster independence (Forrest, Bevans, Riley, Crespo, & Louis, 2013). Adolescents with chronic illness have the same developmental needs as their healthy peers, and attention should be paid to these developmental milestones and outcomes if optimal health outcomes are to be achieved (Yeo & Sawyer, 2005).

### ***Biological and Physical Changes***

The biological transition of adolescence is perhaps the most visible sign that adolescence has begun (Yeo & Sawyer, 2005). Most often referred to as puberty, or the process of physical maturation manifested by an acceleration of growth and appearance of secondary sexual characteristics, this transition begins with changes in brain-neuroendocrine processes, hormone concentrations, changes in physical characteristics, and concludes with reproductive maturity. Traditionally, these biological changes begin to occur at roughly 8 years of age for girls and at 9 years of age for boys, but there is considerable interindividual variability (Susman & Rogel, 2004).

Although the biological changes of puberty are universal, the timing, intensity, and impact of these changes differ across time and culture, and are likely to differ for children with medical conditions. Across many chronic illness groups, the sequelae of an illness and its treatment can impact biological changes in various ways. For example, the onset of puberty in adolescents with spina bifida often occurs earlier than in typically developing youth (McLone & Ito, 1998), whereas adolescents with cystic fibrosis are typically delayed in pubertal development (Arrigo, Rulli, Sferlazzas, & de Luca, 2003). In addition, the physical changes that occur during puberty often lead to an increase in awareness of appearance and attractiveness, as youth compare themselves to peers, often leading to a negative body image. Indeed, it has been found that physical appearance contributes to levels

of overall self-esteem more than any other factor (Harter, 1999). Chronic illness and its treatment may produce visible signs of illness that can exacerbate feelings of self-consciousness. For example, in children with cancer, surgery can result in scarring or disfigurement, radiation can stunt growth and result in skin damage, and chemotherapy can result in hair loss or weight loss/gain (Wallace, Harcourt, Rumsey, & Foot, 2007).

Despite unique challenges that may arise for chronically ill children during puberty, puberty can be a difficult time for typically developing children as well. For example, adolescents affected by delayed puberty, regardless of health status, may be treated as less mature than same age peers (Michaud, Suris, & Viner, 2007). Thus, when working with such youth, it may be important to assess how the medical condition may be impacting puberty, and to respond as one would to any child going through puberty—by providing education and support (Susman & Rogel, 2004).

### *Cognitive and Academic Functioning*

Cognitive development during the transition to adolescence is best characterized by the attainment of a more fully conscious, self-directed, and self-regulating mind. Developmental neuroscience highlights processes most salient to the adolescent period, such as the developing prefrontal cortex, increasingly rapid connectivity, increases in neocortical volume, and synaptic pruning that is central to executive functioning (Keating, 2004). Thus, adolescence is a critical developmental period for cognitive development. The presence of a chronic illness and its treatment may impact cognitive functioning in various ways, depending on the illness, age of illness onset, and treatment. For example, youth with spina bifida are often born with hydrocephalus, which is commonly treated with a shunt placement at birth. Both the presence of hydrocephalus at birth and the surgeries required for shunt placement and to treat shunt malfunctions or infections can negatively impact the cognitive abilities of these youth (Rose & Holmbeck, 2007). Other chronic illnesses are known to have long-term neuropsychological effects in adolescence as a result of the disease process (e.g., cerebrovascular accidents in sickle cell disease and hypoglycemia in diabetes; Michaud et al., 2007). Research on the impact of specific chronic illnesses on cognitive development is growing and, although attention is commonly focused on deficits in cognitive function, attention should also be paid to resilience. For example, one study found that among children with traumatic brain injury, those from families that experienced lower levels of stress demonstrated better cognitive outcomes later, compared to families that experienced higher levels of stress (Taylor et al., 2002).

The impact of chronic illness on academic performance and the need for educational services will depend on the overall impact of the condition on a child's functioning. Cognitive impairments described previously may impact a child's ability to meet academic demands. If problems in this area arise, the child will need educational support services such as an Individual Education Program (IEP).

Chronically ill children without cognitive impairment may still be less interested in school, have more school absences, or experience bullying which could result in lower academic achievement. For example, one study found that the presence of asthma impacts academic performance in children during the transition to adolescence, and this association is mediated by the number of missed days of school as compared to their peers. Despite these challenges, however, this same study found that the presence of a chronic health condition had a weak or nonsignificant association with how children feel toward their teachers or levels of school engagement (Forrest et al., 2013).

### ***Psychological Functioning and Autonomy***

Adolescence is characterized by numerous developmental changes that may result in challenges that negatively impact an adolescent's psychological functioning, including their mental and emotional well-being (Graber, 2004). Although adolescence is a time when the risk for psychological maladjustment increases for all youth (e.g., Kessler, Avenevoli, & Merikangas, 2001), the experience of having a chronic health condition can be particularly challenging during this developmental period. In general, studies across pediatric health conditions have shown that adolescents with medical conditions are at an elevated risk for a range of psychological symptoms (e.g., overall adjustment, internalizing and externalizing symptoms) compared to healthy children (e.g., Lavigne & Faier-Routman, 1992). For example, compared to their healthy counterparts, research on adolescents with diabetes suggest they have higher rates of depression (e.g., Hood et al., 2006), anxiety (Kovacs, Goldston, Obrosky, & Bonar, 1997), and eating disorders (e.g., Jones, Lawson, Daneman, Olmsted, & Rodin, 2000). Other salient stressors, such as concerns about death and dying, are thought to develop during adolescence in youth with cystic fibrosis (Quittner, Barker, Marciel, & Grimley, 2009) and sickle cell disease (Lemanek & Ranalli, 2009). Furthermore, chronically ill children tend to have lower self-esteem than typically developing children (Grey, Cameron, & Thurber, 1991). Despite these results, there is evidence that some pediatric populations show positive adjustment, similar to that of healthy peers. Stam, Grootenhuis, and Last (2001) found evidence for the following predictors of positive adjustment in adolescent survivors of childhood cancer: demographic factors, illness- and treatment-related factors, coping, and family and parental functioning. For example, they found that adolescents were more positively adjusted if they had been diagnosed earlier in childhood, or if they had parents who were less psychologically distressed immediately after diagnosis (Stam et al., 2001).

In North America, the transition to adolescence is also characterized by a striving for individuality, which is often accomplished through an increase in autonomy (Steinberg & Morris, 2001). While previous research has proposed a dichotomy in which parents from individualistic societies encourage autonomy while parents from collectivist societies encourage relatedness, recently, scholars have suggested

that these developmental goals can coexist in families from all cultures (Tamis-LeMonda, Hughes, Yoshikawa, Kalman, & Niwa, 2008). The development of autonomy is considered a major task of adolescence for all youth, and is understood as the interpersonal process by which adolescents begin to develop a greater capacity for independent behavior in the context of continued family connections (Steinberg & Morris, 2001). The construct of autonomy is often deconstructed into the construct of behavioral autonomy, which includes self-reliant behavior and intrinsically motivated behavior, and emotional autonomy, which has been described as part of the process by which adolescents relinquish dependencies on their parents (Friedman, Holmbeck, DeLucia, Jandasek, & Zebracki, 2009). Autonomy development has been identified as one of the most important relational changes to occur within the family during adolescence (Hill & Holmbeck, 1986). The task of autonomy development may be challenging for an adolescent with a chronic illness, especially considering that some dependency on adults is often necessary for an adolescent who is chronically ill. However, some pediatric populations develop independence in ways similar to their healthy counterparts. For example, children with spina bifida and their same-age peers show similar increases in independent behavior and emotional autonomy from their parents over time, suggesting children with spina bifida appear to demonstrate considerable developmental resilience in the face of significant challenges (Friedman et al., 2009).

For many youth with chronic health conditions, the transition to adolescence is also characterized by increased autonomy with medical care. For instance, it has been found that parents of children with diabetes (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997), cystic fibrosis (Modi, Marciel, Slater, Drotar, & Quittner, 2008), and spina bifida (Stepansky, Roache, Holmbeck, & Schultz, 2010) begin to transfer medical responsibilities to children during early adolescence, or around the age of 13. For more on the role of parents in promoting adjustment to chronic conditions see Hoehn et al., this volume. Medical care regimens provide youth with an opportunity for developing responsibility and confidence. However, despite these gains in autonomy, rates of adherence amongst adolescents are generally lower than adherence rates in younger children and adults (i.e., a 50% adherence rate is often found among adolescents with various chronic health conditions; La Greca & Mackey, 2009). This may be because certain developmental events (e.g., increased peer socialization) interfere with the scheduling and completion of medical management tasks, such as taking medication as prescribed, adhering to a specific diet, adhering to a bowel/bladder program, or completing physical therapy exercises. Also, the severe and/or permanent nature of a disease may become more evident and discouraging during adolescence. An adolescent may realize that his or her illness will persist, even if he or she is fully compliant with medical regimens, and this thought process may negatively affect the adolescent's level of adherence and psychological well-being. Thus, the changes that an adolescent is experiencing (in terms of increased responsibility for disease management and salient developmental events) may make it difficult for an adolescent to be successful at caring for their health without additional support.

## ***Social Functioning***

Social functioning in youth with chronic health conditions may be especially important to consider during the transition to adolescence, as this is a time when typically developing youth begin spending more time with friends (Larson & Richards, 1991). Many youth with chronic health conditions are at risk for challenges in social contexts. Social difficulties in pediatric populations are likely related to multiple factors. Children with chronic health conditions may feel they do not “fit in” with their healthy peers because their lives include unique experiences (La Greca, 1990), such as painful medical treatments and complex self-care regimens, fears of future health challenges, and coping with stigma associated with visible physical disabilities (Perlman & Routh, 1980). The increased risk of both internalizing and externalizing symptoms in youth with chronic health conditions (Lavigne & Faier-Routman, 1992) puts them at a further disadvantage in social contexts. Cognitive impairments associated with some health conditions and treatments (e.g., neurocognitive late effects among childhood brain tumor survivors) may also interfere with successful peer relations due to diminished capacity to engage with peers (Wallander & Varni, 1998).

Various social difficulties have been studied in pediatric populations. Such youth may lack the foundation of social skills necessary for successful social interactions (Nassau & Drotar, 1997). They may also have fewer opportunities to socialize with peers outside of school (Wiegerink, Roebroek, Donkervoort, Stam, & Cohen-Kettenis, 2006). Children with chronic health problems may have fewer close friendships (Barrera, Shaw, Speechley, Maunsell, & Pogany, 2005; Holmbeck et al., 2010), with these friendships often lower in quality and emotional support (Devine, Gayes, Purnell, & Holmbeck, 2012; Helms, Dellon, & Prinstein, 2015). In addition, many youth with chronic health conditions encounter bullying and victimization by peers (Nadeau & Tessier, 2009; Petteway, Valerio, & Patel, 2011).

Two recent meta-analyses revealed that youth with chronic health conditions are less socially competent than their healthy peers (Martinez, Carter, & Legato, 2011; Pinquart & Teubert, 2012). Although these studies and others (e.g., McCarroll, Lindsey, MacKinnon-Lewis, Chambers, & Frabutt, 2009) provide evidence for social deficits in pediatric population in general, meta-analytic techniques suggest varying levels of social impairment across health conditions (Martinez et al., 2011; Pinquart & Teubert, 2012). In fact, children with disorders of the central nervous system (CNS; e.g., epilepsy, spina bifida) tend to exhibit greater social difficulties as compared to those with other health conditions (e.g., blood disorders, diabetes, obesity). Social difficulties have also been found for children with diabetes (Helgeson, Reynolds, Shestak, & Wei, 2006), sickle cell disease (Noll et al., 1996), Tourette’s disorder (Stokes, Bawden, Camfield, Backman, & Dooley, 1991), juvenile rheumatoid arthritis (Feldmann, Weglage, Roth, Foell, & Frosch, 2005), and inflammatory bowel disease (Mackner & Crandall, 2006), among others.

Despite evidence for social difficulties in pediatric populations, research has also demonstrated considerable resilience in these youth in the social domain. For instance, and contrary to the findings just noted, some studies have found no

significant social differences were apparent between healthy peers and children with sickle cell disease (Lemanek, Horwitz, & Ohene-Frempong, 1994) and juvenile rheumatoid arthritis (Reiter-Purtill, Gerhardt, Vannatta, Passo, & Noll, 2003). Further, childhood cancer survivors exhibited greater social competence than healthy comparisons in one study (Reiter-Purtill, Vannatta, Gerhardt, Correll, & Noll, 2003). In another study, adolescents with diabetes reported higher numbers of close friends and emotional support from friends than their healthy peers (Helgeson et al., 2006). These findings are consistent with the disruption-resilience model presented earlier (Costigan et al., 1997), in that youth with chronic illness may experience social difficulties due to their medical condition, but other aspects of their social functioning may remain unaffected.

### ***Parent Functioning and Parenting***

Being a parent can be challenging, especially when parenting an adolescent. However, being a parent of a child with a chronic illness may be particularly daunting. Parenting quality and parent–child relationships may be dramatically altered in families with a chronically ill child (e.g., higher levels of parental overprotection and neglect; Pinquart, 2013). Childhood chronic medical conditions may produce significant social, relational, emotional, and financial stress for parents (Barlow & Ellard, 2006; Drotar, 1997; Klassen et al., 2007; Palermo & Eccleston, 2009). Common stressors experienced by parents include increased child-rearing responsibilities (e.g., implementation of therapeutic or medical procedures), changes in daily activities, disruption/shifting of social and family roles, and the burden associated with adherence to complex medical regimens (Drotar, 1997). Parents may also experience increased stress from managing their jobs and careers in response to increased time demands and greater financial burden (Case-Smith, 2007). Further, both mothers and fathers of youth with chronic conditions are at risk for psychological health difficulties (e.g., depression, distress, negative affectivity; Pai et al., 2007), which may impair a parent’s ability to provide quality care for their child (Drotar, 1997). Reductions in distress in parents of chronically ill children should therefore be an important treatment goal for medical practitioners.

### ***Family Functioning***

Researchers have proposed that an adolescent’s ability to effectively manage and cope with his or her chronic health condition is best examined within a family context (Kazak, Rourke, & Navsaria, 2009). The social-ecological model proposed previously in this chapter is especially useful for understanding the manner in which children and their families (and other relevant systems) interact to shape adjustment to chronic illness (Ungar et al., 2013). As most families with chronically ill children

appear to be otherwise healthy families faced with difficult circumstances, understanding the transactional process in which the presence of a pediatric illness changes the family system is essential (Kazak, 1997).

Within pediatric populations, much of the existing body of literature on family adjustment has focused on particular family-centered variables, including family adaptability, social support, the ability to balance the demands of the illness with other family needs and responsibilities, effective communication, adaptive coping strategies, and the effective balance of autonomy-granting in the context of ongoing parental support (Kazak et al., 2009). Understanding these family-centered variables can help to clarify the complex, dynamic relationship between family functioning and child adjustment across salient developmental periods, including the transition to adolescence. For example, lower levels of cohesion were observed in families of preadolescents with spina bifida than in a matched typically developing comparison sample, although differences in family conflict were nonsignificant (Holmbeck, Coakley, Hommeyer, Shapera, & Westhoven, 2002). Notably, this study also found that families of preadolescents with spina bifida who were of low socioeconomic status were most at-risk for low family cohesion, suggesting that the combined experience of having a child with spina bifida and low socioeconomic places families at the highest risk for maladjustment.

The relationship between family functioning and treatment adherence has been studied extensively across childhood chronic illnesses, particularly type 1 diabetes. A number of studies of family functioning found that relationship factors (e.g., communication, problem-solving skills, conflict resolution) significantly predicted adaptive adherence behaviors for children and adolescents with diabetes (Wysocki et al., 1999). This finding has been supported in a spina bifida population, with studies finding that high levels of family conflict predict a decrease in concurrent (Psihogios & Holmbeck, 2013) and later adherence (Stepansky et al., 2010). According to Stepansky et al. (2010), the longitudinal association between family conflict and medical adherence suggests that family conflict and medical adherence become increasingly intertwined during adolescence.

It has also been suggested that siblings of chronically ill children are at greater risk of adjustment difficulties, as they may feel neglected due to decreased time with parents and involvement in family discussions (Yeo & Sawyer, 2005). Indeed, a meta-analysis conducted by Sharpe and Rossiter (2002) found that psychological functioning (i.e., depression and anxiety), peer activities, and cognitive development were lower for siblings of children with chronic illnesses compared to matched controls.

## Promoting Resilience

As the previous section has highlighted, there is wide variation in the functioning of youth with chronic illnesses and their families; while some of these youth and families may function quite well, others may be confronted with significant challenges.

Despite the negative impact that the presence of a chronic illness may have on a child and his/her family during the transition to adolescence, there are multiple individual, family, social, community, and cultural resilience factors that are found in families of youth with chronic illnesses. For medical practitioners to assist in promoting and building upon this resilience, it is important to identify and have an understanding of *what* makes a family resilient, and *how* such resilience emerges in the face of adversity.

### ***Individual Resilience***

Investigations of individual resilience factors facilitate a clinician's understanding of important within-child protective processes that may contribute to positive functioning, despite difficult life circumstances (Betancourt, Meyers-Ohki, Charrow, & Hansen, 2013). Moreover, knowledge of individual-level protective processes is needed to design effective interventions that capitalize on or promote children's natural sources of resilience. Several studies have investigated individual-level strengths and sources of resilience, identifying specific coping strategies children may use to manage illness-related stressors (Betancourt et al., 2013; Jaser & White, 2011; Wu, Sheen, Shu, Chang, & Hsiao, 2013). Research has also found self-esteem and positive future expectations to be important individual-level resilience factors (Betancourt et al., 2013; Grey et al., 1991).

*Coping.* Youth with chronic illnesses may face a number of stressful events; these populations are typically exposed to a large number of disease-related stressors (e.g., invasive medical procedures) in addition to common, developmentally congruent stressors experienced by all children and adolescents (Spirito, Stark, Gil, & Tyc, 1995). Adjustment to these stressors is affected by youth's coping strategies, or the cognitive and/or behavioral processes that reduce or help to manage stressful events (Lazarus & Folkman, 1987). Although multiple conceptualizations of coping exist, the most recent pediatric literature supports making the following three distinctions among coping strategies: *primary control coping* includes strategies intended to directly change the source of stress (e.g., problem-solving) or one's emotional reaction to it (e.g., emotional expression); *secondary control coping* includes efforts to adapt to stress (e.g., acceptance, positive thinking); *disengagement coping* includes efforts to orient away from the source of stress or one's reaction to it (e.g., avoidance, wishful thinking; Compas et al., 2014). Among pediatric populations, primary and secondary control coping have been associated with better adjustment and medical outcomes, while disengagement coping has been associated with poorer outcomes (Compas et al., 2014). For example, among adolescents with type 1 diabetes, primary and secondary control coping were associated with better quality of life and better metabolic control, while disengagement coping was associated with lower social competence and lower metabolic control (Jaser & White, 2011). Others studies have found the use of secondary control coping to be particularly predictive of adjustment. Specifically, secondary control coping was predictive

of fewer anxiety symptoms in youth with functional abdominal pain (Hocking et al., 2011), and it was predictive of fewer anxiety and depressive symptoms in youth with cancer (Compas et al., 2014).

*Self-esteem and Hope for the Future.* Previous research indicates that higher levels of self-esteem are linked to resilience among children with chronic illnesses (Grey et al., 1991). A recent qualitative study found that self-esteem and hope (e.g., “Thinks about her future”; “Feels she must survive”; “Feels strong”) were important contributors to resilience in Rwandan children affected by HIV/AIDS (Betancourt et al., 2011). Increased hope for the future has also been linked to better psychosocial outcomes in children with chronic illnesses (e.g., pediatric burn injury, sickle cell disease; Barnum, Snyder, Rapoff, Mani, & Thompson, 1998; Lewis & Kliever, 1996).

Understanding individual cognitive and behavioral characteristics that help chronically ill children cope with stressful aspects of illness and treatment is important for clinical intervention. Medical practitioners may find it useful to incorporate routine screening of coping strategies, self-esteem, and future expectations into their evaluations of children with chronic illness for prevention purposes (Spirito et al., 1995).

## ***Family Resilience***

As noted earlier, while the impact of chronic illness on the child should not be underestimated, the family may also experience a number of stressors that are a direct result of having an ill child. Nevertheless, there is both research and clinical evidence that many families successfully adapt, demonstrating positive functioning despite increased strains and demands. Similar to individual resilience, family resilience is not only characterized by overcoming adverse or stressful events; an important component of such resilience also includes the influence of relationships between family members (Patterson, 2002), and how positive relational bonds and parent–child interactions can promote family adaptation (McCubbin, McCubbin, Thompson, Han, & Allen, 1997). Historically, research on families of children with chronic illness has not emphasized resilience, but rather, the negative aspects of having a child with a health problem (Tinsley, Castro, Ericksen, Kwasman, & Ortiz, 2002). However, researchers and clinicians have begun to delineate aspects of parenting and family functioning that can be considered optimal in relation to a child’s adjustment to illness.

*Parenting.* Parenting styles and the quality of the child–parent relationship play a critical role in a child’s development (Steinberg, 2010) and in the adaptation of a child with a chronic illness in particular (e.g., adherence to a medical regimen; Ellis et al., 2007). Research on mostly European American samples suggests that authoritative parenting styles, characterized by the combination of both high demandingness and high responsiveness, contribute to positive health behaviors (Tinsley et al., 2002). That is, parenting behaviors characterized by higher levels of behavioral

control (i.e., parenting involving age-appropriate supervision and setting of rules and regulations) and parental acceptance (i.e., emotionally supportive, approving, and involved parenting) have been linked to positive outcomes in youth with chronic illnesses (e.g., preadolescents with spina bifida; Holmbeck, Shapera, & Hommeyer, 2002). Adaptive outcomes may be due to the presence of a warm parent–child relationship in combination with appropriate levels of autonomy and restrictiveness that promote independence skills (Pinquart, 2013). In addition, there is reason to believe that authoritarian parenting styles, characterized by high demandingness and low responsiveness, may lead to better outcomes in families who are not of European descent, such as Asian American families (Van Campen & Russell, 2010). For more on the importance of cultural contexts in resilience processes, see Yi, this volume.

*Family Functioning.* “Family functioning” encompasses several conceptual dimensions, including cohesion, expressiveness, organization, independence, and control (Moos & Moos, 1994). In families of children with chronic illnesses, there is a growing body of evidence that both more cohesion and less conflict are linked to better child adjustment (Knafl & Gilliss, 2002). Associations between family cohesion, or the emotional bond that family members communicate to each other (e.g., expressing belonging and acceptance within the family), and positive adjustment is a consistent finding, with similar results found in studies of pediatric cancer (Kim & Yoo, 2010), diabetes (Pereira, Berg-Cross, Almeida, & Machado, 2008), sickle cell disease (Kliwer & Lewis, 1995), and mixed samples of children with chronic illnesses and physical disabilities (Wallander, Varni, Babani, Banis, & Wilcox, 1989). Greater levels of family expressiveness (e.g., encouragement to express emotions directly) has also been linked to better outcomes (Soliday, Kool, & Lande, 2000).

Identification of the attributes of a resilient family is the first step towards providing interventions to ameliorate stress in families of chronically ill children. Clinic screenings could help identify families that may benefit from interventions aimed to decrease family conflict and increase family cohesion and expressiveness. Facilitation of communication and parenting skills to strengthen the bond between the parent and child (e.g., through parent training interventions; Johnson, Kent, & Leather, 2004) may also be useful.

## ***Social, Community, and Cultural Resilience***

*Social Support.* Peer relationships play a substantial role in the development of resilience in youth with chronic health conditions. First, *friendships* can protect against some of the challenges faced by these youth. Although recent research has been less conclusive (Palladino & Helgeson, 2012), it has generally been found that youth who experience more social support and engage in less peer conflict are better able to manage health-related self-care tasks (Helgeson, Lopez, & Kamarck, 2009; La Greca, Bearman, & Moore, 2002). For instance, the friends of a child with diabetes may encourage healthier food choices and provide emotional support

for diabetes-related challenges. Children are more likely to complete health-related self-care tasks when they perceive that their efforts are supported by their peers (La Greca et al., 2002). Peer support has also been associated with fewer emotional and behavior problems (e.g., in youth with cancer; Feragen, Kvaem, Rumsey, & Borge, 2010).

Second, inclusion of peers in interventions aimed at increasing medical adherence and promoting adjustment to chronic illness has also yielded promising results. Peer-involved group therapy intervention programs, aimed at improving disease knowledge and management and increasing social support, have been studied among youth ages 10–18 with asthma (Shah et al., 2001) and type 1 diabetes (Greco, Pendley, McDonell, & Reeves, 2001). These studies found that youth who participated in group interventions with their friends reported increased quality of life, greater proportion of peer support relative to family support, lower school absenteeism, fewer illness exacerbations, and increased illness-related knowledge (Greco et al., 2001; Shah et al., 2001).

There is also evidence to suggest that youth may benefit from interactions with other children and adolescents with shared health conditions (e.g., HIV; Funck-Brentano et al., 2005) or chronic illnesses in general (Olsson, Boyce, Toumbourou, & Sawyer, 2005). For example, pediatric health-related camps allow children and adolescents to communicate about shared experiences, practice independence skills, increase health-related knowledge, and make supportive friendships with similar peers (Holbein et al., 2013; Odar, Canter, & Roberts, 2013). Social media platforms and online support groups are additional outlets that may foster peer support for youth living with chronic health conditions (Letourneau et al., 2012; Quittner et al., 2012).

*Community Support.* Community factors also contribute to resilience in pediatric populations. Participation in adaptive sports and organized activities provides numerous benefits for the emotional, social, and physical well-being of youth with chronic health conditions (Murphy & Carbone, 2008). Further, access to specialty medical care also has clear implications for resilience in pediatric populations (Newacheck, Hung, & Wright, 2002). Unfortunately, availability of appropriate services is often impacted by sociocultural vulnerability factors, including low socioeconomic status, rural living environment, single-parent households, and ethnic minority status (Bauman, Silver, & Stein, 2006; Murphy & Carbone, 2008; Newacheck et al., 2002; Seid, Opari-Arrigan, & Sobo, 2009). Although access to health insurance has previously been identified as an obstacle for many youth in the United States (Newacheck et al., 2002), the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA; Pub L No. 111-3) and the Patient Protection and Affordable Care Act of 2010 (ACA; Pub L No. 111-148) have succeeded in improving access to insurance, enhancing insurance benefits, and allowing for receipt of appropriate medical services for millions of children with special health care needs (Committee on Child Health Financing, 2014).

*Culture and Spirituality.* Youth with chronic health conditions and their families can derive additional benefits from cultural and spiritual practices. Prayer, meditation, and healing rituals can provide comfort and strength when a child is

experiencing significant health-related stress (Rolland & Walsh, 2006). In fact, recent research suggests that adolescents' utilization of positive spiritual coping techniques may protect against development of depressive symptoms (Reynolds, Mrug, Hensler, Guion, & Madan-Swain, 2014). Building on cultural strengths and diversity allows for the establishment of rapport and collaboration between medical practitioners and pediatric patients, resulting in a more specialized, empowering treatment plan (Hilliard, Ernst, Gray, Saeed, & Cortina, 2012). Within the medical setting, positive outcomes can be attained when the medical team aims to establish a collaborative relationship with families that respects unique cultural beliefs and practices (Rolland & Walsh, 2006). For practice-relevant suggestions to help medical practitioners to build these collaborative partnerships see Munford, this volume.

### *Intervening to Promote Resilience*

Medical practitioners play an important role in facilitating understanding of how a child's chronic illness may, or may not, be impacting a child's development. Clinical interventions can help build resilience by creating a therapeutic collaboration that is designed to utilize and build upon families' existing strengths and abilities across multiple systems (Luther, 1991; Masten, Best, & Garmezy, 1990; Shapiro, 2002). These interventions can teach children and their families how to manage the demands of a chronic illness while also navigating the dynamic transition to adolescence.

A *first step* in identifying what intervention will be most appropriate for a family is to accurately identify their resilience factors as well as barriers. Assessment of resilience involves conceptualizing individual families with a strengths-based approach to the assessment of developmental challenges (Shapiro, 2002). This can be achieved by interviewing families and asking questions to assess the areas of resilience previously mentioned. There are also screeners and measures that have been developed to quickly identify areas of resilience. For example, the Adolescent Resilience Questionnaire (ARQ; Gartland, Bond, Olsson, Buzwell, & Sawyer, 2011) assesses the strengths within the adolescent, family, peer group, school, and community, and was developed with adolescents with chronic illnesses. Example items from the ARQ include "I feel confident that I can handle whatever comes my way" and "There is someone in my family I can talk to about anything" (Gartland et al., 2011). The Haase Adolescent Resilience in Illness Scale (HARS; Haase, 2004) is a single factor scale consisting of 13 items that measure how children with cancer feel or think about managing their health since diagnosis. Family measures are also important, such as the CHIP (McCubbin et al., 1983), a parent self-report inventory that includes 45 behaviors that one might use to cope with a child's chronic illness. Although more research is needed on the psychometric properties of resilience measures, there are multiple reviews on current existing measures (e.g., Alderfer et al., 2008; Blount et al., 2008; Hall, 2010; Windle, Bennet, & Noyes, 2011).

In addition to developing and building upon resilience, clinical interventions can identify barriers that may be disrupting the path to healthy development. Barriers can vary in their nature and seriousness, are multifaceted, and can be related to pragmatics, health beliefs, expectations, skills and knowledge, and/or marginalization. Examples include high costs, misunderstanding the course of a disease, negative expectations of encounters with the health care system, lack of knowledge about care availability, or feeling that a previous bad experience was a personal affront (Seid, Sobo, Zivkovic, Nelson, & Davodi-Far, 2003). As with resilience, most barriers can be identified through an interview with families. There is a pressing need for the development of a validated measure of barriers to care (Seid, 2008). More importantly, there is a need for validated measures that can assess both barriers and resilience factors, in order to aid clinicians in conceptualizing families.

Interventions aimed at promoting resilience and positive child and family outcomes may strive to help families identify positive coping skills, enhance family functioning, and access resources. Interventions may also target parent mental health, parenting behaviors, and/or sibling adjustment as a means to improve the well-being of families and improve child health outcomes. For example, the Child Illness and Resilience Program (CHiRP), based in Australia, is a stepped-care mental health promotion intervention guided by a family resilience framework and designed to support families with a chronically ill child (Harnall, Heard, Inder, McGill, & Kay-Lambkin, 2014). CHiRP aims to help families identify existing strengths and provide strategies to target protective factors and processes that enhance family resilience, such as coping skills, family functioning, and social support. Specific components include providing families with literature on psychoeducation and practical resilience building strategies, facilitating the completion of family-based cognitive-behavioral exercises, and offering parent support groups (Harnall et al., 2014).

In addition to CHiRP, there are other interventions designed for families of youth with chronic illnesses that aim to positively impact parent behavior, mental health outcomes, and child symptoms and behavior (Law, Fisher, Fales, Noel, & Eccleston, 2014). Although these interventions may not be labeled as “resilience” interventions, many utilize a strengths-based approach and aim to improve child, parent, and family outcomes. For example, a recent systematic review and meta-analysis of such interventions found that those that incorporated Problem-solving Therapy demonstrated the greatest positive effects on parental mental health and behavior (Law et al., 2014). In addition, because siblings of chronically ill children are at a greater risk of adjustment difficulties for reasons mentioned previously, it is recommended that siblings be included in family interventions and provided with opportunities for special support, such as through participation in sibling support groups.

Successful interventions are those that focus on the family’s view of the problem, validate their adaptive strategies for managing developmental stress, and provide perspective on and alternatives for their maladaptive strategies. To increase the opportunity for success, clinicians should work with families to set intervention goals that are realistic and attainable. Emphasizing families’ strengths will increase feelings of self-efficacy, which will also aid in helping families to meet their goals

(Shapiro, 2002). The most successful interventions will also be those that promote effective communication. Miscommunication and misunderstanding of an individual's needs and perspectives is common within families during the transition to adolescence. Interventions focused on communication improvement will facilitate increased mutual understanding and support among family members. Miscommunication is also common between families and the health care system. Working with both providers and families on communication will encourage optimal outcomes (Seid et al., 2009).

### ***The Role of Medical Practitioners***

The emphasis on interdisciplinary and integrated health care teams is accelerating (Stancin & Perrin, 2014). The family of a child with a chronic illness will interact with multiple health care providers that are involved in their care, including general and specialist physicians, surgeons, nurses, psychiatrists, psychologists, social workers, physical therapists, occupational therapists, and other behavioral medicine specialists. This interdisciplinary approach requires that these medical practitioners collaborate in care conceptualization, treatment planning, and decision-making. For more on the importance of coordinated multisystemic service-provision, see Ungar, this volume. The family's interaction with each of these practitioners is an opportunity to build resilience through educating and empowering families (Seid et al., 2009). It is important that medical practitioners working with families of chronically ill children remain mindful of the culture of the health care system and be aware that each family faces unique challenges when navigating the system (Seid et al., 2009). The culture of the health-care system includes its social structure, economic implications, and belief systems (Shapiro, 2002). Furthermore, a large responsibility of medical practitioners working with chronically ill children is to assist families with the transition to adult health care. This responsibility currently tends to fall on pediatric specialists; however, for a smooth transition, collaboration with adult providers is critical (Pai & Schwartz, 2011).

### **Conclusion**

The present chapter has identified multiple areas in need of additional research. One such area is measurement development and validation. Although resilience measures exist, their psychometric properties need to be examined within various pediatric populations and among children at different developmental stages. In addition, there is a need for measures that can assess both resilience factors and barriers, as evaluating both of these areas is important when working with families. Importantly, more research needs to be done on how medical practitioners of various disciplines can each contribute to promoting resilience in families of youth with chronic

illnesses. As stated previously, these families interact with numerous practitioners in the health care setting. It is critical to better understand how particular practitioners can play unique and important roles in building resilience. For example, a pediatric mental health professional may be the practitioner directly implementing a family resilience-promoting intervention, but there may be ways in which physicians and/or nurses can help reinforce learning and behavior change. Research is needed on what practitioners are currently doing to promote resilience, and what new strategies they can implement.

Pediatric chronic illness presents families with numerous challenges and stressors, and each family responds to these challenges with a unique set of strengths (Compas et al., 2012). Understanding these strengths and challenges from a developmental perspective allows for the recognition of both individual and shared experiences of the development of a chronically ill child or adolescent. The transition from childhood to adolescence may be a particularly challenging time for families of children with a chronic illness, as this developmental period is marked by rapid changes related to biological, cognitive, social, and emotional functioning (Susman & Rogel, 2004). Thus, it is important that medical practitioners working with such families have an understanding of the impact of chronic illness on children's transition to adolescence. Through identifying and problem-solving challenges, and building upon existing strengths, medical practitioners can help families promote resilience and reach optimal child and family outcomes.

## References

- Alderfer, M. A., Fiese, B. H., Gold, J. I., Cutili, J. J., Holmbeck, G. N., Goldbeck, L., ... Patterson, J. (2008). Evidence-based assessment in pediatric psychology: Family measures. *Journal of Pediatric Psychology*, 33(9), 1046–1061. doi:10.1093/jpepsy/jsm083.
- Anderson, B., Ho, J., Brackett, J., Finkelstein, D., & Laffel, L. (1997). Parental involvement in diabetes management tasks: Relationships to blood glucose monitoring adherence and metabolic control in young adolescents with insulin-dependent diabetes mellitus. *Journal of Pediatrics*, 130(2), 257–265. doi:10.2337/diaspect.16.3.184.
- Arrigo, T., Rulli, I., Sferlazzas, C., & De Luca, F. (2003). Pubertal development in cystic fibrosis: An overview. *Journal of Pediatric Endocrinology and Metabolism*, 16, 267–270. doi:10.1080/08035250310004333.
- Aylward, B. S., Bender, J. A., Graves, M. M., & Roberts, M. C. (2009). Historical developments and trends in pediatric psychology. In M. C. Roberts & R. G. Steele (Eds.), *Handbook of pediatric psychology* (4th ed., pp. 3–18). New York, NY: Guilford.
- Barlow, J. H., & Ellard, D. R. (2006). The psychosocial well-being of children with chronic disease, their parents and siblings: An overview of the research evidence base. *Child: Care, Health and Development*, 32(1), 19–31. doi:10.1111/j.1365-2214.2006.00591.x.
- Barnum, D. D., Snyder, C. R., Rapoff, M. A., Mani, M. M., & Thompson, R. (1998). Hope and social support in psychological adjustment of children who have survived burn injuries and their matched controls. *Children's Health Care*, 27(1), 15–30. doi:10.1207/s15326888chc2701\_2.
- Barrera, M., Shaw, A. K., Speechley, K. N., Maunsell, E., & Pogany, L. (2005). Educational and social late effects of childhood cancer and related clinical, personal, and familial characteristics. *Cancer*, 104(8), 1751–1760. doi:10.1002/cncr.21390.

- Bauman, L. J., Silver, E. J., & Stein, R. E. (2006). Cumulative social disadvantage and child health. *Pediatrics*, *117*(4), 1321–1328. doi:10.1542/peds.2005-1647.
- Betancourt, T. S., Meyers-Ohki, S. E., Charrow, A., & Hansen, N. (2013). Annual research review: Mental health and resilience in HIV/AIDS affected children—a review of the literature and recommendations for future research. *Journal of Child Psychology and Psychiatry*, *54*(4), 423–444. doi:10.1111/j.1469-7610.2012.02613.x.
- Betancourt, T. S., Meyers-Ohki, S., Stulac, S. N., Barrera, A. E., Mushashi, C., & Beardslee, W. R. (2011). Nothing can defeat combined hands: Protective processes and resilience in Rwandan children and families affected by HIV/AIDS. *Social Science & Medicine*, *73*(5), 693–701. doi:10.1016/j.socscimed.2011.06.053.
- Blount, R. L., Simons, L. E., Devine, K. A., Jaaniste, T., Cohen, L. L., Chambers, C. T., & Hayutin, L. G. (2008). Evidence-based assessment of coping and stress in pediatric psychology. *Journal of Pediatric Psychology*, *33*(9), 1021–1045. doi:10.1093/jpepsy/jsm071.
- Bronfenbrenner, U., & Morris, P. A. (2006). The bioecological model of human development. In W. Damon & R. M. Lerner (Eds.), *Handbook of child psychology* (Theoretical models of human development 6th ed., Vol. 1, pp. 793–828). New York, NY: Wiley.
- Case-Smith, J. (2007). Parenting a child with a chronic medical condition. In A. E. Dell Orto & P. W. Power (Eds.), *The psychological and social impact of illness and disability* (pp. 310–328). New York, NY: Springer.
- Children's Health Insurance Program Reauthorization Act of 2009 (Pub L No. 111–3). Retrieved August 17, 2014, from [www.gpo.gov/fdsys/pkg/BILLS-111hr2enr/pdf/BILLS-111hr2enr.pdf](http://www.gpo.gov/fdsys/pkg/BILLS-111hr2enr/pdf/BILLS-111hr2enr.pdf).
- Committee on Child Health Financing. (2014). Children's health insurance program (CHIP): Accomplishments, challenges, and policy recommendations. *Pediatrics*, *133*(3), e784–e793. doi:10.1542/peds.2013-4059.
- Compas, B. E., Desjardins, L., Vannatta, K., Young-Saleme, T., Rodriguez, E. M., Dunn, M., ... Gerhardt, C. A. (2014). Children and adolescents coping with cancer: Self- and parent reports of coping with anxiety/depression. *Health Psychology*, *33*(8), 853–861. doi:10.1037/hea0000083.
- Compas, B. E., Jaser, S. S., Dunn, M. J., & Rodriguez, E. M. (2012). Coping with chronic illness in childhood and adolescence. *Annual Review of Clinical Psychology*, *8*, 455–480. doi:10.1146/annurev-clinpsy-032511-143108.
- Costigan, C. L., Floyd, F. J., Harter, K. S., & McClintock, J. C. (1997). Family processes and adaptation to children with mental retardation: Disruption and resilience in family problem-solving interactions. *Journal of Family Psychology*, *11*(4), 515–529. doi:10.1037/0893-3200.11.4.515.
- Cystic Fibrosis Foundation [CFF]. (2010). *Cystic fibrosis foundation patient registry 2010 annual data report*. Bethesda, MD: Cystic Fibrosis Foundation.
- Dabelea, D., Mayer-Davis, E. J., Saydah, S., Imperatore, G., Linder, B., Divers, J., ... Hamman, R. F. (2014). Prevalence of type 1 and type 2 diabetes among children and adolescents from 2001 to 2009. *The Journal of the American Medical Association*, *311*(17), 1778–1786. doi:10.1001/jama.2014.3201.
- Devine, K. A., Gayes, L., Purnell, J., & Holmbeck, G. N. (2012). Friendships of children and adolescents with spina bifida: Social adjustment, social performance, and social skills. *Journal of Pediatric Psychology*, *37*(2), 220–231. doi:10.1093/jpepsy/jsr075.
- Drotar, D. (1997). Relating parent and family functioning to the psychological adjustment of children with chronic health conditions: What have we learned? What do we need to know? *Journal of Pediatric Psychology*, *22*(2), 149–165. doi:10.1093/jpepsy/22.2.149.
- Ellis, D. A., Podolski, C. L., Frey, M., Naar-King, S., Wang, B., & Moltz, K. (2007). The role of parental monitoring in adolescent health outcomes: Impact on regimen adherence in youth with type 1 diabetes. *Journal of Pediatric Psychology*, *32*(8), 907–917. doi:10.1093/jpepsy/jsm009.
- Feldmann, R., Weglage, J., Roth, J., Foell, D., & Frosch, M. (2005). Systemic juvenile rheumatoid arthritis: Cognitive function and social adjustment. *Annals of Neurology*, *58*(4), 605–609. doi:10.1002/ana.20626.

- Feragen, K. B., Kvalem, I. L., Rumsey, N., & Borge, A. I. (2010). Adolescents with and without a facial difference: The role of friendships and social acceptance in perceptions of appearance and emotional resilience. *Body Image*, 7(4), 271–279. doi:10.1016/j.bodyim.2010.05.002.
- Forrest, C. B., Bevans, K. B., Riley, A. W., Crespo, R., & Louis, T. A. (2013). Health and school outcomes during children's transition into adolescence. *Journal of Adolescent Health*, 52(2), 186–194. doi:10.1016/j.jadohealth.2012.06.019.
- Friedman, D., Holmbeck, G. N., DeLucia, C., Jandasek, B., & Zebracki, K. (2009). Trajectories of autonomy development across the adolescent transition in children with spina bifida. *Rehabilitation Psychology*, 54(1), 16–27. doi:10.1037/a0014279.
- Funck-Brentano, I., Dalban, C., Veber, F., Quartier, P., Hefez, S., Costagliola, D., & Blanche, S. (2005). Evaluation of a peer support group therapy for HIV-infected adolescents. *AIDS*, 19(4), 1501–1508. doi:10.1097/01.aids.0000183124.86335.0a.
- Gartland, D., Bond, L., Olsson, C. A., Buzwell, S., & Sawyer, S. M. (2011). Development of a multi-dimensional measure of resilience in adolescents: The Adolescent Resilience Questionnaire. *Biomed Central Medical Research Methodology*, 11(134), 1–10. doi:10.1186/1471-2288-11-134.
- Graber, J. A. (2004). Internalizing problems during adolescence. In R. M. Lerner & L. Steinberg's (Eds.), *Handbook of adolescent psychology* (2nd ed., pp. 587–626). Hoboken, NJ: Wiley.
- Greco, P., Pendley, J. S., McDonnell, K., & Reeves, G. (2001). A peer group intervention for adolescents with type 1 diabetes and their best friends. *Journal of Pediatric Psychology*, 26(8), 485–490. doi:10.1093/jpepsy/26.8.485.
- Grey, M., Cameron, M. E., & Thurber, F. W. (1991). Coping and adaptation in children with diabetes. *Nursing research*, 40(3), 144–148. doi:10.1097/00006199-199105000-00004.
- Haase, J. E. (2004). The Adolescent Resilience Model as a guide to interventions. *Journal of Pediatric Oncology Nursing*, 21, 289–299. doi:10.1177/1043454204267922.
- Halfon, N., & Newacheck, P. W. (2010). Evolving notions of childhood chronic illness. *The Journal of the American Medical Association*, 303(7), 665–666. doi:10.1001/jama.2010.130.
- Hall, D. K. (2010). *Compendium of selected resilience and related measures for children and youth*. Toronto, ON, Canada: The Child and Family Partnership.
- Harnall, K. M., Heard, T. R., Inder, K. J., McGill, K. M., & Kay-Lambkin, F. (2014). The Child Illness and Resilience Program (CHiRP): A study protocol of a stepped care intervention to improve the resilience and wellbeing of families living with childhood chronic illness. *Biomed Central Psychology*, 2(5), 1–10. doi:10.1186/2050-7283-2-5.
- Harter, S. (1999). *The construction of the self: A developmental perspective*. New York, NY: Guilford.
- Helgeson, V. S., Lopez, L. C., & Kamarck, T. (2009). Peer relationships and diabetes: Retrospective and ecological momentary assessment approaches. *Health Psychology*, 28(3), 273–282. doi:10.1037/a0013784.
- Helgeson, V. S., Reynolds, K. A., Shestak, A., & Wei, S. (2006). Brief report: Friendships of adolescents with and without diabetes. *Journal of Pediatric Psychology*, 31(2), 194–199. doi:10.1093/jpepsy/31.2.194.
- Helms, S. W., Dellon, E. P., & Prinstein, M. J. (2015). Friendship quality and health-related outcomes among adolescents with cystic fibrosis. *Journal of Pediatric Psychology*, 40(3), 349–358. doi:10.1093/jpepsy/jsu063.
- Hill, N. E., Bromell, L., Tyson, D. F., & Flint, R. (2007). Ecological perspectives on parental influences during adolescence. *Journal of Clinical Child and Adolescent Psychology*, 36(3), 367–377. doi:10.1080/15374410701444322.
- Hill, J. P., & Holmbeck, G. N. (1986). Attachment and autonomy during adolescence. *Annals of Child Development*, 3, 145–189.
- Hilliard, M. E., Ernst, M. M., Gray, W. N., Saeed, S. A., & Cortina, S. (2012). Adapting pediatric psychology interventions: Lessons learned in treating families from the Middle East. *Journal of Pediatric Psychology*, 37(8), 882–892. doi:10.1093/jpepsy/jsr084.

- Hocking, M. C., Barnes, M., Shaw, C., Lochman, J. E., Madan-Swain, A., & Saeed, S. (2011). Executive function and attention regulation as predictors of coping success in youth with functional abdominal pain. *Journal of Pediatric Psychology*, *36*(1), 64–73. doi:[10.1093/jpepsy/jsq056](https://doi.org/10.1093/jpepsy/jsq056).
- Holbein, C. E., Murray, C. B., Psihogios, A. M., Wasserman, R. M., Essner, B. S., O'Hara, L. K., & Holmbeck, G. N. (2013). A camp-based psychosocial intervention to promote independence and social function in individuals with spina bifida: Moderators of treatment effectiveness. *Journal of Pediatric Psychology*, *38*(4), 412–424. doi: [10.1093/jpepsy/jst003](https://doi.org/10.1093/jpepsy/jst003).
- Holmbeck, G. N., Coakley, R. M., Hommeyer, J. S., Shapera, W. E., & Westhoven, V. C. (2002). Observed and perceived dyadic and systemic functioning in families of preadolescents with spina bifida. *Journal of Pediatric Psychology*, *27*(2), 177–189. doi:[10.1093/jpepsy/27.2.177](https://doi.org/10.1093/jpepsy/27.2.177).
- Holmbeck, G. N., DeLucia, C., Essner, B., Kelly, L., Zebracki, K., Friedman, D., & Jandasek, B. (2010). Trajectories of psychosocial adjustment in adolescents with spina bifida: A 6-year, four-wave longitudinal follow-up. *Journal of Consulting and Clinical Psychology*, *78*(4), 511–525. doi:[10.1037/a0019599](https://doi.org/10.1037/a0019599).
- Holmbeck, G. N., Shapera, W., & Hommeyer, J. S. (2002). Observed and perceived parenting behaviors and psychosocial adjustment in pre-adolescents with spina bifida. In B. K. Barber (Ed.), *Intrusive parenting: How psychological control affects children and adolescents* (pp. 191–234). Washington, DC: American Psychological Association.
- Hood, K. K., Huestis, S., Maher, A., Butler, D., Volkening, L., & Laffel, L. M. B. (2006). Depressive symptoms in children and adolescents with Type 1 diabetes: Association with diabetes-specific characteristics. *Diabetes Care*, *29*(6), 1389–1391. doi:[10.2337/dc06-0087](https://doi.org/10.2337/dc06-0087).
- Jaser, S. S., & White, L. E. (2011). Coping and resilience in adolescents with type 1 diabetes. *Child: Care, Health and Development*, *37*(3), 335–342. doi:[10.1111/j.1365-2214.2010.01184.x](https://doi.org/10.1111/j.1365-2214.2010.01184.x).
- Johnson, G., Kent, G., & Leather, J. (2004). Strengthening the parent-child relationship: A review of family interventions and their use in medical setting. *Child: Care, Health and Development*, *31*(1), 25–32. doi:[10.1111/j.1365-2214.2005.00446.x](https://doi.org/10.1111/j.1365-2214.2005.00446.x).
- Jones, J. M., Lawson, M. I., Daneman, D., Olmsted, M. P., & Rodin, G. (2000). Eating disorders in adolescent females with and without Type 1 diabetes: Cross sectional study. *British Medical Journal*, *320*, 1563–1566. doi:[10.1136/bmj.320.7249.1563](https://doi.org/10.1136/bmj.320.7249.1563).
- Kazak, A. E., Rourke, M. T., & Navsaria, N. (2009). Families and other systems in pediatric psychology. In M. C. Roberts & R. G. Steele (Eds.), *Handbook of pediatric psychology* (4th ed., pp. 656–671). New York, NY: Guilford.
- Keating, D. P. (2004). Puberty and psychological development. In R. M. Lerner & L. Steinberg's (Eds.), *Handbook of adolescent psychology* (2nd ed., pp. 45–84). Hoboken, NJ: Wiley.
- Kessler, R. C., Avenevoli, S., & Merikangas, K. R. (2001). Mood disorders in children and adolescents: An epidemiologic perspective. *Biological Psychiatry*, *49*(12), 1002–1014. doi:[10.1016/S0006-3223\(01\)01129-5](https://doi.org/10.1016/S0006-3223(01)01129-5).
- Kim, D. H., & Yoo, I. Y. (2010). Factors associated with resilience of school age children with cancer. *Journal of Paediatrics and Child Health*, *46*(7–8), 431–436. doi:[10.1111/j.1440-1754.2010.01749.x](https://doi.org/10.1111/j.1440-1754.2010.01749.x).
- Klassen, A., Raina, P., Reineking, S., Dix, D., Pritchard, S., & O'Donnell, M. (2007). Developing a literature base to understand the caregiving experience of parents of children with cancer: A systematic review of factors related to parental health and well-being. *Supportive Care in Cancer*, *15*(7), 807–818. doi:[10.1007/s00520-007-0243-x](https://doi.org/10.1007/s00520-007-0243-x).
- Kliwer, W., & Lewis, H. (1995). Family influences on coping processes in children and adolescents with sickle cell disease. *Journal of Pediatric Psychology*, *20*(4), 511–525. doi:[10.1093/jpepsy/20.4.511](https://doi.org/10.1093/jpepsy/20.4.511).
- Knafl, K. A., & Gilliss, C. L. (2002). Families and chronic illness: A synthesis of current research. *Journal of Family Nursing*, *8*(3), 178–198.
- Kovacs, M., Goldston, D., Obrosky, D. S., & Bonar, L. K. (1997). Psychiatric disorders in youths with IDDM: Rates and risk factors. *Diabetes Care*, *20*(1), 36–44. doi:[10.2337/diacare.20.1.36](https://doi.org/10.2337/diacare.20.1.36).

- La Greca, A. M. (1990). Social consequences of pediatric conditions: Fertile area for future investigation and intervention? *Journal of Pediatric Psychology, 15*(3), 285–307. doi:[10.1093/jpepsy/15.3.285](https://doi.org/10.1093/jpepsy/15.3.285).
- La Greca, A. M., Bearman, K. J., & Moore, H. (2002). Peer relations of youth with pediatric conditions and health risks: Promoting social support and healthy lifestyles. *Developmental and Behavioural Pediatrics, 23*(4), 271–280. doi:[10.1097/00004703-200208000-00013](https://doi.org/10.1097/00004703-200208000-00013).
- La Greca, A. M., & Mackey, E. R. (2009). Adherence to pediatric treatment regimens. In M. C. Roberts & R. G. Steele (Eds.), *Handbook of pediatric psychology* (4th ed., pp. 130–152). New York, NY: Guilford.
- Larson, R., & Richards, M. H. (1991). Daily companionship in late childhood and early adolescence: Changing developmental contexts. *Child Development, 62*(2), 284–300. doi:[10.1111/j.1467-8624.1991.tb01531.x](https://doi.org/10.1111/j.1467-8624.1991.tb01531.x).
- Lavigne, J. V., & Faiers-Routman, J. (1992). Psychological adjustment to pediatric physical disorders: A meta-analytic review. *Journal of Pediatric Psychology, 17*(2), 133–157. doi:[10.1093/jpepsy/17.2.133](https://doi.org/10.1093/jpepsy/17.2.133).
- Law, E. F., Fisher, E., Fales, J., Noel, M., & Eccleston, C. (2014). Systematic review and meta-analysis of parent and family-based interventions for children and adolescents with chronic medical conditions. *Journal of Pediatric Psychology, 39*(8), 866–886. doi:[10.1093/jpepsy/jsu032](https://doi.org/10.1093/jpepsy/jsu032).
- Lazarus, R. S., & Folkman, S. (1987). Transactional theory and research on emotions and coping. *European Journal of Personality, 1*(3), 141–169. doi:[10.1002/per.2410010304](https://doi.org/10.1002/per.2410010304).
- Lemaneck, K. L., Horwitz, W., & Ohene-Frempong, K. (1994). A multiperspective investigation of social competence in children with sickle cell disease. *Journal of Pediatric Psychology, 19*(4), 443–456. doi:[10.1093/jpepsy/19.4.443](https://doi.org/10.1093/jpepsy/19.4.443).
- Lemaneck, K. L., & Ranalli, M. (2009). Sickle cell disease. In M. C. Roberts & R. G. Steele (Eds.), *Handbook of pediatric psychology* (4th ed., pp. 303–318). New York, NY: Guilford.
- Lennon, J. M., Murray, C. B., Bechtel, C. F., & Holmbeck, G. N. (2015). Resilience and disruption in observed family interactions in youth with and without spina bifida: An eight-year, five-wave longitudinal study. *Journal of Pediatric Psychology, 40*(9), 943–955. doi: [10.1093/jpepsy/jsv033](https://doi.org/10.1093/jpepsy/jsv033).
- Letourneau, N., Stewart, M., Masuda, J. R., Anderson, S., Cicutto, L., McGhan, S., & Watt, S. (2012). Impact of online support for youth with asthma and allergies: Pilot study. *Journal of Pediatric Nursing, 27*(1), 65–73. doi:[10.1016/j.pedn.2010.07.007](https://doi.org/10.1016/j.pedn.2010.07.007).
- Lewis, H. A., & Kliever, W. (1996). Hope, coping, and adjustment among children with sickle cell disease: Tests of mediator and moderator models. *Journal of Pediatric Psychology, 21*(1), 25–41. doi:[10.1093/jpepsy/21.1.25](https://doi.org/10.1093/jpepsy/21.1.25).
- Luther, S. (1991). Vulnerability and resilience: A study of high-risk adolescents. *Child Development, 62*(3), 600–616. doi:[10.2307/1131134](https://doi.org/10.2307/1131134).
- Mackner, L. M., & Crandall, W. V. (2006). Brief report: Psychosocial adjustment in adolescents with inflammatory bowel disease. *Journal of Pediatric Psychology, 31*(3), 281–285. doi:[10.1093/jpepsy/jsj023](https://doi.org/10.1093/jpepsy/jsj023).
- Martinez, W., Carter, J. S., & Legato, L. J. (2011). Social competence in children with chronic illness: A meta-analytic review. *Journal of Pediatric Psychology, 36*(8), 878–890. doi:[10.1093/jpepsy/jsr035](https://doi.org/10.1093/jpepsy/jsr035).
- Masten, A., Best, K., & Garmezy, N. (1990). Resilience and development: Contributions from the study of children who overcome adversity. *Development and Psychopathology, 2*(4), 425–444. doi:[10.1017/S0954579400005812](https://doi.org/10.1017/S0954579400005812).
- McCarroll, E. M., Lindsey, E. W., MacKinnon-Lewis, C., Chambers, J. C., & Frabutt, J. M. (2009). Health status and peer relationships in early adolescence: The role of peer contact, self-esteem, and social anxiety. *Journal of Child and Family Studies, 18*(4), 473–485. doi:[10.1007/s10826-008-9251-9](https://doi.org/10.1007/s10826-008-9251-9).
- McCubbin, H. I., McCubbin, M. A., Patterson, J. M., Cauble, A. E., Wilson, L. R., & Warlick, W. (1983). CHIP-coping health inventory for parents: An assessment of parental coping patterns in the care of the chronically ill child. *Journal of Marriage and the Family, 45*(2), 359–370. doi:[10.2307/351514](https://doi.org/10.2307/351514).

- McCubbin, H. I., McCubbin, M. A., Thompson, A. I., Han, S. Y., & Allen, C. T. (1997). Families under stress: What makes them resilient. *Journal of Family and Consumer Sciences*, *89*, 2–11.
- McLone, D. G., & Ito, J. (1998). *An introduction to spina bifida*. Chicago, IL: Children's Memorial Hospital MM Team.
- Michaud, P. A., Suris, J., & Viner, R. (2007). *The adolescent with a chronic condition: Epidemiology, developmental issues and health care provisions*. Geneva, Switzerland: World Health Organization.
- Modi, A. C., Marciel, K. K., Slater, S. K., Drotar, D., & Quittner, A. L. (2008). The influence of parental supervision on medical adherence in adolescents with cystic fibrosis: Developmental shifts from pre to late adolescence. *Children's Health Care*, *37*(1), 78–92. doi:[10.1080/02739610701766925](https://doi.org/10.1080/02739610701766925).
- Moos, R. H., & Moos, B. S. (1994). *Family Environment Scale manual: Development, applications, research* (3rd ed.). Palo Alto, CA: Consulting Psychologists Press.
- Murphy, N. A., & Carbone, P. S. (2008). Promoting the participation of children with disabilities in sports, recreation, and physical activities. *Pediatrics*, *121*(5), 1057–1061. doi:[10.1542/peds.2008-0566](https://doi.org/10.1542/peds.2008-0566).
- Nadeau, L., & Tessier, R. (2009). Social adjustment at school: Are children with cerebral palsy perceived more negatively by their peers than other at-risk children? *Disability and Rehabilitation*, *31*(4), 302–308. doi:[10.1080/09638280801945899](https://doi.org/10.1080/09638280801945899).
- Nassau, J. H., & Drotar, D. (1997). Social competence among children with central nervous system-related chronic health conditions: A review. *Journal of Pediatric Psychology*, *22*(6), 771–793.
- Newacheck, P. W., Hung, Y. Y., & Wright, K. K. (2002). Racial and ethnic disparities in access to care for children with special health care needs. *Ambulatory Pediatrics*, *2*(4), 247–254. doi:[10.1367/1539-4409\(2002\)002<0247:RAEDIA>2.0.CO;2](https://doi.org/10.1367/1539-4409(2002)002<0247:RAEDIA>2.0.CO;2).
- Noll, R. B., Vannatta, K., Koontz, K., Kalinyak, K., Bukowski, W. F., & Davies, W. H. (1996). Peer relationships and emotional well-being of youngsters with sickle cell disease. *Child Development*, *67*(2), 423–436. doi:[10.1111/j.1467-8624.1996.tb01743.x](https://doi.org/10.1111/j.1467-8624.1996.tb01743.x).
- Odar, C., Canter, K. S., & Roberts, M. C. (2013). Relationship between camp attendance and self-perceptions in children with chronic health conditions: A meta-analysis. *Journal of Pediatric Psychology*, *38*(4), 398–411. doi:[10.1093/jpepsy/jss176](https://doi.org/10.1093/jpepsy/jss176).
- Ogden, C. L., Carroll, M. D., Curtin, L. R., Lamb, M. M., & Flegal, K. M. (2010). Prevalence of high body mass index in US children and adolescents, 2007–2008. *The Journal of the American Medical Association*, *303*(3), 242–249. doi:[10.1001/jama.2009.2012](https://doi.org/10.1001/jama.2009.2012).
- Olsson, C. A., Boyce, M. F., Toumbourou, J. W., & Sawyer, S. M. (2005). The role of peer support in facilitating psychosocial adjustment to chronic illness in adolescence. *Clinical Child Psychology and Psychiatry*, *10*(1), 78–87. doi:[10.1177/1359104505048793](https://doi.org/10.1177/1359104505048793).
- Pai, A. L., Greenley, R. N., Lewandowski, A., Drotar, D., Youngstrom, E., & Peterson, C. C. (2007). A meta-analytic review of the influence of pediatric cancer on parent and family functioning. *Journal of Family Psychology*, *21*(3), 407–415. doi:[10.1037/0893-3200.21.3.407](https://doi.org/10.1037/0893-3200.21.3.407).
- Pai, A. L. H., & Schwartz, L. A. (2011). Introduction to the special issue: Health care transitions of adolescents and young adults with pediatric chronic conditions. *Journal of Pediatric Psychology*, *36*(2), 129–133. doi:[10.1093/jpepsy/jsq100](https://doi.org/10.1093/jpepsy/jsq100).
- Palermo, T. M., & Eccleston, C. (2009). Parents of children and adolescents with chronic pain. *Pain*, *146*(1–2), 15–17. doi:[10.1016/j.pain.2009.05.009](https://doi.org/10.1016/j.pain.2009.05.009).
- Palladino, D. K., & Helgeson, V. S. (2012). Friends or foes? A review of peer influence on self-care and glycemic control in adolescents with type 1 diabetes. *Journal of Pediatric Psychology*, *37*(5), 591–603. doi:[10.1093/jpepsy/jss009](https://doi.org/10.1093/jpepsy/jss009).
- Parker, S. E., Mai, C. T., Canfield, M. A., Rickard, R., Wang, Y., Meyer, R. E., ... Correa, A. (2010). Updated national birth prevalence estimates for selected birth defects in the United States, 2004–2006. *Birth Defects Research Part A: Clinical and Molecular Teratology*, *88*(12), 1008–1016. doi:[10.1002/bdra.20735](https://doi.org/10.1002/bdra.20735).

- Patient Protection and Affordable Care Act of 2010 (Pub L No. 111-148). Retrieved August 17, 2014, from [www.gpo.gov/fdsys/pkg/BILLS-111hr3590enr/pdf/BILLS-111hr3590enr.pdf](http://www.gpo.gov/fdsys/pkg/BILLS-111hr3590enr/pdf/BILLS-111hr3590enr.pdf).
- Patterson, J. M. (2002). Understanding family resilience. *Journal of Clinical Psychology*, 58(3), 233–246. doi:10.1002/jclp.10019.
- Pereira, M. G., Berg-Cross, L., Almeida, P., & Machado, J. C. (2008). Impact of family environment and support on adherence, metabolic control, and quality of life in adolescents with diabetes. *International Journal of Behavioral Medicine*, 15(3), 187–193. doi:10.1080/10705500802222436.
- Perlman, J. L., & Routh, D. K. (1980). Stigmatizing effects of a child's wheelchair in successive and simultaneous interactions. *Journal of Pediatric Psychology*, 5(1), 43–55. doi:10.1093/jpepsy/5.1.43.
- Petteway, R. J., Valerio, M. A., & Patel, M. R. (2011). What about your friends? Exploring asthma-related peer interactions. *Journal of Asthma*, 48(4), 393–399. doi:10.3109/02770903.2011.563807.
- Pinquart, M. (2013). Do the parent–child relationship and parenting behaviors differ between families with a child with and without chronic illness? A meta-analysis. *Journal of Pediatric Psychology*, 38(7), 708–721. doi:10.1093/jpepsy/jst020.
- Pinquart, M., & Teubert, D. (2012). Academic, physical, and social function of children and adolescents with chronic physical illness: A meta-analysis. *Journal of Pediatric Psychology*, 37(4), 376–389. doi:10.1093/jpepsy/jsr106.
- Psihogios, A. M., & Holmbeck, G. N. (2013). Discrepancies in mother and child perceptions of spina bifida medical responsibilities during the transition to adolescence: Associations with family conflict and medical adherence. *Journal of Pediatric Psychology*, 38(8), 859–870. doi:10.1093/jpepsy/jst047.
- Quittner, A. L., Barker, D. H., Marciel, K. K., & Grimley, M. E. (2009). Cystic fibrosis: A model for drug discovery and patient care. In M. C. Roberts & R. G. Steele (Eds.), *Handbook of pediatric psychology* (4th ed., pp. 271–286). New York, NY: Guilford.
- Quittner, A. L., Romero, S. L., Blackwell, L. S., Romero, C. V., Marciel, K. K., Dawkins, K., ... Martinez, J. (2012). Preliminary data on the efficacy of an online social network for adolescents with CF: Age and health severity group comparisons. *Pediatric Pulmonology*, 35(Suppl.), 388.
- Reiter-Purtill, J., Gerhardt, C. A., Vannatta, K., Passo, M. H., & Noll, R. B. (2003). A controlled longitudinal study of the social functioning of children with juvenile rheumatoid arthritis. *Journal of Pediatric Psychology*, 28(1), 17–28. doi:10.1093/jpepsy/28.1.17.
- Reiter-Purtill, J., Vannatta, K., Gerhardt, C. A., Correll, J., & Noll, R. B. (2003). A controlled longitudinal study of the social functioning of children who completed treatment of cancer. *Journal of Pediatric Hematology/Oncology*, 25(6), 467–473.
- Reynolds, N., Mrug, S., Hensler, M., Guion, K., & Madan-Swain, A. (2014). Spiritual coping and adjustment in adolescents with chronic illness: A 2-year prospective study. *Journal of Pediatric Psychology*, 39(5), 542–551. doi:10.1093/jpepsy/jsu011.
- Rolland, J. S., & Walsh, F. (2006). Facilitating family resilience with childhood illness and disability. *Current Opinion in Pediatrics*, 18(5), 527–538. doi:10.1097/01.mop.0000245354.83454.68.
- Rose, B. M., & Holmbeck, G. N. (2007). Attention and executive function in adolescents with spina bifida. *Journal of Pediatric Psychology*, 32(8), 983–994. doi:10.1093/jpepsy/jsm042.
- Rutter, M. (1985). Resilience in the face of adversity: Protective factors and resistance to psychiatric disorder. *The British Journal of Psychiatry*, 147, 598–611. doi:10.1192/bjp.147.6.598.
- Seid, M. (2008). Barriers to care and primary care for vulnerable children with asthma. *Pediatrics*, 122, 994–1002. doi:10.1542/peds.2007-3114.
- Seid, M., Oipari-Arrigan, L., & Sobo, E. J. (2009). Families' interactions with the health care system: Interactions for pediatric psychology. In M. C. Roberts & R. G. Steele (Eds.), *Handbook of pediatric psychology* (4th ed., pp. 703–718). New York, NY: Guilford.

- Seid, M., Sobo, E. J., Zivkovic, M., Nelson, M., & Davodi-Far, M. (2003). Conceptual models of quality care and health-related quality of life for vulnerable children. In E. J. Sobo & P. S. Kurtin (Eds.), *Child health services research: Application, innovation and insights* (pp. 243–274). San Francisco, CA: Jossey-Bass.
- Shah, S., Peat, J. K., Mazurski, E. J., Wang, H., Sindhusake, D., Bruce, C., ... Gibson, P. G. (2001). Effect of peer led programme for asthma education in adolescents: Cluster randomised controlled trial. *British Medical Journal*, *322*(7286), 583–585. doi:[10.1136/bmj.322.7286.583](https://doi.org/10.1136/bmj.322.7286.583).
- Shapiro, E. R. (2002). Chronic illness as a family process: A social-developmental approach to promoting resilience. *Journal of Clinical Psychology*, *58*(11), 1375–1384.
- Sharpe, D., & Rossiter, L. (2002). Siblings of children with a chronic illness: A meta-analysis. *Journal of Pediatric Psychology*, *27*(8), 699–710. doi:[10.1093/jpepsy/27.8.699](https://doi.org/10.1093/jpepsy/27.8.699).
- Smith, J. M., Martz, K., & Blydt-Hansen, T. D. (2013). Pediatric kidney transplant practice patterns and outcome benchmarks, 1987–2010: A report of the North American Pediatric Renal Trials and Collaborative Studies. *Pediatric Transplant*, *17*(2), 149–157. doi:[10.1111/ptr.12034](https://doi.org/10.1111/ptr.12034).
- Soliday, E., Kool, E., & Lande, M. B. (2000). Psychosocial adjustment in children with kidney disease. *Journal of Pediatric Psychology*, *25*(2), 93–103. doi:[10.1093/jpepsy/25.2.93](https://doi.org/10.1093/jpepsy/25.2.93).
- Spirito, A., Stark, L. J., Gil, K. M., & Tyc, V. L. (1995). Coping with everyday and disease-related stressors by chronically ill children and adolescents. *Journal of the American Academy of Child and Adolescent Psychiatry*, *34*(3), 283–290.
- Stam, H., Grootenhuys, M. A., & Last, B. F. (2001). Social and emotional adjustment in young survivors of childhood cancer. *Supportive Care in Cancer*, *9*(7), 489–513.
- Stancin, T., & Perrin, E. C. (2014). Psychologists and pediatricians: Opportunities for collaboration in primary care. *American Psychologist*, *69*(4), 332–343. doi:[10.1037/a0036046](https://doi.org/10.1037/a0036046).
- Steinberg, L. (2010). *Adolescence* (9th ed.). New York, NY: McGraw-Hill.
- Steinberg, L., & Morris, A. S. (2001). Adolescent development. *Annual Review of Psychology*, *52*(1), 83–110. doi:[10.1146/annurev.psych.52.1.83](https://doi.org/10.1146/annurev.psych.52.1.83).
- Stepansky, M. A., Roache, C. R., Holmbeck, G. N., & Schultz, K. (2010). Medical adherence in young adolescents with spina bifida: Longitudinal associations with family functioning. *Journal of Pediatric Psychology*, *35*(2), 167–176. doi:[10.1093/jpepsy/jsp054](https://doi.org/10.1093/jpepsy/jsp054).
- Stokes, A., Bawden, H. N., Camfield, P. R., Backman, J. E., & Dooley, J. M. (1991). Peer problems in Tourette's disorder. *Pediatrics*, *87*(6), 936–942.
- Susman, E. J., & Rogel, A. (2004). Puberty and psychological development. In R. M. Lerner & L. Steinberg's (Eds.), *Handbook of adolescent psychology* (2nd ed., pp. 15–44). Hoboken, NJ: Wiley.
- Tamis-LeMonda, C. S., Hughes, D., Yoshikawa, H., Kalman, R. K., & Niwa, E. Y. (2008). Parents' goals for children: The dynamic coexistence of individualism and collectivism in cultures and individuals. *Social Development*, *7*(1), 183–209. doi:[10.1111/j.1467-9507.2007.00419.x](https://doi.org/10.1111/j.1467-9507.2007.00419.x).
- Taylor, H. G., Yeates, K. O., Wade, S. L., Drotar, D., Stancin, T., & Minich, N. (2002). A prospective study of short- and long-term outcomes after traumatic brain injury in children: Behavior and achievement. *Neuropsychology*, *16*(1), 15–27. doi:[10.1037//0894-4105.16.1.15](https://doi.org/10.1037//0894-4105.16.1.15).
- Tinsley, B. J., Castro, C. N., Ericksen, A. J., Kwasman, A., & Ortiz, R. V. (2002). Health promotion for parents. In M. H. Bornstein (Ed.), *Handbook of parenting* (2nd ed., Vol. 5). Mahwah, NJ: Lawrence Erlbaum.
- Ungar, M., Ghazinour, M., & Richter, J. (2013). Annual research review: What is resilience within the social ecology of human development? *The Journal of Child Psychology and Psychiatry*, *54*(4), 348–366. doi:[10.1111/jcpp.12025](https://doi.org/10.1111/jcpp.12025).
- Van Campen, K. S., & Russell, S. T. (2010). *Cultural differences in parenting practices: What Asian American families can teach us* (Frances McClelland Institute for Children, Youth, and Families ResearchLink 2, No. 1). Tucson, AZ: The University of Arizona.
- Van Cleave, J., Gortmaker, S. L., & Perrin, J. M. (2010). Dynamics of obesity and chronic health conditions among children and youth. *Journal of the American Medical Association*, *303*(7), 623–630. doi:[10.1001/jama.2010.104](https://doi.org/10.1001/jama.2010.104).

- van der Lee, J. H., Mokkink, L. B., Grootenhuis, M.A., Heymans, H. S. & Offringa, M. (2007). Definitions and measurement of chronic health conditions in childhood. *Journal of the American Medical Association*, 297(24), 2741–2751. doi:[10.1001/jama.2010.297.24.2741](https://doi.org/10.1001/jama.2010.297.24.2741).
- Wallace, M. L., Harcourt, D., Rumsey, N., & Foot, A. (2007). Managing appearance changes resulting from cancer treatment: Resilience in adolescent females. *Psycho-Oncology*, 16(11), 1019–1027. doi:[10.1002/pon.1176](https://doi.org/10.1002/pon.1176).
- Wallander, J., & Varni, J. W. (1998). Effects of pediatric chronic physical disorder on child and family adjustment. *Journal of Child Psychology and Psychiatry*, 39(1), 29–46. doi:[10.1111/1469-7610.00302](https://doi.org/10.1111/1469-7610.00302).
- Wallander, J. L., Varni, J. W., Babani, L., Banis, H. T., & Wilcox, K. T. (1989). Family resources as resistance factors for psychological maladjustment in chronically ill and handicapped children. *Journal of Pediatric Psychology*, 14(2), 157–173. doi:[10.1093/jpepsy/14.2.157](https://doi.org/10.1093/jpepsy/14.2.157).
- Ward, E., De Santis, C., Robbins, A., Kohler, B., & Jemal, A. (2014). Childhood and adolescent cancer statistics, 2014. *CA: A Cancer Journal for Clinicians*, 64(2), 83–103. doi:[10.3322/caac.21219](https://doi.org/10.3322/caac.21219).
- Weiss, K. B., Sullivan, S. D., & Lyttle, C. S. (2006). Trends in the cost of illness for asthma in the United States, 1985–1994. *Journal of Allergy and Clinical Immunology*, 106(3), 493–499. doi:[10.1067/mai.2000.109426](https://doi.org/10.1067/mai.2000.109426).
- Wiegerink, D. J. H. G., Roebroek, M. E., Donkervoort, M., Stam, H. J., & Cohen-Kettenis, P. T. (2006). Social and sexual relationships of adolescents and young adults with cerebral palsy: A review. *Clinical Rehabilitation*, 20(12), 1023–1031. doi:[10.1177/0269215506071275](https://doi.org/10.1177/0269215506071275).
- Williams, P. G., Holmbeck, G. N., & Greenly, R. N. (2002). Adolescent health psychology. *Journal of Consulting and Clinical Psychology*, 70(3), 828–842. doi:[10.1037//0022-006X.70.3.828](https://doi.org/10.1037//0022-006X.70.3.828).
- Windle, G., Bennet, K. M., & Noyes, J. (2011). A methodological review of resilience measure scales. *Health and Quality of Life Outcomes*, 9(8), 1–18. doi:[10.1186/1477-7525-9-8](https://doi.org/10.1186/1477-7525-9-8).
- Wu, L., Sheen, J., Shu, H., Chang, S., & Hsiao, C. (2013). Predictors of anxiety and resilience in adolescents undergoing cancer treatment. *Journal of Advanced Nursing*, 69(1), 158–166. doi:[10.1111/j.1365-2648.2012.06003.x](https://doi.org/10.1111/j.1365-2648.2012.06003.x).
- Wysocki, T., Miller, K. M., Greco, P., Harris, M. A., Harvey, L. M., Taylor, A., ... White, N. H. (1999). Behavior therapy for families of adolescents with diabetes: Effects on directly observed family interactions. *Behavior Therapy*, 30(3), 507–525. doi:[10.1016/S0005-7894\(99\)80022-7](https://doi.org/10.1016/S0005-7894(99)80022-7).
- Yeo, M., & Sawyer, S. (2005). Chronic illness and disability. *British Medical Journal*, 330(7493), 721–723. doi:[10.1136/bmj.330.7493.721](https://doi.org/10.1136/bmj.330.7493.721).