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## Coping with Chronic Illness in Childhood and Adolescence

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### Abstract

Chronic illnesses and medical conditions present millions of children and adolescents with significant stress that is associated with risk for emotional and behavioral problems and interferes with adherence to treatment regimens. We review research on the role of child and adolescent coping with stress as an important feature of the process of adaptation to illness. Recent findings support a control-based model of coping that includes primary control or active coping (efforts to act on the source of stress or one's emotions), secondary control or accommodative coping (efforts to adapt to the source of stress), and disengagement or passive coping (efforts to avoid or deny the stressor). Evidence suggests the efficacy of secondary control coping in successful adaptation to chronic illness in children and adolescents, disengagement coping is associated with poorer adjustment, and findings for primary control coping are mixed. Avenues for future research are highlighted.

### Keywords

Coping; illness; children; adolescents

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Major advances in the diagnosis and treatment of chronic illness in children and adolescents have changed the landscape of clinical pediatrics. Diseases that were once fatal are now successfully treated and children survive at much higher rates than 20 to 30 years ago (Halfon & Newacheck 2010; Mookink et al. 2008). These improved outcomes are based on early detection and diagnosis and powerful methods for the treatment and management of many previously life-threatening diseases. As a consequence, millions of children and adolescents in the United States now live with chronic illnesses and medical conditions including type 1 and type 2 diabetes, cancer, sickle cell disease, asthma, and chronic pain. These illnesses and their treatment present children, adolescents and their parents with significant sources of chronic stress that can contribute to emotional and behavioral problems and can compromise adherence to treatment regimens. Further, many pediatric illnesses are exacerbated by stress encountered in other aspects of children's lives. It is therefore essential to understand the ways that children and adolescents cope with stress to better explicate processes of adaptation to illness and to develop effective interventions to enhance coping and adjustment.

The goal of this review is to highlight recent advances in and findings from research on coping with serious chronic illnesses and medical conditions in childhood and adolescence and to identify important directions to advance work in this field. We begin with an overview of the prevalence of chronic illness in childhood and adolescence and the role of

stress in these conditions. Next we briefly address challenges in defining and measuring coping with illness in young people, highlighting the important role of the perceived and objective controllability of medically-related stress. The central focus of our review is on empirical studies that provide evidence for coping strategies that are effective for children coping the diagnosis, treatment, and long-term effects of chronic illness. Finally, we outline potentially fruitful areas for future work.

We build on a number of reviews on topics related to coping (e.g., Compas et al. 2001; Connor-Smith & Flachsbart 2007; Skinner et al. 2003; Skinner & Zimmer-Gembeck 2007; Taylor & Stanton 2008; Zimmer-Gembeck & Skinner 2011), health psychology (e.g., Miller et al. 2009; Stanton et al. 2007), and specific aspects of adults and children coping with illness (e.g., Aldridge & Roesch 2007; Blount et al. 2008; Moskowitz et al. 2009; Rudolph et al. 1995). These prior reviews provide important background and context for the current examination of coping with chronic illness in the lives of children and adolescents.

## Scope of the Problem: Chronic illness in Childhood and Adolescence

A chronic illness or medical condition is a health problem that lasts three months or more, affects a child's normal activities, and requires frequent hospitalizations, home health care, and/or extensive medical care (Mokkink et al. 2008). Specifically, Van Cleave et al. (2010) define chronic health conditions in a child or adolescent as "any physical, emotional, or mental condition that prevented him or her 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" (p. 624). In general, chronic illnesses are characterized by at least three important features—they are prolonged in their duration, they do not resolve spontaneously, and they are rarely cured completely (Stanton et al. 2007).

Most of the significant chronic illnesses that affect children and adolescents are characterized by an acute phase surrounding the diagnosis of the illness followed by prolonged stress associated with extended treatment, recovery, and survivorship. Each phase of a chronic illness can present children and their families with significant challenges and stressors. However, there is evidence that chronic conditions may exert greater psychological and physical stress than acute illnesses that resolve quickly (Marin et al. 2009). This is consistent with more general models of the adverse effects of chronic stress as a consequence of processes of allostatic load that include the physical and psychological wear and tear associated with prolonged or repeated demands that characterize chronic stress (Juster et al. 2010).

## Prevalence of chronic illness in childhood and adolescence

The importance of children's coping with chronic illness is framed in part by the number of children who are affected by chronic illnesses and medical conditions. Although numbers vary depending on methods and definitions, by any estimate the scope of the problem is enormous. Epidemiologic studies suggest that as many as 1 out of 4 children in the U.S., or 15 to 18 million children age 17 years and younger, suffer from a chronic health problem (Van Cleave et al. 2010; van der Lee et al. 2007). The prevalence of specific diseases and conditions ranges widely. For example, in the U.S. alone over 13,000 children are diagnosed with cancer each year; 13,000 children are diagnosed with type 1 diabetes annually and 200,000 children live with either type 1 or type 2 diabetes; 9 million children suffer from asthma; 72,000 Americans (all ages) live with sickle cell disease; and estimates of pediatric recurrent abdominal pain range from 0.3% to 18% of the population (225,000 to 13,500,000 children). Type 2 diabetes is still extremely rare in children and adolescents (.22 cases per 1,000 youth) but these rates are increasing rapidly with rising obesity rates (Ogden et al.

2010). The scope of the problem is further underscored by the increasing prevalence of chronic illness in children, with the epidemic in childhood obesity driving the increase in a number of other chronic conditions (Van Cleave et al. 2010).

## Stress and Chronic Illness in Young People

Chronic illnesses in childhood and adolescence are both causes of significant stress and are affected by stress in other life domains. For example, a child who has been experiencing headaches and nausea is brought to the emergency room by her parents who assume that she is ill with the flu or another relatively benign condition. The family is shocked when they are told that results of a scan identified a tumor in the posterior portion of her brain. She will undergo immediate surgery to remove the tumor followed by an extensive regimen of cranial radiation therapy. In a second example, the parents of an 11-year-old boy note that he is waking several times each night to urinate. They take him to his pediatrician concerned that he has some form of infection in his bladder only to learn that he has type 1 diabetes. His illness will require daily monitoring of his insulin and glucose levels and radical changes to his diet and daily activities. These two examples reflect the challenges and stressors of serious chronic illnesses, which are often unanticipated, uncontrollable and functionally impairing for children and their parents. Further, the acute medical events surrounding the diagnosis of a serious illness are often the beginning of a long process of treatment and adjustment to a chronic condition. For example, treatment of pediatric cancer can extend for months or years, followed by uncertainty about the threat of recurrence and the impact of often significant late effects in endocrine, cardiac, and neurocognitive function (Robison et al. 2009). The diagnosis of diabetes leads to a life time of monitoring blood glucose levels, administering insulin, restrictions on diet and exercise, and the possibility of significant physical complications. Thus, chronic illnesses present children, adolescents and their parents with the acute stress of a diagnosis followed by long-term chronic stress.

### Coping with what?

Because of the complex array of threats and demands that serious and chronic medical conditions present to children and adolescents it is important to be precise about the types of stress that are the targets of children's coping efforts. This requires careful specification and measurement of the aspects of an illness and its treatment that present stressors and challenges to children and their parents. For example, it is not sufficient to ask how a child copes with diabetes, cancer, or asthma. Each of these conditions includes a range of stressors and challenges for children, adolescents and their families.

Research on the stressful aspects of pediatric cancer provides an informative example. Several studies have focused on stressors faced by children with cancer, and most of these studies have examined levels of general life stress. For example, Currier et al. (2009) examined stressful life events that were not directly related to the child's cancer and found that they predicted posttraumatic stress symptoms (PTSS) in these children. However, relatively few studies have focused directly on cancer-related stressors for children undergoing treatment (e.g., Hockenberry-Eaton et al. 1994; Varni & Katz 1997) or off-treatment (e.g., Kazak et al. 2001; Kazak et al. 1996).

To address this gap, a recent study by Rodriguez et al. (2011, in press) asked 106 children with cancer and their parents to report on cancer-related stressors for the child near the time of diagnosis in three domains: daily role functioning, physical effects of cancer treatment, and uncertainty about cancer. Daily role stressors included missing school days or falling behind in school work, not being able to do the things he/she used to do, having to go to hospital or clinic visits, and concerns about family and friends. Stressors related to cancer treatment involved feeling sick or nauseous from treatments, concerns about changes in

appearance, and pain and soreness from medical procedures. Uncertainty about cancer included stress related to not understanding what doctors say about cancer, feeling confused about what cancer is and its causes, and concerns about the future. This diverse set of stressors may require very different types of coping. For example, coping with missing school and falling behind in school work may be best addressed through active and playful problem solving, whereas acceptance and cognitive reappraisal may be better suited to address changes in physical appearance or cancer-related pain.

Based on both children's and parents' reports, all three types of stress were experienced as moderately to highly stressful and with relatively high frequency for children (Rodriguez et al. 2011, in press). For example, more than half of children and parents rated daily role stressors as somewhat or very stressful for children (Rodriguez et al. 2011, in press). Further, children, mothers and fathers all rated daily role functioning as more stressful than cancer uncertainty for children. These results suggest that near the time of diagnosis children with cancer find impairment in daily roles (e.g., not being able to do the things they used to do) more stressful than uncertainty about their disease. Therefore, daily role stressors may require the mobilization of the greatest efforts to cope than other sources of stress. Child and parent reports of all three types of children's cancer-related stressors were significantly correlated with higher levels of children's reports of PTSS, with correlations ranging from .56 to .62 for child reports and .28 to .46 for parent reports (Rodriguez et al. 2011, in press). These correlations suggest that coping with these stressors may have important implications for children's emotional distress.

## **Coping with Chronic Illness: Fundamental Issues**

### **Defining and conceptualizing coping**

After considerable debate and confusion, some consensus is slowly emerging regarding the definition of coping in children and adolescents. Specifically, coping can be viewed as a collection of purposeful, volitional efforts that are directed at the regulation of aspects of the self and the environment under stress (e.g., Compas et al. 2001; Eisenberg 1997; Skinner & Edge 1998). For example, Eisenberg and colleagues (1997) view coping as "involving regulatory processes in a subset of contexts—those involving stress" (p. 42). Skinner and colleagues define coping as "action regulation under stress" (Skinner & Wellborn 1994), including the ways that people "mobilize, guide, manage, energize, and direct behavior, emotion, and orientation, or how they fail to do so" under stressful conditions (Skinner & Wellborn 1994 p. 113). Compas et al. (2001) define coping as, "conscious and volitional efforts to regulate emotion, cognition, behavior, physiology, and the environment in response to stressful events or circumstances" (p. 89). These definitions reflect important links between coping and the regulation of psychological and physiological processes, including emotion, behavior, and cognition, as well as the efforts to regulate interactions with others and the environment (Skinner & Zimmer-Gembeck 2007).

Current perspectives on coping during childhood and adolescence emphasize the distinction between controlled and automatic processes (Compas et al. 2001; Eisenberg et al. 1997; Skinner et al. 2003; see Rudolph et al. 1995, for an earlier discussion of this distinction). Coping responses comprise a component of a larger set of the ways that children and adolescents respond to stress. Automatic stress responses, represented in research on stress reactivity, include temperamentally based and conditioned ways of reacting to stress including emotional and physiological arousal, automatic thoughts, and conditioned behaviors. Coping responses, in contrast, are controlled and volitional in nature—the things that children and adolescents purposefully do to manage and adapt to stress. Furthermore, coping responses emerge later in development than some more automatic, temperamentally based ways of reacting to stress. Therefore, early temperamental ways of reacting to stress

provide a context or backdrop for the emergence of coping strategies during childhood and adolescence.

### **The central role of controllability**

Extensive evidence suggests that coping responses are not universally effective or ineffective (e.g., Taylor & Stanton 2008). Rather the degree to which a coping strategy leads to better or worse emotional and behavioral adjustment depends in part on the match between the demands of the stressor and the goals and nature of the coping response. In understanding coping with health and illness related stressors, the controllability or perceived controllability of the stressor may be a crucial dimension in determining the efficacy of particular coping strategies (e.g., Osowiecki & Compas 1998, 1999; Park et al. 2001).

In a seminal review of children's coping with medical stressors, Rudolph, Dennig and Weisz (1995) presented a multidimensional model of control and coping that remains central to understanding successful adaptation to chronic illness in childhood and adolescence. Drawing on Weisz and colleagues' model of perceived control (Rothbaum, Weisz, & Snyder 1982; Weisz, Rothbaum, & Blackburn 1984), these authors distinguished among primary control, secondary control and relinquished control as both appraisals of control and as subtypes of coping. As outlined by Rudolph et al., primary control refers to coping efforts that are intended to influence objective events or conditions. In contrast, secondary control involves coping aimed at maximizing one's fit to current conditions and relinquished control refers to the absence of any coping attempt. Rudolph et al. note that this framework encompasses both coping responses and coping goals. A coping response is defined as an intentional action, initiated in response to a perceived stressor, which is directed toward either external circumstances or an internal state. A coping goal is defined as the objective or intent of a coping response, which generally entails some form of stress reduction or reduction in some aversive aspect of a stressor. Both coping responses and coping goals can be organized around the perceived or actual controllability of the source of stress.

### **Dimensions, categories and the structure of coping**

One of the major challenges in theory and research on coping has been the specification of the structure of coping responses. This is due in part to the nature of coping which, as noted by Skinner et al. (2003), is not a specific behavior but rather is a broad organizational construct that includes a wide range of behaviors that individuals use to try to manage stressful experiences. This is reflected in the large number of systems that have been used to distinguish subtypes of coping including problem-focused vs. emotion-focused, approach vs. avoidance, and active vs. passive coping.

In their comprehensive review of over 400 subtypes of coping that have appeared in research on coping, Skinner et al. (2003) identified only four frameworks for classifying subtypes of coping that have been empirically tested and validated (Ayers, et al. 1996; Connor-Smith et al. 2000; Tobin et al. 1989; Walker et al. 1997). It is noteworthy that three of these systems were developed and tested with children and adolescents (Ayers et al. 1996; Connor-Smith et al. 2000; Walker et al. 1997) and two have been applied to child/adolescent coping with illness and chronic illness (Connor-Smith et al. 2000; Walker et al. 1997). Skinner et al. (2003) further note that each of these four frameworks "signifies a major program of research, involving serious conceptualization efforts, measurement work, detailed and complex data analyses, and cross-validations with multiple large samples. Although none is perfect, all four represent guideposts for empirical efforts to search for the structure of coping" (p. 232).

Most relevant to coping with childhood chronic illness, the frameworks of Connor-Smith et al. (2000) and Walker et al. (1997) share several elements in common. First, these empirically supported frameworks include a factor that reflects active or primary control coping, or efforts to directly change the source of stress or one's response to the stressor. Second, these frameworks include a factor related to accommodative or secondary control coping, which includes coping efforts to adapt to stress through reappraisal, positive thinking, acceptance, or distraction. Third, these frameworks include a factor that reflects passive, avoidant or disengagement coping, including both behavioral and cognitive avoidance of the source of stress. These multidimensional frameworks of coping have been widely applied to theory and research on child and adolescent coping with a variety of different types of stress including stressful interactions with peers (e.g., Ayers et al., 1996; Flynn & Rudolph 2007), family conflict (e.g., Wadsworth & Berger 2006), stress associated with parental depression (e.g., Jaser et al. 2008), and stress related to economic hardship (e.g., Wadsworth & Compas 2002). As described below, these coping frameworks have also guided recent research on child and adolescent coping with chronic illness.

### Measurement of coping with pediatric illness and health conditions

A scholarly review of evidence-based measures of coping in pediatric psychology was recently presented by Blount et al. (2008). We will build on this review here and highlight several salient issues in the measure of coping with chronic illness in childhood and adolescence. Blount et al. included general self-report measures of coping (e.g., the Kidcope; Spirito et al. 1988), self-report measures of coping with pain (e.g., the Pediatric Pain Coping Inventory; Varni et al. 1996), and observational measures of coping with pain (e.g., the Child Adult Medical Procedure Interaction Scale; Blount et al. 1989). Because of our focus on chronic illness-related stress, we have not reviewed observational studies of coping with medical procedures and procedural pain. We focus here on two measures of coping in pediatric psychology that reflect the control-based model of coping of Weisz and colleagues (e.g., Rudolph et al. 1995)---the Responses to Stress Questionnaire (RSQ; Connor-Smith et al. 2000) and the Pain Response Inventory (PRI; Walker et al. 1997).

The RSQ was developed to assess primary control engagement coping, secondary control engagement coping, and disengagement coping, as well as automatic engagement and disengagement stress responses that do not reflect coping (Connor-Smith et al. 2000). Primary control coping includes strategies intended to directly change the source of stress (problem solving) or one's emotional reactions to the stressor (emotional expression and emotional modulation). Secondary control coping encompasses efforts to adapt to stress, including cognitive reappraisal, positive thinking, acceptance, and distraction. And disengagement coping includes efforts to orient away from the source of stress or one's reactions to it (avoidance, denial, wishful thinking). The structure of the RSQ has been supported by several confirmatory factor analytic studies with culturally diverse samples coping with a wide range of different types of stress including adolescents coping with recurrent abdominal pain (Compas et al. 2006; Connor-Smith et al. 2000), and coping with interpersonal stress in Spanish (Connor-Smith & Calvete 2004), Euro-American (Connor-Smith et al. 2000), Navajo (Wadsworth et al. 2004), and Chinese adolescents (Yao et al. 2010). The RSQ has been used recently to study coping with diabetes, chronic pain, and cancer (see below).

The PRI is a pain-specific measure of coping that was guided by a three-factor model that includes active, accommodative, and passive coping (Walker et al. 1997). Active coping includes problem-solving, seeking social support, rest, and massage/guard (i.e., physical actions to ease stomach pain). Passive coping includes behavioral disengagement, self-isolation and catastrophizing (which cross-loaded with active coping in the original factor analyses), and stoicism and acceptance (which cross-loaded with accommodative coping in

the original factor analyses). In addition to stoicism and acceptance, accommodative coping includes minimizing pain, self-encouragement, and distract/ignore. The model was supported in confirmatory factor analyses with a sample of children and adolescents with recurrent abdominal pain (Walker et al. 1997).

There is considerable convergence in the factor structures of the RSQ and PRI (Connor-Smith et al. 2000; Wadsworth et al. 2004; Walker et al. 1997). Primary control engagement coping and active coping both include strategies that measure problem solving and seeking social support. Secondary control engagement and accommodative coping both include acceptance, aspects of positive thinking and self-encouragement, and distraction. Finally, disengagement and passive coping include forms of avoidance. On the other hand, the PRI and RSQ differ in their focus, as the RSQ is designed to be adapted to specific stressors or domains of stress whereas the PRI is intended exclusively to assess coping with pain. In addition, the results of several confirmatory factor analyses with the RSQ yielded three independent coping factors with no subscales that cross-loaded (e.g., Connor-Smith et al. 2000; Yao et al. 2010), while the PRI includes four subscales of passive coping that cross-load on active and accommodative coping (Walker et al. 1997). We report findings from studies using these two measures with children with chronic illness below.

Validation of measures of child and adolescent coping with chronic illness is a salient issue, as it is important to establish the degree to which their self-reports of coping are accurate. However, little or no data have been reported that directly address this issue. For example, Blount et al. (2008) presented convergent and predictive validity data for six self-report general coping measures and three self-report pain coping measures. No convergent validity data were reported for six of these nine measures and the convergent validity that was presented was limited to correlations with other self-report measures of coping. As an index of predictive validity, Blount et al. (2008) also presented correlations between measures of coping and measures of emotional distress, pain, and other indicators of adjustment. However, these correlations cannot serve as tests of validity of measures of coping and at the same time be used as tests of hypotheses of the relations between coping and adjustment, as this becomes circular (Compas et al. 2001). Using a different approach, some promising validity data have been presented for the RSQ with children ages 10-years and older. For example, Connor-Smith et al. (2000) reported significant correlations between children's self-reports and parents' reports of their children's coping with chronic pain. Further, Connor-Smith et al. (2000) and Dufton et al. (2011) reported significant correlations between self-reports of disengagement coping and heart rate reactivity and recovery in response to laboratory stress tasks. Cross-informant correlations of children's coping and correlations between children's reports of coping and objective measures of relevant constructs provide encouraging evidence that children can report accurately on their cognitive and behavioral efforts to cope with illness-related stress.

### **Important correlates of coping: Emotional and behavioral problems, adherence, disease course**

In order to test the role of coping in adjustment to chronic illness, several measures of psychological and physical health have been used. Most widely used are measures of emotional distress in children and adolescents, including symptoms of anxiety, depression, and post traumatic stress, including the Child Behavior Checklist and the Youth Self-Report (Achenbach & Rescorla 2001). Studies have less often included measures of disruptive behavior problems such as aggression, delinquency, and oppositional or non-compliant behavior. Assessment of pediatric quality of life (QOL) has been included in some studies, including domains of QOL such as physical functioning, social functioning, and school functioning (e.g., Varni et al. 2002). Finally, a small number of studies have included biomarkers of relevant disease-related processes. For example, in diabetes research, the gold

standard physiological outcome is glycated hemoglobin (hemoglobin A1C), which provides objective criteria of metabolic control over the most recent 8–12 weeks and is routinely measured quarterly in patients with T1D (DCCT Research Group 1986).

The assessment of children's coping and its correlates presents several methodological challenges. Most importantly, the use of the same informant or source of information for both the measurement of coping and important correlates (e.g., emotional problems, QOL) is problematic. When the same source is used to assess both constructs it difficult to extract the contribution of shared method variance to the associations that are found. This problem is compounded when data on coping and its correlates are obtained at the same point in time in cross sectional studies. We consider these issues in our review of empirical studies of coping with chronic illness.

## **Coping with Chronic Illness in Childhood and Adolescence: Empirical Findings**

We now describe empirical research on child/adolescent coping with several chronic illness and conditions, specifically type 1 diabetes, chronic pain, and cancer. We selected these illnesses to highlight recent findings on the relationships between coping and emotional and behavioral problems, pain, functional disability/impairment, and disease processes. Further, we have focused primarily on studies that were guided by the control-based model of Weisz and colleagues outlined above (Rothbaum et al. 1982; Rudolph et al. 1995; Weisz et al. 1984). Our review is not intended to be exhaustive but rather to highlight salient examples of findings on the role of coping in adjustment to pediatric illness and to provide examples of advances in methodology. We have summarized the results of these studies of coping in Table 1.

### **Coping with Diabetes**

Type 1 diabetes (T1D) is one of the most common severe chronic childhood illnesses, affecting 1 in every 400 individuals under the age of 20, and recent research suggests that the incidence is rising (e.g., Gale, 2002; Harjutsalo et al. 2008; Liese, 2006). While maintaining blood glucose levels as close to normal as possible significantly prevents or delays medical complications in adolescents (Diabetes Control and Complications Trial Research Group 1994), the regimen required to maintain metabolic control places substantial demands on youth and their families. The recommended intensive regimen for T1D is complex and demanding, requiring frequent monitoring of blood glucose levels (at least 4 times per day), frequent insulin injections (3–4 times per day or use of an insulin pump), monitoring and controlling carbohydrate intake, altering insulin dose to match diet and activity patterns, and checking urine for ketones when necessary (American Diabetes Association 2011). Further, the peak age of onset is at puberty (National Institute of Diabetes and Digestive and Kidney Diseases, 2002). Adolescence presents additional challenges, as this is a developmental period during which youth are struggling for independence from parents. As adolescents strive for autonomy, parents' attempts to monitor treatment may be viewed as intrusive, which may contribute to increased stress for adolescents and their parents (Weinger et al. 2001). In addition to the stress of treatment management, which is potentially more controllable, adolescents with T1D report experiencing stress related to the uncontrollable aspects of diabetes, such as feeling different from peers and feeling guilty about "bad numbers" (Davidson et al. 2004). Thus, it is important to understand which coping strategies are related to better adaptation to T1D.

Early studies of coping in youth with T1D relied primarily on approach-avoidance and problem- and emotion-focused models of coping. These studies often failed to find a



relationship between approach/avoidance coping and metabolic control (e.g., Hanson et al. 1989; Reid et al. 1994). For example, Hanson et al. (1994) found that a coping factor labeled “utilizing personal and interpersonal resources” was not associated with adherence or levels of HbA1c, while “ventilation/avoidance” coping was related to poorer adherence but not to HbA1c levels. Reid et al. used a measure of coping that was divided into two factors: approach and avoidance. They found that higher levels of approach and lower levels of avoidance coping were associated with better adherence to the diabetes treatment regimen, but that neither approach or avoidance coping was related to elevated HbA1c levels.

Using control-based models of coping, two studies have examined children’s use of several forms of primary and secondary control coping strategies in response to diabetes-related stress. In a study by Band & Weisz (1990), children and adolescents reported on five diabetes stressors (diet, injections, insulin reactions, glucose monitoring, and HbA1c tests) and three non-diabetes concerns, rated how much control they had over each, and listed things they did cope with those stressors. Children’s responses were coded into primary control, secondary control, or relinquished control coping strategies. They found that the use of both primary and secondary control coping strategies was associated with better social and behavioral adjustment in adolescents. Similarly, a recent study by Jaser & White (2011) using the RSQ asked adolescents to report on how they coped with 10 common diabetes stressors (e.g., dealing with diabetes care, feeling different from peers). In their sample, the use of primary control coping strategies was related to better self- and parent-reported social competence, better QOL, and lower HbA1c values. The use of secondary control coping was also related to better parent-reported social competence and QOL, but it was not related to HbA1c. On the other hand, disengagement coping was related to lower self-reported social competence and higher HbA1c values (Jaser & White 2011). In these studies, it is likely that adolescents were reporting on how they coped with both the controllable and uncontrollable aspects of the illness, and therefore, both primary and secondary control coping strategies may be adaptive.

Other studies in adolescents with T1D have used coping measures that can be mapped onto control-based models of coping. For example, Graue and colleagues (2004) used items from several coping measures (the COPE, Ways of Coping Questionnaire, and Life Events and Coping) to measure active coping, planning, seeking social support for emotional reasons, seeking emotional support for instrumental reasons, behavioral disengagement, mental disengagement, accepting responsibility, aggressive coping, and self blame. Similar to the study by Jaser and White (2011) using the RSQ, they found that greater use of behavioral and mental disengagement was associated with higher values of HbA1c (Graue et al. 2004). They also found, however, that the use of planning and instrumental support in youth, strategies similar to those found in primary control coping, was associated with poorer quality of life QOL (Graue et al. 2004). Finally, Edgar & Skinner (2003) used the KidCope to ask adolescents to report on a time when their blood sugar was too high. They found that the use of cognitive restructuring, a type of secondary control coping, was associated with less depression and greater positive well-being. Further, adolescents’ use of social support, a type of primary control coping, was associated with greater positive well-being (Edgar & Skinner 2003). These studies provide further support for the use of both primary and secondary control coping strategies to deal with the stress of T1D.

It is noteworthy that the role of parents in coping may be especially important for diabetes as compared with other illnesses, particularly for primary control coping strategies, such as problem solving. One study examined this relationship by measuring “dyadic coping” (Wiebe et al. 2005). Adolescents described what they did in response to a diabetes-related stressor and assigned each coping strategy to a category that applied to their mother (uninvolved, collaborative, controlling, or supportive). Adolescents who perceived their

mothers as uninvolved had poorer adherence and poorer metabolic control, but those who perceived their mothers as collaborative had better adherence and metabolic control (Wiebe et al. 2003). It will be important for future studies to further tease out the difference between primary control coping strategies, such as problem-solving, and treatment management. As such, the role parents play in supporting, or “scaffolding,” their children’s efforts to cope with illness may need to change over time, much in the same way that parents’ role in treatment management must shift from primary caregiver to collaborative partner (Comeaux & Jaser 2010).

### **Coping with chronic pain**

One of the most common sources of chronic pain in youth is recurrent abdominal pain (RAP), affecting 8–25% of children ages 9–12 (Alfven 2001). Children with RAP report experiencing more daily stressors than well children (Walker et al. 2001), and they often miss school and extracurricular activities because of the pain (Roth-Isigkitet et al. 2005). The pain itself is experienced as stressful (Compas & Boyer 2001), and RAP is highly associated with anxiety (Dufton & Compas 2010). Moreover, chronic pain is often perceived as unpredictable and uncontrollable (Walker et al. 2007). In light of the importance of perceptions of controllability of pain in RAP, several recent studies using the PRI (Walker et al. 1997) and the RSQ (Connor-Smith et al. 2000) are informative.

Four studies using the RSQ have shown that secondary control coping (e.g., acceptance, cognitive reappraisal, distraction) is associated with lower levels of somatic complaints and symptoms of anxiety and depression (Compas et al. 2006; Dufton et al. 2011; Hocking et al. 2011; Thomsen et al. 2002). For example, Hocking et al. (2011) found that the use of secondary control coping strategies to deal with abdominal pain was related to fewer symptoms of self-reported anxiety symptoms. Findings regarding accommodative coping as measured by the PRI have been somewhat less consistent. Walker et al. (1997) found that accommodative coping was related to lower levels of pain, whereas four studies found no association between this scale and indicators of adjustment in children and adolescents with RAP (Kaczynski et al. 2011; Shirkey et al. 2011; Walker et al. 2005, 2007) and one study found that accommodative coping was related to higher levels of somatic symptoms (Simons et al. 2008). These mixed findings regarding secondary control coping as compared with accommodative coping may be a consequence of the structure of these factors on the RSQ and PRI, as the acceptance scale on the accommodative coping factor also loaded onto the passive coping factor on the PRI (Walker et al. 1997). Further, the accommodative coping factor on the PRI does not include cognitive reappraisal, a potentially important type of coping with chronic pain.

On the other hand, studies using the PRI have consistently shown that passive coping (e.g., behavioral disengagement, self-isolation, catastrophizing) is related to poorer adjustment (Kaczynski et al. 2011; Shirkey et al. 2011; Simons et al. 2008; Walker et al. 1997, 2005, 2007). Disengagement coping (e.g., denial, avoidance, wishful thinking) has been associated with higher levels of somatic complaints and anxiety/depression in two studies (Compas et al. 2006; Thomsen et al. 2002) but unrelated to measures of adjustment in two other studies (Dufton et al. 2011; Hocking et al. 2011).

Finally, primary control coping or active coping (both of which include problem-solving and seeking social support) has not been consistently related to adjustment in children and adolescents with RAP. Thomsen et al. (2002) found that primary control was related to lower symptoms of anxiety and depression but higher levels of pain, while three studies found no association between primary control coping and adjustment in children with RAP (Compas et al. 2006; Dufton et al. 2011; Hocking et al. 2011). Active coping on the PRI was related to poorer adjustment in two studies (Simons et al. 2008; Walker et al. 1997) and not

related to adjustment in four studies (Kaczynski et al. 2011; Shirkey et al. 2011; Walker et al. 2005, 2007). Because the stress of RAP (i.e., pain) may be largely uncontrollable or perceived as uncontrollable (Walker et al. 2007), it follows that secondary control, or accommodative, coping strategies may be more effective than primary control or active coping strategies.

Parents also play an important role in how children cope with chronic pain. Parental reinforcement of pain complaints, or solicitousness (e.g., allowing children to skip chores or homework during pain episodes, or giving a child special gifts or privileges during pain episodes) is related to greater school absences (Levy, 2011). Interestingly, parents who experienced irritable bowel syndrome themselves were more likely to respond to their children's pain with solicitousness (Levy, 2011). Similarly, an experimental study found that symptom-related talk from parents during an induced episode of pain was related to greater child somatic complaints (Williams et al. 2011). The child's efforts at coping may be shaped by parental reinforcement.

Research on coping in children and adolescents with RAP has been characterized by several methodological advances over much of the research on coping with pediatric illnesses. First, Shirkey et al. (2011) examined the relative association of dispositional vs. episode-specific measures of coping with adjustment in children with RAP. They found that daily diaries of how children coped with specific pain episodes were stronger predictors of functional disability, somatic symptoms, and depressive symptoms than a dispositional measure of how they typically cope with pain (Shirkey et al. 2011). Second, Walker and colleagues (Claar et al. 2008; Walker et al. 2008) used a novel approach to examine profiles of coping in adolescents with RAP. Rather than analyzing coping scales separately, Walker et al. (2008) used cluster analyses to identify profiles of coping on the scales of the PRI. These profiles reflected patterns of the relative use of different types of coping in response to pain episodes. For example, patients labeled Avoidant Copers responded to pain with catastrophizing and activity disengagement and were characterized by high levels of depressive symptoms and disability. Self-Reliant Copers, who relied more on accommodative coping strategies such as acceptance and self-encouragement, had relatively lower levels of depressive symptoms and disability compared to both Dependent and Avoidant Copers. The identification of coping profiles may provide a more nuanced approach to understanding complex patterns of children's coping. Finally, Compas et al. (2006) examined latent indicators of coping and adjustment in structural equation modeling analyses using child and parent reports. Children with RAP and their parents completed the RSQ with regard to children's coping with pain and these reports were used to create latent indicators of primary control, secondary control, and disengagement coping. The latent coping variables were significantly related to latent indicators of children's somatic and anxious/depressed symptoms. This study demonstrated that adolescent and parent reports of coping can be meaningfully merged into cohesive latent constructs, reflecting the existence of underlying coping factors separate from informant effects.

### **Coping with cancer**

Each year approximately 13,000 children and youth under the age of 20-years are diagnosed with cancer in the U.S. (United States Cancer Statistics 2005). Advances in treatment have led to major changes in survival rates for children with cancer. For example, acute lymphocytic leukemia (ALL) is the most common form of childhood cancer, accounting for nearly one-third of all diagnoses (United States Cancer Statistics 2005). An invariably fatal disease prior to 1960, the current five-year survival rate for ALL is 89% (Jemal et al. 2010), owing to the introduction and ongoing modification of powerful treatment protocols, which not only destroy leukemic cells in the bone marrow, organs, and cerebrospinal fluid but also prevent disease metastasis in the central nervous system. As a

result of these advances in treatment, the majority of children diagnosed with ALL are living well into adulthood, and the issue of managing the long-term effects of treatment and preserving quality of life in children treated for ALL has become a major focus of research and clinical practice.

Research on children coping with cancer has been the focus of a recent meta-analytic review (Aldridge & Roesch 2007). The authors examined coping along two dimensions: the focus of children's coping responses (i.e., whether the coping response was focused on the problem or on their emotions), and whether the stressor was approached or avoided (approach vs. avoidance focused). The results of the meta-analysis underscore the limitations of these two coping dichotomies. The authors summarized the relations between the four broad types of coping (problem-focused, emotion-focused, approach, avoidance) and six domains of adjustment (overall adjustment, physical functioning, depression, overall distress, overall anxiety, overall pain). Only one of the 24 effect sizes was statistically significant; i.e., there was a significant association of emotion-focused coping and lower symptoms of depression. Thus, 23 of 24 effect sizes for these four types of coping were non-significant.

However, significant heterogeneity was found for 21 of the 24 effect sizes that were estimated, indicating that the association of these four types of coping with adjustment was quite mixed (Aldridge & Roesch 2007). When the authors examined several moderating variables, they found that time since diagnosis and type of stressor (e.g., overall cancer stress, venipuncture, chemotherapy) moderated the relationship between different types of coping and adjustment. For example, at 6 months to 1 year after diagnosis, approach coping was associated with poorer adjustment, but at 4–5 years post-diagnosis this type of coping was associated with better adjustment. At 6 months to a year after diagnosis, problem-focused coping was associated with poorer adjustment, and emotion focused coping was associated with better adjustment at 2–3 years and 3–4 years after diagnosis. The relatively inconsistent pattern of findings may be due to limitations in the use of the problem vs. emotion-focused and approach vs. avoidance distinctions.

An intriguing issue that lies close to the topic of children coping with cancer involves the concept of “repressive adaptational style” (e.g., Phipps & Srivastava 1997). For example, based on some work suggesting that children with pediatric cancer show similar or lower levels of depression and higher levels of denial coping and “repressive” personality style than healthy controls (e.g., Canning et al. 1992; Worchel et al. 1987), Phipps & Srivastava (1997) examined self-reported coping, personality style, and depressive symptoms in a sample of 107 children ages 7–16 with cancer and 442 healthy controls. The authors assessed approach coping (monitoring/information seeking) and avoidant coping (blunting). They also examined personality style by measuring trait anxiety and defensiveness (social desirability). They classified all participants as one of four personality styles, based on their trait anxiety and defensiveness: high anxious, low anxious, defensive/high anxious, and “repressors” (defensive/low anxious). The results indicated that children with cancer reported lower levels of depression and trait anxiety than controls, and higher levels of avoidant coping than controls. In comparing the groups on personality style, the authors found that there were significantly more repressors in the cancer group compared to the control group. Subsequent analyses indicated that repressors reported significantly fewer depression symptoms than all other personality styles. Correlational analyses indicated that higher levels of defensiveness were related to lower levels of depression in both the cancer and healthy control groups, and higher levels of monitoring/information seeking were related to higher levels of depression in both groups. Interestingly, however, avoidant coping (blunting) was not related to depression, and the difference between cancer and healthy control groups in avoidant coping was significant but small. Phipps & Srivastava (1997)

suggest that these findings may reflect the relative independence of personality style and coping in predicting depression, and that personality style is a stronger predictor of depression; however, they also acknowledge the potential confound of using all self-report data to examine the relationship between distress and personality style.

Several studies have used control-based models to examine children's coping with cancer. Worchel et al. (1987) used a model of control to assess coping strategies in children and adolescents with cancer. The authors assessed 52 children and adolescents ranging in age from 6 to 17 years old on their control-differentiated coping strategies (behavioral control, cognitive control, informational control, and decisional control) and their adjustment, including depressive symptoms, internalizing and externalizing problems. Behavioral control included coping strategies that manifested as behaviors, including deep breathing, holding a parent's hand, and asking a nurse for help. Cognitive control was defined as thinking or talking about the illness and its treatment. Informational control included asking questions to gain information about the disease and its treatment, and decisional control included the child or adolescent's perceived control over decisions about treatment, activities, and meals. Correlational analyses revealed that children and adolescents' reports of behavioral control coping strategies were significantly related to more self-reported depressive symptoms and somatic complaints and nurses' reports of poorer adjustment. Decisional control strategies, however, were significantly related to nurses' reports of better adjustment and to parents' reports of fewer internalizing and externalizing symptoms. Cognitive control strategies were significantly related to nurses' reports of withdrawn and passive non-compliant behavior in children and adolescents. Informational control was not related to adjustment. The authors comment that their measure of behavioral control strategies was perhaps too focused on the quantity and not the quality of the strategies employed. It also did not follow a categorization system of types of behavioral coping strategies. The authors also comment that cognitive control strategies may consist more of rumination-like activities in children and adolescents than the restructuring-processes associated with cognitive control in adults. Decisional control strategies were consistently related to better adjustment, and these findings suggest that children and adolescents who play an active role in treatment-related and life-style related decisions may fare better than other children and adolescents. Decisional control strategies appear to reflect an engagement process characterized by children and adolescents engaging with the stressful situation and attempting to solve related problems and make their own choices.

Frank et al. (1997) assessed 86 children ages 7–18 years on their coping strategies, attributional styles, and adjustment related to their diagnosis of cancer and its treatment. The authors conceptualized coping along two dimensions: positive/approach and negative/avoidance. Approach coping strategies included cognitive restructuring, problem solving, social support, and positive emotion regulation. Avoidance coping strategies included distraction, blaming others, wishful thinking, resignation, and negative emotion regulation. Correlational analyses showed a significant relation between children's avoidance coping strategies and their self-reported depressive and anxiety symptoms. In multiple regression analyses, avoidance coping was a significant predictor of children's depressive symptoms and children's anxiety symptoms, along with a significant effect for children's depressive attributional style in predicting depressive and anxiety symptoms and children's lower social competence in predicting depressive symptoms. There were no significant correlations between approach coping and children's adjustment. Overall, the authors' findings support the idea that avoidance, or disengagement, coping strategies are associated with poorer adjustment in children with cancer.

Weisz et al. (1994) used a model of primary and secondary control coping to conceptualize children's responses to medical procedures associated with leukemia. The authors assessed

33 children ages 5 through 12 on their coping (primary control, secondary control, or relinquishing control), general behavioral and emotional problems, and illness-related adjustment (both self- and parent-reported adjustment to cancer, and observed distress in response to medical procedures). The authors classified children based on coping type into four categories: primary, relinquished, primary-relinquished, and secondary, based on the frequency of each type of coping they used. Analyses of variance indicated that parents reported higher levels of children's emotional and behavioral problems in the primary control group compared to the secondary control group. Additionally, children in the secondary control group were less likely to be in the clinical range on internalizing and total behavioral and emotional problems than children in any other coping group. Results regarding observational data on behavioral distress around medical procedures also indicated that children in the secondary control group showed less distress than children in the other groups in response to medical procedures. The authors suggest that secondary control coping is the most adaptive response to certain aspects of the diagnosis and treatment of leukemia in children, but that the controllability of the stressor plays an important role in the coping strategy used, and that secondary control coping may not be as adaptive with more controllable stressors related to childhood cancer or other illnesses.

Two recent studies have examined primary control, secondary control and disengagement coping using the RSQ in children with cancer (Campbell et al. 2009; Miller et al. 2009). Miller et al. (2009) investigated whether stable characteristics of temperament and situational-specific coping strategies would predict which children with cancer were experiencing higher levels of anxiety and depression. They investigated the temperamental dimensions of negative affectivity, positive affectivity, and effortful control, and assessed coping strategies using the RSQ (Connor-Smith et al. 2000). The authors obtained reports of children's coping from 85 mothers of children with cancer ranging in ages from 5 to 17 years. Primary and secondary control coping were significantly negatively related to anxiety, depression, and negative affectivity, while disengagement coping was not. Primary control coping significantly moderated the association between negative affectivity and symptoms of depression, such that the association was weaker among children who used more vs. less primary control coping. Other tests of coping as a moderator between positive/negative affectivity and anxiety/depression were not significant. The findings also indicated that primary and secondary control coping each mediated the association between negative affectivity and depression, suggesting that the manner in which trait negative affectivity may lead to depressive symptoms is through relatively less reliance on primary and secondary control methods.

The results of Miller et al. (2009) support findings with other populations that primary and secondary control coping are related to fewer symptoms of psychological distress. The lack of significant findings concerning disengagement coping and adjustment departs, however, from previous studies (e.g., Connor-Smith & Compas 2004) that have shown disengagement coping to be related to poorer adjustment. This study was the first involving children with cancer to investigate temperament and coping in relation to adjustment, and findings also indicated that primary and secondary control coping may mediate the association between negative affectivity and depression.

Finally, a study, Campbell et al. (2009) examined primary control, secondary control, and disengagement coping in 30 adolescent survivors of pediatric leukemia. Campbell et al. (2009) examined survivors' executive functioning, emotional and behavioral problems, and their primary control, secondary control, and disengagement coping in response to social stressors (e.g., being teased or hassled by other kids; having problems with a friend). The authors chose to assess coping in response to social stressors due to the higher risk of social problems in childhood cancer survivors (Schultz et al. 2007). Primary and secondary control

coping were negatively correlated with more emotional and behavioral problems in survivors, while higher levels of disengagement coping were positively correlated with more emotional and behavioral problems. Additionally, regression analyses indicated that secondary control coping fully accounted for the relationship between executive functioning and emotional and behavioral problems in these adolescents. These results suggest that secondary control coping is an important predictor of emotional and behavioral problems in survivors, and that poorer executive functioning may affect survivors' ability to use secondary control coping, putting them at greater risk for emotional and behavioral problems (see below).

**Summary of Empirical Studies**—The studies reviewed here (see Table 1) represent both the progress and the challenges in research on coping with chronic illness and medical conditions in childhood and adolescence. It is noteworthy that a substantial number of studies have been published reflecting a control-based model of coping. Findings have been more consistent for some types of coping than others. First, there is considerable evidence that secondary control or accommodative coping is related to better adjustment to chronic illness. Of the 16 studies summarized in Table 1 that measured secondary control/accommodative coping, 10 found this form of coping was related to better adjustment, 5 found no association with adjustment, and only one found an association with poorer adjustment. Second, there is substantial evidence that disengagement or passive coping is related to poorer adjustment. Fourteen of the studies presented in Table 1 measured disengagement/passive coping and 11 found it was related to poorer adjustment, 4 found no association with adjustment, and no studies found this type of coping was related to better adjustment. In contrast, findings for primary control or active coping were less consistent. Five studies out of 17 found evidence that primary control/active coping was related to better adjustment, three found it was related to poorer adjustment, and five found no relation with adjustment.

These findings convey important themes about effective coping with chronic illness in childhood and adolescence. The relatively consistent pattern of associations between secondary control coping, and to a lesser extent accommodative coping, and better adjustment suggests that secondary control coping is a good fit with the often uncontrollable aspects of childhood illnesses. The use of strategies such as acceptance, cognitive reappraisal, and distraction represent efforts to maximize one's fit with the demands of an illness and its treatment (Rudolph et al. 1995). However, the low levels of actual or perceived control of many pediatric chronic illnesses does not provide a good context for the use of disengagement or passive coping, as reflected in the consistent associations between these types of coping and poorer adjustment. The use of avoidance, denial, and wishful thinking do not facilitate effective regulation of emotional distress and further may disrupt or derail engagement coping strategies aimed at adjusting to uncontrollable stress. Finally, the mixed findings for active or primary control coping may indicate the complexity of the different stressful aspects of illnesses and their treatment. It is possible that active or primary control strategies such as problem solving represent a good fit for some sources of stress, such as problems related to missing school or changes in treatment regimen, and a poor fit to others, such as feeling different from peers. This is an important topic for future research.

## Directions of Future Research and Application

Research on coping with chronic illness in childhood and adolescence is now poised to move to the next level on several fronts. These include improving the quality of methodology in future studies, examining the role of impairments in cognitive function in children's ability to cope, the links between children's and parents' coping, and finally, the development and testing of interventions to increase children's coping skills.

## Enhancing methodological rigor

The majority of research on children's coping with chronic illness has been limited to cross-sectional studies that rely solely on children or parents as sources of information on coping and its correlates. As noted above, this approach raises concerns that the associations between coping and adjustment are to some degree inflated due to shared method variance in the assessment of these constructs. Therefore, the use of multiple informants and multiple methods in prospective designs is a high priority in future research.

An example of a multi-method longitudinal study by Schreier & Chen (2008) of the prospective associations between primary and secondary control coping and biomarkers of disease in children with asthma. Schreier & Chen (2008) found that greater secondary control coping at baseline was related to greater increases in peak expiratory flow rate, an important marker of pulmonary function, and a greater likelihood of physician contact over the following year. In contrast, greater primary control coping at baseline was related to greater likelihood of rescue inhaler use, school absenteeism, and physician contact over the following year. This study exemplifies the type of increased methodological rigor that is needed to move the field ahead.

In addition to overall increased methodological rigor, continued attention to the validation of children's self-reports of coping is needed, as adequate validity data have been provided for only a subset of measures that are used to study children's coping with chronic illness.

## Coping and cognitive function

There is mounting evidence that many chronic illnesses are related to impaired cognitive function in children and adolescents, either as a result of disease processes, aggressive forms of treatment, or both. For example, recent meta-analyses have documented significant cognitive impairment in survivors of leukemia (Campbell et al. 2007), brain and CNS tumors (Robinson et al. 2010), type 1 diabetes (Naguib et al. 2009), congenital heart disease (Karsorp et al. 2007), and sickle cell disease (Schatz et al. 2002). Although these adverse neurocognitive late effects are a significant public health problems in and of themselves, there is evidence to suggest that these impairments may be associated with problems in the ability of children to use the types of complex cognitive coping strategies that are needed to effectively cope with stress.

The ability of children to use some of the complex coping strategies, such as cognitive reappraisal and acceptance, may depend on the healthy development of regions of the prefrontal cortex and these brain regions may be vulnerable to disease and treatment processes (Compas, 2006). For example, Hocking and colleagues (2011) measured executive function and attention regulation in youth with RAP and found that children's ability to use selective attention made them more likely to use secondary control coping strategies to cope with abdominal pain, thereby reducing anxiety. Similarly, in a study of children with leukemia, Campbell et al. (2009) found that higher levels of primary and secondary control coping, as measured by composite self- and parent-report on the RSQ, were correlated with better executive functioning (e.g., working memory, cognitive flexibility, and self-monitoring), while disengagement coping was correlated with poorer executive functioning. Further, coping mediated the relationship between executive function and behavioral/emotional problems in these children. In youth with type 1 diabetes, early onset of the disease is one of the strongest predictors of poor neuropsychological performance, with particular deficits in attention and executive function (Guadieri et al. 2008). It is thought that elevated levels of glucose present in people with diabetes may interfere with the formation of myelin and neurotransmitter regulation during critical periods of brain development (Northam et al. 2010).



These recent studies suggest that a high priority for future research will be further investigation of the links between neurocognitive sequelae of childhood illnesses and children's coping. Given the continued high levels of stress associated with many chronic illnesses, impairments in brain development that impede the development of effective coping skills could further compound their risk for emotional and behavioral problems.

### **Coping in the context of families**

Childhood illnesses represent significant stress for affected children, their siblings and their parents. Therefore, it is important for future studies to carefully examine the sources of support and the impediments to effective coping in chronically ill children and adolescents. Examples of the importance of parents' coping were provided in the preceding discussion of diabetes (e.g., Wiebe et al. 2005) and chronic pain (e.g., Levy, 2011; Williams et al. 2011). The role of parents' coping may be important to consider on several levels as parents may serve as resources to support and scaffold children's coping, parents may serve as important models of effective and ineffective coping for their children, and parents' who are ineffective in coping with the stress of their child's illness may contribute to increased distress in their children. These processes are all fertile opportunities for future research.

### **Understanding developmental differences in coping with chronic illness**

Chronic illnesses affect individuals over the course of development from early childhood through adolescence. Therefore, it is important to identify developmental patterns of children's coping, including aspects of coping that are stable as opposed to changing with development. However, relatively little research has examined age and developmental patterns in children's coping with chronic illness. For example, findings have been mixed with regard to age-related effects of coping in children with cancer. A quantitative review (Aldridge & Roesch, 2007) of coping in these children found no significant age-related effects. These findings are consistent with other studies, which have failed to find age-related effects despite enrolling children of a large age range, from school-aged children to older adolescents (e.g., Campbell et al., 2009; Frank et al., 1997; Miller et al., 2009). However, some studies have suggested that adolescents may use more cognitive control coping strategies (Worchel et al., 1987) and secondary control coping (Weisz et al., 1994), which may be due to the cognitive resources needed to employ these types of coping strategies. The lack of consensus regarding age-related differences in coping in children with cancer highlights an important next step in pediatric cancer research (see Zimmer-Gembeck & Skinner, 2011, for a broader discussion of the development of coping across childhood and adolescence).

### **Interventions to enhance coping skills**

A final important direction for future research is the development and evaluation of interventions to enhance children's abilities to cope with the stress of chronic illness. Two recent studies provide examples of promising coping based interventions. First, a coping skills training intervention was developed by Grey and colleagues for adolescents with type 1 diabetes more effective ways to manage stress related to diabetes. This intervention is aimed at improving children's ability to manage stress related to diabetes by teaching skills such as assertive communication, conflict resolution, stress management, and positive thinking. It has been shown to have positive effects on both quality of life and metabolic control (Grey et al. 2000). Second, Szigethy et al. (2007) examined the feasibility and efficacy of a manual-based cognitive-behavioral therapy (CBT) in reducing depressive symptomatology in adolescents with inflammatory bowel disease (IBD). Primary and Secondary Control Enhancement Therapy-Physical Illness (PASCET-PI) modified for youths with IBD was compared to treatment as usual, plus an information sheet about depression, without therapist contact using assessable patient analysis. The PASCET-PI

group showed significantly greater improvement in children's depressive symptoms (based on child and parent report), children's global functioning, and increased perceptions of control at posttreatment than the comparison group.

It will be important for future studies to build on these initial efforts by developing and adapting interventions to enhance coping in children faced with a wide range of chronic illnesses. Further, it will be important for measuring researchers to measure possible changes in coping as an outcome and/or and to test changes in coping as mediators of the effects of the interventions on measures of adjustment is important to consider. By testing mediators and moderators of interventions, we can improve our understanding of how and for whom the interventions may work (Kraemer et al. 2002). Findings from recent studies with preventive interventions have provided promising evidence that interventions can improve children's coping skills and that these changes are important mediators of mental health outcomes in high-risk populations (Compas et al. 2010; Tein et al. 2004, 2006). Studies testing coping as a mediator of the effects of interventions with chronically ill children represent a high priority for future research.

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## Terms and Definitions

<b>Chronic illness</b>	A health problem that is prolonged, rarely cured, and often causes impairment in activities of daily living
<b>Coping</b>	Conscious and volitional efforts to regulate oneself and/or the environment in response to stress
<b>Primary control coping</b>	Efforts to change a stressor (e.g., problem solving) or one's emotional reactions to a stressor (e.g., emotional expression)
<b>Secondary control coping</b>	Efforts to adapt oneself to a stressor, by strategies such as cognitive reappraisal, positive thinking, acceptance, and distraction
<b>Disengagement coping</b>	Efforts to orient away from a stressor or one's reactions to a stressor (e.g., avoidance, denial)

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### Summary Points

1. The diagnosis, treatment, and ongoing management of chronic illness are stressful for children and families, and the onset and course of chronic illness may be affected by other sources of stress.
2. The stressors faced by children, adolescents, and parents dealing with childhood chronic illness are multifaceted, and can include stress related to daily role functioning (e.g., missing school), stress related to treatment (e.g., painful procedures), and stress related to uncertainty (e.g., wondering what caused the illness or condition).
3. Coping involves purposeful efforts to regulate cognitions, emotions, behaviors, physiology, and interactions with others.
4. There are empirically supported methods for measuring coping chronic illness in children and adolescents. Two of these, the Responses to Stress Questionnaire (Connor-Smith et al. 2000) and the Pain Response Inventory (Walker et al. 1997), include a factor that reflects primary control or active coping, a factor related to secondary control or accommodative coping, and a factor that reflects passive, avoidant or disengagement coping.
5. The effectiveness of coping strategies depends on the match between characteristics of the stressor, especially perceived controllability, and the individual's coping responses.
6. Considerable evidence across chronic childhood illnesses and medical conditions suggests that secondary control coping, or accommodative coping, is related to better adjustment in children and adolescents.
7. The use of disengagement coping, including cognitive and behavioral avoidance, is generally related to poorer adjustment.
8. Studies have found mixed effects for primary control coping, such as problem solving, suggesting that these types of coping strategies may be helpful for the more controllable sources of stress, such as problems related to missing school or changes in treatment regimen, and a poor fit for others, such as feeling different from peers.



### Future Issues

1. Use of multiple informants. Most previous studies have relied on only single sources of information about coping and its correlates (e.g., only child self-reports or only parents' reports about their children), making it difficult to determine the extent to which findings are due to the use of single methods. Future studies will benefit from obtaining information from multiple sources to and multiple methods.
2. Use of prospective designs. The majority of previous studies have been cross-sectional, limiting the ability to determine the temporal relations between coping and other variables. Prospective studies are needed in which coping is measured at one point in time and used to account for changes in other variables (e.g., symptoms of anxiety or depression).
3. Measurement of biomarkers. Diabetes, asthma, cancer and other chronic illnesses have important biological markers of disease progression or recovery that may be related to coping. Future research will benefit from greater inclusion of these important biological processes.
4. Child/adolescent coping in context of family, especially parents' coping. Children and their parents face significant stress associated with a child's chronic illness and both are involved in coping with illness-related stress. Future research is needed to address how children's and parents' coping mutually influence one another to provide a more contextualized understanding of children's adaptation to chronic illness.
5. Development and testing of coping interventions. Research has suggested the potential importance of children's use of secondary control or accommodative coping in adapting to chronic illness. However, relatively little research has reported on the development of interventions designed to enhance children's coping. Further, it will be important to carefully measure changes in children's coping and the degree to which changes in coping mediate the effects of interventions on children's mental and physical health and adaptation to illness.

**Table 1**  
 Examples of studies of children's coping with diabetes, chronic pain, and cancer.

<b>Coping with Diabetes</b>					
<b>Study</b>	<b>Sample</b>	<b>Primary Control/Active/Approach Coping</b>	<b>Secondary Control/Accommodative Coping</b>	<b>Disengagement/Passive/Avoidance Coping</b>	
Band & Weisz (1990)	Type 1 Diabetes	Better adjustment	Better adjustment	---	
Edgar & Skinner (2003)	Type 1 Diabetes	---	Fewer depressive symptoms, greater well-being	---	
Graue et al. (2004)	Type 1 Diabetes	Poorer quality of life	---	Poorer metabolic control	
Jaser & White (2011) (RSQ)	Type 1 Diabetes	Better metabolic control, better QoL	Better metabolic control, better QoL	Lower social competence, poorer metabolic control	
<b>Coping with Chronic Pain</b>					
<b>Study</b>	<b>Sample</b>	<b>Primary Control/Active/Approach Coping</b>	<b>Secondary Control/Accommodative Coping</b>	<b>Disengagement/Passive/Avoidance Coping</b>	
Compas et al. (2006) (RSQ)	Recurrent Abdominal Pain	Not related	Fewer symptoms of anxiety/depression, somatic complaints	More symptoms of anxiety/depression, somatic complaints	
Duflon et al. (2011) (RSQ)	Recurrent Abdominal Pain	Not related	Fewer somatic complaints, internalizing problems	Not related	
Hocking et al. (2011)	Recurrent Abdominal Pain	Not related	Fewer symptoms of anxiety	Not related	
Kaczynski et al. (2001) (PRI)	Chronic Pain	Not related	Not related	Greater functional disability	
Shirkey, Smith, & Walker (2011) (PRI)	Recurrent Abdominal Pain	Not related	Not related	More somatic complaints, functional disability, and depressive symptoms	
Simons, Claar, & Legan (2008) (PRI)	Recurrent Abdominal Pain	More somatic symptoms	More somatic symptoms and disability	More somatic symptoms and disability	
Thomsen et al. (2002) (RSQ)	Recurrent Abdominal Pain	Lower anxiety, depression, and somatic symptoms; higher pain	Lower anxiety, depression, somatic symptoms, and pain	Higher levels of pain	
Walker et al. (1997) (PRI)	Recurrent Abdominal Pain	More disability	Lower pain	More pain, somatic symptoms, depressive symptoms, and disability	
Walker et al. (2005) (PRI)	Recurrent Abdominal Pain	Not related	Not related	More somatic symptoms, functional disability, depressive symptoms	
Walker et al. (2007) (PRI)	Recurrent Abdominal Pain	Not related	Not related	More somatic symptoms, functional disability, depressive symptoms	
<b>Coping with Cancer</b>					

Coping with Diabetes					
Study	Sample	Primary Control/Active/Approach Coping	Secondary Control/Accommodative Coping	Disengagement/Passive/Avoidance Coping	
Study	Sample	Primary Control/Active/Approach Coping	Secondary Control/Accommodative Coping	Disengagement/Passive/Avoidance Coping	
Band & Weisz (1990)	Cancer	Better adjustment	Better adjustment		
Campbell et al. (2009) (RSQ)	Cancer	Lower internalizing and externalizing	Lower internalizing and externalizing	Not related	
Frank, Blount, & Brown (1997)	Cancer	Not related	Not related	Greater symptoms of anxiety and depression	
Miller et al. (2010) (RSQ)	Cancer	Lower anxiety and depressive symptoms	Lower anxiety and depressive symptoms	Not related	