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Differentiating Coping Patterns for Illness-Related
and Other Types of Stressors in Adolescents with Chronic Illness

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A thesis submitted to the Faculty of Graduate and Postdoctoral Studies
in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

Thesis Supervisor: Ian Manion, Ph.D.

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Abstract

The aim of this study was to investigate the personal stressors and patterns of coping in adolescents living with a chronic illness. Primary objectives were to: 1) identify salient stressors and to determine the relation between cognitive appraisals and the degree to which a stressor is perceived as illness-related or typical of adolescence; 2) assess differences in coping strategies used for illness-related and other types of stressors; 3) investigate if gender or age influences the frequency, cognitive appraisals or types of stressors reported, or the nature and the overall number of coping strategies reported. A secondary objective was to assess the extent to which health-related quality of life is related to stressors, coping strategies and coping in general.

In the current study, 193 chronically ill adolescents listed up to 20 personal stressors and rated the frequency, control over the cause, perceived impact, control over the outcome, and the extent to which each stressor was related to the chronic illness, and typical of adolescence. Adolescents reported coping strategies (Kidcope) for one self-identified illness related and one non-illness related stressor and for two stressors standardized for the entire sample. Participants also completed a global measure of adolescent coping (A-COPE) and a health-related quality of life measure (Rand 36-item Health Survey).

Results showed that the most frequently identified stressors were similar to those reported for healthy adolescents. Moreover, stressors were rated as more typical of adolescence than they were illness-related. Although perceived control over the cause was negatively related to stressor impact for self-identified stressors, neither controllability ratings nor impact were significantly correlated with illness or typical ratings. Considerable consistency in coping was found across self-identified stressors only. Females employed more social support and emotional regulation than did males. Although the number of stressors and the perceived impact of stressors increased with age, consistent age differences in coping were not obtained. Poorer general health perception was associated with greater impact for illness stressors. Perceived controllability over the outcome was associated with increased approach coping for both self-generated and standard stressors. Study limitations, suggestions for future research, and clinical implications are discussed.

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Differentiating Coping Patterns for Illness-Related and Other Types of Stressors in Adolescents with Chronic Illness

Overview

Adolescence is a period of increased risk for the development of mental health concerns that may carry over into young adulthood (Davidson & Manion, 1996). Changes in physical appearance, increases in both family and academic responsibilities, and the increased importance of interactions with peers introduce a variety of novel, and potentially stressful demands that can challenge existing coping resources. In situations in which coping resources are insufficient or inappropriate to deal with increased stressful demands, the adolescent is at risk for psychosocial maladjustment. The increased rates of depression, suicide (Hanvey et al., 1994; Herbert, Lipskie, Machenzie, & Rusen, 1999) and risk-taking (Baumrind, 1987) during adolescence highlight the vulnerability of this age group. However, it is important to note that the majority of adolescents appear to develop an adequate repertoire of coping strategies to deal with the increased demands with which they are confronted.

Individuals living with a chronic illness are confronted with unique challenges when negotiating the developmental tasks of adolescence. Not surprisingly, the adolescent period is often one in which coping difficulties first emerge for chronically ill children (Goldston et al., 1997; Williams, Holmbeck, & Greenley, 2002). At a time where peer acceptance is key, ill adolescents often feel dissimilar from their peers due to physical limitations and differences in appearance imposed by the illness. In order to control their illness, ill adolescents are often required to adhere to demanding dietary restrictions, lifestyle limitations or medication regimens (Kliwer, 1997; Perrin & Gerrity, 1984). In addition, they are at risk for academic difficulties due to increased absenteeism and/or concentration difficulties, and they often have legitimate concerns about what the future holds for them (Kliwer, 1997). The additional challenges faced by chronically ill adolescents places them at increased risk for coping difficulties and psychosocial adjustment problems. Moreover, the consequences of maladaptive coping can be severe in this population.

In order to identify individuals at risk for adjustment difficulties or to intervene with those currently experiencing difficulties, it is important to identify the types of events that ill

adolescents find demanding and the subsequent coping styles they practice. Both illness-related and non-illness related stressors have significant impacts on the ill adolescent. However, these types of stressors are typically studied independently and it is unclear if adolescents employ different coping strategies to deal with each type of stressor. It is important to understand the extent to which cross-situational consistency of coping occurs. Consistency in coping would indicate that interventions directed at increasing adaptive coping in relation to illness-related or typical stressors should have positive effects on psychosocial adjustment and health outcome. Further, any coping differences that are found to exist may be explained by cognitive appraisals of the stress and coping process, such as an individual's belief regarding their ability to influence the stressor outcome. It should be possible to modify certain coping strategies that have proven ineffective through the alteration of relevant appraisals, such as sense of control.

Despite compelling reasons for exploring stress and coping in adolescents with chronic illness, this area has been understudied. The primary purpose of the current research was to: 1) identify salient stressors and to determine the relation between cognitive appraisals and the degree to which a stressor is perceived as illness-related and/or typical of adolescence; 2) assess differences in coping strategies used for illness-related and other types of stressors, and also in the consistency of coping; and 3) investigate if gender or age influence the frequency, cognitive appraisals or types of stressors reported, or the nature and the overall number of coping strategies reported. A secondary purpose was as follows: 4) to assess the extent to which health-related quality of life is related to stressors, coping strategies and coping in general.

The following sections review the adolescent stress and coping literature. First, the developmental adolescent stress and coping literature is discussed, including the relation between stress and coping variables and psychosocial adjustment. Second, the stress and coping literature pertaining to adolescents with chronic illness is described, including the limitations of current research. The remainder of the document focuses on the current study.

Literature Review

Developmental Issues Over the Adolescent Period

Given the increase in perceived demands associated with adolescence, a brief description of the salient developmental issues that occur over the adolescent period is included.

Developmental theorists propose that the goals of adolescence are to develop: (1) a secure identity, (2) positive feelings of self-worth, (3) the capacity for an intimate relationship, (4) physical and psychological independence and, (5) directions for a future vocation (Erikson, 1964). Before these challenges can be met, a variety of physical, psychosocial and cognitive changes need to occur.

Rapid physical growth and the development of primary and secondary sex characteristics is largely accomplished in early adolescence and fully completed by middle adolescence (Coupey & Wager, 1990). Erikson (1964) proposed that identity formation also occurs during early adolescence and is marked by heightened self-consciousness and preoccupation with one's physical appearance and one's normalcy. It is suggested that the early adolescent tends to be focused on the present, rather than planning for the future (Chassin, Presson, Sherman, & McConnell, 1995). Increased perspective-taking is another cognitive change that occurs during early adolescence (Keating & Clark, 1980). Baumrind (1987) has reviewed the literature and concluded that, along with some desire for independence, there is an increasing tendency to conform to the social norms of the same-sex peer group in some areas, such as style of dress. Nonetheless, parents continue to remain most influential on long-range plans such as future educational and career goals.

During middle adolescence, experimentation with different identities, ideologies, role models, vocations and risk-taking occurs. It is theorized that following peer group norms and experimenting are ways in which the adolescent begins to develop an identity that is separate from their parents (Baumrind, 1987).

It is proposed that by late adolescence, sexual identity is complete and intimate relationships take on more significance. In addition, there is a shift to more of a future orientation (Chassin et al., 1995). Vocational choice, considered a critical aspect of identity, tends to be completed in

this final stage. The adolescent finally faces the challenge of striking out on their own and physically separating from the family (Erikson, 1964).

In summary, there are numerous goals to be met over the course of adolescence. The ensuing physical, psychosocial and cognitive changes occurring over early, middle and late adolescence are believed to be normative aspects of development.

Stress and Coping in Adolescence

Stress in Adolescence

Conceptualization of stress

In the child and adolescent literature there are two models typically used to conceptualize life stress. In the stimulus model life stress is defined as an objectively negative stimuli whereas in the transactional process the person and environment interact to produce a cognitive appraisal of threat or loss (Cohen & Park, 1992). For the latter model, the stress transaction consists of a primary appraisal of what the individual determines is at stake in the situation and a secondary appraisal of the adequacy of available resources for coping with the demand (Lazarus & Folkman, 1984). In situations where the resources are believed to be adequate for dealing with the demand, no stressful event is considered to have occurred. When resources are not believed to be adequate for the demand, a transaction is evaluated as stressful (Lazarus & Folkman, 1984). Specifically, primary appraisal consists of an evaluation of the degree of threat in a given situation. A situation can be appraised as irrelevant, benign-positive, or stressful. For the latter situation, it can be further appraised as leading to harm or loss, a threat of future negative effects, or as a challenge with potential for gain, growth and mastery. Secondary appraisal involves an assessment of available coping resources and options. Coping resources include material, social, and psychological assets. In contrast, options include altering the situation, accepting it, seeking more information, or restraining oneself from responding in an unhelpful manner (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). Secondary appraisals include control appraisals; decisions about whether the stressor is believed to be under the control of oneself, others, or is more random in nature. In addition, secondary appraisals also include efficacy appraisals; decisions regarding one's ability to cope successfully with the perceived demand. Appraisals can affect adjustment to a stressor, choice of coping strategies, and the effectiveness

of coping (Folkman et al., 1986; Lazarus, DeLongis, Folkman, & Gruen, 1985; Lazarus & Folkman, 1984)

Proponents of the stimulus model argue that subjective appraisals of events leads to a confound between individual differences and life stress scores (Dohrenwend & Shrout, 1985). In contrast, Lazarus and Folkman (1984) state that the appraisal of the event is a critical aspect of life stress, and that differences in values, commitments, goals and beliefs will affect the individual's appraisal of a given situation (Lazarus et al., 1985). Differences in stress conceptualizations have led to different categories of stressors and also to alternate modes of measurement of stress. Proponents of the stimulus model tend to use clinical-empirical or normative-empirical methods for rating the valence of events, whereas supporters of the transactional approach use self-reports for both the occurrence and weight of events (for a review see Cohen & Park, 1992).

Two different categories of stressful life events have been developed for exploring the relation between psychological stress and other psychological and physical symptoms. Major life events are believed to involve significant levels of social readjustment (e.g., starting school, divorce, death of family member) (Wagner, Compas, & Howell, 1988). In contrast, minor life events or hassles are the "irritating, frustrating, distressing demands that to some degree characterize everyday transactions with the environment". Examples of hassles include bad weather, losing things and traffic jams (p.3, Kanner, Coyne, Schaefer, & Lazarus, 1981). Major events can be considered distal events, because they do not provide any information about the problems they create, they have different meaning across individuals, and they require a range of coping responses; all of these variables can affect the outcome (DeLongis, Coyne, Dakof, Folkman, & Lazarus, 1982). In contrast, minor events are considered proximal events because they provide immediate information about the individual's appraisal of ongoing daily events and the disruption they have caused (DeLongis et al., 1982). It is believed that minor events are more amenable to intervention because they are likely to reflect the cognitive appraisals individuals make in relation to events or, inappropriate means of dealing with routine events (DeLongis et al., 1982). Instead, major life events may ultimately affect the individual via the minor hassles they create (Kanner et al., 1981).

Inconsistencies exist in the classification of specific stressors as either minor or major (Compas, 1987b). Moreover, some researchers have distinguished between discrete stressors and stressors that are more chronic in nature (Holmes, Yu, & Frenzt, 1999; Moos, 2002). As stated previously, supporters of the stimulus model have assigned categories and standardized weights to stressful events as a measure of stressor severity. This approach is not compatible with the transactional model of stress and coping (Gamble & Woulbroun, 1993). A more compatible approach involves the individual's evaluation of the impact and frequency of the stressful event. For example, events perceived to have a high impact and occur infrequently are classified as major events whereas events perceived to occur frequently with variable impact are classified as daily stressors (Wagner et al., 1988). Clearly, chronic stressors can be of variable impact, but occur frequently.

The transactional model is the model of stress predominantly focused on in this paper for two reasons. First, this model has received considerable support in the stress and coping field. Second, the chronic illness literature suggests that adolescents often differ in their interpretation of the illness experience (Band & Weisz, 1990) and their perception of their physical health (Cappelli et al., 1989). These perceptions have affected coping abilities (Band & Weisz, 1990) and were important sources of stress (Cappelli et al., 1989). In addition, perceived stress level for other life events is related to psychological adjustment (Varni, Katz, Colegrove, & Dolgin, 1994). Therefore, the transactional model allows for evaluation of factors recognized as integral to the stress and coping process, such as self-ratings on a number of cognitive appraisal scales. It also allows for a broad range of salient stressors to be measured on a common matrix.

Developmental changes in stress

As described previously, adolescence is a vulnerable period during which multiple changes occur. The number and types of stressors experienced appear to be influenced by the increased cognitive, emotional and social challenges adolescents face. Therefore, it is not surprising that an increase in the reporting of minor life events occurs as children enter adolescence (Graber & Brooks-Gunn, 1996). An increase in reported negative life events has also been found to occur, with the peak period in early and middle adolescence (Schonert-Reichl & Muller, 1996). In a longitudinal study, significant associations were found between age and different categories of

self-reported stress, with older adolescents reporting more stressors related to parents and less sibling and friend stressors (Timko, Moos, & Michelson, 1993). In addition, certain stressors have been found to be associated with psychological symptoms at different developmental stages. Family, peer and academic issues were most strongly related to psychological distress in junior high, senior high, and college, respectively (Wagner & Compas, 1990).

Gender differences in stress

The number and types of events reported by adolescents appear to be largely influenced by gender. For example, boys have been found to report more life events from the ages of 9-12 years. While both genders showed an increase in the number of events reported after 13 years, girls reported higher number of events than did boys throughout the remaining teenage years (Ge, Lorenz, Conger, Elder, & Simons, 1994). Girls endorsed more negative life events and hassles, and they also reported events as more stressful than did boys (Compas, 1987a; Wagner & Compas, 1990), although there was no evidence of a stronger relation between negative events and psychological symptoms for adolescent girls than for boys (Wagner & Compas, 1990). Gender differences have also been found for the ranking of the reported problems. Boys were more concerned about school, parents, friends and girlfriends, whereas girls were more worried about parents, boyfriends, friends and school (Stark, Spirito, Williams, & Guevremont, 1989).

The Relation between life stress and adjustment

Research has shown that stressful events are associated with measures of psychosocial adjustment (Roberts, 1995). For example, a longitudinal Canadian study found that family, school, and peer-group related stress were all positively related to measures of anxiety, depression, social dysfunction and anergia (Siddique & D'Arcy, 1984). Other prospective studies have also shown an association between adolescent stress and psychological problems (for a review see Compas, 1993). Both chronic and acute stressors are associated with increased risk of depression and problem behaviour (Moos, 2002). In other research, minor and major events each contributed independently to models of psychological adjustment (Rowlison & Felner, 1988). Further, the effect of major events on psychological adjustment was mediated by minor events (Wagner et al., 1988). Also, depressive symptoms predicted young adolescents' reports of future

daily hassles, but not major life events, which are presumably less controllable and thus less influenced by children's symptoms (Bennett & Bates, 1995).

High levels of psychological and somatic symptoms are thought to increase the negative effects of ensuing life events by increasing the perceived severity of these events. Therefore, the relation between the perception of life events and the degree of psychological distress caused by these events may be reciprocal in nature (Jorgensen & Johnson, 1990). Other research indicates that chronic, ongoing stress is more important in predicting distress than an accumulation of discrete negative life events (Cohen, Burt, & Bjorck, 1987; Moos, 2002). In summary, despite the different approaches to the classification of stress, studies have consistently found a relation between stressors and adjustment.

Coping in Adolescence

Conceptualization of coping

There are two major theoretical perspectives that are typically used to conceptualize coping in child and adolescent populations. From the first perspective, coping is viewed as a personality trait that determines the coping strategy employed. For example, in some research with children a "repressor" personality trait has been described (e.g. Canning, Canning, & Boyce, 1992). Repressors are defined as individuals who score low on measures of affective distress, and high on measures of defensiveness. However, research findings indicate that the trait approach may not be the most appropriate way to conceptualize coping. First, the tendency to minimize distress may not reflect a premorbid personality trait; instead it may be a reaction to the illness (Phipps, Steele, Hall, & Leigh, 2001). Also in addition to individual differences in coping, situational differences also exist (Roecker, Dubow, & Donaldson, 1996; Spirito, Stark, Gil, & Tyc, 1995). This approach does not consider coping in relation to specific contexts.

From the second perspective, the cognitive-transactional model of coping focuses on the individual's cognitive and behavioural efforts to manage demands that are appraised as taxing or exceeding the resources of the person (Lazarus & Folkman, 1984). In this model, it is the individual's appraisal of the situation, and the coping resources that the individual has available, that will determine how effectively the individual will be able to cope with the stressful event. Consequently, any effort on the part of the individual to reduce stress, whether it is adaptive or

maladaptive, is considered a coping response. Stress and coping are believed to be interactive processes, because the coping response initiates a new appraisal by altering the relation between the person and the environment. Support for this model is based on the following: (1) specific coping responses have not been consistently found across situations for a given individual (Band & Weisz, 1988; Compas, 1988) and are usually only moderately correlated across situations (Compas, Malcarne, & Fondacaro, 1988; Roecker et al., 1996); (2) individuals tend to employ a range of coping strategies, that are used in specific types of situations (Stark et al., 1989). These findings do not fit with a unidimensional coping trait approach.

According to the transactional model of coping, an individual may have an extensive repertoire of coping strategies with particular strategies used for specific situations. However individuals may also show a preferred overall coping style (Wills, 1986). Coping style can be defined as a generalized strategy or preference for dealing with different types and sources of problems (Patterson & McCubbin, 1987).

One consequence of the different conceptualizations of coping is that studies are not readily comparable because the measures that have been employed may have assessed different constructs of coping. Studies that evaluate preferred coping style do not consider the relation between perceived situational demands and the choice of coping strategy, despite the known relation between these two variables. Also, it is unclear whether or not individuals of any age are able to consider their responses across varied situations in order to develop a general coping profile (Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001). An evaluation of coping strategies used for specific, cognitively appraised stressors should reveal how perceived stressor demands relate to the coping strategy used. This approach does not prevent the identification of a possible coping preference should it exist.

Classification of coping strategies

There are several ways that an individual can cope with an event that they perceive as threatening. However, coping research is complicated by the variety of coping classification schemes found in the literature. The coping response can either be: problem-focused whereby the individual attempts to eliminate or reduce the cause of the stress; or emotion-focused

whereby one attempts to control the emotions that are experienced during the stressful situation (Compas, 1987a; Lazarus & Folkman, 1984).

Other classifications include the two-dimensional model of primary and secondary control (Weisz, 1986) and the monitoring-blunting model (Miller, Brody, & Summerton, 1988). In addition, coping responses can be classified according to external modes of coping versus internal modes of coping (Curry & Russ, 1985; Spirito, Stark, & Williams, 1988). Similar to problem-focused coping and emotion-focused coping, these approaches distinguish between efforts to make some change in the environment or person that is perceived as stressful, versus efforts to regulate the negative emotions associated with the stressful event (for a review see Compas, Worsham, & Ey, 1992).

Developmental research suggests that demands on the individual may also be characterized by approach/active behaviour, versus avoidant behaviour (Herman-Stahl & Petersen, 1996). Approach coping includes attempts to address and resolve the stressful event. In contrast, avoidant coping includes behaviours aimed at ignoring information about the stressor or attempts to avoid the stressor altogether (Spirito, Stark, & Tyc, 1994). Avoidant behaviours may result in additional stressful circumstances, thereby increasing the stressful demands even further (Moos, 2002; Patterson & McCubbin, 1987). Approach coping is related to positive psychosocial adjustment, whereas avoidant coping is related to negative adjustment, such as depression (Ebata & Moos, 1991; Herman-Stahl & Petersen, 1996; Moos, 2002; Sandler, Tein, & West, 1994).

Within the broad bands of problem-focused and emotion-focused coping or approach and avoidant coping, a number of more specific, behaviourally-based scales have been developed for further discriminating among coping strategies. It has been suggested that it is necessary to study the various subtypes of coping within these broad bands in order to determine the developmental sequence in the acquisition of these skills and the outcome of their use. For example, it is believed that the emotion focused coping strategies of early adolescence represent less mature ways of dealing with feelings (Compas et al., 1992). Therefore, a more general category would not discriminate between developmental differences in emotion focused coping. In addition, coping strategies may serve more than one function (Patterson & McCubbin, 1987). For the above-described reasons it is appropriate to evaluate coping strategies at the subscale level.

Although many of the coping measures use similar subscales, cross comparisons are difficult because there are differences in the specific factors evaluated, and in the descriptive statements listed for the various factors. Moreover, some measures are aimed at a global, overall style of coping (Patterson & McCubbin, 1987), whereas other measures are to be used in relation to a specific stressful event (Spirito et al., 1988).

Developmental changes in coping

Consistent differences in coping strategies have been found across age groups. Adolescents are believed to have a more extensive repertoire of strategies to choose from than are younger children (Compas et al., 1992; Donaldson, Prinstein, & Danovsky, 2000). Compared to younger children, adolescents have also been found to practice more emotion-focused coping. This developmental increase in emotion-focused coping has been found for coping with medical/dental stressors (Band, 1990; Band & Weisz, 1988; Curry & Russ, 1985) interpersonal stressors (Compas, Malcarne et al., 1988), and family stress. Although research has shown that adolescents use more emotion-focused coping than do children, there is no difference between adolescents and young adults on the frequency of emotion-focused coping (Compas et al., 1992). Compas and colleagues suggest that developmental changes in the use of emotion-focused coping have tapered off by late adolescence. In contrast, no consistent findings were found for problem-focused coping.

Several explanations have been offered to explain the lower rate of emotion-focused coping in younger, less cognitively advanced children. It has been suggested that young children are unlikely to accomplish the following tasks: i) recognize psychological ways to reduce stress; ii) describe their emotion-focused strategies to others; iii) recognize aspects of stress that cannot be modified (Band, 1990); iv) fully access their own emotional states; or v) learn emotion-focused strategies via modelling (Compas et al., 1992).

Therefore, emotion-focused coping appears to consistently increase with age, but problem-focused coping appears to emerge in a different fashion. It is hypothesized that problem-focused coping results from modelled behaviour, whereas emotion-focused coping may be linked to processes that only becomes accessible after further cognitive development.

Gender differences in coping

Within the developmental child and adolescent literature, studies have found some gender differences for stress and coping, although results are not consistent. For example, some research has found females used more emotion focused coping whereas males used more problem focused coping; other research has not supported this finding (Ptacek, Smith, & Zanas, 1992). No gender differences were found in coping patterns in response to four types of daily stressors (Donaldson et al., 2000). There does seem to be some evidence that adolescent girls use more social support, solving family problems (Patterson & McCubbin, 1987) (Spirito et al., 1988; Stark et al., 1989) (Kurdek, 1987), direct action (Frydenberg & Lewis, 1993) and emotional expression (Spirito et al., 1988), whereas boys use more resignation, acceptance, wishful thinking (Spirito et al., 1988) and humour (Kurdek, 1987; Patterson & McCubbin, 1987). Research with adult and college-age samples found that gender differences in coping were greater for more general patterns of coping in comparison to situational stressors (Porter & Stone, 1995; Sigmon, Stanton, & Snyder, 1995). In terms of coping efficacy, males reported perceived resignation to be a more effective coping strategy than did females (Spirito et al., 1988; Stark et al., 1989). In contrast, females reported emotional expression to be a more effective coping strategy than did males (Spirito et al., 1988).

Relation of coping to adjustment

Previous research has found a relation between coping and a variety of adjustment indices. In junior high students, stress (major and recent life events), was positively related to substance use and four different coping strategies (e.g., behavioral coping, cognitive coping, adult social support and relaxation) were negatively related to substance use (Wills, 1986).

Emotion-focused coping was associated with increases in self-reported and parent-reported emotional and behavioural problems (Compas, Malcarne et al., 1988). As mentioned previously, a relation between emotion-focused coping and psychosocial maladjustment may reflect a less sophisticated style of emotion-focused coping than found for older adolescents. In fact, research has shown that the relation between coping strategies and adjustment is influenced by developmental factors. For early adolescents, problem solving was negatively correlated with depression (Compas, Malcarne et al., 1988; Glyshaw, Cohen, & Towbes, 1989), and social

entertaining was negatively related to anxiety (Glyshaw et al., 1989). These findings were not significant for a sample of middle adolescents (Glyshaw et al., 1989).

In a recent review, Moos (2002) noted for adolescents and young adults, avoidance coping was associated with decreased likelihood of stressor resolution, and increased depression, anxiety, behaviour problems, and alcohol and drug use. In contrast, approach coping was associated with resolution of a stressor, more self-confidence and fewer problems.

Stressor appraisal and coping strategies

The extent to which an event is viewed as controllable is an aspect of the appraisal process that appears to influence the coping strategies of both children and adults. Researchers have noted that controllability is an important variable that warrants further study (Donaldson et al., 2000). Opportunities for control vary with different situations. However, the goodness-of-fit hypothesis states that positive adjustment requires both appraisals and coping to fit the particular circumstance. In situations that are controllable, problem-focused coping efforts are more adaptive, but when situations are uncontrollable, distress is reduced if a less threatening appraisal of the problem is developed instead (e.g. emotion-focused coping) (Folkman et al., 1986).

Compas and colleagues found support for the goodness-of-fit hypothesis in a sample of children and adolescents (Compas, Malcarne et al., 1988). There was a significant interaction between perceived controllability of the cause of social stressors and the number of problem-focused alternatives endorsed. Further, behavioural problems on the Youth Self Report (Achenbach, 1991) were highest for mismatches between coping strategy and perceived controllability. However, support for the goodness-of-fit hypothesis was only found for problem-focused coping for social stressors. When emotion-focused coping and/or academic stressors were evaluated, the hypothesis was no longer supported. As a source of indirect support for the hypothesis, problem solving has been positively correlated with perceived control for school-aged children (Compas, Banez, Malcarne, & Worsham, 1991) and adolescents (Compas, Forsythe, & Wagner, 1988; Gamble, 1994). Young female athletes have also shown a positive relation between control appraisal of stressful sporting events and disengagement coping (Haney & Long, 1995).

Support for the goodness-of-fit hypothesis has also been found in several studies of college students. The relation was found for major life events, but not for minor events (Forsythe & Compas, 1987). In other research, students matched their method of coping with appraised controllability of their daily hassles, but their adjustment was not contingent upon the goodness-of-fit hypothesis (Roberts, 1995). Interestingly, in a longitudinal study, perceived control was related (positively) to problem-focused coping, but not to behavioural disengagement (negatively) until after the first reporting period (Reese, Kliwer, & Suarez, 1997). This finding highlights that coping is an ongoing process and obtained results may depend upon where one is in the process (Lazarus & Folkman, 1984).

In summary, these studies suggest that children, adolescents and young adults often match their choice of coping strategy to the perceived controllability of the event. However, the extent to which a “good match” is associated with positive adjustment is a less consistent finding.

In addition to issues of controllability over the outcome of the event, other areas of appraisal have also received attention in the stress and coping literature. Children and adolescents are typically asked to rate control over the outcomes of events, but perceptions of the controllability of the cause of events may also be important for stress and coping (Compas et al., 1991; Ebata & Moos, 1991). Based on theoretical reasons, several previous child and adolescent stressor measures have included scales where respondents rate the desirability and degree of impact of each event (for a review see Compas, Davis, Forsythe, & Wagner, 1987). In a study designed to develop a measure of stressful life events for adolescents, several appraisal scales were also empirically evaluated (Compas et al., 1987). Events were distinguished based on desirability for early, middle and late adolescents. However, only middle and late adolescents distinguished events based on impact. Therefore, at least for middle and late adolescents situational evaluations of stress and coping should also consider ratings of perceived impact (Compas et al., 1987).

Research with college undergraduates also supports the importance of considering cognitive appraisals for stressors on a situational basis; temporal consistency was found for the same types of stressors, but was lower across stressor types (Compas, Forsythe et al., 1988). However, this study did not control for differences in stressor demands, resources or stressor appraisals. For

example, differences in controllability appraisals may account for situational differences in coping. Therefore it appears that a situational model of stress and coping (i.e., Lazarus & Folkman, 1984) is more appropriate than a model that considers an overall coping style or trait approach to coping.

Summary of Stress and Coping in Adolescence

In summary, stress and coping in adolescents is aptly described using the transactional model put forth by Lazarus and Folkman (1984). Within this approach, coping is influenced by the cognitive appraisals an individual makes when faced with a specific situation. Although researchers have classified stressors in a number of ways (e.g. major, minor, discrete, or chronic), the self-report of cognitive appraisals allows for a variety of salient stressful events to be measured on a common matrix. There is some evidence that perceived controllability and perceived impact of the event may be important aspects of the cognitive appraisal process for adolescents. Finally, there appear to be some developmentally based consistencies for stress and coping variables. However, the research has been less definitive about gender differences.

Chronic Illness in Adolescence

Adjustment Challenges for Ill Adolescents

Living with chronic health problems is a concern for many adolescents, with prevalence rates ranging from 9 to 21 percent (Gortmaker, Walker, Weitzman, & Sobol, 1990; Newacheck, McManus, & Fox, 1991). Adolescents with chronic illness face the traditional challenges of adolescence, such as identity formation, conforming to social norms within a peer group, and developing independence. However, the experience of a chronic illness may impede their ability to meet these goals. For example, physical differences, medications, dietary changes, missed school, and social isolation may serve to alienate the ill adolescent from the healthy peer group. Medically imposed contraindications, parental stereotypes and overprotective behaviors may limit their opportunities for the development of autonomy and independence. Moreover, the number of additional stressors beyond the normative ones, place the ill adolescent at risk for coping difficulties.

Population-based studies demonstrate an approximate two-fold increase in risk for psychosocial adjustment problems among chronically ill children (Cadman, Boyle, Szatmari, & Offord, 1987; Pless & Roghmann, 1971; Walker, Gortmaker, & Weitzman, 1981).

Despite an increased risk to mental health, the majority of adolescents living with a chronic illness do not manifest adjustment difficulties. However, the types of difficulties that often occur in this population can be quite debilitating. These individuals are at risk for impaired social development (Gortmaker et al., 1990; Newacheck et al., 1991; Pless & Nolan, 1991), increased incidence of depression (Bennett, 1994; Burke, Neigut, Kocoshis, Chandra, & Sauer, 1994; Gortmaker et al., 1990; Key, Brown, Marsh, Spratt, & Recknor, 2001; Newacheck et al., 1991; Seigel, Golden, Gough, Lashely, & Sacker, 1990) disordered eating (Neumark-Sztainer, Story, Falkner, Beuhring, & Resnick, 1998) and body image disturbances (Wolman, Resnick, Harris, & Blum, 1994; Zeltzer, Kellerman, Ellenberg, Dash, & Rigler, 1980) self-image disturbances (Seigel et al., 1990) and internalizing or externalizing problems (Soliday, Kool, & Lande, 2000). Because the consequences of maladaptive coping can be severe in this population, it is important to identify the types of events that ill adolescents find demanding and also the range of coping strategies (both adaptive and maladaptive) they employ. Differences in coping strategies used may account for heterogeneity in outcomes.

Stressors, coping and adjustment for ill adolescents

The chronic illness literature has shown a relation between stressors, coping strategies and measures of adjustment. Both diabetes as a chronic stressor, and negative life events as a discrete stressor were related to children and adolescents' behavioural adjustment (Holmes et al., 1999). Pediatric cancer researchers have also established a positive relation between the intensity of perceived stressors and psychological distress (Varni et al., 1994). Perceived problem difficulty was also more strongly associated with depression than the actual number of problems an individual endorsed (DiGirolamo, Quittner, Ackerman, & Stevens, 1997). Moreover, a positive relation was also found between the ill adolescent's perception of family events and depressive symptomatology, despite no difference between the chronic illness group and comparison groups on the amount of family change that had occurred (Kaplan, Grossman, Landa,

Shenker, & Weinhold, 1986). These findings provide converging evidence for a relation between cognitive appraisal of the problem and adaptation (DiGirolamo et al., 1997).

Several studies have demonstrated a relation between illness-related stressors, coping patterns and adjustment. Pain coping strategies predicted adjustment beyond age and pain frequency for children and adolescents with sickle cell disease. Children and adolescents high on negative thinking and passive adherence were less active, required more health care services, and were more psychologically distressed during painful episodes (Gil, Williams, Thompson, & Kinney, 1991). Approach coping with a diabetes-related stressor has been shown to predict better diabetes adherence whereas avoidant coping predicted poorer adherence (Reid, Dubow, Carey, & Dura, 1994). Avoidant coping in relation to a cancer stressor has also been associated with greater depression and anxiety (Frank, Blount, & Brown, 1997). Chronically ill children and adolescents referred for psychological evaluation used more distraction than a control group, and more social withdrawal and distraction than a diabetic group (Spirito et al., 1988). For diabetic adolescents, primary coping was associated with better medical adjustment (Band, 1990) and both primary coping and greater perceived control over diabetes were associated with better socio-behavioural adjustment (Band & Weisz, 1990). For child and adolescent cancer patients, behavioural control of normative and medical situations was positively associated with maladjustment as measured by self-report of depression and somatic complaints, and nurses' ratings of behaviour and compliance (Worchel, Copeland, & Barker, 1987).

Adjustment was also related to global coping measures for ill children and adolescents. In a heterogeneous illness sample, social support and confrontation were predictors of positive social adjustment whereas a depressive coping style was a predictor of poor adjustment (Meijer, Sinnema, Bijstra, Mellenbergh, & Wolters, 2002). Many studies also explored the relation between coping style and adjustment for diabetic children and adolescents. Ventilation and avoidance coping were predicted by high life stress, low family cohesion and older age (Hanson et al., 1989). Also, negative life events were related to poorer psychosocial adjustment to diabetes after controlling for age, gender and illness duration (Kager & Holden, 1992). Avoidance coping and depression were associated with both poorer disease adaptation and metabolic control (Grey, Cameron, & Thurber, 1991).

In contrast, no differences were found between optimally and non-optimally controlled diabetic children and adolescents in relation to coping with a personal stressor of their choice (Weist & Finney, 1993). However, when adolescents with Rheumatic Disease selected a personal stressor of their choice, approach coping was positively related to psychosocial adjustment, whereas avoidance coping was negatively related to adjustment (Ebata & Moos, 1991).

In summary, events unrelated to the illness appear to be strongly associated with perceived distress, whereas illness-related events tend to be associated with illness-related adjustment. Further, studies have demonstrated that patterns of coping are clearly associated with adjustment measures, although specific strategies are not consistently reported across studies. Finally, the perceived impact of the stressor is more strongly related to adjustment than is the frequency of stressful events.

Organization of the Stress and Coping Literature

Findings from the both the developmental and chronic illness literature indicate that both life stress and coping styles are related to adolescent adjustment. In order to appropriately target ill adolescents at risk for adjustment problems, or to intervene with those currently experiencing difficulties, the stressors encountered and the subsequent coping styles practiced in this population must be identified. Many researchers in this field have endorsed Lazarus and Folkman's (1984) conceptualization of the stress and coping process. From this perspective, the frequency and type of coping strategies used by a chronically ill adolescent will vary across time and situations according to both perceived situational demands and coping resources. For example, the adolescent may watch television during a painful episode (distraction), but may contact their physician to cope with a flare-up of their condition (i.e., problem solving) (Spirito, Stark, & Knapp, 1992). This approach has considerable merit, given the diversity in coping responses and stressors identified by ill adolescents.

Although cognitive appraisals have been included in conceptualizations of stress, coping and adjustment (e.g., Ebata & Moos, 1991; Moos, 2002; Thompson, Gustafson, Hamlett, & Spock, 1992; Wallander & Varni, 1992), very few studies have actually collected data on the role of these cognitive processes in stress and coping. Further, studies that have considered cognitive

processes have often focused on the contribution of parental perceptions in the adaptation of the ill child (e.g., Holden, Chmielewski, Nelson, & Kager, 1997) or on the cognitions of other family members who are affected by the adolescent's illness-related stressors (for a review see Compas et al., 1992). For example, in the Double ABCX Model of Family Adaptation, family adjustment to pediatric chronic illness is believed to occur as follows: family coping emerges over time due to a pile up of stressors (illness-related/not illness-related) interacting with existing and new resources, and perception of the stressor and coping abilities (Patterson & McCubbin, 1983).

The most significant body of research that has investigated coping strategies in chronically ill children and adolescents has focused on coping during stressful medical procedures (for a review see Rudolph, Dennig, & Weisz, 1995). Obviously this is an attractive area for study because the medical environment provides an ideal platform for observing coping behaviours in response to naturally occurring, yet predictable and discrete stressors. However, it is unlikely that these studies will help researchers to understand how the ill child or adolescent copes with the full range of stressors they frequently encounter. Therefore, studies in this area will not be reviewed in this paper.

Other studies have compared the coping strategies of healthy adolescents to those with a chronic illness (e.g., Donaldson, Danovsky, Prinstein, & Spirito, April 1997; Ebata & Moos, 1991; Olson, Johansen, Powers, Pope, & Klein, 1993; Phipps, Fairclough, & Mulhern, 1995; Spirito et al., 1988). There is the underlying assumption that both stressors and method of coping differ across these two populations. However, there is considerable variability within each of these two groups for identified stressors and coping styles. Therefore, any differences in coping that exist may be more related to individual differences rather than cross-situational coping variability. Given that different individuals employ different strategies in response to the same stressor, it is important to explore variables that may influence an individual's choice of coping strategies.

Studies have also reported on illness-related coping strategies within the chronic illness population. However, these studies typically report on a specific illness and its related symptoms. The divergent methodologies limit generalizability to the chronic illness population as a whole (Band, 1990; Band & Weisz, 1990; Gil et al., 1993; Gil et al., 1991; Gladstein &

Holden, 1996; Holden, Gladstein, Trulsén, & Wall, 1994; Kovacs, Brent, Steinberg, Paulauskas, & Reid, 1986; Worchel et al., 1987).

Even less research has compared the coping strategies of ill adolescents across illness-related and other types of stressors (Bull & Drotar, 1991; Mastroyannopoulou, Sclaire, Baker, & Mowat, 1998; Reid, Dubow, & Carey, 1995; Spirito et al., 1995). This line of research appears to be most promising because it provides a comprehensive analysis of stress and coping in a number of domains of the ill adolescent's life. However, this area of research is underdeveloped, and therefore limited in its application to general statements about stress and coping in this population.

In the following sections, the literature on stress and coping in adolescents with a chronic illness will be reviewed. First, stressors identified by chronically ill adolescents are briefly reviewed; following this review, each of the above-described lines of coping research is discussed. Priority is given to how each study contributes to a comprehensive understanding of stress and coping in the ill adolescent population. Methodological limitations of these areas of research are also discussed. The table presented in Appendix A provides further details on studies that have investigated the coping strategies of ill adolescents; within this table, studies are grouped according to the presence or absence of a comparison group.

Stressors of the ill adolescent

There have been several different methods used to examine stressors in the pediatric population. Techniques have included interview, provision of a select number of stressors, comprehensive lists of minor or major normative stressors, personal stressors chosen by the participant, and illness-specific lists of stressors. Despite the diversity in methods, several interesting findings have emerged.

First, when chronically ill participants have chosen their own stressors they have selected hospital-related problems (e.g., lack of privacy) (Spirito et al., 1994) or disease-related problems (Spirito et al., 1995) more frequently than pain-related problems. Even when pain was selected, more than 30% described pain related to their disease state, not medical procedures. This is interesting, given the significant body of research that has focused on how children cope during

painful medical procedures. These findings suggest that for children and adolescents, pain may be a less salient stressor than other illness-related situations.

Second, when chronically ill adolescents were provided with four hypothetical stressors, the highest adaptive coping rates were described in response to a personal stressor of their choice. Even more interesting, only 14% of participants identified an illness-related event as their personal stressor (Olson et al., 1993). Other pediatric research has also found that non-cancer related stressors accounted for more than 85% of patients' perceived distress (Bull & Drotar, 1991). Therefore, stressors that are not illness-related may be at least as important as illness-related stressors to the ill child's sense of well being and both should be considered in any assessment of stressors and coping resources.

Third, the content of some normative problems tends to interact with the demands of the chronic illness. A comprehensive, context-specific measure of stressful situations was developed for adolescents with cystic fibrosis (CF) (DiGirolamo et al., 1997). Normative adolescent issues such as "wanting to date", were associated with feeling less attractive due to illness-related short stature. Therefore, the extent to which a problem can be identified as illness-related is not definitive. Instead, the ill adolescent may be the most appropriate person to make this distinction. However, to our knowledge, no study has assessed these dimensions on separate ratings scales.

Fourth, total perceived impact of illness (e.g., leukemia vs. colds) and types of concerns did not differ between chronically ill and healthy adolescents on an illness impact questionnaire (Zeltzer et al., 1980). Freedom and popularity were most frequently reported as disrupted by both ill and healthy adolescents. For the chronic illness group, the total illness impact did not correlate with time since diagnosis, number of hospitalizations, life expectancy, course of illness, or limitation of activities. Adolescents reporting high impact of illness were more likely to report high anxiety and lower self-esteem. Similarly, when adolescent ratings of disease severity were self-reported, they were related to self-reported depression scores. Interestingly, both parent and medical provider severity ratings were not related to adjustment, despite parents' higher ratings of illness severity relative to adolescent or medical provider ratings (Key et al., 2001). In other research, adolescents who rated problems as more difficult endorsed more depressive symptoms,

whereas the number of problems was not as strongly related to depression scores (DiGirolamo et al., 1997).

In summary, these findings suggest the relative impact of stressors and psychosocial adjustment cannot be predicted on the basis of objective levels of illness-related dysfunction. Painful medical procedures have been extensively investigated, yet procedural pain and disease-related pain are not always reported to be the most salient stressors in this population. Ill adolescents face a range of illness-related and other types of stressors. However, the impact of stressors that are unrelated to the illness also appears to be significant for ill adolescents. Further, the distinction between illness-related and other types of stressors can be ambiguous because of their frequent interaction; this determination should be made by the individual. These findings provide strong support for the role of cognitive appraisal in the stress and coping process. That is, the extent to which specific external or internal demands are appraised as taxing is dependent on an interaction between person and environmental variables and cannot be readily predetermined by others (Lazarus & Folkman, 1984).

Coping strategies of chronically ill versus healthy children and adolescents

The following section reviews studies that have compared the coping strategies of ill children and adolescents to those without a chronic illness (refer to Appendix A, Studies with Normative Comparison Groups). To compare coping across ill and healthy children, some research has evaluated coping in terms of trait-specific or global coping styles. For example, adolescents with cancer reported significantly lower levels of depression and were more likely to be classified as repressors compared to healthy high school students. A repressor style was associated with lower rates of depression across groups (Canning et al., 1992). A longitudinal study showed that children and adolescents with cancer and other chronic illnesses had a higher incidence of repressive adaptive style and lower levels of self-reported anxiety than did healthy children and adolescents (Phipps et al., 2001). However, these individuals may be underreporting distress due to the minimization and denial associated with the repressor style (Canning et al., 1992). Phipps and colleagues (2001) suggest the repressor style associated with cancer is not the result of a premorbid personality trait. Instead, it may be a reactive shift towards the repressive adaptive style that remains stable over time. Support for the reactive shift

hypothesis is found in a study of children and adolescents with diabetes. Initial level of coping (defense level, adaptive strength, locus of control) and initial adjustment were predictive of adherence to the diabetic regimen four years later. It is noteworthy that the repressor style could not explain individual adherence change. The authors hypothesized that other variables, such as stressful events may be more likely to predict adherence change, highlighting the importance of contextual factors in coping (Jacobson et al., 1991).

In contrast, no differences on a standardized global measure of coping were found between adolescents with diabetes, cystic fibrosis and healthy controls (Cappelli et al., 1989). However, a semistructured interview showed that ill adolescents were more concerned than were controls about their health and its impact on family members. Although measures of global coping strategies and trait approaches may help to categorize an individual's general coping style or to predict adjustment, they provide little information about modes of coping for specific types of stressors or the repertoire of coping skills used by an individual. The following studies have explored coping strategies in relation to specific stressful situations.

Spirito and colleagues (1988) devised the 10-item Kidcope to assess coping strategies in adolescents. As part of the psychometric development, several different samples completed the questionnaire. A group of children and adolescents with health problems who were referred for psychological evaluation used more distraction and social withdrawal than the diabetic group or the comparison group. In contrast, the comparison group used more self-criticism than the pediatric or diabetic group. A strength of this study is that it introduced an objective way to measure perceived coping strategies. Unfortunately, comparisons between groups are difficult to interpret because each group was asked to identify a different category of stressor (e.g., illness-related vs. school problem). Further, differences between groups in time periods for reporting stressors may have affected the accuracy of the retrospective reporting (Spirito et al., 1988).

In a more recent study by Spirito and colleagues (Donaldson et al., April 1997) a different pattern of coping strategies emerged. Children and adolescents with health problems reported on coping strategies for a personal stressor related to medical treatment. For a comparison group, healthy children and adolescents endorsed coping in response to an interpersonal, family, or school stressor. Coping rates were similar across the four groups, however the pediatric group

reported the greatest use of social support and resignation, and the least frequent use of blaming others. Once again, coping strategies were compared across different stressors and cognitive appraisal ratings were not assessed. Therefore, this study does not provide any insight into how these two groups cope with similar stressors.

Using similar coping methodology, chronically ill and acutely ill children and adolescents identified the same types of stressors during hospitalization (Spirito et al., 1994). Specific coping strategies (i.e., problem-solving, social support, wishful thinking) were associated with problems that generated greater self-reported distress although not with particular stressors. Acutely ill children were more likely to endorse avoidant and negative-coping strategies, and to report anxiety in a specific stressful situation. It may be that coping differences reflect situational variability in perceived distress and exposure. From this perspective, variation is to be expected in the frequency and type of coping strategies employed across time and across different illness related situations (Compas et al., 1992). For example, an adolescent who has not been ill before may appraise a novel stressor as threatening, whereas the chronically ill adolescent may feel less distressed when faced with a familiar stressor (Rudolph et al., 1995). In the latter two studies, different versions of the Kidcope were used for children and adolescents, thus developmental comparisons are methodologically suspect.

Ebata and Moos (1991) assessed the coping strategies of adolescents with Rheumatic Disease, Conduct Disorder, depression, and healthy youth in relation to the most important problem the individual had experienced in the previous year. There were no differences between any of the groups and their use of approach coping. Further, healthy youth and adolescents with Rheumatic Disease did not differ on the type of coping strategies employed. Stressor severity was correlated with seeking support and emotional discharge coping, and stressor challenge was related to the use of logical analysis, positive reappraisal, problem solving and seeking alternative awards. In keeping with a transactional model of stress and coping, appraisals of challenge and severity were controlled for when examining group differences in coping, although stressor severity was not self-rated. The authors highlighted how other appraisals, such as control over the cause may also need to be controlled for in future research.

Other studies provided standard types of stressors for which coping strategies were reported. Chronically ill children and adolescents were compared to healthy students on their spontaneous coping responses to the following hypothetical stressors: i) giving a talk before their class, ii) a personal stressor of their choice, iii) receiving a dental injection, and iv) receiving venipuncture (Olson et al., 1993). Similar rates of adaptive coping were found for both groups, except that ill children and adolescents were more likely to engage in coping in response to venipuncture. Presumably, these children and adolescents had previously learned cognitive coping strategies for this familiar situation (Olson et al., 1993). These findings suggest that situation-specific factors are important. Additionally, the researchers stated that adaptive coping rates were not associated with controllability of illness symptoms because diseases with readily controlled symptoms had lower coping rates (Olson et al., 1993). However, this study did not focus on illness-related stressors, which may be of varied controllability. Further, participants' ratings of perceived control of stressors was not measured. Therefore, a relation may still exist between perceived controllability of specific illness-related stressors and coping responses.

Child and adolescent oncology patients were also compared to healthy school children on blunting and monitoring responses to four stress-invoking scenarios (e.g., "Imagine you are in school and the teacher tells you the principal wants to see you at recess") (Phipps et al., 1995). Overall, the oncology patients endorsed more blunting than did the normative group. There were also positive correlations between blunting and monitoring scores and blunting and time since diagnosis for the oncology group. The authors state that the cancer experience has shaped oncology patients' coping efforts so that they differ from those of healthy school children. In contrast, from a cognitive appraisal perspective, it may be that the appraisals of standard stressful situations have changed as a result of the cancer experience. Finally, both of the latter two studies relied on hypothetical stressors that may have little salience for some individuals.

These findings highlight the variability in coping responses based on differences in methodology and in cognitive appraisal processes. However, studies comparing ill and healthy adolescents are limited for two reasons: i) they use fundamentally different stressors within studies, or ii) they make inferences about coping with illness, based on a comparison of healthy

and ill adolescents coping with stressors unrelated to their illness. Therefore, it is suggested that it is more important to evaluate stress and coping efforts within the chronically ill population.

Coping with illness-related stressors

The following section reviews studies that have compared the coping strategies of ill children and adolescents in reference to illness-related stressors (refer to Appendix A, Studies without Normative Comparison Groups). In addition to pain related to medical procedures, studies have also evaluated the coping strategies used when dealing with disease-related pain. Adolescents grouped according to headache type reported the following similar patterns of coping: distraction, remaining positive, problem solving, relaxation, wishful thinking, seeking family support, becoming helpless, maintaining a future orientation, taking medicine and /or lying down. Withdrawal, blaming self/others, direct emotional expression, and imagining the pain to be a different feeling represent the coping strategies these individuals tended not to employ. Some coping and adjustment differences were found across headache type, but because diagnostic reliability of headache type was not assessed, it is unclear whether these findings reflect true differences (Holden et al., 1994). In a more recent study, the same researchers also found that although the number of different coping strategies employed did not vary by type of headache, individuals whose symptoms were worsening at the time of presentation used few coping strategies (Gladstein & Holden, 1996). Because symptom worsening was also self-reported, the direction of these findings is unclear. In addition, 78% of the sample was female, thus it is unclear if the same pattern would hold for males.

In contrast, for children and adolescents with sickle cell disease pain, active coping, negative thinking and passive adherence were not associated with the frequency of painful episodes (Gil et al., 1991). At follow-up, individuals high on the latter two strategies had more frequent health care contacts whereas adaptive copers were more involved in other activities during painful episodes (Gil et al., 1993). Gil and colleagues' findings suggest that coping style may be more strongly related to adjustment variables than it is to pain frequency or disease complications.

A pilot study assessed the frequency of specific coping strategies and found that adolescents use emotive (emotion-based avoidance) and confrontive (includes problem solving) coping to deal with their chronic illness more than they use palliative strategies (adolescent feels better

about illness, but does not actively adjust to it) (Keller & Nicolls, 1990). However, this study is limited by its small sample size, and the reported methodology is vague, thus findings should be considered only as tentative.

For recently diagnosed diabetic children (ages 8 to 13 years), the most prevalent cognitive coping strategies for illness-related coping included wishful thinking, thoughts of forbidden foods, and resentful thoughts. Behavioural strategies such as information seeking and socially oriented coping were also used. Illness-related coping behaviours evident at diagnosis onset were highly correlated with the illness-related coping approach over the following year. It is possible that more variability would occur once the sample reached adolescence (see Gil et al., 1993). Also, coping might have differentiated if a broader range of events were presented. Interestingly, self-rated psychological adjustment, psychiatric diagnosis and illness-related coping behaviours were unrelated (Kovacs et al., 1986).

In a key study, Band (1990) interviewed diabetic children and adolescents about how they thought or behaved in dealing with the demands of their disease. Coping responses were coded as primary (i.e., problem-focused) or secondary (emotion-focused). In addition coping was further classified as either instrumental, cognitive or emotional. Overall, primary, instrumental coping was preferred by both preformal and formal operational children, but the latter group employed more secondary coping strategies than did the preformal group. Because individuals with diabetes often receive training in how to perform specific diabetes-related self-care behaviours, it is not surprising that problem-focused coping is preferred. Secondary coping may emerge as more mature children recognize the limitations of diabetic management (Band, 1990). Interestingly, preformal and formal children scored similarly on cognitive appraisal scales of perceived control for diabetes-related stressors and perceived efficacy of coping; ratings for both of these scales were relatively high within this study. Band's (1990) study is noteworthy because she employed cognitive appraisal scales. However, this study only evaluated illness-related stressors and appraisal results were not reported relative to specific modes of coping. A related study by Band and Weitz (1990) explored cognitive appraisal scales in relation to adjustment measures and developmental level; this association will be discussed in a later section of this paper.

In summary, it appears that problem solving (i.e., primary coping) is the most consistently identified mode of coping across studies. Also, pain coping style may be more strongly related to adjustment variables than it is to pain frequency or disease complications. Note that in a younger sample, the relation between adjustment and coping was not clearly established. A possible explanation is that adjustment is more consistently tied to coping with non-illness stressors than it is to coping with illness-related stressors. Further, variability in coping may only become apparent if a range of stressful events is evaluated.

Coping strategies across illness-related and other types of stressors

Only four studies were identified in which coping strategies were compared across illness-related and other stressor types; as this line of research is a major focus of the proposed study, these studies will be discussed in some detail. Please refer to Appendix A for further details on the studies discussed below. Within Appendix A, the first three studies are described in Studies without Normative Comparison Groups and the final study is described in Studies with Normative Comparison Groups.

First, Bull and Drotar (1991) compared child and adolescent cancer patients' responses on a number of coping variables across five standard illness-related stressors and five stressors of their own choosing. Each response to the stressors was coded for the focus of coping (i.e., self, environment, other), the function of coping (i.e., problem-solving, emotion-management) and the mode of coping (i.e., information-seeking, support-seeking, direct action, inhibition of action, intrapsychic). Overall, the focus of coping efforts showed comparable rates across cancer and noncancer stressors. However, on an individual level, the type of focus used in one situation was unrelated to its' use in another situation. With respect to function of coping, problem solving and emotion management were used equally for noncancer stressors, but for cancer stressors, emotion management was used more frequently. Modes of coping were not consistently used across cancer and non-cancer related stressors. Within this study, developmental differences interacted with function of coping; adolescents used more emotion management and less problem solving than children for cancer stressors but not for noncancer stressors. This interaction is consistent with other research, in that emotion focused coping was used more by adolescents

compared to children (Compas et al., 1992) and more for uncontrollable stressors compared to controllable ones (Folkman et al., 1986).

Differences in cognitive appraisal processes may have rendered major life events (e.g., getting cancer) as very different from the events patients listed as noncancer stressors. If perceived controllability or impact of events covaried, coping responses would also be expected to be dissimilar. Although these results are intriguing in several ways, the retrospective nature of this study presents some limitations. First, many participants were asked to recall cancer-related coping strategies that occurred several years earlier; comparisons of cancer-related coping strategies to more recent coping strategies used for noncancer stressors is confounded with time. Moreover, developmental differences are difficult to interpret because the cancer and noncancer stressors may have occurred at different developmental stages. Finally, it is unknown if these results would generalize to a heterogeneous chronic illness sample.

Spirito and colleagues (1995) also completed a study that compared coping across illness-related and other stressor types. A heterogeneous sample of chronically ill children and adolescents were asked to describe one everyday problem and one illness-related problem. Participants rated the degree to which the problem situation caused them to feel anxious and depressed and completed the Kidcope (a brief coping checklist) for each stressor. Chronic illness problems were categorized as those related to disease, disease pain, medical procedure pain, or hospitalization. Everyday problems were classified as those related to family, parents, friends, school, or boyfriend/girlfriend.

Several analyses were conducted to determine if coping in this population is more situational or stable in nature. First, age and gender effects were found to be dissimilar for everyday and illness-related problems, suggesting more situational variation in coping (Spirito et al., 1995). For example, adolescents engaged in blaming others more frequently than did children for the chronic illness problem, whereas children employed blaming others more often than did adolescents for the common problem. The only consistent age effect across problems was that adolescents engaged in more resignation than did children. Further, gender differences were found only for the chronic illness problem. Second, many strategies (e.g., social withdrawal, cognitive restructuring, self-blame, problem-solving, wishful thinking, social support, and

resignation) were used equally across different illness problems, whereas other strategies (e.g., distraction, blaming others, emotional regulation) varied by type of problem. Mood also had little impact on the choice of coping strategy; only cognitive restructuring varied by level of anxiety. Spirito and colleagues (1995) suggested these two findings show support for the stability of coping strategies. Third, moderately consistent coping patterns were found when comparing across illness problems and everyday problems for the same individual (Spirito et al., 1995). It was concluded that coping strategies used by chronically ill children show some stability although situational differences in coping also exist. However, this study did not consider other variables, (e.g. control appraisals) that might account for some of the inconsistency in coping strategies found across illness and common problems.

Differences found in coping strategies across illness-related and everyday problems may be the product of limitations in the study methodology. First, the types of problems identified across disease-related and everyday stressors may also have varied on dimensions in addition to the illness/non-illness distinction, such as controllability and perceived impact of the stressor; anxiety ratings may be associated with these appraisals. Second, participants were instructed to provide a common stressor and a stressor that was illness-related. However, stressors may involve both illness and common dimensions. If participants are expected to only choose stressors that unequivocally include either the illness or common dimension, the breadth of self-identified stressors available for either type of problem is limited.

Mastroyannopoulou's group of researchers (1998) included three groups of children and adolescents: liver transplant recipients; individuals with ongoing liver disease; and a healthy control group. Participants completed the Kidcope in reference to a self-identified illness-related stressor (only the first two groups) and also a stressor unrelated to illness. No differences between groups were found in the number of coping strategies used for the common problem. There was no difference between the transplant group and the liver disease group on coping strategy use or perceived efficacy of coping. Stability of coping across stressors was also evaluated. For the transplant group, there was no difference in coping strategies used for the common and illness-related problem. However, for the liver disease group, strategy use was less consistent. Distraction and wishful thinking were the only strategies used consistently across

both types of problems. These two strategies were reported by over 80% of children and adolescents in the transplant and liver disease groups for the common problem. It was concluded that similarities in coping between the three groups is an indicator of positive adjustment for the ill children.

In addition to the limitations described for Spirito and colleagues' (1995) study, Mastroyannopoulou's (1998) findings were limited to children and adolescents with liver disease (either ongoing, or transplant recipient). In addition, differences found between the liver disease and transplant group is confounded with medical procedures experienced and disease severity (Mastroyannopoulou et al., 1998). Given the discrepant findings between the liver disease and liver transplant groups, it might be concluded that there is a need to look at differences between illness groups. However, the liver disease group rated themselves as less healthy and as having less perceived control over health compared to the liver transplant group. For the liver disease group, situational differences in coping may occur because they experience illness stressors as relatively more uncontrollable than common stressors, whereas for the liver transplant group, illness and common stressors may be perceived as having similar degrees of controllability.

Finally, Reid and colleagues (1995) compared children and adolescents with diabetes on approach and avoidant coping strategies across three diabetes-related situations (social problem, diet management, fingerpricks) and a general peer argument situation. An advantage of this study was that participants rated perceived controllability and how effective they felt their coping efforts were for each of the four problems. Grade point average, self-reported depression, and teacher ratings served as adjustment indices in this study. Overall, approach and avoidance coping were highly correlated across all four situations. Within each of the four situations, approach coping was used more than avoidance coping, although the former was used less for the fingerprick situation than it was for the other three situations. These findings indicate that cross-situational consistency in coping occurred, although situational differences also exist.

Other findings of interest were that children used more approach coping than did adolescents. Also, females employed more avoidance coping than did males for the fingerprick and general peer-argument situations only. Although perceived controllability was positively related to higher approach coping for the diet and peer argument situations, very few significant

relations were found between controllability and coping or adjustment in this study. An unexpected finding is that avoidance coping was used more frequently for the general peer argument situation than it was for the three diabetes situations, despite the former situation being rated as more controllable. Overall, higher levels of approach coping and lower levels of avoidance coping were generally related to more positive outcomes. In addition, avoidance and approach coping were related to coping effectiveness.

Although this study considered illness-related stressors and one normative stressor, several limitations are present. First, the sample size of diabetic youth was small and a broad age range was used (8-18 years). Therefore, the power to detect differences and the generalizability of these findings to other chronically ill adolescents is limited. Also, this study only included standardized stressors and did not allow participants to choose stressors of personal salience. Although perceived controllability was related to approach coping for two situations, this variable was not controlled for in analyses that compared coping across stressor types. Finally, participants were asked to rate how effective they felt their coping efforts were in response to each problem. However, participants were asked to consider the overall efficacy of varied coping responses for a situation, rather than the efficacy of coping in relation to each specific coping strategy employed.

In summary, the relation between coping strategies used for illness-related and other types of stressors is unclear. Both similarities and differences in coping were found across the illness/non-illness dimension, but methodological inconsistencies limit the interpretation of these findings. In the former study, retrospective reporting interacted with developmental and normative/illness findings (Bull & Drotar, 1991). In another study, adolescents did not choose stressors of personal relevance (Reid et al., 1995). For three of the studies, adolescents were not always reporting on similar stressors, yet attempts to group stressors on other commonalities were limited. Spirito and colleagues (1995) did assess emotional indices for each stressor, but these measures may not have tapped into the most salient and distinguishing features, such as perceptions of controllability and impact. Although Reid and colleagues (1995) did consider perceptions of controllability as well as efficacy of coping, these variables were not assessed in coping strategy comparisons across different stressors.

Developmental changes in stress and coping

Chronically ill adolescents are at risk for delayed physical and psychosocial development, thus developmental patterns of stress and coping may emerge differently than those found for healthy adolescents. Age appears to be a key variable in the stress and coping literature that warrants further study in the chronically ill population. Consistent with normative developmental findings, negative life events were found to be positively related to age in a sample of diabetic children and adolescents (Kager & Holden, 1992). Similar to healthy children, researchers have noted that chronically ill children's appraisals of stressors may change over developmental stages (Rudolph et al., 1995). In fact, adolescents are more likely to pick disease-related problems whereas children pick pain as a problem (Spirito et al., 1995; Spirito et al., 1994). The appraisal of what is at stake and the explanations children and adolescents give for their behaviour during a stressful event is also linked to level of cognitive development (Thies & Walsh, 1999). In cancer patients, threat of loss was greater in early adolescents versus children (Fearnow-Kenney & Kliwer, 2000).

Recent pediatric research also supports developmental changes in coping strategies that are comparable to those found for healthy children (Compas et al., 1992). In general coping strategies were more stable for younger children but changed for adolescents (Gil et al., 1993). Increased divergence in coping strategies is related to adolescent development (Compas et al., 1992). More specifically, diabetic children and adolescents showed an increase with age or cognitive-developmental level in the use of emotion-focused or secondary-control coping (Band, 1990; Band & Weisz, 1990; Hanson et al., 1989). Also, adolescents with cancer used more emotion-focused coping and less problem-solving coping than younger children (Bull & Drotar, 1991).

Although the majority of research has focused on developmental differences in emotion-focused and problem-focused coping, other developmental differences have been found less frequently. Cognitive coping strategies have also been demonstrated to increase with age or developmental level (Band, 1990; Worchel et al., 1987). Compared to younger cancer patients, adolescent with cancer engaged in more decision-related control regarding nonmedical events and more thinking about their illness and treatment as a means of coping (Worchel et al., 1987).

Preadolescents with Diabetes engaged in more ventilating feelings, compared to postpubescents who employed more avoidance and relaxation coping (Grey et al., 1991). Hospitalized adolescents used more cognitive strategies, despite the fact that younger children used more coping strategies overall (Spirito et al., 1994). In other research, adolescents used less wishful thinking, but more resignation than children across illness-related and common stressors. In contrast, an interaction was found for blaming others across problem and age categories; adolescents used blaming others more than children for illness problems, but for common problems, children had higher rates of this coping strategy (Spirito et al., 1995). However, Spirito's developmental findings are ambiguous because different versions of the Kidcope were used for children and adolescents.

A common limitation of many of these studies is that developmental differences are explored by comparing children to adolescents. However, there are differences in physical, emotional and cognitive development within the adolescent period (Baumrind, 1987; Chassin et al., 1995; Erikson, 1964; Keating & Clark, 1980). In order to further our understanding of developmental differences in stress and coping, it is also important to explore differences within the adolescent period.

Age differences have also been found for other categories of coping strategies. For example, adaptive coping increased with age, although catastrophizing did not (Olson et al., 1993). Blunting (Phipps et al., 1995), and the use of passive adherence or negative thinking in response to sickle cell pain were both negatively correlated with age (Gil et al., 1991). In contrast, no significant correlation was found between age and active or avoidant coping for children and adolescents with Sickle Cell Disease (Kliwer & Lewis, 1995). However, the latter study results should be considered tentative because the sample size was small, a broad age range (7-16 years) was used, and coping was measured globally (Kliwer & Lewis, 1995). In other research, children with diabetes used approach coping strategies more frequently than did adolescents (Reid et al., 1995).

In summary, studies have consistently shown that rates of emotion-focused and cognitive coping are higher for adolescents than for younger children. However, other differences in coping strategies are less clear because differences in the populations studied and in stress and

coping measurement have limited the replicability of findings (Gil et al., 1991; Grey et al., 1991; Holden et al., 1994; Olson et al., 1993; Spirito et al., 1995; Spirito et al., 1994). It would be useful to consider a broad sample of chronic illnesses, because only a few of the studies reported included a mixed chronic illness group.

Gender differences in stress and coping

Gender differences have also been explored in relation to stress and coping for chronically ill adolescents. Compared to chronically ill boys, ill girls reported more stressors across different domains and specifically, within dating/pubertal development and friends domains (DiGirolamo et al., 1997). Girls also rated clinic/hospital visits as more difficult than did boys.

Although gender differences have been found for coping strategies, the only consistent finding was that girls practiced more emotional regulation than did boys. Across all medical stressors chosen, females used more coping strategies than males and employed more emotional regulation (for a review see Spirito, Stark, & Tyc, 1989). In contrast, the only study that has reported a higher number of coping strategies for males than females was specific to headache patients (Holden et al., 1994). Girls used more avoidant coping than did boys in relation to diabetes fingerpricks and a general peer argument situation, but not in relation to other diabetes stressors (Reid et al., 1995). Girls used more emotion management and less problem solving than did boys for cancer stressors (Bull & Drotar, 1991). Spirito et al. (1995) found that girls used more emotional regulation and social support whereas boys used more cognitive restructuring and self-blame. These differences were apparent for the illness-related problem and not the common problem. Spirito and colleagues (1995) have suggested that each gender picks qualitatively different strategies to deal with repeated stress; these differences may not have been present for less chronic, common stressors. This finding is surprising because some similar gender differences were found for healthy teenage girls (Patterson & McCubbin, 1987). However, no gender effects were found for children with cancer or a healthy comparison group on monitoring or blunting scores (Phipps et al., 1995).

In summary, it has been demonstrated that girls consistently report more negative stressful events, and that they employ more emotional regulation than do boys as a way of coping. However, the literature is inconsistent regarding other gender differences across illness-related

and other types of stressful events. Therefore, research should investigate gender differences in coping across common and illness-related stressors. Differences may be more likely to occur if participants are encouraged to list their own personally salient choice of stressors.

Limitations of previous research

As described throughout this paper, methodological limitations impair the generalizability of these findings. The following section summarizes many of the limitations found in this body of literature. A number of studies have only included a homogeneous illness group that cannot be generalized to a heterogeneous illness population (Band, 1990; Band & Weisz, 1990; Bull & Drotar, 1991; Canning et al., 1992; Ebata & Moos, 1991; Gil et al., 1993; Gil et al., 1991; Gladstein & Holden, 1996; Grey et al., 1991; Hanson et al., 1989; Holden et al., 1994; Jacobson et al., 1991; Kager & Holden, 1992; Kliwer, 1997; Lewis & Kliwer, 1996; Mastroyannopoulou et al., 1998; Phipps et al., 1995; Phipps et al., 2001; Reid et al., 1995; Worchel et al., 1987). Also, sampling biases may have occurred for studies with either low recruitment rates (Bull & Drotar, 1991; Reid et al., 1995) or with only seriously ill adolescents (Olson et al., 1993; Worchel et al., 1987). Retrospective reporting was employed in some studies (Bull & Drotar, 1991; Gladstein & Holden, 1996), and several comparisons covaried with time since treatment (Bull & Drotar, 1991) or duration of the reporting period (Spirito et al., 1988). Parent reporting was relied on for a variety indices, including child pain level, but reliability checks were not systematically sampled across different age groups (Gil et al., 1991). Also, different versions of coping inventories were used to compare coping strategies across age groups (Holden et al., 1994; Spirito et al., 1995; Spirito et al., 1994). Finally, for some of the studies with large age ranges (i.e., 7-18 years) small sample sizes have resulted for specific age categories (Bull & Drotar, 1991; Canning et al., 1992; Gladstein & Holden, 1996; Mastroyannopoulou et al., 1998; Reid et al., 1995).

Other limitations were more specifically linked to the measurement of stress, coping and adjustment variables. For example, some studies relied on single stressors (Donaldson et al., April 1997; Ebata & Moos, 1991; Spirito et al., 1994; Spirito et al., 1988) to compare coping strategies across groups. For many studies participants selected stressors of their own choice; these may have varied on other dimensions, in addition to those that were being systematically

compared (Bull & Drotar, 1991; Donaldson et al., April 1997; Mastroyannopoulou et al., 1998; Spirito et al., 1995; Spirito et al., 1994). In contrast, other research relied on hypothetical stressors that may be less relevant for some individuals (Olson et al., 1993; Phipps et al., 1995; Reid et al., 1995).

Summary of Previous Research

In conclusion, stress and coping in healthy adolescents is well described using the transactional model put forth by Lazarus and Folkman (1984). However, the majority of the studies of ill adolescents have not applied this model to the study of stress and coping. Although methodological inconsistencies are common in the entire stress and coping literature, the situation appears particularly problematic for the pediatric population. Developmental differences, gender findings and the relation of stress and coping variables to adjustment are difficult to interpret. In addition, many studies have investigated a single disease, thus limiting any possible generalization to other illness groups. Studies have attempted to clarify the relation between illness-related events and other types of stressful events by comparing across healthy and ill individuals, or by comparing across illness-related and other types of stressful events within the illness group. However, few studies have considered the latter approach for this issue. Other dimensions on which illness events unrelated to the illness could potentially vary are typically not recognized in this line of research. However, there is some evidence that perceived controllability and perceived impact of the event may be important aspects of the cognitive appraisal process for these adolescents.

The Present Study

Research Rationale

For many individuals, the challenges encountered during the adolescent period can lead to a heightened level of stress and coping difficulties. In fact, suicide is the second leading cause of death in this age group, after accidents (Herbert et al., 1999; Statistics Canada, 1997). Individuals living with a chronic illness are confronted with unique challenges when negotiating the developmental tasks of adolescence, complicated by physical limitations imposed by the illness, such as dietary and lifestyle restrictions and medication regimens. Not surprisingly, for chronically ill children, the adolescent period is often the one in which coping difficulties first

emerge, as evidenced by increased rates of emotional difficulties, suicidal ideation, risk-taking and noncompliance to treatment regimens (Goldston et al., 1997). Because the consequences of maladaptive coping can be severe in this population it is important to identify individuals at risk for adjustment difficulties or to intervene with those currently experiencing difficulties. In order to accomplish this, it is necessary to identify the types of events that ill adolescents typically find stressful and also the subsequent coping styles they practice.

Pediatric research has provided few definitive findings regarding the stress and coping of adolescents with a chronic illness. In part, this has occurred because alternative approaches to the conceptualization of stress and/or coping have resulted in divergent measurement techniques being practiced by different groups of researchers. For example, some researchers have conceptualized coping as a relatively stable and enduring trait (i.e. Canning et al., 1992). In contrast, other researchers have considered coping to be more situational in nature (i.e., Bull & Drotar, 1991). It is likely that ill adolescents have a repertoire of preferred coping strategies, although the choice of coping strategy employed for a given stressor may be related to other factors.

Preliminary evidence indicates that for ill individuals, normative events are of major concern during adolescence (Bull & Drotar, 1991; DiGirolamo et al., 1997; Olson et al., 1993). Coping strategies are associated with psychosocial adjustment for healthy and chronically ill adolescents, respectively (Compas, Malcarne et al., 1988; Glyshaw et al., 1989; Wills, 1986), (Band, 1990; Band & Weisz, 1990; Ebata & Moos, 1991; Gil et al., 1993; Gil et al., 1991; Meijer et al., 2002; Reid et al., 1995; Worchel et al., 1987). Therefore, it is important to establish the types of coping strategies ill adolescents use across illness-related stressor categories as well as those stressor categories that are unrelated to the illness. Investigations of coping with illness-related and other types of stressors have begun to emerge in the adolescent pediatric literature, but most studies have either (i) focused only on illness-specific stressors and ignored other stressors (Band, 1990; Band & Weisz, 1990; Gil et al., 1993; Gil et al., 1991; Gladstein & Holden, 1996; Holden et al., 1997; Keller & Nicolls, 1990; Worchel et al., 1987), or (ii) evaluated other stressors and ignored illness-related ones (Hanson et al., 1989; Kager & Holden, 1992; Phipps et al., 1995). Studies

that have considered non illness-related stressors have typically not assessed coping strategies at the individual stressor level (Hanson et al., 1989; Kager & Holden, 1992).

The few studies that have evaluated both illness-related stressors and other types of stressors are limited by the methodologies followed. Single diseases were assessed in three of the studies, thus limiting application of research findings to other illnesses (Bull & Drotar, 1991; Mastroyannopoulou et al., 1998; Reid et al., 1995). In other research, several hypothetical common stressors and only one illness-related stressor (venipuncture) were included (Olson et al., 1993). Thus the salience of these stressors to the individual is in question. In the final study, adolescents provided one stressor for each of the two categories. Because other aspects of stressors were not considered, inconsistencies in the types of stressors included have restricted any possible interpretations (Spirito et al., 1995).

Typically, researchers who have compared illness-related and other types of stressors have assumed that the only dimension on which the stressors vary is the illness versus non-illness distinction; consequently they have not considered other variables such as the controllability, impact and frequency of stressors. However, current conceptualizations of stress and coping highlight that the extent to which specific external or internal demands are appraised as taxing is dependent on an interaction between person and environmental variables and cannot be readily predetermined by others (Lazarus & Folkman, 1984). From this perspective, the appraisal process is believed to be more important than the type of stressful event in determining coping strategy and adjustment.

In the developmental literature, the adolescent's appraisal of the perceived impact and controllability of events has been demonstrated to be important in determining the dynamic relation between stress and coping (Compas et al., 1991). In the chronic illness literature, several researchers have discussed the relative importance of perceived stressor controllability (Bull & Drotar, 1991; Ebata & Moos, 1991; Hanson et al., 1989; Olson et al., 1993). When perceived controllability was included, it was only assessed in relation to adjustment and developmental level (Band, 1990; Band & Weisz, 1990); it has not been controlled for when comparing coping strategies across stressor types (Reid et al., 1995). Another study found that the perceived impact

of the stressor is more strongly related to adjustment than is the frequency of stressful events (DiGirolamo et al., 1997) but this variable is also rarely considered.

Finally, it is important to study the effects of age and gender in the chronically ill population in order to establish appropriate norms for assessment and intervention purposes. However, inferences about the effects of age and gender on stress and coping in this population are participant to many of the methodological limitations describe above. In addition, studies have used large age ranges (i.e., 7-18 years) and have explored age effects by correlational methods or splitting the sample between children and adolescents (i.e., 7-12 years vs. 13-17 years). However, the normative adolescent literature has shown some developmental differences in stressor identification and coping strategy use within the adolescent period (Schonert-Reichl & Muller, 1996; Wagner & Compas, 1990). Therefore, it is important to pursue further examination of these variables for ill adolescents. However, this broad approach has made it difficult to evaluate more subtle developmental differences within the ill adolescent population.

Objectives

Objective 1

The first objective was to develop a list of salient stressors self-generated by ill adolescents and to investigate the number, categories and cognitive appraisals of these stressors. Adolescents provided lists of stressors of their own choosing. This approach was used for two reasons. Researchers have begun to highlight the theoretical and practical importance of developing lists of stressors that are specifically salient to chronically ill adolescents (DiGirolamo et al., 1997). To-date, lists have only been developed for specific illnesses, rather than for a mixed heterogeneous population of chronically ill adolescents.

However, many researchers have chosen to follow a noncategorical approach to investigating psychosocial issues in chronic illness because studies have found that there are many more commonalities than differences shared by children and adolescents coping with different illnesses (Stein & Jessop, 1982) and these differences have not been related to unique patterns of coping and adjustment (Stein & Jessop, 1989). Within a heterogeneous population, the assessment of health-related quality of life allows comparisons to be made between the relative burden of different diseases or treatments and its relation to stress and coping variables.

Therefore, a noncategorical compendium of stressors was developed in the present research. Instructing adolescents to provide a list of their own stressors was a practical solution to an existing research limitation. Also, the distinction between illness-related and other types of stressors can be ambiguous because of their frequent interaction (DiGirolamo et al., 1997) and may be considered separate constructs most appropriately determined by the individual. This individualistic approach allowed each adolescent to identify personally salient stressors, and to rate the perceived frequency, controllability over the cause, impact and controllability over the outcome of each stressor. In addition, adolescents rated the extent to which each stressor was perceived as illness-related and typical of adolescence on two separate scales.

Objective 2

The second objective was to assess differences in coping strategies used for illness-related and other types of stressors, after controlling for stressor appraisals. Also, the individual consistency of coping style was compared across types of stressful events for each participant. A realistic sampling of the individual stressor and coping patterns was obtained because adolescents endorsed coping strategies based on personally salient stressors.

Objective 3

In the pediatric stress and coping literature, age and gender have often been found to have effects, although the direction of the variables is unclear. Therefore it is salient and important to clarify age and gender differences in this population. The third objective of the current research was to investigate age or gender influences on the frequency and types of stressors reported, their appraisal, as well as the nature and the overall number of strategies identified as being used by ill adolescents.

Objective 4

Given the noncategorical approach of this study, illness factors may still be relevant, particularly for those individuals who are more seriously ill. Within a heterogeneous population, health-related quality of life provides a way to account for possible differences because illness burden provides a common measure across different diseases. Therefore, a secondary objective was to explore illness burden as assessed by the extent to which health-related quality of life was related to stressors and coping strategies.

Major Hypotheses

1. The Relation Between Stressor Appraisal Ratings

- 1a) The perceived impact of stressors is related to perceived frequency (positively) and controllability (negatively) of stressors.

2. Coping Strategies Across Illness-Related and Other Types of Stressors

- 2a) There is a positive relation between the frequencies of each coping strategy used by the same participant for illness-related and other types of stressful events.
- 2b) For each coping strategy, if controllability is held constant, there is no significant difference between typical stressors and illness-related stressors on the perceived frequency or efficacy of coping.

3. Age and Gender Differences in Stress and Coping

- 3a) Girls report a greater number of stressors than boys.
- 3b) The number of stressors reported increases with age.
- 3c) Girls practice more coping strategies overall, more emotional regulation and social support, whereas boys practice more problem solving.
- 3d) The use of emotional regulation, cognitive restructuring, and the overall number of different coping strategies practiced increases with age.

METHOD

Participants

Participants in the present study were 207 chronically ill adolescents and one of their parents. This sample was recruited from the following outpatient clinics at the Children's Hospital of Eastern Ontario (CHEO): cardiology (n = 6, 2.9%), chest (n = 41, 19.8%), cystic fibrosis (n = 6, 2.9%), diabetes (n = 80, 38.6%), endocrinology (n = 12, 5.8%), gastroenterology (n = 7, 3.4%), haematology (n = 21, 10.1%), nephrology (n = 17, 8.2%), neuromuscular (n = 6, 2.9%), oncology (n = 3, 1.4%) and rheumatology (n = 8, 3.9%). Criteria for inclusion in the study were:

- 1) Adolescents were between the ages of 13 and 18.
- 2) A minimum of 12 months had passed since the diagnosis of chronic illness.
- 3) A chronic illness was defined as a condition that requires ongoing medical evaluation or management and places the adolescent's health at risk. Oncology participants could still be included if their cancer had been in remission for five or more years, if other study criteria were met.
- 4) One parent, living with the adolescent a minimum of one year, had to be willing to participate.

Adolescents who were currently hospitalized were not asked to participate in the study. Adolescents from the Oncology clinic were also not included if they were receiving current treatment for an acute episode or undergoing intensive chemotherapy treatment (maintenance chemotherapy was not an exclusion criteria).

Potential participants were excluded if their chronic illness involved CNS involvement for two reasons: (i) a significant percentage may have impaired or delayed cognitive functioning and thus lack the cognitive ability necessary to complete the questionnaires accurately (ii) they are at significantly greater risk of psychological maladjustment than are chronically ill adolescents without CNS involvement (Pless & Nolan, 1991). Adolescents diagnosed with a psychiatric disorder for which they were currently receiving ongoing therapy (psychopharmacological or otherwise) were excluded. Additionally, individuals who were visually impaired, or who were

not fluent in the English language or who would otherwise be unable to complete the assessment battery were not accepted in the study.

Subsequent to participation, several participants' data were excluded for the following reasons: i) additional information obtained through participation indicated that 12 adolescents did not meet inclusion criteria ii) for one adolescent and parent, the majority of the protocol was incomplete, iii) for another participant pair, the protocol was completed only by the parent. The final sample comprised 193 adolescents and one of their parents.

Justification of sample size

For the multiple regressions, the maximum number of independent variables identified was eight. A sample of 123 (the minimum sample size in the present regression analyses) should be sufficient to detect a medium effect size (.15) with alpha set at .05 (Cohen, 1992).

For the within-group coping comparisons across stressor types, with a minimum sample of 125, the estimated power to detect a small to medium effect size ($d' .41$) is equal to .87 (Cohen, 1992).

For the gender difference hypotheses, a sample of 64 should be sufficient to detect a medium effect size (.50) at power equal to .80, with alpha set at .05. In the present study, using a harmonic mean of a sample of 96 (105 females, 88 males), estimated power to detect a medium effect size is equal to .93 (Cohen, 1992).

Procedure

Recruitment Procedures

Approval for this study was received from the CHEO Ethics Review Committee. Potential participants were sent a letter, in cooperation with the clinic in question, offering them the opportunity to participate in a study examining how adolescents cope with their illness (Appendix B). The information letter indicated that adolescent participants would be reimbursed a nominal fee (\$10) for any expenses they may have incurred through their participation in the study.

Interested individuals were invited to contact the researcher or to return the stamped reply form indicating their interest in receiving further information. Individuals who preferred not to be contacted also had the opportunity to indicate this choice on the reply form (Appendix C). For

individuals where interest was indicated, telephone contact by the researcher was initiated using a standardized telephone protocol. If no response was received, telephone contact was also initiated to determine if they (a) received the letter, (b) had any questions, and (c) were interested in participating (Appendix D).

Adolescents were informed that they could be assessed either at CHEO ($n=161$) or in their own home ($n=32$). There were no differences between the two groups on adolescents' age, combined family income or clinic of recruitment. Allowing participants their choice of settings was intended to reduce refusal rates for individuals with transportation difficulties and/or those who preferred not to visit CHEO unnecessarily. Participants who chose to complete the study in their own home were encouraged to provide two private spaces for the researcher and each participant to complete the protocol together.

One parent of each adolescent also participated in the study. Parents were not required to complete the protocol concurrent with their adolescent's participation, however the majority of parents chose to participate at the same time for convenience.

Interviewers

In addition to the principal researcher, five others individuals conducted interviews. All six interviewers were female. Three of the interviewers were graduate students in psychology at the time of the study, one interviewer had completed some training in graduate psychology, and the final interviewer had prior research experience working on similar types of studies. Training involved reviewing the administration procedure with the principal researcher, observing the researcher conduct one interview, and conducting at least one interview under the supervision of the principal researcher. To ensure consistency, each interviewer was provided with detailed instructions of the protocol administration, including standardized prompts and responses (Appendix E).

Administration of the Protocol

Prior to the research protocol being administered to the participants, the researcher briefly described the protocol to the adolescent and parent (if both completing protocol in the same visit). Participants were invited to ask questions about the nature of their own participation before informed consent was obtained (Appendix F). To reduce potential anxiety and establish

rapport, the researcher asked the adolescent several basic background questions including age, current grade, and if they were regularly attending a traditional school program. If both parent and adolescent participants were completing the protocol concurrently, the interviewer placed individuals in adjacent rooms in order to ensure privacy for each participant. Although families were informed that either the mother or father's participation was needed, in the majority of cases, it was the participant's mother who completed the parent measures (82%). Generally, one interviewer assisted both adolescent and parent. She was available to answer any questions using standardized responses and prompts at any point during the completion of the measures, review the written instructions and later ensure that the participant was following directions for each task. A break was offered midway through completion of the protocol, or at any other point upon their request. At the end of the interview, participants were thanked for their participation, and told the results of the research would be sent to them as soon as they were available. Adolescent participants seen at CHEO were given \$10 upon completion. A clinician was on call during all interviews in the event that acute distress or the presence of suicidal risk was evident. If distress was evident from any answer on any of the questionnaires or throughout the assessment process, a list of appropriate resources was provided. If the participant consented, the researcher facilitated a referral to appropriate resources within the hospital or the community. Six participants received referrals for mental health services.

Adolescent administration

Adolescents first completed the Adolescent Coping Orientation for Problem Experiences (A-COPE) to prevent participants from endorsing individual items based on specific stressors they described for the Personal Stressor List (PSL). Next, respondents completed the Personal Stressor List (PSL), endorsing appraisal ratings (frequency, control over cause of event, impact, can you make it better?) for each stressor prior to generating additional stressors. Following this, respondents were distributed an additional sheet on which they completed the same appraisal ratings for two standard stressors (*problems with parents* and *having to undergo medications or treatments*). After these tasks were completed, the self-generated and standard stressors measures were folded back to reveal two additional scales for which participants were asked to rate the extent to which each stressor is related to their chronic illness and also how typical it is

of adolescence. Based on a series of decision rules applied by the interviewers (Appendix G), participants were requested to complete a series of Kidcope questionnaires in reference to personal stressors that were perceived to be highly related to their illness or highly typical of adolescence. It was hoped that participants would be able to generate two illness-related stressors and two typical of adolescence stressors to apply to the Kidcope. Finally, the participant completed the RAND 36-Item Health Survey 1.0.

Parent administration

For each adolescent, a parent independently completed the Sociodemographic and Medical questionnaires.

Measures

Adolescent measures

Adolescent Coping Orientation for Problem Experiences scale (A-COPE; Patterson & McCubbin, 1987): In the present study, this measure was used to cross validate the range of coping strategies identified in the Kidcope as well as to provide a measure of global coping. Respondents rate how frequently they engage in each of 54 behaviours (on a five-point scale) when facing difficulties or when feeling tense. Nine of the original 12 subscales were employed in the current study: ventilating feelings, seeking diversions, developing self-reliance, developing social support, solving family problems, investing in close friends, engaging in demanding activity, being humorous, and relaxing (Appendix H; Patterson & McCubbin, 1987). Two additional subscales (seeking spiritual support and seeking professional support) were not included due to skewedness, as over half of the adolescents reported that they never used over 50% of the items contributing to the scale. The avoiding problems subscale also resulted in a similar pattern of skewedness, but after splitting this scale (risk-taking behaviours and denial/avoidance), only risk-taking remained significantly skewed and was not included in the current study. Concurrent validity is satisfactory. The A-COPE has adequate internal reliability with Cronbach's alpha for each of the twelve subscales ranging from 0.50 to 0.76 (Patterson & McCubbin, 1987). In the current study, internal consistency reliability estimates for the subscales had a median value of .71 (range .41 to .78). Subscales with internal consistency reliability estimates below .71 were engaging in demanding activity (.70), developing self-reliance (.64), seeking diversions (.55), relaxing (.41) and avoidance/denial (.28). In addition, the

12 scales can be collapsed into active and avoidant coping. Active coping consists of the following scales: developing self reliance, investing in close friends, engaging in demanding activity, being humorous, developing social support, solving family problems, seeking spiritual support, and seeking professional support. Avoidance coping includes ventilating feelings, seeking diversions, avoiding problems, and relaxing. The active and avoidance scale scores were calculated by summing the relevant scales and dividing the sum by the total by the number of scales (Patterson & McCubbin, 1987). In the current study, internal consistency reliability estimates for these two scales are .68 and .57, respectively.

Kidcope Scale (modified, Spirito, 1988). In the current study, this measure was used to compare coping strategies used on different types of stressors. This 12-item self-report checklist assesses the following 10 cognitive and behavioural coping strategies: distraction, social withdrawal, wishful thinking, self-criticism, blaming others, problem-solving, emotional regulation, cognitive restructuring, social support, and resignation (Spirito et al., 1988). It was decided to split the emotional regulation item into three separate items because it appears to be comprised of three different types of coping strategies (personal communication, Crombie, 1998). Therefore, the emotional regulation scale was split as follows: discussing feelings; demonstrating anger; and self-calming.

Overall, the ten Kidcope coping strategies can be collapsed into approach and avoidant coping strategies. The approach scale is comprised of cognitive restructuring, problem solving, self-calming, and social support. The avoidant scale consists of distraction, social withdrawal, self-criticism, blaming others, wishful thinking, and resignation. The scale scores are calculated by computing the average frequency of all coping frequency items contributing to the respective scales (Spirito, Francis, Overholser, & Frank, 1996). In the present study, internal consistency reliability estimates for approach and avoidant coping in reference to self-generated stressors (highly illness-related, highly typical of adolescence) ranged from .18 to .41. For these two-factors in reference to standard stressors (*Problems with parents; Having to undergo medications or treatments*), internal consistencies ranged from .25 to .61.

The frequency and perceived efficacy of each coping strategy endorsed are rated on Likert-type scales in relation to a specific stressor (Appendix I). Test-retest correlations over 3-7 days for frequency ratings were moderate (.41) to high (.83) for all strategies except for blaming others, but efficacy ratings were more variable (ranging from .01 to .74) (Spirito et al., 1988). Reliability was substantially lower over a 10-week test-retest period in which participants were instructed to select different stressors at the second time (Spirito et al., 1988). Because the Kidcope was developed based on a process model of coping, high test-retest correlations may not be attainable (Spirito et al., 1988). One week test-retest correlations measured on the pilot sample were acceptable. For the Kidcope completed separately for self-generated stressors, moderate to high correlations (.33 - .91) were found on all strategies except for self-calming, blaming others, and social support ($M = .58$). For the Kidcope completed in reference to standard stressors, moderate to high correlations (.34 - .84) were found on all strategies except for resignation ($M = .56$). Moderate to high test-retest correlations (.47 - .85) were also found for the two-factor model of approach and avoidant coping. A more detailed description of the piloting phase is outlined in the Results section. Evidence for construct validity of this measure has also been reported (Spirito, Overholser, & Stark, 1989; Spirito, Stark et al., 1989; Spirito et al., 1988). Moderate to high correlations were found between Kidcope items and corresponding subscales on the Coping Strategies Inventory (CSI) (.33 to .77) and (.08 to .62) scales. It is not unexpected that the latter correlations are lower because the A-COPE is a measure of general coping strategies and therefore it does not instruct the respondent to select coping strategies with one stressor in mind (Spirito et al., 1988).

Personal Stressor List (PSL): This measure was constructed for the current study to assess the types of stressors, cognitive appraisals of stressors, and to provide a comparison of coping strategies across stressor dimensions. Respondents list up to 20 recent stressors and rate the frequency, perceived controllability over the cause, perceived impact and can you make it better? (control over the outcome) for each stressful event on a series of Likert-type scales. Respondents are also asked to make the same ratings for two standard stressors, *Problems with parents* and *Having to take medications or undergo treatments*. Finally, they indicate the extent to which

each stressor is related to their chronic illness and also how typical it is of adolescence. For the pilot study, two raters assigned listed stressors into one of 13 categories. A calculation of Cohen's kappa revealed high interrater agreement (95.5%), supporting the reliability of the classification system. Test-retest reliability and inter-rater reliability of this measure were also previously established through the pilot study. All test-retest correlations for the appraisal scales were significant (range = .49-.84) except for the illness-related scale for *Problems with parents*. For further detail on the development of the PSL, refer to the Results section. To my knowledge, the PSL is unique in the use of separate ratings scales for the illness/typical dimensions (Appendix J).

The RAND 36-Item Health Survey 1.0: (Hays, Sherbourne, & Mazel, 1993): This measure is used to determine the extent to which illness quality of life affects stressors, coping strategies, and coping in general. This 36-item health-related quality of life (QoL) measure is scored on eight multi-item scales: 1) limitations in physical activities because of health problems 2) limitations in usual role activities because of physical health problems 3) limitations in social activities because of physical or emotional problems 4) bodily pain 5) general mental health (psychological distress and well-being) 6) limitations in usual role activities because of emotional problems 7) vitality (energy and fatigue) and 8) general health perceptions. This measure allows Health-related QoL to be assessed from the youth's perspective, rather than their parent's. Typically, it is self-administered by individuals 14 and older and takes less than 10 minutes to complete. As previously stated, our sample ranged from 13 to 18 years. This measure contains the same items as the SF-36 (Ware, 1993), with only slight scoring differences on the Pain scale and the General Health Scale (Hays et al., 1993). In the pilot study, The RAND 36-Item Health Survey was completed by adolescents as young as 13 years without any burden or obvious comprehension difficulties. In order to maintain consistency within the present study, the RAND 36-Item Health Survey was used for the entire adolescent sample. For each scale, scores are converted to ratings on a scale from 0 to 100 with 100 indicating best health outcome (VanHook, Berkman, & Dunkle, 1996). Internal consistency within the eight scales is good, ranging from .78 -.93 (Garratt, Ruta, Abdalla, Buckingham, & Russell, 1993; Hays et al., 1993).

Median reliability coefficients across studies was typically greater than 0.80 (Ware, Barbara, & Group, 1994). Content, construct and criterion validity have also been established (Fryback, Lawrence, Martin, Klein, & Klein, 1997; Garratt et al., 1993; Ware et al., 1994). For the present study, the General Health Perception scale was used for the following reasons: i) it assesses an individual's overall perception of their global health, and does not require the respondent to attempt to determine the contribution of specific factors (e.g., chronic illness, other medical problems, emotional problems) to perceived health status ii) due to the general nature of the scale, individual ratings are not biased by specific types of physical problems associated with certain illnesses, and can provide a useful indicator of burden across diverse illnesses; and iii) it has been validated in an adolescent population (Goodman et al., 1997). Internal consistency reliability estimates for this study ranged from .63 to .89 (median = .73). For General Health, internal consistency estimate was .73. Questions 1, 33, 34, 35, and 36 comprise the General Health Perception scale (Appendix K). The RAND 36-Item Health Survey scoring method correlates .99 with the SF-36, with General Health Perception scores being slightly lower for the RAND 36-Item Health Survey versus the SF-36.

Parent measures

Socio-demographic Questionnaire: This measure assessed demographic and background characteristics of the families including, parental level of education, family income, parent marital status and the adolescent's type of school program (Appendix L).

Medical Questionnaire: Several medical variables were assessed including, the adolescent's age at illness onset, current treatment demands and previous psychological/psychiatric interventions (Appendix M).

RESULTS

Pilot Testing

Prior to commencement of the current study, a pilot project was conducted to: 1) determine the acceptability and clarity of the assessment battery; 2) provide an estimate of the number stressors (illness-related and typical of adolescence) that would be available for the Kidcope; and 3) to provide a reliability check for the stressors described the week before and for the coping strategies endorsed on the Kidcope.

A sample of 26 adolescents with a chronic illness participated in the pilot study. The procedure closely followed the current study. Each adolescent participant and at least one parent completed the assessment battery initially. All of the current study's measures were tested in the pilot study. One week later, adolescents completed the Personal Stressor List (PSL) a second time. In addition, participants were asked to describe any significant stressor(s) that occurred in the past week. Adolescents also completed the Kidcope task a second time; they were asked to recall how they coped with stressors they described a week earlier.

At 68%, the participation rate exceeded our previous expectations. Also, time needed to complete the protocol was 1 ½ to 2 hours. There were no indications of any distress with participation and there were unsolicited comments about the benefits of participation.

The mean of age of participants was 15.4 years (range = 13.2-18.6 years, SD = 1.6). The sample was fairly evenly split between male and female adolescents (46%, 54%, respectively) with mothers (77%) being more likely to participate than fathers (23%).

The mean total number of self-identified stressors was 10.8 (SD = 5.3, range= 3-20). Females generated on average 12.3 stressors (SD = 5.8), whereas males identified 8.8 stressors (SD = 4.5). A test-retest Pearson correlation computed on the total number of stressors reported was significant (.90, $p < .01$).

Categories of stressors were derived by reviewing listed stressors and classifying them into 13 categories. Each category included more than 3% of all stressors listed. Two researchers independently rated each of the individual stressors assigning them to one of the 13 categories. Discrepancies between the two raters were discussed and resolved. A calculation of Cohen's

kappa revealed high interrater agreement (95.5%), supporting the reliability of the classification system.

It was hoped that participants would rate two of their self-generated stressors as highly illness-related and two stressors as highly typical of adolescence. This would enable participants to complete four Kidcope questionnaires in relation to each of the above-described stressors. Based on decision rules developed for the current study, the majority of participants ($n = 19$, 73%) described one stressor as being highly related to their illness; a smaller group ($n = 12$, 46%) also rated a second stressor as highly illness-related. All participants rated two self-generated stressors as highly typical of adolescence.

A qualitative analysis was undertaken to determine the proportion of the stressors identified at Time 2 that were previously identified at Time 1. Across all adolescents, 65% of time 1 stressors were also identified at time 2. Of the remaining stressors, 46% were identified as stressors that had newly occurred since the previous administration. Overall, when the total number of unique stressors is considered, 55% matched. Using only those stressors that qualitatively matched, test-retest Pearson correlations were computed based on average score for all the appraisal scales for each individual. Significant correlations were found for each scale, ranging from .70 (control) to .90 (frequency) ($p < .01$). Using the entire stressor list, an average score was computed for each individual on each of the illness-related and typical of adolescence scales. For these respective scales, the significant Pearson correlations were .66 and .73 ($p < .01$).

Test-retest Pearson correlations were computed separately for the appraisal scales for each of the four standard stressors. All correlations were significant (range = .49 - .83) except for the illness-related scale for *Problems with parents*, the typical of adolescence scale for *Having to come to the hospital for clinic visits*, and the control over cause scale for *Dissatisfaction with school* (See Table 1). Anecdotally, some of these reliability ratings may have suffered due to unclear instructions. In discussions with participants, minor modifications were made. This entailed no changes to the measure itself, but to administration and instructions for the chronic illness and typical ratings.

Test-retest Pearson correlations were computed separately for the frequency ratings for each Kidcope completed in relation to each of the four self-generated stressors and four standard

stressors. As shown in Table 2, the majority of items resulted in significant correlations (.45 - .87) for the self-generated stressors. For the first illness-related, self-generated stressor, all correlations were significant except for self-calming. For the second illness-related stressor, blaming others, discussed feelings, expressed anger, social support, and resignation were not significant. For the first self-generated stressor rated as highly typical of adolescence, social withdrawal and self-calmed were not significant. For the second highly typical of adolescence stressor, all correlations were significant except for self-calming.

For the four Kidcope questionnaires completed in relation to the four standard stressors, significant correlations ranged from .44 to .89, but test-retest reliability was more variable (see Table 3). For *Problems with parents*, social withdrawal, cognitive restructuring and self-criticism were not significant. For *Having to take medications or undergo treatments*, social withdrawal and resignation were not significant. Reliability was weaker for the remaining two standard stressors. For *Clinic visits*, social withdrawal, blaming others, problem solving, discussed feelings, social support, and resignation were not significant. For *Dissatisfaction with school*, distraction, social withdrawal, cognitive restructuring, blaming others, social support, and resignation were not significant.

It was decided a priori, that given the poorer reliability for both appraisal scales of *Clinic visits* and *Dissatisfaction with school*, and for Kidcope items completed in relation to these two stressors, only the appraisals for *Problems with parents* and *Medications/treatments* would be used in analyses for the present study.

Table 1
Test-Retest Correlations of Appraisal Scales for Standard Stressors

Appraisal	Problems with parents	Clinic visits	Dissatisfaction with school	Medications/ treatments
Frequency	.84*	.74*	.76*	.82*
Control over cause	.50*	.56*	.76*	.70*
Impact	.76*	.67*	.70*	.66*
Control over outcome	.53*	.57*	.40	.49*
Illness-related	.32	.77*	.64*	.83*
Typical of Adolescence	.62*	.35	.53*	.59*

* $p < .05$

Table 2
Test-Retest Reliability of Kidcope Self-Generated Stressors

Kidcope Strategy	Illness-related stressor (1)	Typical of adolescence stressor (1)	Illness-related stressor (2)	Typical of adolescence stressor (2)
	*n=18	*n=25	*n=13	*n=25
1. Distraction	.53	.51	.87	.53
2. Social withdrawal	.86	.37	.61	.52
3. Cognitive restructuring	.69	.49	.57	.58
4. Self-criticism	.76	.70	.59	.53
5. Blaming others	.91	.72	-.08	.68
6. Problem solving	.72	.50	.85	.58
7. Discussing feelings	.81	.58	.50	.46
8. Expressing anger	.87	.82	.52	.75
9. Self-calming	.19	.36	.80	.04
10. Wishful thinking	.70	.72	.65	.51
11. Social support	.81	.45	.07	.57
12. Resignation	.71	.49	.33	.48

Note. * Number (maximum = 25) of pilot participants who generated a stressor they rated highly on the *Illness-related* or *Typical of adolescence* dimension.

Table 3
Test-Retest Reliability of Kidcope Standard Stressors

Kidcope Strategy	Problems with parents	Clinic visits	Dissatisfaction with school	Medications/ treatments
1. Distraction	.64	.54	.43	.70
2. Social withdrawal	.34	-.06	.39	.34
3. Cognitive restructuring	.36	.72	.24	.69
4. Self-criticism	.35	a	.60	.80
5. Blaming others	.65	-.06	.43	.69
6. Problem solving	.56	.14	.62	.62
7. Discussing feelings	.79	.46	.76	.57
8. Expressing anger	.78	a	.83	.50
9. Self-calming	.44	.89	.60	.77
10. Wishful thinking	.53	.49	.48	.84
11. Social support	.55	.38	.19	.55
12. Resignation	.52	.38	.10	-.16

Note. a=Not computed

Participation Rate

Four hundred and ninety two adolescents from the 11 clinics were approached about participation. 114 of these adolescents either did not meet study criteria ($n=87$) or were unreachable ($n=27$). Two hundred and seven adolescents and a parent began the study with 205 pairs completing the study protocol. This represented a participation rate of 54%. The participation rate from the different clinics was as follows: 88% from the Gastroenterology clinic (7 out of the 8 families contacted), 67% from the Cardiology clinic (6 out of the 9 families contacted), 65% from the Chest clinic (41 out of the 63 families contacted), 60% from the Endocrinology clinic (12 out of the 20 families contacted), 60% from the Oncology clinic (3 out of the 5 families contacted), 55% from the Neuromuscular clinic (6 out of the 11 families contacted), 54% from the Diabetes clinic (78 out of the 145 families contacted), 49% from the Haematology clinic (21 out of the 43 families contacted), 46% from the Cystic Fibrosis clinic (6 out of the 13 families contacted), 42% from the Rheumatology clinic (8 out of the 19 families contacted), and 40% from the Nephrology clinic (17 out of the 42 families contacted). The reason cited most frequently by adolescents and parents who chose not to participate was lack of time.

Independent-samples t-tests were conducted to examine if there were any statistically significant differences between participants and nonparticipants on the following continuous adolescent demographic variables: current age, age of adolescent when diagnosed, and disease duration. A chi-square analysis was also conducted to determine if there were group differences in gender. No significant differences were found between the two groups on any of the demographic variables examined.

Data Cleaning Procedures

All variables were checked for accuracy of data entry and missing values. The majority of demographic variables had missing values for five or less participants (refer to Table 4). There were 14 missing values for Grade level; each of these cases had an entry for a related variable (Type of school program). The variable with the highest number of missing values was combined family income (16.1% of all cases). An independent samples t-test was conducted to compare missing values on income to non-missing values for parental level of education. No

significant differences were found between the two groups on maternal or parental level of education, suggesting that missing data on family income was random. Because the missing data for combined family income appeared to be random and was not included in any of the main hypotheses, it was decided to keep these cases in further analyses. Other missing values were not replaced because demographic variables with missing values were not included in any of the main hypotheses (Tabachnick & Fidell, 1996).

Preliminary analyses were conducted to examine if data met the assumptions underlying univariate and multivariate analyses. Variables were examined for normality, linearity and homoscedasticity, as well as for univariate and multivariate outliers. Given the small range of possible values on the appraisal scales of the PSL and Kidcope frequency and efficacy scales, it was decided to include all values since the true magnitude of any difference would be very small. For the A-COPE, univariate outliers were found on the following four scales: seeking diversions (one outlying case), developing self-reliance (two outlying cases), avoidance/denial (six outlying cases) and relaxing (one outlying case). For the RAND 36-Item Health Survey, no univariate outliers were found on the General Health Perception scale. Univariate outliers were assigned the score of the highest non-outlying case (within three standard deviations of the mean) in the distribution (Tabachnick & Fidell, 1996).

Sample Background Information

Table 4 summarizes demographic characteristics of participants. The sample consisted of 105 female adolescents and 88 male adolescents (mean age: 15.9 years, SD = 1.54, range: 13.0-18.9). The average age of participants' mothers was 44 years (SD = 4.6, range: 28-55). The average age of participants' fathers was 46 years (SD = 4.9, range: 34-68).

The median combined annual income was \$70,000. According to available census data (1996), the average annual income of married or common-law families in Ontario was \$59,830, and in Ottawa-Hull it was \$69,649 (www.statcan.ca).

The majority of parents were married or living with common law partners at the time of the study (74%). The age of diagnosis of chronic illness ranged from birth to 15 years with the average age being 7 years. The time since diagnosis of chronic illness ranged from 1 to 18 years with the average time being eight years. The number of school days missed per year ranged from

0 to 120 with the average number being 11 days (SD=14.8). The majority of participants were enrolled in regular academic programs (85%). Participants' grade levels ranged from Grade 7 to university, with the majority of participants enrolled in high school. The smallest percentage of participants were from the Oncology clinic (1%) and the greatest percentage of participants were from the Diabetes clinic (39%). The sample sizes of the majority of clinics closely reflect prevalence rates of diseases found in previous research. However, the percentage of participants with diabetes in the current study is greater than predicted by existing prevalence rates (Gortmaker et al., 1990; Kliewer, 1997)

Table 4
Demographic Characteristics of Participants (N=193)

Characteristic	n	%
Gender of participants		
Male	88	45.6
Female	105	54.4
Age of participant (years)		
13	18	9.3
14	39	20.2
15	39	20.2
16	42	21.8
17	30	15.5
18	25	13.0
Age of mother (years)		
25-29	1	.5
30-39	36	18.7
40-49	136	69.9
50-59	20	10.4
Missing	1	.5
Age of father (years)		
30-39	12	6.2
40-49	129	66.8
50-59	44	22.8
60-69	2	1.0
Not applicable	6	3.2
Clinic of recruitment		
Cardiology	4	2.1
Chest	37	19.2
Cystic fibrosis	6	3.1
Diabetes	76	39.4
Endocrinology	11	5.7
Gastroenterology	7	3.6
Haematology	19	9.8
Nephrology	17	8.8
Neuromuscular	6	3.1
Oncology	2	1.0
Rheumatology	8	4.1
Mother's level of education		
No high school diploma	17	8.8
High school graduate	54	28.0
Some college or university	18	9.3
College or university graduate	86	44.6
Graduate or professional training	15	7.8
Missing	3	1.6
Father's level of education		
No high school diploma	28	14.5
High school graduate	41	21.2
Trade school	4	2.1
Some college or university	13	6.7
College or university graduate	66	34.2
Graduate or professional training	31	16.1
Missing	5	2.6
Not applicable	5	2.6

Marital status		
Married or Common law	142	73.5
Separated	18	9.3
Divorced	27	14.0
One-parent	3	1.6
Other	3	1.6
Combined annual income (\$)		
19,000 or less	8	4.1
20,000 to 39,000	21	10.9
40,000 to 59,000	31	16.1
60,000 to 79,000	29	15.0
80,000 to 99,000	22	11.4
100,000 to 119,000	26	13.5
120,000 to 139,000	11	5.7
140,000 or more	14	7.3
Missing	31	16.1
Age at diagnosis (years)		
Less than 1	21	10.9
1 to 3	30	15.5
4 to 7	45	23.2
8 to 12	74	37.8
13 to 15	23	12.0
Missing	1	.5
Time since diagnosis (years)		
1 to 2	19	9.9
3 to 7	79	41.1
8 to 12	46	23.9
13 to 18	48	24.3
Missing	1	.5
School days missed (per year)		
0-10	140	72.5
11-30	36	18.6
31-50	12	6.2
51 or more	3	1.5
Not in school	1	.5
Missing	1	.5
Type of school program		
Regular	164	85.0
Regular with tutor	13	6.7
Learning disabilities	6	3.1
Other	8	4.1
Not in school	2	1.0
Grade level		
7 or 8	18	9.3
9	37	19.2
10	40	20.7
11	33	17.1
12	27	14.0
13	18	9.3
University	4	2.0
Not in school	2	1.0
Missing	14	7.3

Objective 1: Development of the Personal Stressor List

Initially, each of the individual stressors was rated and assigned to one of the 13 categories used for the pilot study. However, as more participant data was obtained it became clear that the diversity of stressors was not fully captured, and more categories were developed. The principal researcher and another researcher independently rated each of the individual stressors and assigned them to one of 19 categories. Appendix N provides a description of the types of stressors found within each of the 19 categories. Each category included more than 1% of all stressors listed. Discrepancies between the two raters were discussed and resolved. Uncorrected percentage agreement was 88%, supporting the reliability of the classification system. Table 5 presents the percentage of stressors assigned to each of the 19 categories based on the total number of stressors reported across adolescents. Table 6 depicts the percentage of adolescents who reported at least one stressor in a given category. Adolescents reported problems in the areas of “School”, “Relationship with adolescents”, and “Relationship with parents” most frequently. Moreover, these top three stressors were reported in the same order, across age groups (13 to 15 year-olds versus 16 to 18 year-olds) and gender. Further, there was no difference between the proportion of adolescents in each clinic who reported at least one health concern ($\chi^2 (10) = 12.13, p = .276$), restrictions due to illness ($\chi^2 (10) = 5.85, p = .828$), or clinic/hospital visits or medications/treatments ($\chi^2 (10) = 16.06, p = .098$).

The mean number of stressors listed by adolescents ranged from 1 to 20 with the average being 8.59 ($SD = 4.85$). A paired-samples t-test showed that on average, adolescents rated their stressors as significantly more typical of adolescence ($M = 3.09, SD = 1.02$) than chronic illness related ($M = 1.36, SD = 1.18$), $t(192) = 12.7, p < .001$. This finding was consistent for younger and older adolescents, males and females, and for the majority of clinics.

In addition, participants rated two standard stressors, *Problems with parents* and *Medications/treatments* on the illness-related and typical of adolescence scales. Paired-samples t-tests showed that adolescents rated *Problems with parents* as significantly more typical of adolescence ($M = 4.28, SD = 1.16$) than *Medications/treatments* ($M = 1.50, SD = 1.27$), $t(160) = 21.26, p < .001$, and *Medications/treatments* as significantly more illness-related ($M = 4.43, SD = 1.30$) than *Problems with parents* ($M = 1.23, SD = 1.36$), $t(160) = 25.00, p < .001$.

Appraisal scale ratings were also compared across the two types of standard stressors. The Bonferroni correction for multiple comparisons was computed ($.05/4$ comparisons = P value .013). Paired t-tests showed that *Medications/ treatments* occurred at a significantly greater frequency than *Problems with parents*. In contrast, ratings of control over cause, control over outcome, and impact were significantly greater for *Problems with parents* than for *Medications/treatments*. Results of these t-tests are shown in Table 7. Additional paired t-tests were computed for appraisal ratings in relation to a self-identified stressor delineated as highly illness-related and a self-identified stressor delineated as highly typical of adolescence. Similar to the standard stressor, control over cause and control over outcome were significantly greater for the typical stressor than for the illness-related stressor. Table 8 displays the results of these analyses.

Table 5
Percentage of Stressors Reported per Category by Adolescents

<u>Category</u>	<u>Frequency %</u>
School	17.7
Relationship with adolescents	15.8
Relationship with parents	10.6
Health concerns	8.2
Money/finance	7.9
Daily hassles	6.0
Relationship with siblings	4.2
Body image/sexual maturation	4.1
Relationship with girl/boyfriend (dating)	3.7
Sports & Extracurricular activities	3.7
Clinic/hospital visits & Medications/Treatment	3.1
Relationship with other family members	2.5
Mental health/emotional well-being	2.4
Future concerns (other than health)	1.9
Restrictions due to illness	1.2
Physical limitations due to illness	1.2
Independence/responsibilities	1.2
Discontinuity/change	1.1
Other	3.3

Table 6
Percentage of Adolescents with at Least One Stressor in a Given Category

<u>Category</u>	<u>Frequency %</u>
School	81.9
Relationship with adolescents	74.6
Relationship with parents	53.9
Health concerns	44.0
Money/finance	38.9
Daily hassles	34.7
Relationship with siblings	31.6
Body image/sexual maturation	27.5
Relationship with girl/boyfriend (dating)	25.9
Clinic/hospital visits & Medications/treatment	22.8
Sports & Extracurricular activities	20.7
Relationship with other family members	17.1
Mental health/emotional well-being	15.0
Future concerns (other than health)	13.0
Physical limitations due to illness	8.8
Independence/responsibilities	8.8
Restrictions due to illness	7.8
Discontinuity/change	7.8
Other	23.3

Table 7
Comparison of Appraisals for Standard Stressors

Appraisal Scale	<u>M</u> Medications/ treatments	<u>M</u> Problems with parents	<u>t</u>	<u>p</u>
Frequency	3.71 (1.88)	2.62 (1.22)	7.08	<.001*
Control over cause	1.46 (1.95)	2.64 (1.14)	7.25	<.001*
Impact	2.50 (1.75)	3.05 (1.16)	3.51	.001*
Control over outcome	2.23 (1.90)	3.15 (1.28)	5.90	<.001*

Note. Standard deviations are displayed in brackets for each respective mean.

For each standard stressor, degrees of freedom for frequency does not correspond with respective appraisal scales because the remaining appraisal scales are not completed when frequency of the stressor equals zero.

Degrees of freedom equals 192 for frequency comparison.

Degrees of freedom equals 162 for remaining appraisal comparisons

* $p < .013$ (Bonferroni correction; 05/4 comparisons)

Table 8
Comparison of Appraisals for Illness-related Stressors and Typical Stressors

Appraisal Scale	<u>M</u> Illness stressor	<u>M</u> Typical stressor	<u>t</u>	<u>p</u>
Frequency	3.11 (1.36)	2.90 (1.35)	1.33	.186
Control over cause	1.98 (1.70)	2.51 (1.59)	2.64	.009*
Impact	3.58 (1.14)	3.24 (1.30)	2.32	.022
Control over outcome	2.65 (1.47)	3.22 (1.48)	3.78	<.001*

Note. Standard deviations are displayed in brackets for each respective mean.
 Degrees of freedom equals 124 for each pairwise comparison.

* $p < .013$ (Bonferroni correction; 05/4)

Hypothesis 1a:

It was hypothesized that the perceived impact of stressors would be related to perceived frequency (positively) and controllability (negatively) of stressors. A series of Pearson-Product Moment Correlations were computed on the first self-generated stressor listed on the Personal Stressor List to investigate the relation between the different cognitive appraisal variables. The Bonferroni correction for multiple comparisons was employed (.05/3 comparisons= P value .016). No significant relation was found between the impact and frequency of a stressor ($r = .083$, $p = .250$). Stressor impact was negatively related to control over cause ($r = -.205$, $p = .004$). However, no significant relation was found between the impact of a stressor and control over outcome ($r = -.103$, $p = .156$).

The same analyses were undertaken for the two standard stressors, using the same correction for multiple comparisons (.05/3) for each of *Problems with parents* and *Medications/treatments*. For *Problems with parents* ($n=183$), there was a significant relation between impact and frequency ($r = .292$, $p < .001$). Although trends were apparent, no significant relations were found between impact and control over cause ($r = -.158$, $p = .033$), or between impact and control over outcome ($r = -.143$, $p = .053$). For *Medications/treatments* ($n=169$), there was no significant relation between impact and frequency ($r = .094$, $p = .220$), or between impact and control over cause ($r = -.060$, $p = .434$). Although a trend was found, stressor impact was not significantly correlated with control over outcome ($r = .185$, $p = .016$).

Although no specific hypotheses were made, a series of exploratory correlations was computed between remaining cognitive appraisals for the first PSL stressor listed by all participants. Using the Bonferroni correction for multiple comparisons (.05/12, P value .004), a significant positive relation was found between stressor frequency and the extent to which it is chronic illness-related ($r = .212$, $p = .003$) and a negative relation was found between the extent to which a stressor is typical of adolescence and the extent to which it is chronic illness-related ($r = -.504$, $p < .001$). Also, control over cause was significantly correlated with control over outcome ($r = .607$, $p < .001$), suggesting that although associated, they represent different constructs. Table 9 lists all exploratory correlations for the first PSL stressor listed by participants.

Table 9
Correlations between Stressor Appraisal Ratings for the First Self-Generated Stressor

	Frequency	Impact	Control over cause	Control over outcome	Illness-related	Typical of adolescence
Frequency		.083 (.250)	.022 (.762)	-.034 (.636)	.212 (.003)**	.016 (.823)
Impact			-.205 (.004)*	-.103 (.156)	.113 (.117)	.054 (.458)
Control over cause				.607 (<.001)**	-.045 (.535)	.134 (.063)
Control over outcome					-.022 (.757)	.195 (.006)
Illness-related						-.504 (<.001)**

Note. Listwise deletion, n = 193

First value listed is correlation coefficient, value in brackets is associated p value

*p < .016 (Bonferroni correction; .05/3 applied for entries in bold)

**p < .004 for exploratory correlations (Bonferroni correction; .05/12)

Objective 2: Coping with illness-related and other types of stressors

Hypothesis 2a:

As a preliminary measure of coping consistency, a series of Pearson Product-Moment correlations were computed between the frequency ratings for the same coping strategies across two Kidcope questionnaire administrations. Specifically, the Kidcope was administered in reference to self-identified stressors most clearly delineated as chronic illness related, as well as in reference to self-identified stressors most clearly delineated as typical of adolescence. Using the Bonferroni correction (.05/12, P value .004), significant correlations were found for the following eight coping strategies: distraction, social withdrawal, problem solving, discussing feelings, self-calming, wishful thinking, social support, and resignation. Non-significant trends were observed for all other strategies. Table 10 presents correlations for all 12 coping strategies in reference to the illness-related and typical of adolescence stressors. Figure 1 provides a visual presentation of the pattern of coping responses across illness-related and typical of adolescence stressors. The same correlational analyses were computed between the two standard stressors *Problems with parents* and *Medications/treatments*. Similarly, significant correlations were also found for the following seven coping strategies: distraction, social withdrawal, problem solving, discussing feelings, self-calming, wishful thinking, and social support. In addition, expressing anger also yielded a significant correlation for the standard stressors. Non-significant trends were observed for two additional strategies, cognitive restructuring and resignation. Table 11 presents correlations for all 12 coping strategies in reference to the two standard stressors. Figure 2 provides a visual presentation of the pattern of coping responses across the two standard stressors.

Table 10

Correlations between Frequency of Individual Coping Strategies Employed Across Illness-related and Typical of Adolescence Stressors

Kidcope Strategy	r	p
Distraction	.285	.001*
Social withdrawal	.360	<.001*
Cognitive restructuring	.222	.013
Self-criticism	.193	.032
Blaming others	.211	.019
Problem solving	.325	<.001*
Discussing Feelings	.540	<.001*
Expressing Anger	.243	.007
Self-calming	.500	<.001*
Wishful thinking	.281	.002*
Social support	.313	<.001*
Resignation	.333	<.001*

Note. Listwise deletion, n=123

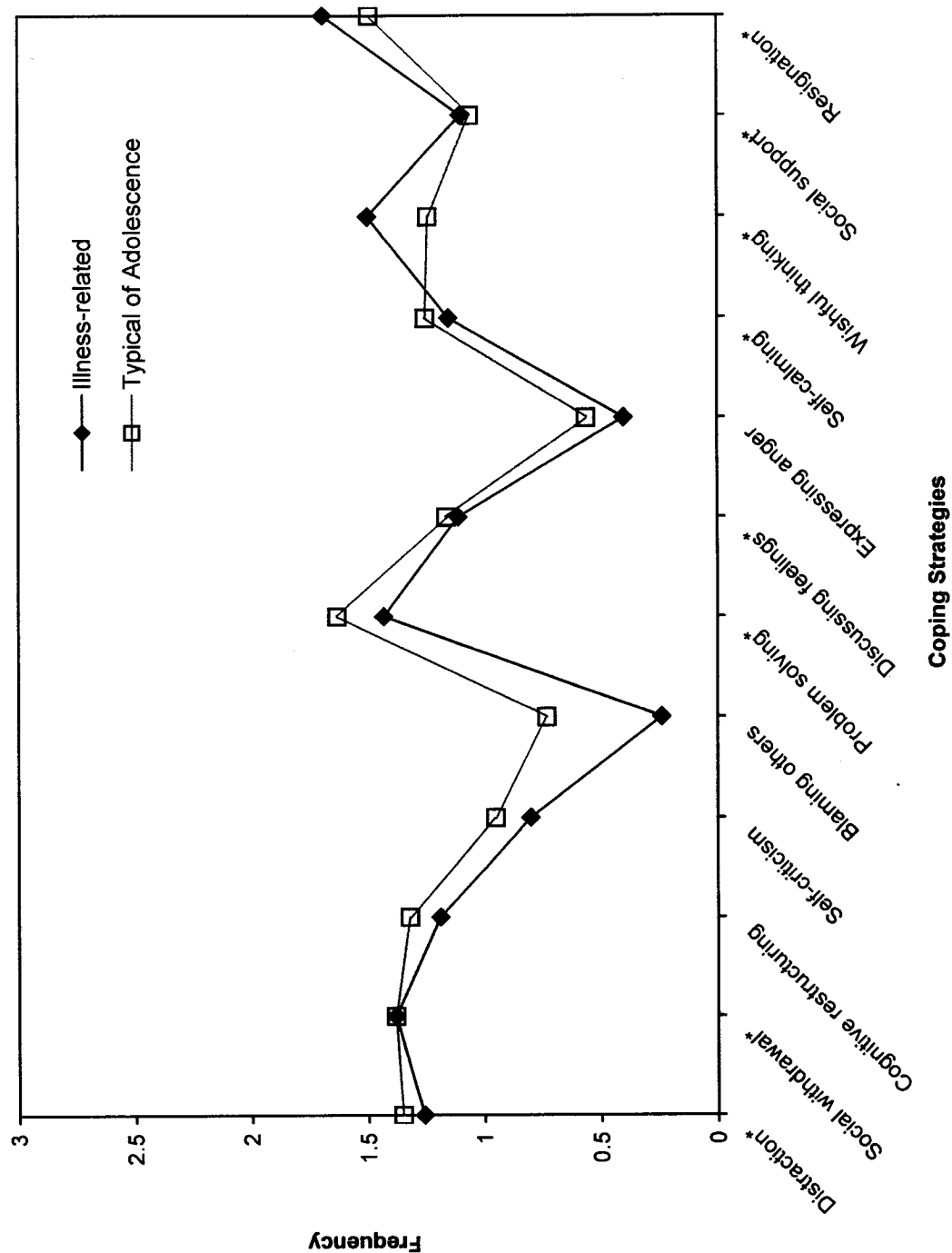
125 participants experienced a stressor delineated as illness-related and a stressor delineated as typical of adolescence

138 participants experienced a stressor delineated as illness-related

179 participants experienced a stressor delineated as typical of adolescence

* $p < .004$ (Bonferroni correction; .05/12)

Figure 1. Pattern of Coping Responses for an Illness-Related Stressor Versus a Typical of Adolescence Stressor



* $p < .004$ (Bonferroni correction; .05/12)

Table 11

Correlations between Frequency of Individual Coping StrategiesEmployed Across Standard Stressors (*Problems with parents* and *Medications/treatments*)

Kidcope Strategy	<i>r</i>	<i>p</i>
Distraction	.258	.001*
Social withdrawal	.281	<.001*
Cognitive restructuring	.182	.024
Self-criticism	-.059	.466
Blaming others	.108	.181
Problem solving	.259	.001*
Discussing feelings	.540	<.001*
Expressing anger	.389	<.001*
Self-calming	.329	<.001*
Wishful thinking	.239	.003*
Social support	.471	<.001*
Resignation	.206	.010

Note. Listwise deletion, n=154

163 participants experienced both types of standard stressors within the past six months;

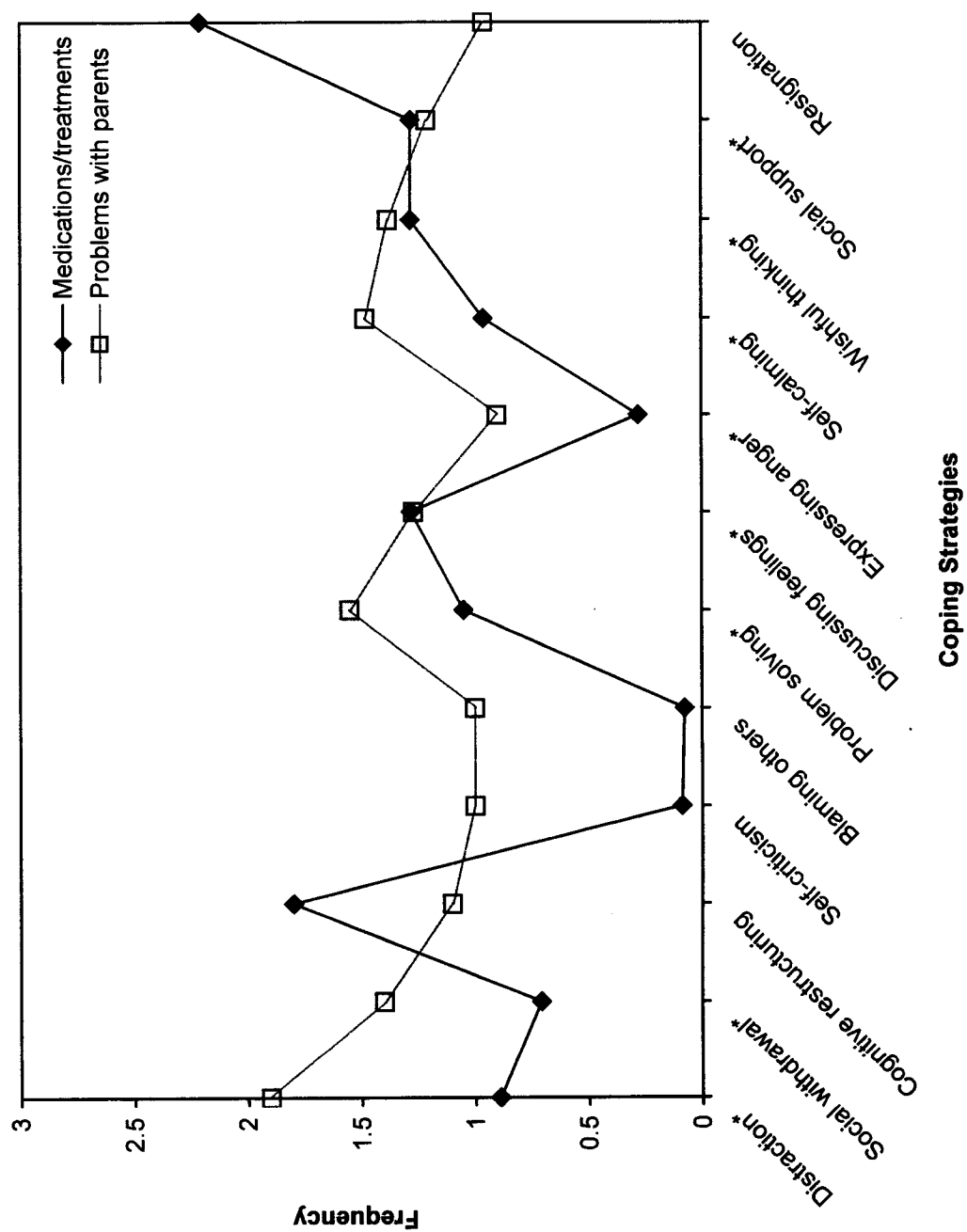
Kidcope data missing for 5 participants (n=158)

169 participants experienced the Medications/treatments stressor

183 participants experienced the Problems with parents stressor

**p* < .004 (Bonferroni correction .05/12)

**Figure 2. Pattern of Coping Responses for Medications/Treatments
Versus Problems with Parents**



* $p < .004$ (Bonferroni correction; .05/12)

Hypothesis2b:

It was hypothesized that, for each coping strategy, if controllability were held constant, there would be no differences between illness stressors and typical stressors on frequency of coping or the perceived efficacy of coping.

The coping strategy data (frequency and efficacy) were derived from four Kidcope questionnaire administrations (illness-related and typical of adolescence; *Problems with parents* and *Medications/treatments*). Other researchers have typically employed a Multivariate Analysis of Variance (MANOVA) approach when making comparisons across Kidcope data sets; however they have not followed a within-subjects approach, with multiple Kidcope administrations per individual (Donaldson et al., April 1997; Spirito et al., 1995; Spirito et al., 1994). It was decided that Analysis of Covariance (ANCOVA) was the most appropriate analyses strategy for the following reasons: i) Interpretation of the MANOVA results for this within-subjects design would be unwieldy and hypothesis testing would still require a significant MANOVA result to be followed up with multiple univariate analyses; ii) Control of Type I error is not improved with a MANOVA design. Moreover, a liberal approach to detecting differences was warranted because no differences in frequency or efficacy of coping strategies were expected if controllability is held constant (null hypothesis). Also, in keeping with this rationale, no correction for multiple comparisons was introduced for these analyses. Assumptions of normality, linearity, and homogeneity of variance of covariates were met. The model is assumed to be robust with respect to homogeneity of regression in the present study (Tabachnick & Fidell, 1996).

Differences in coping strategy use for illness versus typical of adolescence stressors was evaluated taking into consideration two potential covariates, control over cause and control over outcome. Within the ANCOVA approach, the linear relationship between each covariate and the various dependent variables was evaluated. Control over the cause was positively related to self-criticism and negatively related to resignation. Social withdrawal and discussing feelings were negatively related to control over outcome. In contrast, self-criticism was positively related to control over outcome. After controlling for the covariates, no significant differences were found between the frequency of use of the above-described coping strategies for illness-related stressors and typical stressors. For remaining coping strategies, neither covariate had an effect on the

frequency of coping. Therefore, the covariates were removed in order to increase the statistical power to detect any differences in coping across stressor type. Blaming others was employed more frequently for the typical problem, whereas wishful thinking was used more frequently for the illness-related problem. There were nonsignificant trends for problem solving and expressing anger to be employed more for typical problems than for illness-related ones. Table 12 shows the results of these analyses comparing illness and typical stressors.

The same analyses were undertaken for the two standard stressors, *Problems with parents* and *Medications/treatments*. Cognitive restructuring and resignation were both negatively related to control over cause of the stressor; after controlling for the covariate, these strategies were employed more frequently for *Medications/treatments* compared to *Problems with parents*. Social support was also negatively related to control over cause, however there was no significant difference in use of this coping strategy in relation to the two standard stressors after controlling for the covariate. Resignation was negatively related to control over outcome and was used more frequently for *Medications/treatments* compared to *Problems with parents* after controlling for the covariate. In contrast, self-criticism and problem solving were both positively related to control over outcome, and used significantly more often to cope with *Problems with parents* compared to *Medications/treatments* after controlling for the covariate. Neither covariate was related to the frequency of any of the remaining coping strategies. With covariates removed from analyses, discussing feelings and wishful thinking did not differ for *Problems with parents* or *Medications/treatments*. Distraction, social withdrawal, blaming others, expressing anger, and self-calming were used more frequently for *Problems with parents* than they were for *Medications/treatments*. The results of these analyses for the two standard stressors are shown in Table 13. The power achieved and the sample sizes required for the obtained effect sizes to reach significance for self-generated and standard stressors were computed (see Table 14). For self-generated stressors, the sample size required ranged from 130 participants for problem solving to 6,324 participants for self-criticism. For standard stressors, more than 1,000 participants would be required for effect sizes to reach significance for wishful thinking and social support.

A series of ANCOVA's was conducted on each coping strategy to investigate differences in efficacy of coping strategy use for illness versus typical of adolescence stressors, taking into consideration the same two covariates; control over cause and control over outcome. Note that because efficacy values are only obtained for those coping strategies that are employed by participants, the number of efficacy scores varied across coping strategies. Distraction and cognitive restructuring were negatively related to control over outcome, whereas self-criticism was positively related to control over outcome. No significant difference in coping efficacy for illness-related and typical stressors were found for these coping strategies after controlling for the covariate. Because neither covariate was related to any other coping variables, further analyses were computed without the covariates. As shown in Table 15, there were no significant differences between efficacy of coping for any of the coping strategies for the illness-related and typical stressor.

A similar series of ANCOVA's was conducted to compare coping efficacy across *Problems with parents* and *Medications/treatments*. Distraction was negatively related to control over cause, with no significant difference between coping efficacy for the two standard stressors after controlling for the covariate. Neither covariate was related to any other coping variables. Therefore, further analyses were computed without the covariates. Efficacy of cognitive restructuring and resignation were significantly greater for *Medications/treatments* compared to *Problems with parents*. In contrast, efficacy of expressing anger and wishful thinking was significantly greater for *Problems with parents* compared to *Medications/treatments* (Table 16). The power achieved and the sample sizes required for the obtained effect sizes to reach significance for self-generated and standard stressors were computed (see Table 17). For self-generated stressors, the sample size required ranged from 57 participants for blaming others to 7,329 participants for self-calming. For standard stressors, the sample size required for effect sizes to reach significance was only 19 participants for blaming others and 98 participants for distraction (with the covariate).

A Comparison of Frequency of Coping Strategies for Self-Generated Stressors

Kidcope Strategy	Illness-related Stressor		Typical of Adolescence Stressor			df	F	p	Partial ETA sqd
	M	SD	M adjust	M	SD	M adjust			
Distraction	1.25	1.08		1.35	1.04		124	.84	.361
Social withdrawal	1.37	1.09		1.37	1.10		124	.00	1.00
Control cause									
Control outcome			1.37			1.37	123	.42	.518
Cognitive restruct.	1.18	1.07		1.34	1.04		124	1.61	.207
Self-criticism	.79	1.06		.94	1.08				
Control cause			.84			.90	123	.07	.789
Control outcome			.86			.88	123	.00	.975
Blaming others	.24	.64		.73	.96		124	27.71	<.001**
Problem solving	1.42	1.03		1.63	1.04		124	3.75	.055
Discussing feelings	1.12	1.05		1.15	1.06		124	.13	.721
Control cause									
Control outcome			1.14			1.10	123	1.88	.172
Expressing anger	.39	.78		.55	.88		124	3.08	.082
Self-calming	1.15	1.02		1.24	1.04		124	.92	.339
Wishful thinking	1.49	1.15		1.23	1.17		124	.4.31	.040*
Social support	1.10	1.02		1.06	1.03		124	.20	.658
Resignation	1.68	1.19		1.50	1.21		124	2.05	.155
Control cause			1.65			1.54	123	.73	.394
Control outcome									

Note. Coping strategies were compared across stressors separately for each covariate (control over cause and control over outcome).

Adjusted mean coping frequencies are listed where covariates are significantly related to coping strategies. Where a covariate is not related to a coping strategy, the results of the analysis rerun without the covariate is presented instead. For coping strategies where neither covariate is related to a coping strategy, the table shows only one analysis without either covariate.

*p<.05. **p<.01.

A Comparison of Frequency of Coping Strategies for Standard Stressors

Kidcope Strategy	Medications/ Treatments		Problems with Parents			df	F	p	Partial ETA sqd
	<u>M</u>	<u>SD</u>	<u>M</u> <u>adjust</u>	<u>M</u>	<u>SD</u>				
Distraction	.90	1.09		1.90	.94	157	105.56	<.001**	.404
Social withdrawal	.72	.98		1.40	1.02	157	50.77	<.001**	.246
Cognitive restruct.	1.81	1.13		1.10	1.01	157	43.26	<.001**	.217
Control cause			1.79			1.13 156	20.45	<.001**	.116
Control outcome									
Self-criticism	.10	.40		1.01	.90	157	130.47	<.001**	.455
Control cause									
Control outcome			.12			.98 156	91.32	<.001**	.369
Blaming others	.08	.31		.99	1.01	157	125.69	<.001**	.446
Problem solving	1.06	1.06		1.56	.96	157	25.92	<.001**	.142
Control cause									
Control outcome			1.13			1.51 156	9.29	.003**	.056
Discussing feelings	1.28	1.11		1.28	1.00	154	.01	.937	.000
Expressing anger	.28	.62		.90	.99	155	67.41	<.001**	.303
Self-calming	.96	1.03		1.47	.95	156	31.29	<.001**	.167
Wishful thinking	1.29	1.16		1.37	1.00	156	.60	.440	.004
Social support	1.29	1.16		1.23	1.04	157	.51	.475	.003
Control cause			1.33			1.20 156	.45	.505	.003
Control outcome									
Resignation	2.21	1.10		.96	.98				
Control cause			2.14			1.01 156	83.48	<.001**	.349
Control outcome			2.16			.99 156	96.62	<.001**	.382

Note. Coping strategies were compared across stressors separately for each covariate (control over the cause and control over the outcome).

Adjusted mean coping frequencies are listed where covariates are significantly related to coping strategies. Where a covariate is not related to a coping strategy, the results of the analysis rerun without the covariate is presented instead. For coping strategies where neither covariate is related to a coping strategy, the table shows only one analysis without either covariate.

** $p < .01$.

Table 14

Power Achieved and Sample Size Required for Frequency of Coping Strategies Across Stressor Types

Coping strategy	<u>Self-Generated Stressors</u>		<u>Standard Stressors</u>	
	Power achieved	Sample required	Power achieved	Sample required
Distraction	.172	577		
Social withdrawal	.033	a		
Control cause				
Control outcome	.072	1165		
Cognitive restruct.	.240	303		
Self-criticism				
Control cause	.045	6324		
Control outcome	.033	a		
Blaming others				
Problem solving	.484	130		
Discussing feelings	.049	3460	.033	a
Control cause				
Control outcome	.274	251		
Expressing anger	.413	158		
Self-calming	.172	531		
Wishful thinking			.157	1016
Social support	.048	2365	.123	1185
Control cause			.078	1352
Control outcome				
Resignation	.295	2545		
Control cause	.172	663		
Control outcome				

Note. Coping strategies were compared across illness-related and typical of adolescence stressors, and across *Medications/treatments* and *Problems with parents* stressors. Power achieved is presented only for nonsignificant findings. Sample required is the number of participants that would be required in order for the obtained effect size to achieve significance at $p < .05$.

a = cannot be computed

A Comparison of Efficacy of Coping Strategies for Self-Generated Stressors

Kidcope Strategy	Illness-related Stressor		Typical of Adolescence Stressor				df	F	p	Partial ETA sqd
	<u>M</u>	<u>SD</u>	<u>M</u> <u>adjust</u>	<u>M</u>	<u>SD</u>	<u>M</u> <u>adjust</u>				
Distraction	1.80	1.28		1.92	1.30		70	.30	.585	.004
Control cause										
Control outcome			1.82			1.90	69	1.49	.227	.021
Social withdrawal	1.65	1.00		1.65	1.05		73	.00	1.00	.000
Cognitive restruct.	2.18	1.14		2.27	1.27		65	.25	.616	.004
Control cause										
Control outcome			2.21			2.25	64	1.40	.241	.021
Self-criticism	1.18	1.27		1.29	1.24		33	.22	.644	.007
Control cause										
Control outcome			1.26			1.21	32	.07	.798	.002
Blaming others	1.77	1.42		2.15	1.21		12	1.00	.337	.077
Problem solving	2.36	1.22		2.53	1.22		82	1.04	.310	.013
Discussing feelings	2.19	1.12		2.33	1.15		62	.91	.344	.014
Expressing anger	1.35	1.27		1.30	1.22		19	.05	.834	.002
Self-calming	2.43	1.07		2.40	1.15		69	.04	.850	.001
Wishful thinking	.80	1.01		.902	1.01		60	.36	.549	.006
Social support	2.18	1.04		2.31	1.07		60	.84	.363	.014
Resignation	1.96	1.39		2.07	1.29		69	.71	.403	.010

Note. This sample consisted of 125 participants who endorsed both stressors. A pairwise deletion method was used because efficacy scales are only completed for strategies that are employed.

Coping strategies were compared across stressors separately for each covariate (control over cause and control over outcome). Adjusted mean coping frequencies are listed where covariates are significantly related to coping strategies. Where a covariate is not related to a coping strategy, the results of the analysis rerun without the covariate is presented instead. For coping strategies where neither covariate is related to a coping strategy, the table shows only one analysis without either covariate.

A Comparison of Efficacy of Coping Strategies for Standard Stressors

Kidcope Strategy	Medications/ Treatments		Problems with Parents				df	F	p	Partial ETA sqd
	M	SD	M adjust	M	SD	M adjust				
Distraction	2.16	1.15		2.20	1.23		74	.06	.800	.001
Control cause			2.23			2.12	73	2.90	.093	.039
Control outcome										
Social withdrawal	1.71	1.10		1.57	1.12		62	.65	.421	.010
Cognitive restruct.	2.79	1.10		2.10	.92		90	35.24	<.001**	.281
Self-criticism	1.00	1.16		.86	1.22		6	.30	.604	.048
Blaming others	.56	.73		1.00	1.00		8	2.29	.169	.222
Problem solving	2.20	1.23		2.33	1.00		83	.84	.361	.010
Discussing feelings	2.71	1.08		2.52	1.02		91	2.47	.120	.026
Expressing anger	1.17	1.14		1.62	1.40		28	4.39	.045*	.136
Self-calming	2.42	1.15		2.51	1.03		84	.39	.534	.005
Wishful thinking	.84	.93		1.22	1.08		87	12.43	.001**	.125
Social support	2.57	1.00		2.45	.97		92	1.05	.308	.011
Resignation	2.58	1.41		1.28	1.00		91	77.35	<.001**	.459

Note. This sample consisted of 158 participants who endorsed both standard stressors as occurring in the past six months with completed Kidcope data (n=163 –5 missing). A pairwise deletion method was used because efficacy scales are only completed for strategies that are employed.

Coping strategies were compared across stressors separately for each covariate (control over the cause and control over the outcome). An adjusted mean coping frequency is only listed for Distraction, with ‘control over cause’ as the covariate. This was the only coping strategy to have a significant relationship with one of the covariates. For all other coping strategies, covariates were not related to coping strategies and the results are shown for analyses rerun without covariates.

*p < .05. **p < .01.

Table 17

Power Achieved and Sample Size Required for Efficacy of Coping Strategies Across Stressor Types

Coping strategy	<u>Self-Generated Stressors</u>		<u>Standard Stressors</u>	
	Power achieved	Sample required	Power achieved	Sample required
Distraction	.046	929	.045	4563
Control cause			.390	98
Control outcome	.223	186		
Social withdrawal	.034	a	.163	380
Cognitive restruct.	.047	1033		
Control cause				
Control outcome	.212	183		
Self-criticism	.055	621	.078	122
Control cause				
Control outcome	.048	1877		
Blaming others	.156	57	.267	19
Problem solving	.177	315	.175	393
Discussing feelings	.170	274	.375	148
Expressing anger	.048	2293		
Self-calming	.040	7329	.118	858
Wishful thinking	.056	649		
Social support	.168	288	.178	350
Resignation	.168	387		

Note. Coping strategies were compared across illness-related and typical of adolescence stressors, and across *Medications/treatments* and *Problems with parents* stressors. Power achieved is presented only for nonsignificant findings. Sample required is the number of participants that would be required in order for the obtained effect size to achieve significance at $p < .05$.

a = cannot be computed

Objective 3: Age and Gender Findings

The third objective of this study was to examine age and gender influences on stress and coping variables. In order to examine gender differences for the categories of stressors reported, the percentages of male and female adolescents who reported at least one stressor in a given category were computed. School, relationship with adolescents, relationship with parents, health concerns, and money/finance were the most frequently endorsed categories; these five categories were ranked in the same order for both genders. The rank ordering for all stressor categories for both genders is shown in Table 18. A greater percentage of females than males reported a stressor in the body image/sexual maturation category. Females were also more likely than males to report physical limitations due to illness, restrictions due to illness, and future concerns.

A similar approach was taken to assess age differences for the categories of stressors reported. Table 19 shows the percentage of 13 to 15 year-olds and 16 to 18 year-olds that reported at least one stressor in a given category. School, relationship with adolescents, and relationship with parents were ranked in the same order for both age groups.

The current section describes exploratory age and gender findings for stressor appraisals. There were no a priori hypotheses made for any appraisal variables. Based on average ratings for the illness-related and typical of adolescence scales across all self-generated stressors, females rated their stressors as more highly related to their chronic illness ($M_{\text{females}} = 1.53$, $SD = 1.18$, $M_{\text{males}} = 1.16$, $SD = 1.16$, $t(191) = 2.21$, $p = .028$) and also as more highly typical of adolescence ($M_{\text{females}} = 3.24$, $SD = 1.00$, $M_{\text{males}} = 2.92$, $SD = 1.02$, $t(191) = 2.12$, $p = .029$) than did males. Using the Bonferroni correction for multiple comparisons (.05/4 comparisons = P value .013), male and female adolescents were compared on the different cognitive appraisal variables for the first self-generated stressor listed on the PSL. No significant gender differences were found on stressor appraisal ratings for frequency, control over cause, impact, or control over outcome. There were also no differences found between males and females on any of the appraisal scales for the standard stressors, *Problems with parents* or *Medications/treatments*. Table 20 shows a comparison of cognitive appraisals across gender for the first self-generated stressor, and the two standard stressors.

As stated earlier, based on average ratings for the illness-related and typical of adolescence scales across all self-generated stressors, both younger and older adolescents rated their stressors as being more highly typical of adolescence than chronic illness-related. A comparison across age groups showed that 13 to 15 year-olds ($M = 1.57$, $SD = 1.37$) rated their stressors as more highly related to their chronic illness than did 16 to 18 year-olds ($M = 1.15$, $SD = .92$), $t(165.23) = 2.45$, $p = .015$). In contrast, older adolescents ($M = 3.31$, $SD = .91$) rated their stressors as more highly typical of adolescence than did younger adolescents ($M = 2.87$, $SD = 1.08$), $t(191) = 3.02$, $p = .003$).

To investigate age differences, Pearson Product correlations were computed between the age of the adolescent and the cognitive appraisal variables for the first self-generated stressor (Bonferroni correction $.05/4$, P value $.103$). Impact was significantly positively correlated with age. However, no significant correlations were found between age and stressor appraisal ratings of frequency, control over cause, or control over outcome. Similar analyses on the standard stressor *Problems with parents*, revealed no significant correlations between age and stressor appraisal ratings of control over cause or control over outcome. Although not significant, there was a trend for age to be positively associated with stressor frequency and stressor impact. For *Medications/treatments*, there were no significant correlations found between age and frequency, control over cause, impact, or control over outcome. Table 21 lists the correlations between appraisal variables and age for the first stressor and the standard stressors.

Table 18
Percentage of Male and Female Adolescents with at Least One Stressor in a Given Category

Female		Male	
<u>Category</u>	<u>Frequency</u> %	<u>Category</u>	<u>Frequency</u> %
School	82.7	School	80.7
Relationship with adolescents	81.0	Relationship with adolescents	67.1
Relationship with parents	55.2	Relationship with parents	52.3
Health concern	45.7	Health concerns	42.1
Money/finance	36.2	Money/finance	42.1
Body image/sexual maturation	36.2	Daily hassles	37.5
Daily hassles	32.4	Relationship with siblings	34.1
Relationship with siblings	29.5	Boy/girlfriend/dating	23.9
Boy/girlfriend/dating	27.6	Sports/Extracurricular activities	22.7
Clinic/hospital visits	24.8	Clinic/hospital visits	20.5
Medication/treatment		Medication/treatment	
Sports/Extracurricular activities	19.1	Relationship with other family members	18.2
Mental health/emotional well-being	18.1	Body image/ Sexual maturation	17.1
Future concerns (other than health)	18.1	Mental health/emotional well-being	11.4
Relationship with other family members	16.2	Discontinuity/change	8.0
Independence/responsibilities	11.4	Future concerns (other than health)	6.8
Physical limitations due to illness	11.4	Physical limitations due to illness	5.7
Restriction due to illness	10.5	Independence/ responsibilities	5.7
Discontinuity/change	7.6	Restrictions due to illness	4.6
Other	20.0	Other	27.3

Table 19
Percentage of Younger and Older Adolescents with at Least One Stressor in a Given Category

13-15 years		16-18 years	
<u>Category</u>	<u>Frequency</u> %	<u>Category</u>	<u>Frequency</u> %
School	77.1	School	86.7
Relationship with adolescents	72.9	Relationship with adolescents	76.3
Relationship with parents	46.9	Relationship with parents	60.8
Health concern	41.7	Money/finance	52.6
Relationship with siblings	40.6	Health concerns	46.4
Daily hassles	27.1	Daily hassles	42.3
Body image/sexual maturation	25.0	Boy/girlfriend/dating	39.1
Money/finance	25.0	Body image/ Sexual maturation	29.9
Clinic/hospital visits	24.0	Relationship with other family members	27.8
Medication/treatment		Sports/Extracurricular activities	25.8
Sports/Extracurricular activities	15.6	Relationship with siblings	22.7
Mental health/emotional well-being	14.6	Clinic/hospital visits	21.7
Boy/girlfriend/dating	12.5	Medication/treatment	
Restrictions due to illness	10.4	Future concerns (other than health)	21.7
Physical limitations due to illness	7.3	Mental health/ emotional well-being	15.5
Discontinuity/change	7.3	Independence/ responsibilities	13.4
Relationship with other family members	6.3	Physical limitations due to illness	10.3
Independence/responsibilities	4.2	Discontinuity/change	8.3
Future concerns (other than health)	4.2	Restrictions due to illness	5.2
Other	15.6	Other	30.9

Table 20
Gender Comparison for Mean Stressor Appraisal Scale Ratings

Stressor type	Appraisal Scale	<u>Male</u>	<u>Female</u>	<u>d.f.</u>	<u>t</u>	<u>p</u>
Self-generated stressor	Frequency	2.84 (1.36)	2.87 (1.35)	191	.13	.895
	Control over cause	2.35 (1.62)	2.24 (1.60)	191	.49	.624
	Impact	3.00 (1.26)	3.32 (1.14)	191	1.87	.062
	Control over outcome	3.09 (1.45)	2.98 (1.51)	191	.51	.608
Problems with parents	Frequency	2.56 (1.23)	2.67 (1.21)	191	.62	.533
	Control over cause	2.48 (1.12)	2.82 (1.13)	181	2.05	.042
	Impact	2.89 (1.15)	3.12 (1.17)	181	1.32	.187
	Control over outcome	3.12 (1.26)	3.18 (1.22)	181	.34	.733
Medications/ Treatments	Frequency	3.81 (1.77)	3.63 (1.97)	189.959	.66	.509
	Control over cause	1.58 (2.03)	1.41 (1.94)	168	.54	.592
	Impact	2.36 (1.79)	2.58 (1.74)	168	.80	.427
	Control over outcome	2.38 (1.90)	2.18 (1.92)	168	.67	.50

Note.

Standard deviations are displayed in brackets for each respective mean.

For each standard stressor, degrees of freedom for frequency does not correspond with respective appraisal scales because the remaining appraisal scales are not completed when frequency of the stressor equals zero.

* $p < .013$ (Bonferroni correction $.05/4$)

Table 21
Correlations between Age and Stressor Appraisal Scales

Stressor type	Appraisal Scale	r	p
Self-generated stressors n= 193	Frequency	.056	.439
	Control over cause	-.044	.540
	Impact	.236	.001*
	Control over outcome	-.013	.853
Problems with Parents n=183	Frequency	.172	.020
	Control over cause	.035	.637
	Impact	.163	.028
	Control over outcome	-.005	.951
Medications/ Treatments n=169	Frequency	-.042	.584
	Control over cause	.120	.120
	Impact	-.023	.767
	Control over outcome	.080	.300

Note.

Within each stressor type, listwise deletion was employed.

For each of the two standard stressors, frequency correlations were also computed for the entire sample, including participants who rated stressor frequency as zero: Problems with parents, $r = .209$, $p = .003^*$; Medications/treatments, $r = .030$, $p = .679$.

* $p < .013$ (Bonferroni correction; 05/4 comparisons)

Hypothesis 3a):

An independent samples t-test revealed no significant difference between the numbers of stressors reported by male ($M = 7.84$, $SD = 4.51$) versus female adolescents ($M = 9.18$, $SD = 5.09$), $t(191) = 1.92$, $p = .057$).

Hypothesis 3b):

A significant positive Pearson Product correlation was found between adolescents' age and the total number of stressors reported ($r = .355$, $p < .001$).

Hypothesis 3c):

A series of independent samples t-tests were computed to compare male and female adolescents on the total number of coping strategies employed. An individual strategy was considered employed on the Kidcope if used "a lot of the time" or "almost all of the time", and not employed if used "never" or "sometimes". It was hypothesized that females would practice more coping strategies overall. Instead, no significant gender differences were found for the total number of Kidcope strategies used for the illness related stressor (M Male = 4.39, $SD = 1.87$, M Female = 3.80, $SD = 1.78$), $t(136) = 1.86$, $p = .066$), or for the typical stressor (M Male = 4.29, $SD = 1.92$, M Female = 4.61, $SD = 1.87$), $t(174) = 1.14$, $p = .255$). For the standard stressor, dealing with *Medications/treatments*, there was also no significant gender difference for the total number of coping strategies employed (M Male = 3.46, $SD = 2.24$, M Female = 4.06, $SD = 2.02$), $t(167) = 1.81$, $p = .072$). However, female adolescents used a greater number of coping strategies when dealing with *Problems with parents* than did male adolescents (M Male = 4.27, $SD = 2.50$, M Female = 5.01, $SD = 2.53$), $t(182) = 1.97$, $p = .050$).

Male and female adolescents were also compared on the A-COPE total score. Note that this measure of general coping strategies is completed without reference to a specific stressor. Female adolescents ($M = 32.08$, $SD = 4.19$) obtained a significantly greater total score than did male adolescents ($M = 30.50$, $SD = 4.22$), $t(191) = 2.60$, $p = .010$).

It was hypothesized that females would practice more emotional regulation and social support, whereas males would practice more problem solving. For these analyses, all emotional regulation items on the Kidcope were considered: discussing feelings, expressing anger, and self-calming; a correction for multiple comparisons was made (.05/3 comparisons = P value .016).

For the illness related stressor, there was no significant gender difference in the use of discussing feelings, expressing anger, self-calming, or problem solving. Females practiced significantly more social support than did males. For the typical of adolescence stressor no significant gender differences were found for discussing feelings, expressing anger, self-calming, or social support. Females engaged in significantly more problem solving than did males. For the standard stressor, *Problems with parents*, there were no significant gender differences found for self-calming or problem solving. There was a trend for females to employ discussing feelings and expressing anger more than males. Similar to the illness-related stressor, females practiced significantly more social support than did males. For *Medications/treatments*, there was a trend for females to employ discussing feelings more than males. There were no gender differences found for expressing anger, self-calming, problem solving, or social support. The results of these analyses are displayed in Table 22.

In order to provide cross validation for some of the Kidcope findings, male and female adolescents were also compared on three similar coping strategies found on the A-COPE. Table 23 shows that females reported the use of social support as a coping strategy significantly more often than did males. Ventilating feelings and relaxing were examined because they are respectively consistent with discussing feelings and self-calming items found on the Kidcope. Females practiced significantly more relaxing than did males. There was also a strong trend for females to engage in ventilating feelings more frequently than males. For exploratory purposes, a series of independent samples t-tests comparing remaining coping strategies across gender were computed. Females employed investing in close friends as a coping strategy more often than did males. In contrast, males engaged in being humorous more often than did females.

Hypothesis 3d):

It was hypothesized that the overall number of different coping strategies practiced would increase with age. As described for Hypothesis 3c), an individual strategy was considered employed if used “a lot of the time” or “almost all of the time”, and not employed if used “never” or “sometimes”. There was no significant correlation between age and the total number of coping strategies employed for the illness related stressor ($r = .013$, $p = .876$), nor for the typical of adolescence stressor ($r = .003$, $p = .972$). For the standard stressor, *Problems with parents*,

there was no significant correlation between age and the number of coping strategies used ($r = -.042$, $p = .575$). For *Medications/treatments*, there was a significant negative correlation between age and the number of coping strategies practiced ($r = -.166$, $p = .031$).

This hypothesis was also examined using the A-COPE total score. A Pearson Product correlation showed a significant positive relation between adolescent age and the number of coping strategies used ($r = .217$, $p = .002$).

It was further hypothesized that the use of emotional regulation and cognitive restructuring would increase with age. All three emotional regulation items were analyzed, and the Bonferroni correction for multiple comparisons ($.05/3$ comparisons = P value $.016$) was introduced for these items. As shown in Table 24, for the illness-related stressor, age was not significantly correlated with discussing feelings, expressing anger, self-calming, or cognitive restructuring. Similarly, for the typical of adolescence stressor, age was also not correlated with the above-described coping strategies. For the standard stressor, *Medications/treatments*, age was not correlated with discussing feelings or cognitive restructuring. Self-calming was negatively correlated with age and there was a trend for expressing anger to decrease with age. For *Problems with parents*, age was also not significantly correlated with these coping strategies.

The above-described hypothesis was also explored using the A-COPE as a source of cross validation for Kidcope emotional regulation items. Ventilating feelings and relaxing were significantly correlated with adolescent age. For exploratory purposes, the remaining eight A-COPE coping strategies were also correlated with age. In addition, age was significantly correlated with developing self-reliance and also with investing in close friends. Ten correlations between age and A-COPE coping strategies are shown in Table 25.

Table 22
Gender Comparison Across Mean Frequency of Coping Strategies

Stressor type	Coping Strategy	Male	Female	t	p
Illness-related Stressor (<u>df</u> =136)	Discussing feelings	1.00 (1.02)	1.28 (1.07)	1.51	.132
	Expressing anger	.42 (.79)	.39 (.78)	.240	.811
	Self-calming	1.04 (.96)	1.28 (1.04)	1.37	.172
	Social support	.75 (.89)	1.37 (1.06)	3.64	<.001**
	Problem solving	1.36 (1.04)	1.48 (1.04)	.65	.515
Typical of adolescence stressor (<u>df</u> =174)	Discussing feelings	1.01 (.99)	1.27 (1.06)	1.66	.099
	Expressing anger	.64 (.98)	.48 (.77)	1.20	.232
	Self-calming	1.16 (1.01)	1.30 (1.02)	.91	.365
	Social support	1.10 (1.06)	1.15 (1.07)	.284	.776
	Problem solving	1.48 (.98)	1.85 (1.04)	2.48	.014*
Medications/ treatments (<u>df</u> =167)	Discussing feelings	1.10 (1.08)	1.44 (1.10)	2.02	.045
	Expressing anger	.21 (.56)	.32 (.66)	1.22	.223
	Self-calming	.90 (1.04)	1.00 (1.03)	.612	.541
	Social support	1.15 (1.13)	1.44 (1.06)	1.72	.088
	Problem solving	.93 (1.10)	1.17 (1.05)	1.49	.139
Problems with parents (<u>df</u> =182)	Discussing feelings	1.12 (1.00)	1.41 (.96)	2.01	.046
	Expressing anger	.67 (.92)	.99 (1.03)	2.22	.027
	Self-calming	1.43 (.95)	1.46 (1.01)	.216	.829
	Social support	1.05 (1.05)	1.40 (.98)	2.34	.020*
	Problem solving	1.40 (1.01)	1.61 (.94)	1.43	.155

Note. Standard deviations are displayed in brackets for each respective mean.

Discussing feelings, expressing anger, and self-calming are all emotional-regulation strategies; $p < .016$ (Bonferroni correction; $.05/3$)

* $p < .05$. ** $p < .01$.

Table 23
Gender Comparison Across Mean Frequency of A-COPE Strategies

Coping Strategy	Male	Female	t	p
Ventilating feelings	2.63 (.77)	2.84 (.72)	1.95	.053
Seeking diversions	2.67 (.56)	2.70 (.55)	.33	.740
Developing self reliance	3.23 (.58)	3.27 (.56)	.39	.700
Developing social support	2.66 (.60)	3.21 (.68)	5.82	<.001**
Solving family problems	2.66 (.67)	2.76 (.69)	1.01	.315
Investing in close friends	2.94 (1.05)	3.26 (1.01)	2.14	.034 *
Engaging in demanding activity	2.88 (.75)	2.93 (.87)	.39	.701
Being humorous	3.38 (1.02)	3.07 (.96)	2.16	.032 *
Relaxing	2.74 (.66)	3.13 (.60)	4.30	<.001**
Avoiding problems (Denial)	2.51 (.77)	2.48 (.80)	.26	.795

Note. n = 193

*p < .05. ** p < .01.

Table 24
Correlations between Age and Selected Kidcope Strategies

Stressor type	Coping strategy	r	p
Illness-related	Discussing feelings	.028	.748
	Expressing anger	-.036	.678
	Self-calming	-.141	.099
	Cognitive restructuring	.032	.705
Typical of adolescence	Discussing feelings	.067	.376
	Expressing anger	-.093	.221
	Self-calming	.084	.266
	Cognitive restructuring	.104	.170
Problems with parents	Discussing feelings	-.050	.502
	Expressing anger	-.026	.725
	Self-calming	-.123	.097
	Cognitive restructuring	.114	.125
Medications/Treatments	Discussing feelings	-.122	.115
	Expressing anger	-.151	.050
	Self-calming	-.267	<.001*
	Cognitive restructuring	-.010	.896

* $p < .016$ (Bonferroni correction; 05/3 comparisons)

Table 25

Correlations between Age and A-COPE Strategies

Coping Strategy	r	p
Ventilating feelings	.212	.003**
Seeking diversions	-.127	.079
Developing self-reliance	.162	.024*
Developing social support	.120	.097
Solving family problems	.086	.235
Investing in close friends	.259	<.001**
Engaging in demanding activity	-.055	.449
Being humorous	.088	.224
Relaxing	.170	.018*
Avoiding problems (Denial)	.071	.324

Note. The entire sample completed the A-COPE (n= 193).

* p <.05. ** p <.01.

Objective 4: Relation between Health-Related QoL and Stress and Coping

As stated in the objectives, a secondary objective was to explore health-related QoL (as an indicator of illness burden) and its relation to stressors and coping strategies. Health-related QoL was measured by the General Health Perception subscale of the RAND 36-Item Health Survey. An ANOVA showed no difference between clinics on General Health Perception ratings, $F(0, 182) = 1.624$, $p = .103$. Table 26 presents average General Health Perception ratings for each clinic, with higher scores indicating better perceived general health.

A series of hierarchical multiple regression analyses were conducted to determine the extent to which health-related QoL is related to stressors and coping variables. The first analysis assessed the incremental variance in health-related QoL accounted for by stressors for the total sample. When the analyses were performed with the dependent variable of General Health Perception, demographic variables (age and gender) were entered simultaneously on the first step to control for their effects. The total number of self-identified stressors, average stressor ratings on the chronic illness-related scale, and average ratings on the typical of adolescence scale were entered simultaneously on the second step. Results of evaluation of assumptions led to transformations of the variables to reduce skewedness. A square root transformation was used on the total number of self-identified stressors, a logarithmic transformation was used on the average ratings on the chronic illness-related scale, and a reflect and square root transformation was used on the average ratings on the typical of adolescence scale. Using a $p < .001$ criterion for Mahalanobis distance, no outliers were identified (Tabachnick & Fidell, 1996). As there was no substantial difference between the transformed and untransformed model, the untransformed model is presented in Table 27. The overall model accounted for significant proportions of variance in General Health Perception ($R^2 = .072$, $F(5, 187) = 2.92$, $p = .015$). Total number of stressors, average illness-related ratings, and average typical of adolescence ratings contributed a significant incremental proportion of the variance in General Health Perception (6.5%) beyond age and sex group, which did not contribute significantly. Only adolescents' average illness-related ratings contributed independently to the prediction of General Health Perceptions, based on the standardized regression coefficient. The sign of this coefficient indicated that adolescents

who rated their stressors as being, on average, more illness-related, rated their General Health Perception as worse.

A second series of analyses were computed to assess the incremental variance in stressor impact accounted for by stressor appraisals, beyond General Health Perception. Separate analyses were computed for the following stressor types: highly illness-related; highly typical of adolescence; *Medications/treatments*; and *Problems with parents*. When the analyses were performed with the dependent variable of stressor impact, demographic variables (age and gender) were entered simultaneously on the first step to control for their effects. General Health Perception was entered on the second step. Stressor appraisal ratings of frequency, control over cause, and control over outcome were entered simultaneously on the third step.

First, for both the illness-related and typical of adolescence analyses, no multivariate outliers were found and no transformation of variables were required. These two analyses were conducted using the shared sample of participants who delineated both an illness-related and a typical of adolescence stressor ($N=125$). As shown in Table 28, the overall model did not account for significant proportions of variance in the impact of a stressor rated as illness-related ($R^2 = .092$, $F(6, 118) = 2.003$, $p = .071$). That is, General Health Perception and stressor appraisals did not significantly predict stressor impact. Similarly, Table 29 shows the overall model did not account for significant proportions of variance in the impact of a stressor rated as typical of adolescence ($R^2 = .068$, $F(6, 118) = 1.435$, $p = .207$).

Second, for both the *Medications/treatments* and *Problems with parents* analyses, no multivariate outliers were found. These two analyses were conducted using the shared sample of participants who endorsed experiencing both stressors in the past six months ($N=163$). For *Medications/Treatments*, results of evaluation of assumptions led to transformations of the variables to reduce skewedness. A logarithmic transformation was used on the control over cause scale. The frequency scale was dichotomized into daily use and less than daily use. No multivariate outliers were identified (Tabachnick & Fidell, 1996). As there was no substantial difference between the transformed and untransformed model, the untransformed model is presented. As shown in Table 30, the overall model accounted for significant variance in stressor impact ($R^2 = .095$, $F(6, 156) = 2.735$, $p = .015$). At the second step, General Health Perception

contributed a significant incremental proportion of the variance in impact (2.7) beyond age and sex group, which did not contribute significantly. In addition, stressor appraisals contributed a significant incremental proportion of the variance in impact (6.2) beyond the incremental variance explained by General Health Perception. Only adolescents' General Health Perception and control over outcome contributed independently to the prediction of stressor impact based on the standardized regression coefficients. For the former, the sign of the coefficient indicates adolescents who rated their General Health Perception as poorer, rated their stressor impact as higher. For the latter, the sign of the coefficient indicates that adolescents who rated their control over outcome higher, rated their stressor impact as higher.

For *Problems with parents*, the overall model accounted for significant variance in stressor impact ($R^2 = .108$, $F(6, 156) = 3.154$, $p = .006$). Table 31 shows that at the second step, General Health Perception did not contribute a significant incremental proportion of the variance in impact (1.3) beyond age and sex group, which did not contribute significantly. At the third step, stressor appraisals contributed a significant incremental proportion of the variance in impact (7.0) beyond that contributed jointly by age and sex group. Only stressor frequency contributed independently to the prediction of stressor impact, based on the standardized regression coefficient. The sign of the coefficient indicates adolescents whose stressors occurred more frequently, rated their stressor impact as higher.

A similar analysis was conducted based on the first stressor listed for all participants. At the third step, illness-related ratings and typical of adolescence ratings were also included. These ratings were added because in contrast to the four above-described stressors, the first stressor listed was not selected to be highly illness-related or highly typical of adolescence. Results of evaluation of assumptions led to transformation of the illness-related ratings to reduce skewedness. Illness ratings were dichotomized into illness-related and not illness-related. As there was no substantial difference between the transformed and untransformed model, the untransformed model is presented in Table 32. No multivariate outliers were detected. The overall model accounted for significant variance in stressor impact ($R^2 = .146$, $F(8, 184) = 3.93$, $p < .001$). At the second step, General Health Perception did not contribute a significant incremental proportion of variance in impact (1.7) beyond that contributed jointly by age and sex

group (7.1). At the third step, stressor appraisals contributed a significant incremental proportion of variance in impact (5.7). Age and control over cause contributed independently to stressor impact, based on the standardized regression coefficients. The sign of the former coefficient indicates that as age increased, stressor impact was rated as higher. The sign of the latter coefficient indicates that as control over the cause decreased, stressor impact was rated as higher.

A second series of analyses were computed to assess the incremental variance in coping strategies accounted for by stressor appraisals, beyond General Health Perception. Once again, separate analyses were computed for the following stressor types: illness-related; typical of adolescence; *Medications/treatments*; and *Problems with parents*. For each of the stressor types, analyses were performed with two dependent variables; approach coping and avoidance coping scales derived from the Kidcope data. Demographic variables (age and gender) were entered simultaneously on the first step to control for their effects, and General Health Perception was entered on the second step. Stressor appraisal ratings of frequency, impact, control over cause, control over outcome, and the total number of stressors listed were entered simultaneously on the third step.

The illness-related stressor coping analyses was conducted using the shared sample of participants who delineated both an illness-related and a typical of adolescence stressor with corresponding Kidcope data ($N=124$). For the illness-related analysis, one multivariate outlier was removed from both approach and avoidant coping analyses. As shown in Table 33, the overall model accounted for significant proportions of variance in approach coping ($R^2 = .273$, $F(8, 115) = 5.386$, $p < .001$). General Health Perception did not contribute a significant incremental proportion of the variance in approach coping (1.1%) beyond that contributed jointly by age and sex group (8.9). Stressors contributed a significant incremental proportion of the variance in approach coping (17.2). For the full model, gender, impact, and control over outcome all contributed independently to the prediction of approach coping, based on the standardized regression coefficient. The sign of the coefficients indicates that approach coping increased with stressor impact and the ability to make it better. The overall model also accounted for significant proportions of variance in avoidance coping ($R^2 = .142$, $F(8, 115) = 2.383$, $p = .021$). General Health perception did not contribute a significant incremental proportion of

variance in avoidance coping (0.5). Stressors contributed significant incremental proportion of the variance in avoidance coping (13.2). For the full model, stressor frequency and impact contributed independently to the prediction of avoidance coping. The sign of the coefficients indicates that as the frequency and impact of the illness stressor increased, so did avoidance coping (26).

For the typical of adolescence stressor, no multivariate outliers were detected. As shown in Table 34, the overall model accounted for significant proportions of variance in approach coping ($R^2 = .142$, $F(8, 116) = 2.404$, $p = .019$). General Health perception did not contribute a significant incremental proportion of variance in approach coping (1.8) beyond age and sex, which did not contribute significantly. Stressors contributed a significant incremental proportion of variance in approach coping (10.1). However, for the full model, control over outcome was the only variable that contributed independently to the prediction of approach coping. The sign of the coefficient indicates that approach coping increases along with the perceived ability to make it better. The overall model also accounted for significant proportions of variance in avoidance coping ($R^2 = .183$, $F(8, 116) = 3.249$, $p = .002$). General Health perception contributed a significant incremental proportion of variance in avoidance coping (3.2) beyond age and sex, which did not contribute significantly. Stressors also contributed a significant incremental proportion of variance in avoidance coping (14.4). For the full model, age, General Health Perception, impact, and total number of stressors each contributed independently to the prediction of avoidance coping. The coefficients indicate that avoidance coping decreased with age and better perceived general health, and increased with stressor impact and the number of stressors reported.

Standard stressors analyses consisted of the shared sample of participants who endorsed experiencing both stressors in the past six months, with corresponding Kidcope data ($N=157$). No multivariate outliers were detected for *Medications/treatments* or *Problems with parents* analyses. As shown in Table 35, for *Medications/treatments*, the overall model accounted for significant proportions of variance in approach coping ($R^2 = .230$, $F(8, 148) = 5.523$, $p < .001$). General Health perception did not contribute a significant incremental proportion of variance in approach coping (0.0) beyond age and sex, which did not contribute significantly. Stressors

contributed a significant incremental proportion of variance in approach coping (19.6). For the full model, age, impact, control over outcome, and the total number of stressors each contributed independently to the prediction of approach coping. The coefficients indicate that approach coping tends to increase with age, impact and perceived ability to make it better. The overall model also accounted for significant proportions of variance in avoidance coping ($R^2 = .209$, $F(8, 148) = 4.876$, $p < .001$). Similarly, General Health Perception did not contribute a significant incremental proportion of variance in avoidance coping (0.9) beyond age and sex, which did not contribute significantly. Stressors contributed a significant incremental proportion of variance in avoidance coping (19.0). For the full model, impact and the total number of stressors each contributed independently to the prediction of avoidance coping. The coefficients indicate that higher stressor impact and a greater number of stressors are related to a higher frequency of avoidance coping.

Table 36 shows that for *Problems with parents*, the overall model accounted for significant proportions of variance in approach coping ($R^2 = .144$, $F(8, 148) = 3.104$, $p = .003$). General Health Perception did not contribute a significant incremental proportion of variance in approach coping (2.2) beyond age and sex, which did not contribute significantly. Stressors contributed a significant incremental proportion of variance in approach coping (9.8). For the full model, General Health Perception, total number of stressors, impact, and perceived ability to make it better each contributed independently to the prediction of approach coping. The coefficients indicate that better perceived health, increasing number of stressors, increasing stressor impact, and greater control over outcome are related to an increase in approach coping. The overall model also accounted for significant proportions of variance in avoidance coping ($R^2 = .198$, $F(8, 148) = 4.567$, $p < .001$). General Health Perception did not contribute a significant incremental proportion of variance in avoidance coping (1.8) beyond age and sex, which did not contribute significantly. Similar to approach coping, stressors also contributed a significant incremental proportion of variance in avoidance coping (16.9). For the full model, frequency and impact each contributed independently to the prediction of avoidance coping. The coefficients indicate that greater stressor frequency and stressor impact are related to a higher frequency of avoidance coping.

A pair of analyses was also computed with the dependent variables of active and avoidant coping scales derived from the A-COPE data. These analyses provided a strategy for exploring the relation between stressors and coping in general.

On the first step, age and gender were entered to control for their effects. General Health Perception was entered on the second step. On the third step, average illness-related stressor ratings, average typical of adolescence stressor ratings and the total number of stressors listed were entered simultaneously. No multivariate outliers were detected for either active or avoidant coping analyses. As shown in Table 37, the overall model accounted for significant proportions of variance in active coping ($R^2 = .103$, $F(6, 186) = 3.54$, $p = .002$). General Health Perception did not contribute a significant incremental proportion of variance in active coping (1.7) beyond age and gender (5.7). Moreover, stressors also did not contribute a significant incremental proportion of variance in active coping (2.8). For the full model, only General Health Perception contributed independently to the prediction of active coping. Better perceived health was related to more frequent active coping. The overall model also accounted for significant proportions of variance in avoidance coping ($R^2 = .119$, $F(6, 186) = 4.18$, $p = .001$). General Health Perception did not contribute a significant incremental variance in avoidant coping (1.6) beyond age and gender (6.2). Stressors contributed a significant incremental proportion of variance in avoidant coping (4.0). For the full model, only the number of stressors reported contributed independently to the prediction of avoidant coping. That is, an increase in stressors was related to a greater frequency of avoidant coping.

Table 26
Comparison of General Health Perception* by Clinic

Clinic	<u>M</u>	<u>SD</u>	<u>n</u>
Endocrinology	70.45	14.91	11
Diabetes	69.47	18.41	76
Cardiology	68.75	12.50	4
Rheumatology	65.63	21.62	8
Nephrology	62.35	23.86	17
Cystic Fibrosis	60.83	16.86	6
Haematology	60.53	26.03	19
Oncology	60.00	28.28	2
Gastroenterology	57.86	19.33	7
Chest	56.89	21.03	37
Neuromuscular	48.33	26.01	6
Total			193

Note.* Scale on the RAND 36-Item Health Survey 1.0.

Table 27

Hierarchical Multiple Regression Analysis with General Health Perception Scale (RAND-36) as Dependent Variable (N=193)

Step	Predictor variable	General Health Perception	Age	Gender	Stressor total	Average Illness ratings	Average typical ratings	R ²	R ² change	SEB	β
Step 1	Age	.003						.007	.007	1.042	.010
	Gender	.084	-.023							3.118	.013
Step 2	Stressor total	-.071	.355**	-.127*				.072*	.065**	0.326	-.080
	Average illness ratings	-.240**	-.154*	-.175**	-.061					1.461	-.288**
	Average typical Ratings	.028	.228	-.147*	.085	-.444				1.714	-.092
	Mean	63.99	15.98		8.59	1.33	3.11				
	Standard deviation	20.83	1.54	.50	4.85	1.16	1.00				

* $p < .05$. ** $p < .01$.

Table 28
Hierarchical Multiple Regression Analysis with Illness-Related Stressor Impact as Dependent Variable (N=125)

Predictor Variable	Stressor impact	Age	Gender	General Health Perception	Frequency	Control over cause	Control over outcome	R ² Change	SEB	β
Step 1										
Age	.068							.007	.066	.087
Gender	.046	-.080							.206	.034
Step 2										
General Health Perception	-.161*	-.084	.080					.033	.026	-.128
Step 3										
Frequency	.031	.069	-.079	-.116				.092	.059	.031
Control over cause	-.223**	.131	-.104	.111	.111				.070	-.147
Control over outcome	-.221**	.070	-.116	.065	.020	.519**			.080	-.139
Means	3.58	16.18	.40	61.44	3.11	1.98	2.65			
Standard Deviations	1.14	1.55	.49	20.14	1.36	1.70	1.47			

* $p < .05$. ** $p < .01$.

Table 29
Hierarchical Multiple Regression Analysis with Typical of Adolescence Stressor Impact as Dependent Variable (N=125)

Predictor Variable	Stressor impact	Age	Gender	General Health Perception	Frequency	Control over cause	Control over outcome	R ²	R ² Change	SEB	β
Step 1											
Age	.167*							.032	.032	.076	.134
Gender	-.076	-.080								.240	-.067
Step 2											
General Health Perception	-.053	-.084	.080					.033	.001	.006	-.038
Step 3											
Frequency	.065	.090	.063	-.062				.068	.035	.087	.086
Control over cause	-.068	-.073	-.119	.198*	.081					.089	-.178
Control over outcome	.103	.019	-.108	.201*	-.081	.549**				.095	.205
Means	3.24	16.18	.40	61.44	2.90	2.51	3.22				
Standard Deviations	1.30	1.55	.49	20.14	1.35	1.59	1.48				

* $p < .05$. ** $p < .01$.

Table 30
Hierarchical Multiple Regression Analysis with Medications/Treatments Stressor Impact as Dependent Variable (N=163)

Predictor Variable	Stressor impact	Age	Gender	General Health Perception	Frequency	Control over cause	Control over outcome	R ²	R ² Change	SEB	β
Step 1 Age	-.035							.006	.006	.090	-.045
Gender	-.069	-.085								.268	-.064
Step 2 General Health Perception	-.166*	-.026	.054					.033	.027*	.006	-.191*
Step 3 Frequency	.105	-.035	.001	.033				.095*	.062*	.099	.106
Control over cause	-.024	.174*	.032	-.015	-.104					.076	-.105
Control over outcome	.178*	.089	.018	.091	-.031	.402**				.077	.246**
Means	2.50	16.00	.47	63.22	4.21	1.46	2.23				
Standard Deviations	1.75	1.51	.50	20.67	1.35	1.95	1.90				

* $p < .05$. ** $p < .01$

Table 31
Hierarchical Multiple Regression Analysis with *Problems with Parents* Stressor Impact as Dependent Variable (N=163)

Predictor Variable	Stressor impact	Age	Gender	General Health Perception	Frequency	Control over cause	Control over outcome	R ²	R ² Change	SEB	β
Step 1 Age	.130							.025	.025	.059	.092
Gender	-.104	-.085								.180	-.098
Step 2 General Health Perception	-.121	-.026	.054					.038	.013	.004	-.099
Step 3 Frequency	.254**	.160*	-.078	-.055				.108**	.070**	.088	.180*
Control over cause	-.188**	.020	-.151*	.031	-.301**					.091	-.139
Control over outcome	-.126	-.011	-.012	.053	-.211**	.459**				.078	-.019
Means	3.05	16.00	.47	63.22	2.77	2.64	3.15				
Standard Deviations	1.16	1.51	.50	20.67	1.07	1.14	1.27				

* $p < .05$. ** $p < .01$.

Table 32
Hierarchical Multiple Regression Analysis with First Self-Generated Stressor Impact as Dependent Variable (N=193)

Predictor Variable	Stressor impact	Age	Gender	General Health Perception	Frequency	Control over cause	Control over outcome	Average illness ratings	Average typical ratings	R ²	R ² Change	SEB	β
Step 1 Age	.236**									.071**	.071	.055	.219**
Gender	-.129*	-.023										.169	-.088
Step 2 General Health Perception	-.141*	.003	.084							.089**	.017	.004	-.085
Step 3 Frequency	.079	.056	-.015	-.071						.146**	.057*	.064	.026
Control over cause	-.212**	-.044	.027	.124*	.018							.065	-.201*
Control over outcome	-.107	-.013	.030	.051	-.040	.604**						.072	.004
Average illness ratings	.114	-.097	-.034	-.192**	.206**	-.056	-.034					.049	.162
Average typical ratings	.061	.161*	-.138*	.067	.024	.146*	.211**	-.495**				.059	.128
Means	3.16	15.98	.45	63.99	2.85	2.28	3.02	1.50	3.17				
Standard Deviations	1.21	1.54	.50	20.83	1.35	1.60	1.47	2.05	1.73				

* $p < .05$. ** $p < .01$.

Table 33

Hierarchical Multiple Regression Analysis for Illness-Related Stressor with Approach and Avoidant Coping Scales as Dependent Variables (N=123)

NB: 1 outlier removed

<u>Approach Coping</u>					<u>Avoidant Coping</u>				
Step	Predictor variable	R ²	R ² change	SEB	β	R ²	R ² change	SEB	B
Step 1	Age	.089**	.089	.034	-.026	.005	.005	.029	-.116
	Gender			.102	-.285**			.086	.027
Step 2	General Health Perception	.101**	.011	.002	.114	.010	.005	.002	-.005
Step 3	Stressor total	.273**	.172**	.011	.160	.142*	.132**	.009	.030
	Frequency			.037	-.131			.031	.270**
	Control over cause			.036	.024			.030	-.130
	Impact			.048	.306**			.041	.243*
	Control over outcome			.042	.242**			.035	.182

Correlations for Multiple Regression Variables

Predictor variable	Approach	Avoid	Age	Gender	General Health Perception	Stressor total	Frequency	Control over cause	Impact	Control Over outcome
Age	.083	-.069								
Gender	-.293**	.032	-.085							
General Health Perception	.080	-.060	-.086	.074						
Stressor total	.264**	.081	.360**	-.155**	-.031					
Frequency	-.114	.243**	.076	-.065	-.109	.082				
Control over cause	.120	-.060	.126	-.124	.103	-.062	.128			
Impact	.229**	.214**	.082	.081	-.151*	.233**	-.009	-.187*		
Control over outcome	.214**	.029	.077	-.100	.076	.056	-.003	.559**	-.282**	
Means	1.22	1.14	16.18	.40	61.33	9.70	3.13	1.95	3.60	2.67
Standard deviations	.61	.47	1.55	.49	20.18	4.95	1.36	1.68	1.10	1.45

* $p < .05$. ** $p < .01$.

Table 34

Hierarchical Multiple Regression Analysis for Typical of Adolescence Stressor with Approach and Avoidant Coping Scales as Dependent Variables (N=124)

Step	Predictor variable	Approach Coping				Avoidant Coping			
		R ²	R ² change	SEB	β	R ²	R ² change	SEB	B
Step 1	Age	.024	.024	.035	.064	.007	.007	.032	-.222*
	Gender			.106	-.059			.095	.093
Step 2	General Health Perception	.041	.018	.003	.084	.039	.032*	.002	-.185*
Step 3	Stressor total	.142*	.101*	.012	.156	.183**	.144**	.010	.297**
	Frequency			.040	-.072			.035	.016
	Control over cause			.040	-.109			.035	.116
	Impact			.041	-.023			.036	.210*
	Control over outcome			.043	.310**			.038	-.052

Correlations for Multiple Regression Variables

Predictor variable	Approach	Avoid	Age	Gender	General Health Perception	Stressor total	Frequency	Control over cause	Impact	Control over outcome
Age	.120	-.082								
Gender	-.106	.023	-.080							
General Health Perception	.114	-.170*	-.084	.080						
Stressor total	.200*	.257**	.354**	-.165*	-.037					
Frequency	-.072	.114	.090	.063	-.062	.246**				
Control over cause	.093	.076	-.073	-.119	.198*	.111	.081			
Impact	.050	.217**	.167*	-.076	-.053	.181*	.065	-.068		
Control over outcome	.302**	.028	.019	-.108	.201*	.159*	-.081	.549**	.103	
Means	1.32	1.19	16.18	.40	61.44	9.66	2.90	2.51	3.24	3.22
Standard deviations	.59	.54	1.55	.49	20.14	4.95	1.35	1.59	1.30	1.48

* $p < .05$. ** $p < .01$.

Table 35

Hierarchical Multiple Regression Analysis for *Medications/Treatments* Stressor with Approach and Avoidant Coping Scales as Dependent Variables (N=157)

Step	Predictor variable	Approach Coping				Avoidant Coping			
		R ²	R ² change	SEB	β	R ²	R ² change	SEB	B
Step 1	Age	.033	.033	.036	-.161*	.009	.009	.022	-.087
	Gender			.104	-.094			.063	-.009
Step 2	General Health Perception	.034	.000	.003	.049	.018	.009	.002	-.014
Step 3	Stressor total	.230**	.196**	.012	.259**	.209**	.190**	.007	.192*
	Frequency			.039	.086			.024	.024
	Control over cause			.030	-.125			.019	-.064
	Impact			.032	.278**			.019	.385**
	Control over outcome			.031	.162*			.019	-.051

Correlations for Multiple Regression Variables

Predictor variable	Approach	Avoid	Age	Gender	General Health Perception	Stressor total	Frequency	Control over cause	Impact	Control over outcome
Age	-.085	-.050								
Gender	-.154*	-.075	-.088							
General Health Perception	.004	-.099	-.034	.057						
Stressor total	.236**	.203**	.332**	-.152*	-.060					
Frequency	.118	.068	-.022	-.003	.068	-.074				
Control over cause	-.095	-.092	.183*	.046	.001	.003	-.149*			
Impact	.343**	.402**	-.029	-.108	-.187**	.101	.117	.031		
Control over outcome	.143*	-.023	.096	-.011	.101	-.008	-.048	.416**	.174*	
Means	1.28	.88	15.99	.48	63.38	8.78	4.20	1.39	2.59	2.25
Standard deviations	.71	.43	1.53	.50	20.69	4.78	1.35	1.90	1.71	1.87

* $p < .05$. ** $p < .01$.

Table 36

Hierarchical Multiple Regression Analysis for *Problems with Parents Stressor with Approach and Avoidant Coping Scales as Dependent Variables (N=157)*

Step	Predictor variable	Approach Coping				Avoidant Coping			
		R ²	R ² change	SEB	β	R ²	R ² change	SEB	B
Step 1	Age	.024	.024	.035	-.097	.011	.011	.028	-.123
	Gender			.104	-.132			.082	-.048
Step 2	General Health Perception	.045	.022	.002	.156*	.029	.018	.002	-.093
Step 3	Stressor total	.144**	.098**	.012	.177*	.198**	.169**	.010	.128
	Frequency			.054	-.107			.042	.206*
	Control over cause			.055	-.084			.043	-.056
	Impact			.047	.179*			.037	.269**
	Control over outcome			.047	.247**			.037	.090

Correlations for Multiple Regression Variables

Predictor variable	Approach	Avoid	Age	Gender	General Health Perception	Stressor total	Frequency	Control over cause	Impact	Control Over outcome
Age	-.030	-.011								
Gender	-.147*	-.088	-.088							
General Health Perception	.140*	-.034*	-.034	.057						
Stressor total	.132*	.216**	.332**	-.152*	-.060					
Frequency	-.055	.291**	.154*	-.082	-.056	.335**				
Control over cause	.070	-.101	.031	-.138*	.024	.047	-.279**			
Impact	.152*	.337**	.126	-.116	.069	.224**	.219**	-.151*		
Control over outcome	.198**	-.047	-.009	-.024	.069	-.098	-.235**	.502**	-.165*	
Means	1.34	1.27	15.99	.48	63.38	8.78	2.76	2.64	3.04	3.18
Standard deviations	.67	.54	1.53	.50	20.69	4.78	1.06	1.13	1.15	1.26

* $p < .05$. ** $p < .01$

Table 37

Hierarchical Multiple Regression Analysis with A-COPE Active and Avoidance Coping Scales as Dependent Variables (N=193)

Step	Predictor variable	Active Coping				Avoidance Coping			
		R ²	R ² change	SEB	β	R ²	R ² change	SEB	B
Step 1	Age	.057**	.057*	.020	.112	.062**	.062**	.020	.106
	Gender			.060	-.127			.059	-.140
Step 2	General Health Perception	.074**	.017	.001	.163*	.079**	.016	.001	-.122
Step 3	Stressor total	.103**	.028	.006	.128	.119**	.040*	.006	.212**
	Average illness ratings			.029	.130			.029	-.036
	Average typical ratings			.033	.125			.033	-.017

Correlations for Multiple Regression Variables

Predictor variable	Active	Avoidance	Age	Gender	General Health Perception	Stressor total	Average illness ratings	Average typical ratings
Age	.170**	.186**						
Gender	-.173**	-.171**	-.023					
General Health Perception	.116	-.140*	.003	.084				
Stressor total	.175**	.277**	.355**	-.127*	-.071			
Average illness ratings	.032	-.004	-.154*	-.175**	-.240**	-.061		
Average typical ratings	.127*	.058	.228**	-.147*	.028	.085	-.444**	
Means	2.65	2.55	1.98	.45	63.99	8.59	1.33	3.11
Standard deviations	.41	.40	1.54	.50	20.83	4.85	1.16	1.00

* $p < .05$. ** $p < .01$.

Two-factor Model of Approach Versus Avoidant Coping

As described in the previous section, several hierarchical regressions were computed with either approach or avoidant coping as the dependent variable. Several of the coping analyses in this study were also repeated using this two-factor approach. This strategy was undertaken in order to increase the possible detection of more general coping differences.

As a preliminary measure of coping consistency, a series of Pearson Product-Moment correlations were computed between the frequency ratings for the same coping strategies across two Kidcope questionnaire administrations. Specifically, the Kidcope was administered in reference to self-identified stressors most clearly delineated as chronic illness related, as well as in reference to self-identified stressors most clearly delineated as typical of adolescence. Significant correlations were found for both approach ($r = .448, p < .001$) and avoidant coping ($r = .448, p < .001$). The same correlational analyses were computed between the two standard stressors *Problems with parents* and *Medications/treatments*. Similarly, significant correlations were also found for both approach ($r = .468, p < .001$) and avoidant coping ($r = .493, p < .001$).

As stated previously, it was hypothesized that there would be no difference in coping frequency for illness-related and typical stressors after controlling for appraisals. Analyses were repeated with control over cause and control over outcome serving as covariates. For coping frequency in relation to illness versus typical stressors, there was no significant effect of either covariate for approach or avoidant coping. Further analyses were computed without the covariates, and no significant difference in the frequency of approach coping for illness stressors ($M = 1.22, SD = .61$) and typical stressors ($M = 1.32, SD = .59$), $F(124) = 3.17, p = .077$ was found. Similarly, no difference in the frequency of avoidant coping for illness stressors ($M = 1.14, SD = .47$) and typical stressors ($M = 1.19, SD = .54$), $F(124) = 1.18, p = .279$ was present.

For coping in relation to standard stressors, there was also no significant effect of either covariate for approach or avoidant coping. After covariates were removed, there was no significant difference in the frequency of approach coping in relation to *Problems with parents* ($M = 1.33, SD = .69$) and *Medications/treatments* ($M = 1.26, SD = .71$), $F(165) = 1.55, p = .215$). However, Avoidance coping was employed more frequently in dealing with *Problems*

with parents ($M = 1.24$, $SD = .55$) than in dealing with *Medications/treatments* ($M = .87$, $SD = .43$), $F(165) = 90.08$, $p < .001$).

Gender hypotheses were also explored using the Kidcope data and the two-factor model of approach versus avoidance coping. Females employed more approach coping versus avoidance coping for both self-generated stressors and *Medications/treatments*. For the standard stressor, *Problems with parents*, there was also a similar trend. In contrast, males did not differ in their use of approach versus avoidance coping for both self-generated stressors or for *Problems with parents*. However, males did employ more approach coping versus avoidant coping in dealing with *Medications/treatments*. The results of these analyses are displayed in Table 38. Similar results were also obtained with the global coping measure (A-COPE). Females employed significantly more active ($M = 2.71$, $SD = .41$) versus avoidance coping strategies ($M = 2.61$, $SD = .38$), $t(104) = 2.21$, $p = .03$. In contrast, males did not significantly differ in their use of active ($M = 2.57$, $SD = .40$) versus avoidance coping ($M = 2.48$, $SD = .42$), $t(87) = 1.64$, $p = .104$.

Pearson Product correlations were computed between age and the frequency of both approach and avoidant coping for self-generated and standard stressors. As shown in Table 39, age was only significantly correlated with approach coping for the typical of adolescence stressor. In contrast, both active ($r = .170$, $p = .018$) and avoidance ($r = .186$, $p = .010$) coping were significantly positively correlated with age on the A-COPE.

Table 38
Mean Frequency of Approach Versus Avoidant Coping for Each Gender

Stressor type	Gender	Approach	Avoidant	df	t	p
Illness-related Stressor	Male	1.06 (.58)	1.14 (.47)	53	0.83	.412
	Female	1.36 (.62)	1.11 (.45)	83	2.90	.005**
Typical of adolescence stressor	Male	1.25 (.63)	1.12 (.52)	82	1.45	.152
	Female	1.40 (.60)	1.18 (.53)	95	2.74	.007**
Medications/treatments	Male	1.17 (.76)	0.84 (.42)	81	4.42	<.001**
	Female	1.37 (.67)	0.91 (.41)	87	6.36	<.001**
Problems with parents	Male	1.21 (.65)	1.19 (.55)	84	0.31	.761
	Female	1.40 (.68)	1.26 (.56)	100	1.89	.060

Note. Standard deviations are displayed in brackets for each respective mean.

**p < .01.

Table 39
Correlations between Age and Approach and Avoidant Strategies

Stressor type	Coping strategy	r	p
Illness-related	approach	.059	.489
	avoidant	-.041	.636
Typical of adolescence	approach	.150	.045*
	avoidant	-.091	.227
Problems with parents	approach	-.017	.817
	avoidant	.000	.995
Medications/treatments	approach	-.101	.188
	avoidant	-.040	.603

* $p < .05$

DISCUSSION

Interpretation of Findings

Stressors of Adolescents with a Chronic Illness

The first research objective was to develop a list of salient stressors self-generated by chronically ill adolescents and to investigate the number, categories and cognitive appraisals of these stressors. We found that 19 categories effectively captured the range of stressors generated by adolescents, and that stressors could be reliably assigned to these categories. Many adolescents in our sample identified at least one stressor from illness-related categories such as Health concerns (44%) or Clinic/hospital visits and Medications/treatment (23%). However, these categories only comprised a small percentage of the total number of stressors reported across all adolescents (8% and 3% respectively). Initially, we anticipated separate categories for stressors related to medications or treatments and hospital and clinic visits, but we found that the percentage of stressors reported across adolescents for the latter category was small (less than 1%). Therefore, hospital/clinic visits was combined with undergoing medications or treatments.

Considerably fewer adolescents in our sample reported at least one stressor related to either physical limitations due to illness (9%) or restrictions due to illness (8%). Also, on average, adolescents reported that their self-generated stressors were more typical of adolescence, than chronic illness related. Taken together, these findings indicate that categories of stressors that are clearly illness-related were not the predominant stressors reported by chronically ill adolescents. There are several explanations that may contribute to this finding. First, it is important to consider that these adolescents have the typical, normative stressors to deal with, in addition to the illness stressors. Second, these chronically ill adolescents may prefer to see themselves foremost as adolescents; they may cope with the chronic illness through denial and avoidance. Third, many illness-related events may not be considered stressful by these individuals.

The present study's finding that adolescents reported problems most frequently in the areas of school, relationship with adolescents and relationship with parents is similar to results found in the developmental literature for healthy adolescents (Phelps & Jarvis, 1994; Spirito, Overholser et al., 1989; Stark et al., 1989). Once again, this finding emphasizes the importance of the normative adolescent experience for these individuals. Other studies of chronically ill

adolescents have also found that much of the focus of stress for chronically ill adolescents was unrelated to their chronic illness (Bull & Drotar, 1991; Olson et al., 1993) and that the most frequently reported non illness-related stressors were similar in nature to those stressors described by healthy adolescents (Bull & Drotar, 1991; Spirito et al., 1995). For example, other studies of chronically ill adolescents found that, school, family, peers and social situations (Bull & Drotar, 1991) or family, parents, friends, school, and boyfriend/girlfriend (Spirito et al., 1995) were the most frequently reported stressors. Although the majority of stressors described in the current study are not unique to chronically ill adolescents, it is important to recognize that chronic stressors from parents, teachers and friends have been associated with more depression and problem behaviour (Moos, 2002). Therefore, an evaluation of coping resources also needs to be considered in reference to these normative stressors.

Similarly, school and the parent-teen relationship were amongst the most frequently described stressors for a sample of adolescents with cystic fibrosis (DiGirolamo et al., 1997). However, for adolescents with cystic fibrosis, undergoing medications or treatments and attending clinic and hospital visits were also frequently occurring stressors (second and fourth respectively, out of ten stressor domains). Moreover, those stressors that appeared to be normative in nature (ie. school, dating) were affected by the chronic illness. In contrast to our findings, their study found that very few problems involving siblings were reported. However, 31% of our sample had at least one stressor in this area. DiGirolamo and colleagues' study (1997) did not report on the number of participants with siblings, so it is unclear if lower numbers of siblings can account for this difference.

In our study, although the range of stressors generated was broad (1-20), adolescents generated an average of 8.6 stressors ($SD=4.87$). This number is considerably lower than the average number of problem situations (18, $SD=18.6$) elicited in the study of adolescents with cystic fibrosis described above (DiGirolamo et al., 1997). What can account for these divergent findings between the present study and DiGirolamo and colleagues' (1997) study? First, their study may have elicited more stressors overall, and more illness-related problems because interviewers prompted participants about stressor domains as part of the procedure. Also, in the present study, ten participants (5%) generated the maximum number of stressors requested;

presumably, some of these individuals may have generated even further stressors if allowed to do so, thus increasing the overall average. However, the Median and Modal number of stressors in the current study were 7 and 5, respectively, suggesting that it was unnecessary to provide an option for participants to list more than 20 stressors. Also, it is likely that the most salient situations are listed at the start of the list, and that as further stressors are listed, they may be of less relevance to the individual. Differences between illnesses may also account for some of the diversity in reported stressors. Adolescents with cystic fibrosis typically require extensive and frequent treatments and monitoring, and therefore, may experience more illness-related stressors than do other chronically ill adolescents.

A substantial percentage of our sample also reported at least one stressor related to finances (40%). For many individuals, this stressor focused on issues related to work, or insufficient funds to purchase desired items. This does not appear to be related to family financial stressors, as on average, our sample had an income comparable to the average family income for the Ottawa/Hull region, and higher than the average family income for the province of Ontario.

The basis for including the two standard stressors employed in this study was to provide two prototypical stressors shared by the majority of participants; one related to the illness and one typical of adolescence. In fact, *Problems with parents* was rated as more typical of adolescence than was *Medications/treatments*. Also, *Medications/treatments* was rated as more illness-related than was *Problems with parents*, thus validating these choices as prototypical stressors.

However, these stressors may provide an unrealistic representation of the types of stressors faced by chronically ill adolescents because it is believed that there is often an interaction between illness and typical dimensions for a given stressor (DiGirolamo et al., 1997). For example, even for these prototypical stressors, many participants indicated that *Problems with parents* was related to their chronic illness to some extent, and that dealing with *Medications/treatments* was typical of adolescence to some extent. Further the moderate negative correlation between chronic illness ratings and typical of adolescence ratings (-.504) for the first self-generated stressor supports the concept that illness-related and typical of adolescence dimensions for stressors are separate constructs, and are not simply opposing poles on a single scale.

Measurement discrepancies may account for some of the differences found for standard versus self-generated stressors. First, self-generated stressors were only reported, and thus rated, if the situation was stressful for the participant. This is consistent with a transactional approach to stress and coping; that is, in situations where resources are believed to be adequate for dealing with the demand, no stressful event is considered to have occurred (Folkman et al., 1986; Lazarus & Folkman, 1984). In contrast, participants were instructed to rate appraisal scales for the standard stressors if the situation had occurred, regardless of whether or not the participant found the situation stressful. This approach was taken in order to ensure that participants responded in a uniform manner to the standard stressors. Unfortunately, this approach also resulted in a slightly different methodology for standard versus self-generated stressors. Theoretically, a different cognitive set may be employed when responding to standard stressors. Although instructions were provided to try and overcome this difficulty, it could still possibly explain differences obtained.

Also, presumably the salience of standard and self-generated stressors is dissimilar. In fact, in the past six months, 5% of participants did not experience any problems with their parents and 12% of participants did not undergo medications or treatments. This finding suggests that even within the two standard problems, there may be different degrees of salience for this study sample. It is important to consider that the conflict with parents may be related to treatment or medication issues, and that a chronic illness can exacerbate a parent-adolescent relationship. As highlighted by the normative literature, parent-adolescent relationship conflicts are a key stressor; it is not surprising that illness-related issues can impact on this type of conflict.

Additionally, note that the two standard stressors occurred at different rates. For those chronically ill adolescents who experienced the standard stressors in the past six months, *Medications/treatments* occurred at a greater frequency than did *Problems with parents*. For the majority of our sample, *Medications/treatments* was experienced as a daily, chronic stressor (63%) whereas very few participants experienced *Problems with parents* as a daily stressor (5%). No difference in frequency rate was present between illness-related and typical self-generated stressors.

For the standard stressors, adolescents rated having more control over both the cause of the situation and over the outcome for *Problems with parents* than for *Medications/treatments*. In other research, children and adolescents also rated a general peer-argument situation as more controllable than several diabetes stressors (Reid et al., 1995). Despite these ratings, the impact of *Problems with parents* was greater than for *Medications/treatments*, supporting the notion that, for these chronically ill adolescents, *Medications/treatments* was not as salient a stressor as was *Problems with parents*. Instead, it also suggests that similar to their healthy peer group, chronically ill adolescents are experiencing parent-teen conflict. Medication or treatment issues may play a role in the conflict.

It was hypothesized that the perceived impact of stressors would be positively related to the frequency of stressors. Consistent with our hypothesis, as the frequency of *Problems with parents* increased, so did the perceived impact of this stressor. However, perceived stressor impact was not consistently related to the frequency of the self-generated stressors, or *Medications/treatments*. This finding suggests that one cannot predict the impact a given stressor will have for an individual based on knowledge of the frequency for which the stressor occurs. Instead, other appraisals are likely to influence the impact of a given stressor.

The literature has discussed the role of stressor controllability in both the appraisal of stressors as well as the coping responses employed (Compas et al., 1991; Donaldson et al., 2000; Ebata & Moos, 1991; Folkman et al., 1986; Reid et al., 1995). This study considered two different types of stressor controllability since they may each have relevance for stress and coping. Consistent with our hypothesis, for the self-generated stressor, perceived control over the cause of the event was negatively related to stressor impact. There was a trend for both types of control to be negatively related to the impact of *Problems with parents*, but for *Medications/treatments*, a trend was only found between control over outcome and impact. These findings suggest that both control over the cause of events, as well as control over the outcome of events may be related to other stress and coping appraisal variables.

Coping Strategies Used for Illness-Related and Other Types of Stressors

It was hypothesized that coping consistency across stressors would result in a positive relation between the frequencies of each coping strategy used by the same participant for illness-

related and other types of stressful events. Overall, consistency of coping strategies was supported. Significant correlations were found for distraction, social withdrawal, problem solving, discussing feelings, self-calming, wishful thinking, social support and resignation. In addition, trends were observed for remaining coping strategies (cognitive restructuring, self-criticism, blaming others, expressing anger). For the standard stressors, significant correlations or trends were found for all strategies except for self-criticism or blaming others. Similar to the findings of Reid and colleagues, (1995), consistency of coping was also supported for the two-factor model of approach and avoidant coping. These findings are consistent with the conclusion reached by other researchers (Reid et al., 1995; Spirito et al., 1995). That is, coping is a process that shows some variability across situations for the individual, but also has some stability. It may be that there is nothing fundamentally different about coping with an illness versus a typical stressor. Instead, there appears to be some stability within individuals in the way they choose to cope with different stressors. Consistent with the transactional model of stress and coping, individual differences in coping may be of greater importance (Folkman et al., 1986; Lazarus & Folkman, 1984).

Other researchers have compared coping consistency across illness-related and common stressors for the same participant and found that most of the Kappa coefficients or correlations fell in the moderate range (Reid et al., 1995; Spirito et al., 1995). Moderate correlations for cross-situational coping consistency across different situations have also been found for healthy children (Band & Weisz, 1988; Causey & Dubow, 1992; Compas, 1988; Roecker et al., 1996). Some of the correlations in the present study were lower than those found by other researchers. However, these other studies consisted solely of, or included younger children. Since children have a less extensive repertoire of coping strategies from which to choose compared to adolescents (Compas et al., 2001; Compas et al., 1992; Donaldson et al., 2000), greater consistency in coping may be more likely to occur at a younger age. In terms of measurement of coping, other studies have also classified coping differently, with fewer categories of coping strategies (Band & Weisz, 1988; Reid et al., 1995; Roecker et al., 1996); this approach may have affected coping consistency. In fact, when approach and avoidance coping were considered in this study, greater correlations across stressor types were obtained.

The consistency of coping patterns was more similar between the self-generated stressors versus the standard stressors. What can account for this difference? First, as stated previously, stressor salience, stressor frequency, and instruction to participants may account for the discrepancy in consistency of coping patterns between self-generated and standard stressors.

Also, as discussed earlier, prototypical stressors may not offer a realistic representation of the stressors usually faced by chronically ill adolescents. The fact that standard stressors were selected to be strongly illness-related (*Medications/treatments*) or strongly typical of adolescence (*Problems with parents*) may set them apart from other stressors. In fact, in our study, we were not always able to identify self-generated stressors strongly delineated as illness-related, or strongly delineated as typical of adolescence, based on our decision criteria. Typically, in cases where no stressors were delineated as typical of adolescence, participants' ratings on these two scales were similar. In cases where no stressors were delineated as illness-related, participants often endorsed very low ratings on the illness-related scale for some stressors, or ratings on the two scales were similar. Consistent with other research (DiGirolamo et al., 1997), these findings indicate that a stressor that appears to be largely illness-related may also be influenced by the more normative challenges of adolescence.

Overall, the present findings are consistent with previous research with healthy adolescents (Donaldson et al., 2000; Roecker et al., 1996) and chronically ill adolescents (Donaldson et al., April 1997; Spirito et al., 1995). That is, coping across stressors involves situational variability as well as consistency of coping. This finding supports the conceptualization of coping outlined by Lazarus and Folkman (1984).

It was hypothesized that for each coping strategy, if controllability was held constant, no significant differences would be found between stressors delineated as typical of adolescence and stressors delineated as illness-related on the perceived frequency or efficacy of coping. First, it is important to recognize that adolescents in our study rated more perceived control over the cause and outcome of the stressor for the typical problem and *Problems with parents*, versus the illness-related problem and *Medications/treatments*, respectively. In other research, children and adolescents also rated more control over the outcome of a general peer-related stressor compared to diabetes-related stressors (Reid et al., 1995). The current finding provides initial support for

the notion that any differences in coping between illness and typical stressors would be attributable to differences in control. In fact, no differences in the frequency of coping were found for eight of the twelve coping strategies, although controllability covariates (control over cause of the event; control over event outcome) did not consistently have an effect on coping. Reid and colleagues (1995) also noted that perceptions of control were related to approach coping in only two out of four situations. In the present study, when controllability covariates did affect coping, no significant differences in coping frequencies remained after controlling for the covariates. These findings suggest that although perceptions of controllability may be related to the frequency of some coping strategies, the chronically ill adolescent's individual style of coping and the strategies they choose to cope with are likely to be consistent across different stressors.

A potential limitation of this thesis is that the lack of significant coping findings across stressor types is a reflection of low power, rather than support for the null hypothesis findings. Note that effect sizes (partial Eta squared) for coping comparisons with nonsignificant findings were very small, explaining only up to two percent of the overall variance. As stated previously, the current minimum sample size of 125 is sufficient to detect a small to medium effect size with estimated power equal to .87. Moreover, the sample sizes required in order for this study's obtained effect sizes to reach significance were at least 130 for self-generated stressors, and well over 1,000 for standard stressors. This suggests that the failure to find coping differences was not a result of low statistical power. Instead, the large sample sizes required to detect these small effects indicates that these differences are clinically irrelevant.

Interestingly, wishful thinking was used more for the illness-related problem, and blaming others was used more for the typical problem. There were also trends for problem solving and expressing anger to be employed more frequently for the typical problem versus the illness-related problem. Given that support for this particular hypothesis requires a lack of significant findings, a conservative approach should treat a strong trend as a significant finding.

In other research, emotion-focused coping has been negatively associated, and problem solving has been positively associated, with control over the outcome of events (Compas et al., 1991; Compas, Forsythe et al., 1988; Compas, Malcarne et al., 1988; Forsythe & Compas, 1987;

Gamble, 1994; Reese et al., 1997; Roberts, 1995). However, in our study, neither control over the cause or control over the outcome were related to wishful thinking, blaming others, problem solving or expressing anger. Note that control covariates only affected four of the twelve coping strategies; self-criticism, resignation, social withdrawal and discussing feelings, and there was inconsistency regarding which of the two control covariates had an effect.

Overall, very few coping strategies were affected by perceptions of controllability, although illness-related stressors were rated as less controllable than were typical stressors. Therefore, for coping strategies such as wishful thinking, there must be other appraisal variables that can account for the coping differences across stressor types.

Even when control variables and coping were related, the direction of this relation was unclear. For example, on the one hand, chronically ill adolescents may employ self-criticism when they believe they have the opportunity to prevent or alter the original stressful situation or to improve on the outcome of the stressor. On the other hand, adolescents may believe they had the opportunity to prevent, alter or remedy the stressful situation because they engaged in self-criticism. This particular issue cannot be resolved within a retrospective study design.

When standard stressors were analysed in the same manner, a different pattern of results emerged. No differences in the frequency of coping were found for only three of the twelve coping strategies, although controllability covariates did not consistently have an effect on coping. In contrast to self-generated stressor findings, no difference in frequency of wishful thinking was found for *Problems with parents* versus *Medications/treatments*. Consistent with self-generated stressor findings, discussing feelings and social support were employed equally across *Problems with parents* and *Medications/treatments*. Also consistent, blaming others was engaged in more frequently for *Problems with parents* than for *Medications/treatments*. Problem solving and expressing anger were employed significantly more frequently for *Problems with parents* than for *Medications/treatments*, a finding that provides support for the trend found across illness-related and typical stressors. Self-criticism, distraction, social withdrawal, blaming others, and self-calming were also employed more frequently for *Problems with parents* than for *Medications/treatments*. In contrast, cognitive restructuring and resignation were employed more frequently for *Medications/treatments* than for *Problems with parents*.

Differences between self-generated stressors and standard stressors were also present when the two broader coping categories of approach coping and avoidance coping were considered. Frequencies of approach coping and avoidance coping were similar for self-generated illness-related stressors and typical stressors. However, more avoidance coping was employed when dealing with *Problems with parents* than with *Medications/treatments*. Diabetes research also found avoidance coping was used more for a general peer stressor versus diabetes-related stressors (Reid et al., 1995). Chronically ill adolescents may receive encouragement and guidance from their treatment team on ways to actively cope with illness-related stressors. However, they may not be given any advice on how to cope with stressors that are not directly related to their illness.

One might argue that differences in coping strategy frequencies found for the self-generated stressors and standard stressors may be related to the different samples that contributed to each analysis. Restricting the sample to those participants who generated both a highly illness-related stressor, a highly typical of adolescence stressor, and who experienced both types of standard stressors would have reduced our sample to slightly over half of the adolescents in our study (106/193). It was decided that such a tactic would further reduce our power to detect any true coping differences, and also limit the generalizability of our findings. Moreover, the analyses were also conducted with the restricted sample and results were very similar.

Another possible interpretation is that collapsing across self-generated stressors produced more variability than is found for standard stressors, thus masking any differences in coping that may exist. However, this notion is not supported empirically. A comparison of the standard deviations associated with coping strategies for self-generated stressors versus standard stressors indicates that variability in coping frequency was not greater for self-generated stressors.

Taken together, the above findings for the self-generated stressors and standard stressors can be summarized as follows. First, there was some coping consistency across stressors, but situational differences also existed. Second, differences in coping frequency across stressors were not always explained by perceived control over the cause of the event, or by perceived control over the outcome of the event. Third, divergent results for standard and self-generated stressors may be related to differences in the salience or chronicity of the stressors.

It was also hypothesized that for each coping strategy, if controllability was held constant, no significant differences would be found between stressors delineated as typical of adolescence and stressors delineated as illness-related on the perceived efficacy of coping. In support of our hypothesis, efficacy of each coping strategy was similar across illness-related and typical stressors. Similar to frequency of coping, efficacy of self-criticism was related to control over the outcome of the event, but no difference in the efficacy of any strategies was found across illness-related and typical stressors. Also, the efficacy of very few coping strategies was related to either control over the cause or outcome of events. For standard stressors, consistent with the frequency data, efficacy of cognitive restructuring and resignation were greater for coping with *Medications/treatments* versus *Problems with parents*. Also, consistent with the frequency data, the efficacy of expressing anger was greater for *Problems with parents* versus *Medications/treatments*. In contrast to the frequency findings, the efficacy of wishful thinking was also greater when dealing with *Problems with parents*.

These findings suggest that very few differences in perceived efficacy of individual coping strategies exist across stressor types, and that appraisals of control are not likely to account for any existing differences in coping efficacy. Research with healthy adolescents also revealed no differences in efficacy of coping across common problems, although a between-subjects design was used to investigate this issue (Stark et al., 1989). However, in the present study, for coping strategies where efficacy was perceived to differ across stressors, a similar difference is found for the coping frequency.

Intuitively, it is logical that adolescents would report greater frequency of coping strategies for stressors where they believe a particular strategy is more likely to be helpful. However, the direction of this relation cannot be determined based on this self-report methodology. One might presume that adolescents would be more accurate in their reporting of frequency of coping versus efficacy of coping. However, adolescents may have been inclined to rate coping strategies they employed as effective based on a desire to appear competent, or, they may have inadvertently or intentionally only endorsed employing coping strategies they considered effective. Corroborative reporting from other sources could help to address the latter concern. However, other parties would have difficulty rating strategies that are more cognitive in nature.

Conclusions about differences in efficacy of coping should be considered tentative because sample sizes varied considerably according to the number of participants who endorsed employing a given strategy. For example, based on the obtained effect sizes, samples of only 57 and 19 participants would be required for blaming others to be significantly more effective in coping with typical of adolescence stressors, or *Problems with parents*, respectively.

Because unique aspects of chronic illnesses exist, one could argue that there may have been advantages to following a categorical approach in the current study. However, there are theoretical and practical issues that support the noncategorical approach followed. In this study, the common elements across illnesses and the subjective appraisals within individuals were of interest. Significant individual differences exist within illnesses; this study focused on these, rather than disease-specific differences. As noted previously, disease variables (e.g., severity) are not related to the adjustment, history, or the impact of stressors. Within a noncategorical approach, functional status, such as the amount of burden to an individual or family can be assessed. On a practical note, a noncategorical sample provided an opportunity to include a larger sample than is often found in chronic illness research. However, a limitation of this approach is that a heterogeneous sample also makes it more difficult to detect differences due to increased variance within the chronic illness group.

Age and Gender Influences on Stress and Coping Variables

In the present study, no gender difference was found for the number of stressors reported. Both the developmental literature (Compas, 1987b; Ge et al., 1994; Wagner & Compas, 1990) and the chronic illness literature (DiGirolamo et al., 1997) found that females reported a greater number of stressors than did males. Also, in the present study, the same relative ranking for the top five stressors (school, relationship with adolescents, relationship with parents, health concerns, money/finance) was found for both males and females. In contrast, gender differences were found for types of stressors in research with healthy adolescents. For example, males were more concerned about school, parents, friends and girlfriends, whereas girls were more worried about parents, boyfriends, friends and school (Stark et al., 1989). Researchers have explained these findings as an inclination for females to be more concerned about interpersonal situations, whereas boys show more concern about achievement-related stressors.

Of interest, in the present study, a substantially greater percentage of females than males reported a stressor in the body image/sexual maturation category. This is not surprising given the preoccupation with body image, weight and appearance that has been found for chronically ill females (Neumark-Sztainer et al., 1998). Female adolescents with cystic fibrosis also reported more stressors related to friends and dating/pubertal development than did males (DiGirolamo et al., 1997). In the current study, the discrepancy between the percentages of females versus males with stressors related to other adolescents was not as dramatic as it was for body image. For dating, there was also little difference for males and females. These findings may reflect a delay in the socialization process that can occur as a result of living with a chronic illness. Therefore, these types of interpersonal situations may not take on heightened relevance for female versus male adolescents at this stage of development. Note that a greater percentage of females than males reported restrictions and physical limitations due to the illness. Perhaps for these chronically ill adolescents, females are more focused than are males on how their illness makes them different than their peers. In the present study, a greater percentage of females (18%) versus males (7%) reported future concerns. This difference may reflect a gender bias for items included in the category. In addition to items of presumably equal relevance (e.g., career, university), other interpersonal items may have been more salient to females (e.g., marriage, having children).

Interestingly, in our study, female adolescents' average ratings on both illness-related and typical of adolescence scales were higher than they were for males. However, females still reported that their stressors were on average, more typical of adolescence than they were illness-related. This finding may reflect a general response style with a tendency for females to provide higher ratings on these self-report scales.

With respect to coping strategies, it was hypothesized that gender differences would be found for the number, and types of coping strategies. Only partial support was provided for our hypothesis that females would employ a greater number of coping strategies than would males. In the present study, females employed more coping strategies than did males in relation to the standard stressor, *Problems with parents*. This diverges from other chronic illness research that has found a similar gender split for medical stressors as well (for a review see Spirito, Stark et

al., 1989). However, in our study when a global coping measure was employed, the total coping score was greater for females than for males. In the present study, the frequency scores across all coping strategies were summed in order to derive a total coping score. In contrast, total situational coping scores were derived by summing up strategies where the coping strategy was reported to be used a lot of the time or almost all of the time. This highlights the difficulty in synthesizing the literature based on divergent methodology and coping constructs.

In partial support of our hypothesis, and consistent with previous research, females employed more social support than did males in dealing with the illness-related stressor, *Problems with parents*, and on the global coping measure. Also in support of our hypothesis, females employed more emotional regulation than did males in dealing with both standard stressors and on the global coping measure. Other researchers have noted these gender differences for illness stressors (Spirito et al., 1995) and normative stressors (Patterson & McCubbin, 1987; Spirito et al., 1988). These findings may reflect a gender difference in the socialization process; females may be more strongly encouraged to rely on their relationships with others and to communicate their feelings of distress at stressful times. Interestingly, Spirito and colleagues (1995) only found these gender differences for a self-identified illness problem. However, their study coded coping according to whether or not it occurred, or did not occur, rather than a more extensive frequency scale. Thus, more subtle gender differences in coping frequency may have been missed.

Contrary to our hypothesis, and previous research (Bull & Drotar, 1991), females used more problem solving than did males in coping with a stressor delineated as strongly typical of adolescence. No other significant gender differences were found for problem solving. However, even previous research has not consistently supported gender differences in problem solving or emotional regulation (Donaldson et al., 2000; Ptacek et al., 1992). Consistent with previous research (Kurdek, 1987; Patterson & McCubbin, 1987), scores on the global coping measure showed that females invested in close friends more than did males, whereas males used humour more than females.

Approach coping was used more often than was avoidant coping for females for all stressor types. In contrast, for the self-generated stressors, males did not differ in their use of approach or

avoidant coping. Similar gender differences were also found for the active and avoidance scales on the global coping measure. In contrast, female diabetic adolescents used more avoidance coping than did males in some situations (Reid et al., 1995). In a study of healthy adolescents, neither males nor females differed in their use of approach and avoidance coping in response to three stressors (Griffith, Dubow, & Ippolito, 2000).

It was hypothesized that the number of stressors reported by adolescents would increase with age. Consistent with previous research with a diabetic sample (Kager & Holden, 1992) and a healthy sample (Schonert-Reichl & Muller, 1996), the present study supported this hypothesis. However, a different group of researchers found that for adolescents with cystic fibrosis, this was not the case (DiGirolamo et al., 1997). With respect to this hypothesis, Kager and Holden's (1992) results must be interpreted with caution as their participants included both children and adolescents (7 to 15 years). An increase in stressors later in adolescent development is consistent with the greater number of roles, responsibilities and future concerns within and outside their family environment (Chassin et al., 1995; Erikson, 1964).

It is possible that differences between studies may reflect variation in methodology. For example, age differences may be more apparent when adolescents generate their own stressors without domain prompts because of a greater ability to identify the different facets of their life that contribute to their subjective feelings of stress. However, it is also equally possible that the lower number of stressors reported by younger adolescents involves an unwillingness to spend the extra time required to list greater numbers of stressors, or a reluctance to acknowledge many of their stressors.

Our study also found the same relative ranking of the top three stressors (school, relationship with adolescents, relationship with parents) across younger and older chronically ill adolescents. Studies that have included healthy adolescents have not consistently found age differences in the most frequently reported stressors. For example, earlier research found no age differences across adolescents for the most commonly reported stressors (Stark et al., 1989). In contrast, older adolescents reported more stressors related to parents and less sibling and friend stressors than did younger adolescents (Timko et al., 1993). Methodological differences in the attainment of

stressor ratings (i.e., self-generated versus standardized stressor list) may account for discrepancies in gender and developmental findings across studies.

With respect to illness stressors, Spirito and colleagues (Spirito, Stark et al., 1989; Spirito et al., 1994) found that children were focused on pain whereas adolescents were more focused on disease-related problems. Their study did not include finer analyses within the adolescent period. In the current study, a greater percentage of younger adolescents reported restrictions due to illness than did older adolescents. Because younger adolescents tend to be preoccupied with normalcy and their physical appearance, it is not surprising that they are more likely to identify illness restrictions as a stressor compared to older adolescents. However, it was still a relatively small percentage of adolescents in both age groups who identified this stressor, relative to the entire sample.

Other discrepancies between younger and older adolescents' identification of stressors were also found. Relationship with siblings was identified as a stressor by younger adolescents more frequently than by older adolescents. In contrast, money/ finances, boyfriend/girlfriend/dating, relationship with other family members, and future concerns were each identified by greater percentages of older adolescents than younger adolescents. A possible explanation for this may be that younger adolescents may have more frequent interactions with siblings, whereas older adolescents may spend more time away from home. In the present study, the money/finances category included employment; a greater percentage of older adolescents may have reported this stressor because they are more likely to hold jobs or be searching for work. Consistent with developmental theory, intimate relationships and future concerns are believed to take on more significance in later adolescence (Chassin et al., 1995).

Younger adolescents rated their stressors as more illness-related relative to older adolescents, whereas the reverse pattern was true for the typical of adolescence ratings. This may reflect a greater desire for younger adolescents to attribute their problems, in part, to factors beyond their control. However, it is important to recall that for both age groups, participants reported on average, their stressors as more typical of adolescence than illness-related. For the self-generated stressors, the perceived impact of a stressor increased with age. Other research has shown that early adolescents did not evaluate events based on impact (Compas et al., 1987).

Perhaps, the lower impact ratings found for younger adolescents reflects a reduced level of salience for this appraisal variable.

With respect to coping strategies, it was hypothesized that age differences would be found for the number, and types of coping strategies. Contrary to our hypothesis, the total number of coping strategies was not related to age for the standard stressor *Problems with parents*, or for either of the self-generated stressors. Interestingly, the number of coping strategies was negatively related to age for *Medications/treatments*; a similar relation was found in relation to medical stressors for a sample of chronically ill children and adolescents (Spirito et al., 1994). It may be that older adolescents are better able to recognize the futility of certain coping strategies for this illness-related stressor, either as a result of more advanced cognitive skills or greater experience living with their illness. Consequently, they may be more selective in the strategies they practice in relation to this stressor. However, consistent with research conducted with healthy adolescents (Compas et al., 1992; Donaldson et al., 2000), age was associated with an increase in the total coping score on the global coping measure. Taken together, these findings indicate that inconsistencies in age effects may be related to differences in the measurement of the coping construct (i.e., global versus situational coping) or for the situation in which coping is evaluated.

It was further hypothesized that the use of emotional regulation and cognitive restructuring would increase with age. Contrary to our hypothesis, no relation was found between age and either of these coping strategies for the self-generated stressors or for *Problems with parents*. For *Medications/treatments*, age was associated with a decrease in self-calming (a subtype of emotional regulation). Perhaps self-calming is a strategy that is practiced in relation to stressors that are relatively uncontrollable, but of strong impact for the adolescent. In fact, for *Medications/treatments*, impact was unrelated to adolescent age, and was less than the impact of *Problems with parents*. In contrast, previous research found age was associated with an increase in emotion-focused coping (Band, 1990; Band & Weisz, 1990; Bull & Drotar, 1991; Hanson et al., 1989), but these studies have often included children in their sample. Recall that in our study, emotional regulation was split into three items that appeared to represent three unique coping strategies. It is interesting that only self-calming had a relation with age. Note that on the

global coping measure, ventilating feelings and relaxing were associated with an increase in age. A similar increase in ventilating feelings was found for youth with Diabetes (Hanson et al., 1989).

However, in other research, relaxation increased with age, whereas ventilating feelings showed the opposite relation to age (Grey et al., 1991). The latter study compared children and adolescents; these findings may not be applicable to an age comparison within an adolescent sample. These findings highlight how differences in measurement and samples can affect coping findings. Inconsistent with our hypothesis and previous research (Band, 1990; Spirito et al., 1994; Worchel et al., 1987), cognitive restructuring was not associated with age for any of the stressor types. Consistent with theorized developmental tasks (Baumrind, 1987), investing in close friends and developing self-reliance were associated with an increase in age on the global coping measure.

In the present study, age was also unrelated to the frequency of approach or avoidant coping for illness-related or standard stressors. In fact, approach coping increased with age for the typical stressor only. In contrast, both active and avoidance coping were found to increase with age on the global coping measure. In a study of children and adolescents with sickle cell disease, age was not significantly correlated with active or avoidant coping (Kliewer & Lewis, 1995). In contrast, in a study of children and adolescents with diabetes, children used more approach coping than did adolescents (Reid et al., 1995). Some studies of healthy adolescents have also shown that approach coping increases with age (Griffith et al., 2000), whereas other research has found the opposite (Band, 1990).

In addition to the developmental differences discussed above, several of the other coping hypotheses in this study were repeated using the two-factors of approach versus avoidant coping. As stated previously, it may be necessary to study the various subtypes of coping in order to determine the developmental sequence in the acquisition of these skills and the outcome of their use. For example, a more general category may not discriminate between developmental differences in approach or avoidance coping. Likely, there are aspects of both active and avoidant coping that require the advanced cognitive abilities of older adolescents. It is notable that in this study, internal consistencies for avoidance coping were poorer for the self-generated

and standardized illness stressors compared to the other stressor types. Therefore, more heterogeneity is present in how chronically ill adolescents perceive these strategies for illness-related stressors compared to typical of adolescence stressors. It may be that these adolescents are reporting very few strategies from the scale. This suggests that these factors may not provide a good fit to the data for adolescents with a chronic illness.

One group of diabetes researchers (Reid et al., 1995) found that approach versus avoidant approach is a robust classification system that holds across medical and social situations for children and adolescents. However, other researchers have found that this two-factor model did not provide a good fit for the data in healthy children (Ayers, Sandler, West, & Roosa, 1996) or in children and adolescents experiencing recurrent pain (Walker, Smith, Garber, & Van Slyke, 1997). Ayers and colleagues (1996) found that the four factors of active coping, social support, distraction, and avoidance coping were necessary to fit the data. Note that distraction was not considered a subtype of avoidance in either of the above-described studies. Medically, distraction is often taught as a strategy to deal with medical procedures. Clearly it cannot be considered avoidant in situations where individuals are specifically instructed in its use. Taken together, these findings suggest that two-factor models may not adequately reflect the factor structure of coping in young people (Compas et al., 2001).

Relation Between Health-Related Quality of Life and Stress and Coping

As stated previously, a secondary objective was to explore health-related QoL (as an indicator of illness burden) and its relation to stressors and coping strategies. First, health perception did not vary across clinics, suggesting that illness burden did not systematically differ across the illnesses included in this study. Earlier research also found that the relative impact of stressors and psychosocial adjustment could not be predicted on the basis of disease variables (DiGirolamo et al., 1997; Key et al., 2001; Zeltzer et al., 1980).

In the current study, there was no difference between the proportion of adolescents in each clinic who reported at least one of the following: health concerns; restrictions due to illness; or clinic/hospital visits and medications/treatment. Also, adolescents from the majority of clinics reported on average, their stressors to be significantly more typical of adolescence than illness-related. Both of the above-described findings support the current application of a noncategorical

approach to investigating stress and coping in adolescents with a chronic illness. As stated previously in the objectives, there are more commonalities than differences shared by adolescents coping with different illnesses (Stein & Jessop, 1982), and these differences have not been related to unique patterns of coping and adjustment (Stein & Jessop, 1989).

In the present study, variability in General Health Perception was not associated with age, gender or the number of stressors listed. However, illness ratings averaged across all self-generated stressors were positively associated with poorer General Health Perception. It is not surprising that this relation was found given that both variables can be considered subjective ratings of the relevance their illness has in their life. However, only a modest proportion of the variance (6.5) was accounted for by stressor ratings.

Overall, General Health Perception did not account for the impact of stressors. Although greater impact of *Medications/treatments* was associated with poorer General Health Perception, it accounted for less than three percent of the variance. Neither impact of a highly illness-related stressor nor a highly typical stressor was explained by stressor appraisals of controllability or frequency. In contrast, the impact of *Medications/treatments* was associated with greater perceived control over the outcome of the stressor. Greater impact of *Problems with parents* was only associated with increased frequency of the stressor. However, for both these analyses, stressor appraisal ratings only accounted for a small proportion of the variance. One explanation for the different findings across stressors is that they are due to variation in the samples contributing to each analysis. However, analyses were repeated with the same restricted sample for each stressor and results were highly similar. Additionally, it is possible that the lack of a relation for the self-generated stressors may reflect a power issue. A smaller sample size was available for these analyses, and if the effect size is small, significant findings may not be found. However, additional analyses were run using the full sample available for both the illness stressor and for the typical stressor, and stressor impact continued to lack an association with stressor appraisals variables.

Consistent with the findings for the *medications/treatment* stressor, General Health Perception was associated with stressor impact for the illness stressor. For chronically ill adolescents, perceived general health appears to be modestly associated only with the appraisals

of illness stressors and not normative stressors. Thus appraisals of more normative-based stressors do not appear to be influenced by perceived health status. As converging evidence for this finding, neither General Health Perception, nor average illness ratings were associated with the impact of a strongly salient stressor (the first stressor participants listed; not selected to be strongly delineated as either illness-related or normative). In the chronic illness literature, difficulty of a problem (DiGirolamo et al., 1997) and subjective ratings of disease severity (Key et al., 2001) have been related to poorer adjustment. It is possible that the association between General Health Perception and the impact of illness stressors is a reflection of adjustment in this population.

When approach and avoidance coping were evaluated, the association between General Health Perception and stressors varied considerably across self-generated and standard stressors. However, greater stressor impact was associated with increases in both approach and avoidance coping in relation to the illness-related stressor and *Medications/treatments*. Thus, adolescents exhibit greater coping efforts (whether helpful or unhelpful) if a stressor is perceived to be having a major effect on their life. Perceptions of increased control over the outcome were associated with increased approach coping for both self-generated stressors and standard stressors. The finding that perceived controllability is related to approach coping is consistent with previous research that has evaluated coping via the problem focused and emotion focused dimensions for children, adolescents, or young adults (Compas et al., 1991; Compas, Forsythe et al., 1988; Compas, Malcarne et al., 1988; Reese et al., 1997; Roberts, 1995).

Other researchers have hypothesized that control over the cause of events may be important for stress and coping (Compas et al., 1991; Ebata & Moos, 1991). However, this control variable was unrelated to either approach or avoidance coping in the current study.

A number of findings were inconsistent across stressor types. For example, better General Health Perception was modestly associated with both decreased avoidant coping in relation to a typical stressor and with increased approach coping in relation to *Problems with parents*. These findings provide some initial support for our previous suggestion that poorer perceived General Health may be a reflection of adjustment problems; such difficulties have been linked to avoidant coping in the literature (Ebata & Moos, 1991; Grey et al., 1991; Lewis & Kliever, 1996).

Our findings also suggest that, for some stressors, avoidance coping may be related to the frequency of the stressor. Also, the total number of stressors reported by adolescents may be related to greater coping efforts. The lack of consistency of these finding across stressor types suggests that there are other factors that may mediate these associations.

Once again, it is important to note that the association between coping and the standard stressors was based on a different sample than the one that was used to explore the association between coping and the self-generated stressors. Interestingly, some variables only became significant when the analyses were repeated using the same restricted sample for each stressor. However, for the latter analyses, the generalizability of the results is reduced because close to half of the participants in the study would be excluded.

Active and avoidance coping in reference to a global coping measure yielded different results. Although age and gender explained some of the initial variance in coping, they did not make unique contributions to our understanding of coping once other variables were also considered. Other research investigating chronically ill adolescents demonstrated a positive relation between age and avoidance coping on a global coping measure (Hanson et al., 1989; Phipps et al., 1995), although other research found no such relation (Kliewer & Sandler, 1992).

Only Better General Health Perception was associated with increased active coping. The fact that this modest relation was found for a global measure of coping provides some limited support for its relation to adjustment. In contrast, only the total number of stressors reported was modestly related to avoidant coping.

Once again, it must be stated that lower internal consistencies found for coping with illness-related stressors and *Medications/Treatments* suggests that the approach versus avoidance model of coping may not be appropriate for these chronically ill adolescents. As described previously, researchers have started to suggest that two factor models of coping (e.g., emotion-focused vs. problem-focused; approach vs. avoidant) do not provide an accurate representation of the structure of coping in adolescence (for a review see Compas et al., 2001). Therefore, the inconsistencies described above may be related to this limitation. In summary, although many of the above findings suggest interesting interpretations, it is important to consider that any

conclusions that are drawn from these findings consider the exploratory nature of these analyses and the limited contribution of the factors explored.

Limitations of the Present Study

The current study tackled several of the methodological limitations found in previous research by including adolescents with a variety of chronic illnesses. The relation between disease burden and the types of chronic illness, as well as other stress and coping variables, was considered. For many analyses, sample size was also very satisfactory, allowing meaningful gender and age comparisons to be made. The noncategorical approach and within-design employed provided a stronger test of the consistency of coping than previously found in the chronic illness literature. A conceptual model of coping guided this study, such that stressor appraisals, including two types of perceived control, and their relation to coping was assessed. The present study included both self-identified stressors as well as stressors standardized for the entire sample. This approach allowed participants to rate the extent to which their stressors were perceived as illness-related and typical of adolescence, on two separate scales.

Coping comparisons were made across illness and typical stressors based on ratings on the above-described scales. Therefore, no a priori assumptions were made regarding the extent to which stressors were related to their illness or more typical of adolescence in general. For the majority of this study, multiple coping strategies were evaluated, rather than reducing coping to a two-factor model that could mask actual differences between stressor types. All of the above represent the strength of the present study and add to the contribution that it makes to the chronic illness literature.

Despite these advances, several limitations exist for the current study. The representativeness of the sample is not ideal, given that the number of participants varied (from 2 to 76) across clinics. However, the participation rates are satisfactory, ranging from 42% to 88% of potential participants. Further, the sample sizes of many of the clinics in this study closely follow the prevalence rates of diseases described in studies of children and adolescents (Gortmaker et al., 1990; Kliwer, 1997). An exception is that the percentage of adolescents with diabetes in the present study is greater than studies of prevalence rates suggest. However, the participation rate from the Diabetes clinic (54%) matches the average participation rate across

clinics. In this study, the larger percentage of participants with diabetes is a reflection of the overall number of individuals seen in this clinic. On a practical level, it was necessary to approach all available potential participants in order to achieve the large sample size found in this study. The discrepancy in the number of participants recruited from the various clinics prohibits comparisons across diseases. However, from a noncategorical perspective, and given that subjective appraisals are key to this study, this is not a significant study limitation. Different recruitment rates may also reflect variation in how the clinics are organized in terms of providing lists of potential participants. Adolescents from clinics that are actively involved in research may choose to decline further participation in studies, or instead, they may be more receptive to participation. Also, adolescents who had recently experienced an exacerbation of their chronic illness may not have wanted to be reminded of their illness experience; this is likely related to their need to focus on the normative experience of adolescence.

This study did not include a control group, consisting of healthy adolescents. This may be viewed as a weakness because this study relies on self-reports of non-standardized measures of stressors and the extent to which stressors are typical of adolescence. However, a large body of knowledge already exists on the common stressors in a healthy adolescent population. Further, the typical of adolescence ratings assessed in this study were expected to be subjective, and would not benefit from a control group comparison. Therefore, although there is some value in the addition of a control group, it was deemed to be a somewhat redundant and costly addition beyond the scope of this project.

A cross-sectional approach was taken in this study. As in many studies, the ability to make claims about the direction of the relation between stress and coping variables was limited.

Self-report for all measures (other than demographic information) allowed information to be gathered on important variables, such as cognitive appraisals of stressors. However, this approach also involved retrospective reporting of up to six months. Research has shown that retrospective reporting of coping is influenced by the extent of stressor resolution at the time of reporting and by poor recall within days of stressor occurrence (see Compas et al., 2001). However, pilot research was conducted and test-retest reliability was found to be satisfactory for many of the coping strategies. Moreover, a process-based model of coping is unlikely to result in

high test-retest reliability. Also, self-report may have resulted in a tendency to underreport unsuccessful coping strategies or those considered low in social desirability (Compas et al., 2001). Although difficult to directly assess, a review of the coping strategies employed in this study suggests that adolescents were willing to report undesirable strategies in relation to specific stressors. For example, over half of participants reported that they employed blaming others (60%) or expressing anger (52%) as coping strategies at least some of the time.

Although the inclusion of self-identified stressors includes several advantages, the lack of consistent stressor specificity is a disadvantage of this approach. Therefore, different participants could be describing the same stressful event as several different stressors, or one more general stressor. However, it is equally possible that different individuals given checklists of stressors may focus on different components of the stressful event. Also, not all participants generated stressors delineated as illness-related or typical of adolescence. This finding may be related to the self-generated approach to stressor identification.

The Kidcope was used in this study because of its brevity and use in previous chronic illness studies. However, single-item scales do not allow for the assessment of content validity and internal consistency (Compas et al., 2001; Spirito, 1996). In addition, several items on the Kidcope appear to combine multiple strategies into a single item (e.g., social withdrawal; emotional regulation)(Compas et al., 2001). Emotional regulation was split into three unique coping strategies. Splitting the original coping strategies makes it difficult to compare results across studies.

Limitations of the A-COPE have been reviewed by Compas and colleagues (2001). In summary, the goals of specific behavioural items may vary for a specific item. Similarly, although the goal of coping is considered important, it may not be reported if the behavioural strategy is too specific. Most importantly, it is unknown whether or not individuals of any age are able to consider their responses across varied situations in order to develop a general coping profile.

General Health Perception was employed in this study as a measure of disease burden in the context of a noncategorical approach to chronic illness. The intention of employing this general scale was to find a way of evaluating the relation between the level of disease burden and its role

in the stressors identified and the coping strategies used. There were, however, some limitations. Scales that assessed emotional functioning were not considered so that disease burden would be less likely to be confounded with stressor appraisals and coping variables. However, it is possible that ratings on the General Health Perception scale are also influenced by emotional functioning. Further, items included in this measure may not be the most appropriate items for assessing this construct in an adolescent population. It should be noted that a newer measure, more appropriate for an adolescent population has been developed (Waters, Salmon, Wake, Wright, & Hesketh, 2001).

Directions for Future Research

Although the relative representation of the various chronic illnesses was satisfactory in the current study, the actual number of participants from some of the less populated clinics was very small (e.g., $n=2$ for oncology; $n=4$ for cardiology; $n=6$ neuromuscular; $n=6$ for cystic fibrosis, $n=7$ for gastroenterology, $n=8$ for rheumatology). Therefore, future research should consider a multi-site approach in order to increase the numbers of participants representing some of the less common chronic illnesses. This would enable some comparisons across disease groups.

As stated previously, the direction of effects is ambiguous in a cross-sectional research design. A prospective design is needed to untangle the direction of effects of stress and coping variables. It would be interesting to evaluate the trajectories in coping strategy use over the development of the chronic illness.

In order to improve upon the validity of the information obtained, future research should consider additional sources of informants, such as parents. Although the information obtained may not be consistent, this approach would provide further information on perceived stress and coping as observed by others. In particular, this information may be most useful in tracking more concrete, external stressors (e.g., failed a math test) and behavioural coping strategies (e.g., cried) as opposed to more internal stressors (e.g., feel unattractive) and cognitive coping strategies (e.g., tell myself appearance is less important than personality). Also, future research could reduce the period for which stressors are rated from six months to one month in order to improve recall for appraisals and coping strategies and to reduce the influence of stressor resolution on reporting of coping.

Many stressors are complex and change in terms of appraisal and problem specifics over the course of the stressor. Future research could evaluate stress and coping variables over the course of the coping episode (Compas et al., 2001). An interview procedure would result in detailed information related to the appraisal and coping process in relation to various stages of coping with the stressor, the context of the adolescent's life and the relevance of the specific stressor to the individual (Compas et al., 2001). Further, it would provide detailed information on how a given stressor is perceived to be related to the illness, or typical of adolescence (DiGirolamo et al., 1997). This information would be particularly helpful for those stressors where the above-described relationships are not intuitive. However, individuals have been shown to report less coping responses on interview compared to self-report measures or checklists (Compas et al., 2001). Therefore, the latter approaches are also required in order to obtain the most detailed analysis of stress and coping.

Future research could also include a standardized checklist of commonly reported stressors (based on categories derived in the current research) for chronically ill adolescents. The checklist could be administered after other study measures are completed to prevent it from influencing the reporting of self-generated stressors. Results could be compared to self-generated stressors in order to determine if differences exist between these two methods. Further, not all participants in the current study met study criteria for delineating stressors as highly illness-related or highly typical of adolescence. Since this may have been an artifact of study methodology, this checklist could also include scales on which participants rate the extent to which the stressor is considered illness-related and/or typical of adolescence.

Consistency in instruction and prompts provided to participants could improve the specificity of stressors generated. For example, if school is listed as a problem, participants could be requested to elaborate further on the nature of the problem (i.e., academic workload too heavy, poor grades, test anxiety, peer related, teacher related).

Future research should also consider standard illness-related and typical stressors that are more similar in terms of frequency of occurrence and discreteness. Also, in the current study, for the majority of participants, health concerns was found to be a more salient stressor than was

undergoing medications/treatments. Therefore, future research should consider adopting health concerns as the standard, illness-related stressor.

Because other researchers have noted some inconsistency in the factor structure of the A-COPE in the chronically ill population, future research could also include a confirmatory factor analysis of this measure. In order to accomplish this, a sample of 300 to 500 chronically ill adolescents is suggested (Tabachnick & Fidell, 1996). Further, the assessment of test-retest reliability of this measure would indicate whether or not these individuals are responding in the same manner; this would provide some evidence regarding one's ability to consider responses across a variety of situations.

Also, a health-related QoL measure that provides items with more relevance to adolescents is suggested for investigating the relation between perceived illness burden and stress and coping variables. Recently, a self-report version of the Child Health Questionnaire has been validated (Waters et al., 2001). This measure should provide more specific indices of health-related QoL to be considered in relation to stress and coping variables. Adolescent health-related QoL could be assessed from both the adolescent and parent perspective. In addition, an objective measure of illness severity could be included along with a subjective appraisal of disease burden.

In the current study, perceived control over the cause of the event and control over the outcome were not consistently related to coping strategies. Further, some situational differences in coping did arise between illness and typical stressors. Therefore, other appraisals considered as integral to the stress and coping process should be considered. For example, perceived threat, severity, and self-relevance could be evaluated in relation to coping. It may be that some of these appraisals may also contribute to our understanding of coping differences across illness-related and typical stressors.

Many studies have investigated the relation between stress and coping variables and adjustment for chronically ill adolescents. However, studies typically focus on either illness stressors (Band, 1990; Gil et al., 1991; Reid et al., 1994; Worchel et al., 1987) or stressors that are unrelated to the illness (Hanson et al., 1989; Kager & Holden, 1992; Meijer et al., 2002). Future research could explore the relative contribution of coping with common stressors and illness-related stressors to measures of illness adjustment and psychosocial adjustment.

Also, studies of children and adolescents with sickle cell disease have found some consistencies in coping strategies across parent and child (Gil et al., 1991; Kliwer & Lewis, 1995). It would be interesting to explore cross-generational transmission of coping strategies for a heterogeneous sample of chronically ill adolescents.

Finally, since perceived control has been associated with increased active coping, future research could consider a medically based intervention. For example, using a standardized approach, physicians could extend more control to the adolescent for treatment decisions and routine care. Coping strategy use could be evaluated prior to, and after this treatment is introduced. In addition, these results could be compared to other chronically ill adolescents who do not receive this specialized treatment.

Clinical Implications

The current research provided a compendium of illness-related and other types of stressful situations identified as stressful by a heterogeneous mixed sample of chronically ill adolescents. This compendium should provide a springboard for querying chronically ill adolescents about their personal stressors and preferred coping strategies. Clinicians should be able to identify adolescents at risk for adjustment difficulties because they will recognize the types of illness-related and other stressful situations that are frequently appraised as highly demanding.

It is important for both clinicians and parents to recognize that for chronically ill adolescents, many of their stressors are similar to those reported by healthy adolescents, and on average, they rate their stressors as more typical of adolescence than illness-related. These typical stressors are reported more frequently, despite being appraised as more controllable than illness-related stressors. The identification of normative stressors is essential to understanding the total level of stress the ill adolescent faces. It is important to recognize that adolescent developmental tasks are still crucial for these individuals, although challenged at times. Chronically ill adolescents may prefer for others to acknowledge the importance of these normative issues. Also, there is often an interaction between illness-related stressors and more typical stressors, clinical interventions must also consider typical stressors and how illness-related stressors are tied to the general adolescent experience. For example, coping skills groups need to consider a variety of stressful situations. Chronically ill adolescents might also be responsive to a support group that

allows for a discussion about the interaction between these stressors and benefit from the modeling of successful coping by other group members.

Clinicians also need to realize that adolescents do not use unique coping strategies for their chronic illness. Instead, they apply the same strategies that they use in other situations they perceive as stressful. It is the underlying aspects, such as subjective appraisals, that influence the coping strategies employed in given situation. Clinicians need to recognize that the individual style that any adolescent brings to coping is the appropriate focus. It is possible to become too focused on the chronic illness aspect and to not appreciate that their coping style will transcend the chronic illness. Cross-situational consistency has implications for intervention programs aimed at coping. Interventions directed at increasing adaptive coping in relation to illness-related or typical stressors should have positive effects on psychosocial adjustment and health outcome.

Instead, it is important to consider that individual differences exist in stressor appraisals and in choice of coping strategies. Therefore, it is essential to refrain from making assumptions about the individual's stressors and preferred coping strategies without specific information. Querying chronically ill adolescents about how they cope in relation to standard lists of stressors may also not provide an accurate picture of how they cope with stressors of personal salience. Therefore, it is not sufficient to administer a standard battery to assume an individual is stress-free or coping well. Instead, chronically ill adolescents should be asked to describe how they cope in relation to personally salient stressors.

It is also worthwhile to inquire about individual perceptions of stressor controllability because it relates to many coping strategies. For example, reduced controllability over the outcome is associated with greater use of withdrawal, discussing feelings and resignation, whereas greater controllability over the cause and outcome of the event is associated with increased self-criticism. It may be possible to modify certain coping strategies that have proven ineffective by altering the adolescent's sense of control.

Summary

This study was aimed at addressing gaps in the existing literature on stress and coping in adolescents living with a chronic illness. First, this study showed that chronically ill adolescents experience many of the same stressors as healthy adolescents. Also, there is often an interaction

between illness-related stressors and stressors that are more typical of adolescence. With regards to coping, it varies across individuals, but within individuals there appears to be some consistency in coping strategies used across different types of stressors.

Historically, research has looked at disease-specific stressors and coping strategies. This study highlights the importance of individual differences and subjectivity in the stress and coping experience. There is likely more stability of coping within individuals than there is within a specific illness group or for a chronic illness group versus a healthy group. In fact, illness-related factors were only of limited relevance in this study, as indicated by the limited relation between a measure of disease burden and stress and coping variables. This study helps improve our understanding of why some of the findings have differed across previous studies or across illness; subjective appraisals are central and these have often been overlooked.

These findings provide clinicians with a strategy they can use for the identification of stressors which well may differ across individuals. Some stressors may be key within certain illnesses, developmental periods or within one gender. However, it is also essential to focus on the individual's style of coping and the coping strategies they use, since these are likely to show some consistency across stressors.

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Appendices

Appendix A

Studies Assessing Coping Strategies in Adolescents with Chronic Illness

Study	Sample	Measures	Results	Comments
Studies without normative comparison groups				
Band (1990)	64 children treated for diabetes at 3 hospitals, split into 2 groups based on Piagetian task 7-17 years of age Pre-formal operations (PF) group; Mean age = 8.8 years Formal operations (F) group; Mean age = 14.6 years Diagnosed at least one year prior to study See Band & Weitz (1990) for sample and method details	Structured interview of 8 stressors of diabetes, and treatment, coping Rated perceived control, coping style (primary, secondary or relinquished control), perceived coping efficacy Coping classified: instrumental (I), cognitive (C), or emotional (E) Medical adjustment measure	Primary- I strategies preferred overall by both groups (PF)-higher ratio primary I and E strategies (F)-higher ratio of secondary instrumental and cognitive strategies (PF)-combining primary and secondary, greater I strategies vs. greater C strategies for (F) Primary style copers better adjusted (PF) better adjusted than (F) (PF) vs. (F)-no difference on perceived efficacy or perceived control of coping	Authors suggest secondary control coping may emerge later than primary control (PF) may have less developed cognitive abilities (may not recognize ways to reduce stress, unable to communicate strategies), or as mature may recognize unmodifiable aspects of stress High primary-I may be related to Diabetes education, focus on self-care Cross sectional design
Band & Weitz (1990)	See Band (1990) for sample description.	Child measures: structured interview (see Band, 1990) Diabetes knowledge - multiple choice and open-ended questions Socio-Behavioral Adjustment Scale (SBAS), Connors Parent Questionnaire (CPQ)	(F)-more secondary coping vs. (PF) (F)-more primary styles of coping, greater perceived control and coping efficacy associated with better SBAS ratings (F)-lower perceived coping efficacy had more conduct problems on CPQ, and better SBAS scores (PF) - lower perceived control associated with more conduct problems on CPQ	Authors highlight importance of developmental perspective for understanding adaptation to chronic illness -different patterns emerged for formal and pre-formal children
Bull & Drotar (1991)	39 children with cancer Participants recruited from a list of children who previously attended a cancer camp and followed at 1 of 4 centres In remission and off treatment 7-17 years of age (M = 12.4 yrs) (50% recruitment rate)	Children's Stress Inventory (CSI) -5 personal stressful situations (cancer or non-cancer related) and coping responses (coping focus-self, environment, other; coping function -problem solving-PS, emotion management-EM; coping mode-information seeking, support seeking, direct action, inhibition of action, intrapsychic) Cancer stress and coping measure (McCabe & Weisz, 1988)	General life stressors explained 86% perceived distress Modes of coping not consistent across cancer and noncancer; Coping focus - same rate for cancer vs. noncancer, but strategy use unrelated to use in other situation PS and EM used same for noncancer; for cancer, EM used more than PS Adolescents used more EM and less PS vs. children for cancer only Females used more EM and less PS than males for cancer	Limited to specific stage of cancer Retrospective account of coping with cancer Generally reported different strategies to cope with cancer-related vs. general life stressors Intrapsychic coping was used across cancer and noncancer stressors -may learn and practice internal types of coping in response to uncontrollable illness stress)

Study	Sample	Measures	Results	Comments
Gil et al. (1991)	72 child (sickle cell disease-SCD)-parent diads participated Recruited from university sickle cell centre and satellite clinics 47 children (7-12 years of age) 25 adolescents (13-17 years of age)	Coping Strategies Questionnaire (CSQ) child- completed for SCD pain; parent- completed for own pain experienced **New subscales specific to SCD added Structured Pain Interview (parent + adolescents) assesses pain status, activity pattern, health care utilization Missouri Children's Behavior Checklist (MCBC)-parent report Child Assessment Schedule (CAS) child self-report SCL-90-R-adolescents	3 types of coping: coping attempts, negative thinking, passive adherence SCD high on negative thinking and passive adherence less active, more health care services, more distressed during painful episodes # painful episodes unrelated to coping, negative thinking, passive adherence Passive adherence, negative thinking increased with age Pain coping strategies predict adjustment beyond age and pain frequency	Pain status, health care utilization, activity reduction data by parent report- reliability checks for adolescents only Ineffective coping strategies may become fixed during adolescence Parents high on coping attempts and low on passive adherence had more active children and/or children lower on negative thinking; parent passive adherence related to child passive adherence
Gil et al. (1993)	9 month follow-up to Gil et al., 1991 70 child SCD-parent diads (66/70 mothers) 7-18 years (M=11.8 yrs)	(Gil et al., 1991) CSQ Structured Pain Interview	Younger children showed positive correlations between baseline and follow-up on pain coping strategies, but adolescents only significant correlation for coping attempts Coping attempts associated with more activity during painful episodes Baseline passive adherence, negative thinking associated with more health care contacts during follow-up	Coping strategies more stable in younger children vs. adolescents Many outcome measures obtained from parent; pain ratings also from parent
Gladstein & Holden (1996)	37 chronic daily headache (CDH) patients and a parent; included all children diagnosed with CDH over a 2 year period 7-17 years (M=13.0 yrs)	Semistructured interview CBCL Matthews Youth Test for Health Kidcope in relation to a pain episode	No difference between headache type and number of coping responses or other behavioural and psychological functioning Participants with worsening symptoms at time of presentation used fewer coping strategies	Authors stated that presence of worsening of migraine symptoms predicted degree of disability and coping response Retrospective self-report on worsening of symptoms; could be confounded with psychological functioning Sample bias (78% female)

Study	Sample	Measures	Results	Comments
Grey et al. (1991)	103 IDDM patients from 3 treatment centres 8-18 years (M=12.9 yrs) Average duration IDDM=5.3 yrs Sample was also divided into preadolescent (Tanner 1), pubescent (Tanner 2-4) and postpubescent (Tanner 5) by stage of secondary sexual development	Child and Adolescent Profile (CAAP) Self-Perception Profile for Children (SPPC) State-Trait Anxiety Inventory for Children (STAI-C) Children's Depression Inventory (CDI) Hemoglobin A1c A-COPE Self-Care Questionnaire (SCQ) Life Events Checklist (LEC) Parent measure: Coping Health Inventory for Parents (CHIP)	Ventilating feelings used more by preadolescents whereas avoidance and relaxation behaviours used more by postpubescents Avoidance coping and depression associated with poorer adaptation and metabolic control Stressors did not predict adaptation	Authors state that preadolescents and adolescents cope differently with a chronic illness; however, coping assessed only with global coping measure Cross-sectional design and lack of comparison group; adjustment changes with age should be considered tentative
Hanson et al. (1989)	135 insulin dependent diabetes mellitus (IDDM) clinic patients and parents 10.4-20.0 years of age (M=14.5 yrs) Mean age at diagnosis=8.9 yrs Average duration IDDM=66.3 months	A number of health status variables measured, but not presented here A-COPE Family Inventory of Life Events and Change (A-FILE)-McCubbin et al., 1985 Family relations-Family Adaptability and Cohesion Evaluation Scales	Ventilation and avoidance predicted by high life stress, low family cohesion and older age; also predicted by interaction of Family Adaptability X IDDM duration Using interpersonal and personal resources negatively related to IDDM duration	Used global measures for assessment of both stress and coping Based on correlations between specific stressors and ventilation and avoidance coping, authors hypothesize that children with high stress use more ventilation and avoidance coping when stressors perceived as uncontrollable (researcher-rated)
Holden et al. (1994)	70 patients -tertiary care referral clinic for children and adolescents with headache; 40 diagnosed with migraine (M), 15 with migraine and chronic daily headache (MCDH), 13 with chronic daily headache (CDH) 7-19 years of age (M=12)	Child Behavior Checklist (CBCL) Kidcope - Interviewed and asked if used specific strategies from Kidcope (+ 3 coping strategies specific to headache) during headache episodes Functional Disability Rating (for headache pain e.g.) school missed)	Across headache types less likely to report: withdrawal, blaming self, blaming others, direct emotional expression, imagining pain to be different feeling than other coping strategies More impairment for CDH-increased rates of psychiatric diagnoses vs. M Males use more coping strategies	Diagnostic reliability for headache types not assessed CBCL internalizing scale has items related to headache symptoms No difference between groups on CBCL School avoidance may reflect increased withdrawal in CDH
Jacobson et al. (1990)	9-12 years (n=19) 13-16 years (n=42) 1 year diagnosis of IDDM; presenting to Diabetes pediatric unit Followed annually over a 4 year period	Coopersmith Self-Esteem Inventory Behavioural problems and social competence scores for CBCL, YSR Diabetes Adjustment Scale Locus of Control Scale for Children Semi-structured clinical interview to assess ego defence mechanisms and adaptive strengths Diabetes adherence ratings obtained at each medical visit	Initial level of coping (defense level, adaptive strength, locus of control) and initial adjustment predictive of adherence 4 years later Younger age group at initial diagnosis were more adherent at follow-up than older group at follow-up No psychological factors predicted adherence change at 4 years	Authors highlight identification of initial psychosocial characteristics predicted later adherence and may assist in intervention strategies Adherence behaviour rated by health provider; aware of prior medical data Coping follows a trait conceptualization Authors discuss how other variables (e.g. stressful events) may be more likely to predict adherence change

Study	Sample	Measures	Results	Comments
Kager & Holden (1992)	64 patients with IDDM attending summer camp and their mothers 56% response rate 7-15 years of age (M=11.8) 1-13 years since diabetes onset	Life Events Checklist Child Perceived Coping Questionnaire The Mathews Youth Test for Health Self Perception Profile for Children Peer Relations (Asher et al. 1984) Diabetes Adjustment Scale	Negative life events increase with age Negative life events related to poorer psychosocial adjustment to diabetes after controlling for age, gender and illness duration Coping positively related to self-competence and peer relations	Global measure of coping behaviours may not predict disease adjustment Used total coping score, vs. other studies that assessed coping styles (e.g. Delamater et al., 1987) Assessed helpfulness and frequency of coping responses, but not related to specific disease stressors
Keller et al. (1990)	15 adolescents with eight different chronic illnesses 20 parents represented 13/15 adolescents	Jalowiec Coping Scale (1979) parent and child completed in relation to self 40 items-3 factors: confrontive coping, emotive coping, palliative coping	Adolescents used emotive and confrontive coping equally, and palliative coping less Adolescents showed more emotive behaviours than parents	Exploratory study with very small sample size Age range of adolescents not provided Appears coping completed in reference to illness for adolescent, but unclear reference of coping for parents
Kliewer & Lewis (1995)	39 children and adolescents (25 girls, 14 boys) with sickle cell disease and parent 7-16 years of age (M=11.0) Home interview	Parent measures: Parental Socialization of Coping Questionnaire (PSCQ) COPE Family Environment Scales, cohesion subscale (FES) Child measures: The Children's Coping Strategies Checklist (CCSC) Children's Hope Scale	Children's active coping was associated with a cohesive family environment, avoidance coping was predicted by less parental use of restructuring coping and greater parental use of active coping strategies Age was not significantly correlated with active nor avoidant coping	Global measure of coping Small sample with broad age range limited assessment of developmental differences Cross-sectional design
Lewis & Kliewer (1996)	See Kliewer & Lewis (1995) for sample description.	The Children's Hope Scale The Children's Coping Strategies Checklist (CCSC) Children's Depression Inventory (CDI) The Revised Children's Manifest Anxiety Scale (RCMAS) Structured Pain Interview Total health care contact score Activity reduction score	Coping strategies moderated the relationship between hope and adjustment Hope was negatively associated with anxiety when active, support and distraction coping were high Avoidance coping positively related to anxiety No relationship between hope, coping and functional adjustment	Evaluation of disease threat (appraisal) may be effected by hope; consistent with Transactional model of stress and coping Authors indicate that hope or coping may not impact on functional adjustment because they have no control over these factors Relied on parent report for health care utilization

Study	Sample	Measures	Results	Comments
Meijer et al. (2002)	84 chronically ill (CI): asthma, cystic fibrosis, constitutional eczema, juvenile chronic arthritis 13-16 years of age (M=14.5) CI diagnosed minimum of 1 year prior (M= 11.2 yrs) Dutch speaking	Utrecht Coping List for Adolescents (UCL-A) Internal and External Locus of Control Scale (LOC) CBCL Self-Perception Profile for Adolescents (SPPA) Scale of Interpersonal Behavior for Adolescents (SIG-A) Matson Evaluation of Social Skills with youngsters (MESSY) CBCL	Coping styles seeking social support and confrontation were predictors of positive social adjustment whereas depression coping style was a predictor of poor adjustment Avoidance and locus of control not strongly associated with psychosocial adjustment	Authors highlight the relationship between coping and psychosocial adjustment may be bi-directional, but cannot be fully tested within this cross-sectional design Global coping measure used Limited psychometrics on Dutch LOC
Reid et al. (1995)	56 patients with diabetes from diabetes care center 8-18 years of age (M=13) Diagnosed minimum of 1 year prior Average duration of diabetes=5.4 yrs	Parent measures: demographic questionnaire Child measures: modified self-reported coping measure (Causey & Dubow, 1992) Rated 5 coping strategies and coping effectiveness in response to 4 situations: diabetes-related situations (social problem; diet, fingerpricks); and general peer argument Rated controllability of situation GPA, CDI, Teacher-Rated Adjustment (SSRS)	Both approach and avoidant coping highly correlated across situations Approach coping used more than avoidance coping in all situations Avoidance coping used most for general peer argument Approach coping used least for fingerprick Children used more approach coping than adolescents Females used more avoidance coping than males (fingerprick and peer argument) Peer argument rated most controllable Higher control related to greater approach coping (diet and peer argument) Coping effectiveness related to avoidance and approach coping Increased approach, decreased avoidance coping positively related to outcomes	Authors suggest high degree of cross-situational consistency in coping across situations, although some differences in strategies applied to different situation Small sample size with broad age range limited assessment of developmental differences Only standard stressors were used Coping effectiveness was not measured specifically for each coping strategy Despite association between controllability and approach coping for diet and peer argument, not controlled for in analyses
Spirito et al., (1995)	177 chronically ill (CI): sickle cell disease, diabetes, cancer, migraine, congenital orthopedic problems, cystic fibrosis, ulcerative colitis and others 7-18 years of age CI diagnosed minimum of 1 year prior Assessed at outpatient clinic visits or inpatient hospitalization	Kidcope completed for (1) illness-related stressor (CI); (2) stressor unrelated to illness (both chosen by patient) Rated anxiety, sadness for stressor Illness problems described: disease-related, disease -related pain, medical procedure-related pain Common problems: family, parents, friends, school, boyfriend/girlfriend	CI problem: adolescents chose disease-related, children chose pain Gender affected coping with CI problem Adolescents less blaming others, wishful thinking, more resignation than children Anxious reported more cognitive restructuring than non-anxious Adolescents used blaming others more than children for CI problem, reverse for common problem Equal use of some coping strategies across illness-related stressors	Smaller sample size for common problem analyses (n=76) Coping differs within individuals across situations, but also some stability: (situational) age and gender effects different for common and CI problem; (stable) many strategies used for pain and disease-related CI problems, mood state even smaller effect on coping for CI problems; (mixed) moderately consistent coping across common and CI problems.

Study	Sample	Measures	Results	Comments
Worchel et al. (1987)	52 pediatric oncology patients undergoing treatment Aged 6-17 years Split sample 6-12 years, 13-17 years	Control Questionnaire - perceptions and strategies for gaining control; behavioural (e.g., deep breathing during bone marrow aspiration), cognitive (e.g., how often think, talk about illness), informational (e.g., amount information desired), decisional techniques (e.g., for treatment, school absence, meals) to decrease cancer-related anxiety) CDI, Somatic Complaints Scale, CBCL, Nurses Rating Form	Behavioral control positively associated with emotional maladjustment; quality of behavioral control strategies more important than quantity Cognitive and decisional control negatively related to maladjustment Adolescent group used more cognitive control than children Adolescent group showed more decisional control for nonmedical events	Investigated illness-related stressors and relation to different control types (limited coping assessment)- can be conceptualized as different preferred coping strategies Each of the types of control included examples of related behaviours Behavioural control assesses # contradictory actions; high # may indicate ineffective coping solution Not evaluation of perceived controllability

Study	Sample	Measures	Results	Comments
Studies with normative comparison groups				
Canning et al. (1992)	31 cancer patients 12-18 years of age (M= 14.7 yrs) Diagnosed at least 2 months prior and received treatment within previous 2 years 44% off treatment at time of study 83 students in comparison group (M=15.8 yrs)	Children's Depression Inventory (CDI) Classification of repressors: repressors-below mean on Spielberger Trait Anxiety Inventory, above median on Children's Social Desirability Inventory (CSD); other categories include high anxious, impression manager, low anxious	CDI scores higher in comparison group Higher percentage of repressors in cancer group Controlling for sex and age, repressor status added to variance in CDI scores beyond that explained by illness status (repressor status associated with lower CDI scores across groups)	Based on trait approach to coping; does not assess situational stressors Limitations - mean age comparison group significantly higher than cancer group- repressors may be inadvertently misrepresenting level of distress Canning states repressive style of coping may be protective against psychological distress in short term Unclear how repressor style denial, minimizing affects long term
Cappelli et al. (1989)	31 cystic fibrosis patients attending either CF clinic or CF summer camp; matched by age and gender to: 31 diabetes clinic patients 31 controls attending children's hospital for minor injury or acute upper respiratory illness	A-Cope The Revised Kaplan Scale Social Self-Efficacy Scale The Mastery Scale The Centre for Epidemiologic Studies Depression Scale (CES-D) Assessed sources of stress by semi-structured interview	No difference between control group and either chronic illness group on any of standardized measures, including coping strategies Interview found adolescent's perception of own physical health and family reactions to adolescent's illness were important stressors	Coping assessed with global coping measure (A-Copes); does not assess coping strategies in relation to specific events Unknown if ill adolescents considered illness-related stressors when completing A-Copes

Study	Sample	Measures	Results	Comments
Donaldson et al. (1997)	165 pediatric patients 801 students-control group 9-17 years of age Mean=12.3 years	Kidcope Pediatric group completed for medical treatment-related stressor (eg. pain, hospitalization) Control group- 3 groups based on 3 different stressor types; each group filled out Kidcope for one specified stressor (interpersonal, family or school)	Pediatric group -more social support, resignation and less blaming others compared to control group Pediatric group-less self-criticism vs. controls reporting on school or interpersonal problem Those reporting a pediatric or school problem used more cognitive restructuring vs. children reporting a family stressor Control group - patterns of coping across different stressors similar	Coping styles cannot be compared for similar stressors for pediatric versus control group.
Ebata & Moos (1991)	Participants 12-18 years of age 45 adolescents with Rheumatic disease 58 Conduct disorder youth 49 depressed youth Control group - 38 healthy youth	Coping Responses Inventory-Youth Form (CRI-Y) -in reference to most important problem in previous year Severity of stressor rated by researcher Challenge of stressor rated by participant Psychological well-being and distress, and behavior problems assessed by subscales from the following: Weinberger Adjustment Inventory Harter's Self-Perception Profile for Adolescents Spielberger State Anxiety Inventory Deviant Behavior Scale Youth Health and Daily Living Form	Groups do not differ on use of approach coping There were no differences between control group and rheumatic disease group on coping strategies Overall, those who use more approach and less avoidance coping are better adjusted Stressor severity correlated with seeking guidance/support and emotional discharge coping Stressor challenge related to use of logical analysis, positive reappraisal, problem solving and seeking alternative awards Rheumatic disease group had higher well-being score and few behavior problems compared to controls	Authors highlight how approach coping strategies are important for psychosocial adjustment; avoidant coping may have more difficulty adjusting to later stressors Authors note the overlap between some coping dimensions as well as the unique contribution of others Stressor severity is rated by researcher and does not represent participant's own perception Focal stressors varied Controlled for challenge appraisal and stressor severity when looking at group differences in coping; however authors state that other appraisals, such as controllability, control over cause may need to be controlled for
Mastroiannopoulou (1998)	3 groups (n=15, 6-15 years of age for each group) Gp1-had liver transplant at least 6 months prior Gp2- ongoing chronic liver disease Gp3-healthy control group; age and sex matched Mean age: Gp1 (10.1); Gp2 (10.9); Gp3 (10.3)	Kidcope completed for (1) illness-related stressor (Gps1 & 2 only); (2) stressor unrelated to illness (both chosen by patient) -used a yes/no version Understanding of illness questions The Children's Health Locus of Control Scale Self-perception of current health: asked to describe how to tell if child in story was healthy or unhealthy, and to rate self along same chosen dimensions	For common problem, no differences between groups in number of coping strategies used No difference between Gp1 and Gp2 on strategies used or perceived efficacy No differences between strategies used for coping with common and illness-related problems, for Gp1 Gp2 used different coping strategies for different situations, except for distraction and wishful thinking Gp1 rated themselves as more healthy than Gp2 Perceived control over health was lowest for Gp2, higher for Gp1, and highest for the control group	Authors state that similarities between all 3 groups on coping suggests that the ill children are well adjusted Variability in time since transplant Gp1 and Gp2 differ on procedures experienced and disease severity Interviewers could not be blinded to group membership

Study	Sample	Measures	Results	Comments
Olson et al. (1993)	175 chronically ill children (CI) at juvenile arthritis (JRA), asthma or diabetes summer camps 8-18 years of age Control group - 145 healthy school children	Cognitive Questionnaire (Brown et al., 1986)- responses to 4 hypothetical stressors: dental injection, class talk, personal stressful event, venipuncture coded as coping or catastrophizing Revised Children's Manifest Anxiety Scale (RCMAS)- trait anxiety Some analyses split-children (8-12yrs) vs. adolescents (13-18 yrs)	Coping equal in CI and controls (>60%) and varied by age No difference in anxiety rates (decreased with age) Coping rates varied across stressful events (highest for personal event and venipuncture) Adolescents-highest coping rates for personal events; CI gave more complex coping responses than controls CI children had higher coping rates vs. healthy children for venipuncture, but not dental injection	Low power reduced ability to assess disease type and severity Sampling bias -only severely ill CI Did not assess illness-specific stressors, except venipuncture CI-learn cognitive strategies for familiar painful events, but may not generalize to other painful procedures Lack of relationship between coping and perceived controllability of illness symptoms because diabetes, asthma more immediately controlled and lower coping rates (Olson), but perceived controllability not assessed
Phipps et al. (1995)	66 child and adolescent oncology patients 6-8, 9-11 and 12-15 years of age 66 parent-child dyads Prior exposure to at least two invasive procedures (bone marrow aspiration or lumbar puncture), no more than one year post treatment Control- 414 children in grades 1-7	Children's Behavioral Style Scale - child report and parent report versions (CBSS/CBSS-P) CBSS lists 4 stress-invoking scenarios followed by 6 blunting (B) & monitoring (M) responses	Oncology group endorsed more (B) items than controls (B) scores decreased with increasing age, but (B) increased with time since diagnosis (M)-scores not correlated with age Controls-small negative correlation between (B) and (M) scores Oncology group-positive correlation between (M) and (B) scores	CBSS measures limited situations Authors state change in (B) since diagnosis in part due to adjustment to cancer experience; (M) may be more stable Correlation between (M) and (B) in oncology group may reflect general coping effort, skewed toward avoidance
Phipps et al. (2001)	130 child and adolescent oncology patients; No more than 4 weeks post diagnosis Cancer group assessed at diagnosis, 6 months and 1 year Comparison group- 121 outpatients with diabetes, cystic fibrosis, juvenile rheumatoid disorders (CI) Control- 368 healthy school children 7-18 years of age	Children's Social Desirability Questionnaire (CSD) State-Trait Anxiety Inventory for Children (STAIC) Oncology group only tested at diagnosis, 6 months, 1 year post diagnosis	At diagnosis oncology and CI (time varied since diagnosis) groups had higher incidence of repressive adaptive style than healthy children, but did not differ from each other Oncology group -repressive adaptive style remained stable over time Oncology and CI groups significantly less anxiety than control but did not differ from each other	Shift towards more repressive adaptation appears to occur reactively and be maintained over time CI and healthy school children groups tested one time only Procedural differences for control group (group administration) Sampling bias- CI group had longstanding disorders (Mean = 5.72 years)

Study	Sample	Measures	Results	Comments
Spirito et al. (1988)	38 patients, 10-18 years of age Abdominal pain, Inflammatory bowel disease, headaches, cancer, encopresis, hemophilia, pain, and others referred for psychological evaluation emotional difficulties 34 children attending diabetes camp 12-18 years of age Control group - 68 school children Mean = 14 years of age	Kidcope completed for: pediatric sample-specific illness-related stressor; diabetes sample-disease-related problem in previous month; Control group-school problem Psychometric study of Kidcope	Pediatric referred group used more distraction, social withdrawal than diabetic or controls Controls used more self-criticism than diabetic Pediatric referred vs. Diabetic group-pediatric group used more distraction and social withdrawal	Different time periods were used to assess stressor/coping in each sample Distraction used more than control group only for pediatric referred group-important to get normative data on pediatric coping with stressors from nonreferred group (Spirito, 1988) Disengagement coping can be maladaptive (referred patients used more social withdrawal and distraction)
Spirito et al. (1994)	54 chronically ill (CI): congenital orthopedic conditions, asthma, cystic fibrosis, kidney disorders, ulcerative colitis, sickle-cell anemia, hemophilia and others Diagnosed minimum 1 year prior Inpatients 1-24 days at assessment 71 acutely ill (AI): bone fractures, severe sprains, mild head trauma, appendicitis, severe abdominal pain and others 7-17 years of age >50% assessed within 2 days	Described hospital-related problem and rated if problem caused anxiety, sadness, or anger Kidcope- rated frequency and efficacy of endorsed coping strategies Some analyses split: Children ≤ 12 years, Adolescents ≥ 13 years	Length of hospital stay, problem, & distress level unrelated to coping No difference for AI vs. CI on problem (illness, hospital, pain) Adolescents chose diagnosis problem most vs. children chose pain most Children used more strategies, but adolescents used more cognitive ones Strategies same across problem types CI used avoidant+ negative coping < AI (AI more anxious than CI) Increased distress related to specific coping strategies	Time since diagnosis varied, wide age range, different formats for child and adolescent Kidcope 50% CI chose hospitalization stressor vs. more serious illness or pain-related concerns CI did not use more active coping strategies than AI, but CI used less avoidant and negative strategies Differences in coping strategies may reflect amount of distress related to problem and stressor exposure

Appendix B
Cover Letter to Participating Adolescents

INFORMATION LETTER
ADOLESCENT STRESS AND COPING STUDY

Date: _____

Dear (Adolescent's first name):

A research study is being undertaken to explore the stressors that exist in the lives of adolescents with chronic illness and how they cope with them. The study is being conducted under the direction of Dr. Ian Manion, a psychologist at the Children's Hospital of Eastern Ontario, and Amanda Pontefract, a senior doctoral student in Clinical Psychology at the University of Ottawa. We are approaching all adolescents and their families at the (name of clinic) to participate. Your treatment team is aware of this study and has provided us with the names of their adolescent patients.

A chronic illness during adolescence can affect a teenager's day-to-day life and may cause problems. However, we know that not everyone experiences the same types of problems or copes in the same way. To help us in our work with adolescents, we need to know more about the different types of problems adolescents report and the different ways they cope with them. That is why we are writing to you and your parent(s) to participate in this research. Even if you are doing well right now, the information you will share with us is still very important.

If you are interested in participating in this research, a member of our team will meet with you at the Children's Hospital of Eastern Ontario at your convenience, or if you prefer, we can visit you in your home instead. Although the majority of the study involves your participation, we also request the involvement of a parent in the study. During your visit, you will be asked to complete a questionnaire about how your illness affects different areas of your life. You will also be asked to make some ratings concerning the stressful situations in your life and how you cope with them. Although we will meet with each of you separately, you and your parent may wish to meet with us at the same visit. Some of the questionnaires you and your parent will be asked to complete will be the same, but you will also each be asked to complete different ones. Therefore, the time it will take to complete the meeting may not be the same for both of you. It should take you up to 2 hours to complete your meeting, although your parent may require less time to

complete it. If you both prefer to attend at the same time, we suggest your parent brings along some reading material to keep them busy while they wait for you to finish.

You will be given \$10 if there have been expenses through your participation in this project.

If you and your parent decide to participate, you will be free to drop out of the study at any time. Your participation is completely voluntary and will in no way affect any services that you receive or could receive from the Children's Hospital of Eastern Ontario. There are no known risks or benefits from your participation. However, we hope that your participation will improve our understanding of how effectively adolescents with chronic illnesses deal with different situations they encounter. All of the information we receive from you is completely confidential and will not be shared with the members of your treatment team unless you agree. A summary of the results of this research will be available to you at your request. If you have any concerns or questions, they can be directed to Amanda Pontefract at

If you and your parent are interested in participating and would like to be contacted by a member of our team, please complete the attached form and return it in the envelope provided. If not, please indicate so, and return your reply in the envelope provided. If we have not heard from you in 2 weeks, we will be contacting you by telephone regarding your decision.

Thank you.

Sincerely,

Ian Manion, Ph.D.
Psychologist

Amanda Pontefract, M.Sc.

Attachs.

Cover Letter to Participating Parents

INFORMATION LETTER

ADOLESCENT STRESS AND COPING STUDY

Date: _____

Dear Mr. and Mrs. (parents' surname):

A research study is being undertaken to explore the stressors that exist in the lives of adolescents with chronic illness and how they cope with them. The study is being conducted under the direction of Dr. Ian Manion, a psychologist at the Children's Hospital of Eastern Ontario, and Amanda Pontefract, a senior doctoral student in Clinical Psychology at the University of Ottawa.

We are approaching all adolescents and their families at the (name of clinic) to participate. The (name of clinic) is aware of this study and has provided us with the names of their adolescent patients.

A chronic illness during adolescence can affect a teenager's day-to-day life and may cause problems. However, we know that not everyone experiences the same types of problems or copes in the same way. To help us in our work with adolescents, we need to know more about the different types of problems adolescents report and the different ways they cope with them. That is why we are writing to you and (adolescent's name) to participate in this research. Even if (adolescent's name) is doing well right now, the information you will share with us is still very important.

If you and (adolescent's name) are interested in participating in this research, a member of our team will meet with you at the Children's Hospital of Eastern Ontario at your convenience, or if you prefer, we can visit you in your home instead. Although the majority of the study involves (name of adolescent)'s participation, we also request your involvement in the study. During your visit, you will be asked to complete a series of brief questionnaires that ask about background information and (name of adolescent)'s medical condition. You will also be asked to make some ratings concerning stressful situations in (name of adolescent)'s life and how (name of adolescent) copes with them. Although we will meet with each of you separately, you and (name of adolescent) may wish to meet with us at the same visit. Some of the questionnaires you and (name of adolescent) will be asked to complete will be the same, but you will also each be asked to complete different ones. Therefore, the time it will take to complete the meeting may not be the same for both of you. It should take up to 2 hours to complete the meeting although

you will probably require less time to complete it. If you both prefer to attend at the same time, we suggest you bring along some reading material to keep you busy while you wait for (name of adolescent) to finish.

(name of adolescent) will be given \$10 if there have been expenses through participation in this project.

If you and (name of adolescent) decide to participate, you will be free to drop out of the study at any time. Your participation is completely voluntary and will in no way affect any services that you receive or could receive from the Children's Hospital of Eastern Ontario. There are no known risks or benefits from your participation. However, we hope that your participation will improve our understanding of how effectively adolescents with chronic illnesses deal with different situations they encounter. All of the information we receive from you is completely confidential and will not be shared with the members of (name of adolescent)'s treatment team unless you agree. A summary of the results of this research will be available to you at your request. If you have any concerns or questions, they can be directed to Amanda Pontefract at

If you and (name of adolescent) are interested in participating and would like to be contacted by a member of our team, please complete the attached form and return it in the envelope provided. If not, please indicate so, and return your reply in the envelope provided. If we have not heard from you in 2 weeks, we will be contacting you by telephone regarding your decision.

Thank you.

Sincerely,

Ian Manion, Ph.D.
Psychologist

Amanda Pontefract, M.Sc.

Attachs.

Appendix C
Reply Form

ADOLESCENT STRESS AND COPING STUDY

PLEASE CHECK ONE OF THE FOLLOWING

I AM INTERESTED IN RECEIVING MORE INFORMATION: _____

**I AM NOT INTERESTED IN PARTICIPATING.
PLEASE REMOVE ME FROM YOUR CONTACT LISTS _____**

Name of Adolescent: _____

Date of Birth: _____

Name of Parent: _____

Date: _____

Parent's Signature: _____

Adolescent's Signature: _____

Telephone: (Home) _____ (Office) _____

THANK YOU!

Appendix D
Protocol for First Telephone Contact

1) **IF THEY SENT BACK A YES REPLY FORM**

Could I please speak to adolescent name? Hi! This is researcher's name from the Children's Hospital. I am a member of a team that is doing research on the stressors that exist in the lives of adolescents with chronic illness and how they cope with them.

We have received your answer sheet in the mail and are pleased that you and your parent are interested in participating in our study.

Do you have any questions about the study and about what we are asking you to do?

YES ____ (answer questions)

NO ____ (see 5)

If initial contact made by parent only, speak to parent briefly and confirm interest. Let parent know you need to first check with son/daughter, and then speak with parent to answer any questions and set up appointment if agree to participate.

2) **IF THEY DID NOT SEND BACK THE REPLY FORM**

Could I speak to adolescent name? Hello. This is researcher's name from the Children's Hospital. I am a member of a team that is doing research on the problems or stressors of adolescents with chronic illness and how they cope with them. Your name was given to us by a member of your treatment team at the name of clinic at the hospital.

We have sent you and your parents an information letter explaining our research. Did you receive it?

YES__ (see 2.1)

NO __ (see 3.1)

2.1 **IF YES to 2)**

Have you and your parents made a decision about participating?

YES __ (see 2.2)

NO __ (see 2.4)

2.2 **IF YES to 2.1**

What did you decide?

YES, WILL PARTICIPATE ____ (see 2.3)

NO, WON'T PARTICIPATE ____ (see 4.1)

2.3 **IF YES TO 2.2**

Do you have any questions about the study or what we are asking you to do?

YES __ (answer questions)

NO __ (see 5)

2.4 **NO to 2.1**

Is there a reason why you have not decided or are not sure about your decision?

Adolescent has not talked to parents yet

How about I call you back in a few days, let's say ____, so you can have some more time to talk it over with your parents?

Does not want to be called back __ (ask why?)

Wants to be called back ____

But before I let you go, do you have any questions or concerns about the study that I could answer for you now?

YES __ Answer questions.

NO __ Alright Adolescent's name, I will talk to you in a few days. Thanks.

Adolescent has some questions

Give answers and ask: Do you have any more questions?

Now that you know more about the study, do you want to participate?

YES __ (see 5)

NO __ (see 4.1)

3) EXPLANATION IF INFORMATION LETTER NOT RECEIVED**3.1 Adolescent explanation:** Let me quickly explain what the study is about.

A chronic illness during adolescence can affect a teenager's day-to-day life. However, we know that not everyone experiences the same types of problems or copes in the same way. To help us in our work with adolescents, we need to know more about the different types of problems or stressors adolescents report and the different ways they cope with them. That is why we are asking you and a parent to participate in this research.

If you decide to participate, we will meet with you and a parent either at the Children's Hospital, or if you prefer, we can visit you in your home. Although we will meet with each of you separately, you and your parent may wish to meet with us at the same visit.

We will ask you and your parent to fill out several questionnaires. Some of the questionnaires you and your parent will be asked to complete will be the same, but you will also be asked to complete different ones. It will probably take your parent less time to complete the meetings than it will for you.

You will be asked about how your illness affects different areas of your life and you will also be asked to make some ratings concerning the stressful situations in your life and how you cope with them. It should take up to 2 hours for you to complete the meeting. All information collected will be confidential and you will be free to drop out of the study at any time.

We will give you \$10 each time you meet with us if there have been expenses through your participation in this project.

Before going any further, do you have any questions for me? (answer questions) Do you think that you and one of your parents would be interested in participating in the study?

YES ☐ (see 5)

NO ☐ (see 4.1)

3.2 Parent explanation: Introduce oneself to parents and say:

Your son/daughter told me that you did not receive the information letter that we sent. I have just explained to him/her what the study is about and he/she was interested in participating. I asked to talk to you because I would like to know if you would also be interested in participating. Is it a good time now to quickly explain what the study is about and discuss it with you?

Let me quickly explain what the study is about: A chronic illness during adolescence can affect a teenager's day-to-day life. However, we know that not everyone experiences the same types of problems or copes in the same way. To help us in our work with adolescents, we need to know more about the different types of problems or stressors adolescents report and the different ways they cope with them.

That is why we are asking you and adolescent's name to participate in this research. If you and adolescent's name decide to participate, we will meet with each of you at the Children's Hospital, or if you prefer, we can visit you in your home. Although we will meet with each of you separately, you and your son/daughter may wish to meet with us at the same visit. We will ask you and your son/daughter to fill out several questionnaires. Some of the questionnaires you and adolescent's name will be asked to complete will be the same, but you will also be asked to complete different ones. Because it will probably take you less time than your son/daughter to complete each meeting, we recommend that you bring along some reading material to keep you busy while you wait for adolescent's name.

During the meeting, your son/daughter will be asked about how their illness affects different areas of their life and they will also be asked to make some ratings concerning the stressful situations in their life and how they cope with them. You will be asked to complete some questionnaires that ask about background information and adolescent's name medical condition. You will also be asked to make some ratings concerning stressful situations in adolescent's name life and how s/he copes with them. This meeting should take up to 2 hours for you both to complete.

We will give adolescent's name \$10 after he/she meets with us if there have been expenses through his/her participation in this project. All information collected will be confidential and you will be free to drop out of the study at any time.

Do you want to participate?

YES ☐ (see 7)

NO ☐ (4.2)

4) **IF DECIDE NOT TO PARTICIPATE**

4.1 **IF NO to 2.2 or 3.1**

Adolescent declines:

It is helpful for us to know why people choose to participate or not. Can I ask you what made you decide not to participate?

Depending on the answer, give more explanations and ask if they will change their mind or just say: "I understand, Thank you very much for your time."

4.2 **IF NO to 3.2 or 6)**

Parent declines:

Oh! That's too bad. Adolescent's name sounded quite interested in participating. It is helpful for us to know why people choose to participate or not. May I ask you if there is any reason why you have decided not to?

Depending on the answer, give more explanations and ask if they will change their mind or just say: "I understand. Thank you very much for your time."

If family would like to participate but only later in the year, ask if we can call them back in a few months and check again. (If adolescent will still be 18 years or less)

5) INCLUSION CRITERIA

I have to ask you a few questions just to make sure that you and your family fit within the requirements of the study:

- Are you between 13 and 18 years old? *or* How old are you?
- Some of the teens that will participate in the study are French-speaking, so we want to make sure that you can read and write in English. Is that a problem for you?
- Do you live at home with one or both of your parents? If not, whom do you live with? or Who do you live with? Have you always lived with your parent(s)?

No ____ (see 5.1)

Yes ____ (see 5.2)

5.1 **If fail to meet inclusion criteria:**

I'm sorry to hear that. Unfortunately you won't be able to participate in our study. Thank you very much anyway adolescent's name. Can I please talk to one of your parents to let them know you will not be able to participate.

YES ____ (talk to parent)

NO ____ (see below)

Please let your parents know that I called you and that you won't be able to participate. They can still call me if they have any questions. Thanks.

After the phone call send a letter to parents to confirm the exclusion of their son/daughter from the study and to thank them for their interest in the study.

5.2 **If meet inclusion criteria:**

Did not receive information letter

Great! The next thing we have to do is to explain the study to one of your parents to see if they also agree to participate and then set up a time to meet. Could I speak to one of your parents?

YES ____ (see 2.2)

NO ____ (see below)

When is it a good time to call back and talk to one of your parents? Alright, adolescent's name. I will call back on ____ to talk to one of your parents about the study and set up an appointment with you and them. But, before I let you go, do you have any questions or concerns about the study that I could answer for you now? Please let your parents know that I talked to you and that I will call them on _____. Thanks.

Received information letter

Great! You fit with the requirements of the study. The next thing we have to do is set up a time to meet but before doing so could I talk to the parent who has signed the answering sheet, or, if not at home, the other parent to make sure that your parents also agree?

YES ____ (see 6)

NO ____ (see below)

When do you think is a good time to talk to one of your parents? Alright, name of adolescent, I will call back on ____ to talk to one of your parents about the study. Please let your parents know that I talked to you and that I will call them back on _____. Thanks.

6) **PARENT CONFIRMATION**

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Hello parent's name. My name is researcher's name from the Children's Hospital. I was just talking to your daughter/son adolescent's name about the study we are doing on the stressors or problems reported by adolescents with chronic illness and how they cope with them. Your son/daughter told us that you received the information letter about the study and that he/she has agreed to participate. Let me quickly go over some details about the study before I ask if you also agree to participate.

You may remember from the letter that we sent you that we will be asking both you and adolescent's name to fill out several questionnaires. The meeting should take up to 2 hours for you and adolescent's name to complete. Do you have any questions or concerns?

YES ___ (answer questions)

NO ___ (see below)

Knowing this, do you agree to participate with your son/daughter?

NO ___ (see 4.2)

YES ___ (see below)

Terrific! Let's set up an appointment. Would it be possible for you to come to CHEO for the meetings?

YES ___ (see 7.1)

NO ___ (see 7.2)

7) TO SET UP AN APPOINTMENT

Let's set up an appointment. You have the choice of either coming to the hospital or, if it is more convenient, we could come to your home. However, if we come to your home, adolescent's name will not receive the \$10 since they should not have had any expenses through their participation in this project.

7.1 CHEO appointments: When is a good time for you to come? It can be most any evening during the week, during the day, or any time during the weekend. Is ____ at ____ am/pm a good time then? Good!

Now, let me tell you where the meeting will take place. Do you know how to come to CHEO? (If not, give directions before describing meeting location)

Our meeting will take place in the Research Institute. You can park your car in CHEO's parking lot and enter by CHEO's main entrance. Then follow the directions to go to Emergency. On your way there, you will pass the Gift Shop and Coffee Shop. Turn right after the Coffee Shop. Then turn left after Radiology towards Emergency. You will see a green door at the end of the corridor. This is the door to get into the Research Institute. Proceed straight through the two green doors, turn left, then turn right at the end of the hallway and you will see one of the doors with a poster marked "Adolescent Stress and Coping Study". The room number is R212A. This is where we will meet. Do you have any questions?

If you ever need to cancel the meeting you can reach us at _____. Would you like me to confirm the evening before the appointment? Just a reminder that we suggest you bring along some reading material for yourself. So, if everything is fine with you and with adolescent's name, I will see you _____. Thank you. (If they never received letter tell them will send information letter in the mail that outlines the study)

7.2 Home appointments: When is a good time for me to come to your home? It can be during the week, after school, evenings or any time during the weekend. Is ____ at ____ am/pm a good time then? Good.

Let me verify your address with you: Do you still live on _____? Could you tell me how to get there? Thanks.

If you ever need to cancel our meeting, you can reach us at _____. Would you like me to confirm the evening before the appointment?

So, if everything is fine with you and with adolescent's name, I will see you _____. Thank you!

If they never received letter tell them will send information letter in the mail outlining study

Appendix E
Standardized Prompts for Administration of the Personal Stressor List

INITIAL PROMPT

Administer to all participants after they read the initial instructions.

Problems or stressors include things that happen to you or than bug you: they can be big things or little things.

For all remaining prompts, place * on PSL to indicate where you delivered it

1—IF NEEDS FURTHER CLARIFICATION

Give example that can be rated, but not particularly relevant to adolescent's life (*1 on sheet)

For example, for me, a problem or stressor might be losing my job or not getting along with my supervisor.

2—WHEN INDICATE CAN'T THINK OF ANY MORE (*2 on sheet)

A problem or stressor can have something to do with family, friends, school or work or, it can have something to do with your (their) illness.

IMPACT PROMPT

If participant is unclear about how much problem had an effect/impact on them because it has varied over time prompt with the following:

If the impact has changed, rate the impact of the stressor when it was happening. (* on sheet)

IF STATE THAT STANDARD STRESSOR IS THE SAME AS SELF-IDENTIFIED ONE

Place an SI or SO (1 or 2) by self-identified stressor to indicate which standard is the same.

Which of the stressors that you described is the same?

STANDARD STRESSOR - having to undergo medications and treatments

If don't think this applies or are unsure say:

This includes special things you need to do or wear because of your illness. (* on sheet)

If they still don't think it applies but you do

I see that you mentioned (e.g., braces). Is that related to you CI? – write specific prompt on PSL

OR give a frame of reference - some adolescents with ____ have to ____; is that something you have to do?

TYPICAL TO ADOLESCENCE

Administer to all participants

Do you think this stressor is something that happens to many adolescents?

Appendix F
Adolescent Consent Form

STRESSORS AND COPING PATTERNS IN
 ADOLESCENTS WITH CHRONIC ILLNESS

The following study is being conducted at the Children's Hospital of Eastern Ontario, directed by Dr. Ian Manion, a psychologist at the hospital, and Amanda Pontefract, a doctoral student in clinical psychology at the University of Ottawa, along with the (name of clinic). The purpose of this study is to look at the stressors that can exist in the lives of adolescents with chronic illness and how they cope with them.

If you decide to participate, a member of our team will meet with you at the Children's Hospital of Eastern Ontario at your convenience, or if you prefer, we can visit you in your home instead. During your meeting, you will be asked to complete several questionnaires that ask about different aspects of your adjustment. Your participation in the project should take no longer than 2 hours. A member of the research team will be present throughout the meeting to help you with any questions that you may have.

Once you have agreed to participate, you are free to end your participation at any time. You can also skip any questions that you do not wish to answer or withdraw any answer that you have already given. Your participation in this research is strictly voluntary and will not affect the quality of any care you receive at the Children's Hospital of Eastern Ontario.

All of the information we receive from you is confidential. Only members of the research team will have access to your records, and all of the questionnaires that you complete will be identified only by a number code. Your identity will not be revealed without your written consent. However, there are three exceptions for which the law says we must share information with others, even if you do not agree. The exceptions are: (1) if you tell us that you are in danger of harming yourself or somebody else; (2) if you tell us about any possible child abuse; (3) if there is ever a court case and a judge asks for our records.

There are no known risks or benefits from your participation. However, we hope that your participation will improve our understanding of how adolescents with chronic illnesses deal with different situations they encounter.

You will be given \$10 if there have been expenses through your participation in this project.

If you have any questions concerning this research you can contact Amanda Pontefract at

You may also contact the Chair of the Research Ethics Committee for information regarding patient's rights in research studies at _____ however, this person cannot provide any medical information with regard to this study.

I have read the above information and I agree to participate in the research project "Stressors and Coping Patterns in Adolescents with Chronic Illness".

Name _____ Date _____

Witness _____ Date _____

I have explained this study to the person authorized to sign above and I am satisfied that it is understood.

Investigator or Designee _____ Date _____

Parent Consent Form

STRESSORS AND COPING PATTERNS IN ADOLESCENTS WITH CHRONIC ILLNESS

Your adolescent has agreed to participate in a research study that explores the stressors that exist in the lives of adolescents with chronic illness and how they cope with them. The study is being conducted at the Children's Hospital of Eastern Ontario, directed by Dr. Ian Manion, a psychologist at the hospital, and Amanda Pontefract, a doctoral student in clinical psychology at the University of Ottawa, along with the name of clinic.

Although the majority of the study involves your adolescent's participation, we also request your involvement in the study. A member of our team will meet with you at the Children's Hospital of Eastern Ontario at your convenience, or if you prefer, we can visit you in your home instead. If you decide to participate, during your visit we will ask you to complete brief questionnaires that ask about background information and your adolescent's medical condition. Also, you will be asked to make some ratings concerning stressors in your adolescent's life and how they cope. Your participation in the project should take no longer than 2 hours. A member of the research team will be present throughout the meeting to help you with any questions that you may have.

There are no known risks or benefits from your participation. However, we hope that your participation will improve our understanding of how effectively adolescents with chronic illnesses deal with different situations they encounter.

Your participation is completely voluntary and you are free to stop at any time without penalty to yourself, or your adolescent's medical care at the Children's Hospital of Eastern Ontario. You can also skip any questions that you do not wish to answer or withdraw any answer that you have already given.

All of the information we receive from you is confidential. Only members of the research team will have access to your records, and the questionnaire that you complete will be identified only by a number code. Your identity will not be revealed without your written consent. However, there are three exceptions for which the law says we must share information with others, even if you do not agree. The exceptions are: (1) if you tell us that you are in danger of harming yourself or somebody else; (2) if you tell us about any possible child abuse; (3) if there is ever a court case and a judge asks for our records.

Your adolescent will be given \$10 if there have been expenses through their participation in this project.

If you have any questions concerning this research you can contact Amanda Pontefract at

You may also contact the Chair of the Research Ethics Committee for information regarding patient's rights in research studies at _____; however, this person cannot provide any medical information with regard to this study.

I have read the above information and I agree to participate in the research project "Stressors and Coping Patterns in Adolescents with Chronic Illness".

Name _____ Date _____

Witness _____ Date _____

I have explained this study to the person authorized to sign above and I am satisfied that it is understood.

Investigator or Designee _____ Date _____

Appendix G
Decision Rules for Selecting Stressors for the Kidcope

Start with one dimension. Look for 5's.

Select in order they appear.

If there is a tie (e.g., 5's on both scales) select, but add one more stressor to each dimension.

If not a tie, take it for that dimension.

Proceed to 4's then 3's if selection not complete (e.g. no more 5's) or only ties left and have already included one tie.

Apply same procedure to other dimension.

There should be a minimum of 4 problems (2 for each dimension) and a maximum of 5 (if include one tie) selected.

Rule 1: Include only up to one tie unless no other stressors available. If tie already selected earlier for same dimension or for other dimension, do not select additional tie.

Rule 2: In order to be used for a dimension, the score should be a 3, 4, or 5.

Rule 3: There must be a difference of at least +1 for a stressor to be selected for a dimension (other dimension must not have a higher score for same stressor).

NB: REMEMBER TO COUNTERBALANCE

If a stressor meets criteria but appears to be same as standard one, it should still be used despite apparent redundancy.

Appendix H

The Adolescent Coping Orientation for Problem Experiences scale (A-COPE)

Name: _____

Date: _____

ID#: _____

WE ARE TRYING TO FIND OUT HOW ADOLESCENTS DEAL WITH DIFFERENT SITUATIONS.**PLEASE READ EACH ITEM CAREFULLY AND CIRCLE YOUR ANSWER.****“WHEN YOU FACE DIFFICULTIES OR FEEL TENSE, HOW OFTEN DO YOU...?”****CIRCLE YOUR ANSWER**

1.	Go along with parents' requests and rules.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
2.	Read.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
3.	Try to be funny and make light of it.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
4.	Apologize to people.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
5.	Listen to music - stereo, radio, etc.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
6.	Talk to a teacher or a counsellor at school about what bothers you.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
7.	Eat food.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
8.	Try to stay away from home as much as possible.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
9.	Use drugs prescribed by a doctor.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
10.	Get more involved in activities at school.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
11.	Go shopping; buy things you like.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
12.	Try to reason with parents and talk things out; compromise.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
13.	Try to improve yourself (get body in shape, get better grades, etc.).	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
14.	Cry.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
15.	Try to think of the good things in your life.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME

16.	Be with a boyfriend or girlfriend.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
17.	Ride around in the car.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
18.	Say nice things ("warm fuzzies") to others.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
19.	Get angry and yell at people.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
20.	Joke and keep a sense of humour.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
21.	Talk to a spiritual leader (e.g., minister/priest/rabbi)	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
22.	Let off steam by complaining to family members.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
23.	Go to a house of worship (e.g., church, temple, synagogue, mosque)	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
24.	Use drugs (not prescribed by a doctor).	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
25.	Organize your life and what you have to do.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
26.	Swear.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
27.	Work hard on schoolwork or school projects.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
28.	Blame others for what's going on.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
29.	Be close with someone you care about.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
30.	Try to help other people solve their problems.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
31.	Talk to your mother/stepmother about what bothers you.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
32.	Try, on your own, to figure out how to deal with your problems or tension.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
33.	Work on a hobby you have (sewing, model building, etc.).	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
34.	Get professional counselling (not a school teacher or school counsellor).	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
35.	Try to keep up friendships or make new friends.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME

36.	Tell yourself the problem(s) is not important.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
37.	Go to a movie.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
38.	Daydream about how you would like things to be.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
39.	Talk to a brother or sister about how you feel.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
40.	Get a job or work harder at one.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
41.	Do things with your family.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
42.	Smoke.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
43.	Watch T.V.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
44.	Pray.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
45.	Try to see the good things in a difficult situation.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
46.	Drink beer, wine, or liquor.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
47.	Try to make your own decision.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
48.	Sleep.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
49.	Say mean things to people: be sarcastic.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
50.	Talk to your father/stepfather about what bothers you.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
51.	Let off steam by complaining to your friends.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
52.	Talk to a friend about how you feel.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
53.	Play video games (Nintendo, Playstation, Sega), pool, pinball, etc.	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME
54.	Do a strenuous physical activity (jogging, biking, etc.).	NEVER	HARDLY EVER	SOMETIMES	OFTEN	MOST OF THE TIME

PLEASE READ EACH STATEMENT AND DETERMINE WHICH PHRASES APPLY (IF ANY) TO HOW YOU DEALT WITH THE PROBLEM/STRESSOR THAT YOU IDENTIFIED EARLIER. # _____

THEN ANSWER BOTH QUESTIONS TO THE RIGHT OF EACH STATEMENT, CIRCLING THE BEST ANSWER.

FOR THOSE STATEMENTS THAT YOU ANSWER "NOT AT ALL" TO THE FIRST QUESTION, THE SECOND QUESTION DOES NOT REQUIRE A RESPONSE.

		First Question - Circle your answer HOW OFTEN DID YOU DO THIS?				Second Question - Circle your answer HOW MUCH DID IT HELP?				
		Not at all	Some- times	A lot of the time	Almost all the time	Not at all	A little	Some- what	Pretty Much	Very Much
Q-1	I thought about something else; or tried to forget it; like watch TV or play a game to get it off my mind Q-1	0	1	2	3	0	1	2	3	4
Q-2	I stayed away from people; or kept my feelings to myself; or just handled the situation on my own..... Q-2	0	1	2	3	0	1	2	3	4
Q-3	I tried to see the good side of things; or concentrated on something good that could come out of the situation..... Q-3	0	1	2	3	0	1	2	3	4
Q-4	I realized I brought the problem on myself and blamed myself for causing it..... Q-4	0	1	2	3	0	1	2	3	4
Q-5	I realized that someone else caused the problem and I blamed them for making me go through it Q-5	0	1	2	3	0	1	2	3	4
Q-6	I thought of ways to solve the problem; or talked to others to get more facts and information about the problem; or tried to actually solve the problem Q-6	0	1	2	3	0	1	2	3	4
Q-7	I talked about how I was feeling..... Q-7	0	1	2	3	0	1	2	3	4
Q-8	I yelled, screamed, or hit something Q-8	0	1	2	3	0	1	2	3	4
Q-9	I tried to calm myself by talking to myself or praying, or taking a walk, or just trying to relax Q-9	0	1	2	3	0	1	2	3	4
Q-10	I kept thinking and wishing this had never happened; or that I could have changed what had happened Q-10	0	1	2	3	0	1	2	3	4
Q-11	I turned to my family, or friends, or other adults to help me feel better..... Q-11	0	1	2	3	0	1	2	3	4
Q-12	I just accepted the problem because I knew I couldn't do anything about it..... Q-12	0	1	2	3	0	1	2	3	4

Appendix J

Personal Stressor List

PERSONAL STRESSOR LIST

NAME _____
DATE _____

ID # _____

We are trying to find out about the different problems and stressors of adolescents. These problems may or may not be related to your chronic illness. There are no right or wrong answers.

Please list the problems that have happened to you in the past 6 months.

For each problem rate:

- How often the problem occurred in the past 6 months.
- How much control you had over the cause of the problem.
- How much the problem had an effect or an impact on you.
- How much can you help yourself to make it better?

PROBLEM/STRESSOR	FREQUENCY How often did the problem occur in the past 6 months?	CONTROL OVER CAUSE How much control did you have over the cause of the problem?	IMPACT How much did the problem have an effect or an impact on you?	CAN YOU MAKE IT BETTER? How much can you help yourself to make it better?
	0 Never 1 Only once a month 2 About once a month 3 About once a week 4 About several times a week 5 Every day	0 No Control 1 2 3 4 5 Complete Control	0 No Impact at all 1 2 3 4 5 Very High Impact	0 Not at all 1 2 3 4 5 Very Much
	0 Never 1 Only once a month 2 About once a month 3 About once a week 4 About several times a week 5 Every day	0 No Control 1 2 3 4 5 Complete Control	0 No Impact at all 1 2 3 4 5 Very High Impact	0 Not at all 1 2 3 4 5 Very Much
.... 20	0 Never 1 Only once a month 2 About once a month 3 About once a week 4 About several times a week 5 Every day	0 No Control 1 2 3 4 5 Complete Control	0 No Impact at all 1 2 3 4 5 Very High Impact	0 Not at all 1 2 3 4 5 Very Much

PERSONAL STRESSOR LIST

NAME _____
DATE _____

ID # _____

Rate for each of the four problems listed below.

- How often the problem occurred in the past 6 months.
- How much control you had over the cause of the problem.
- How much the problem had an effect or an impact on you.
- How much can you help yourself to make it better?

PROBLEM/STRESSOR	FREQUENCY How often did the problem occur in the past 6 months?	CONTROL OVER CAUSE How much control did you have over the cause of the problem?	IMPACT How much did the problem have an effect or an impact on you?	CAN YOU MAKE IT BETTER? How much can you help yourself to make it better?
Problems with parent(s).	0 Never 1 Only once 2 About once a month 3 About once a week 4 About Several times a week 5 Every day	0 No Control 1 2 3 4 5 Complete Control	0 No Impact at all 1 2 3 4 5 Very High Impact	0 Not at all 1 2 3 4 5 Very Much
Having to come to the hospital for clinic visits.	0 Never 1 Only once 2 About once a month 3 About once a week 4 About Several times a week 5 Every day	0 No Control 1 2 3 4 5 Complete Control	0 No Impact at all 1 2 3 4 5 Very High Impact	0 Not at all 1 2 3 4 5 Very Much
Dissatisfaction with school.	0 Never 1 Only once 2 About once a month 3 About once a week 4 About Several times a week 5 Every day	0 No Control 1 2 3 4 5 Complete Control	0 No Impact at all 1 2 3 4 5 Very High Impact	0 Not at all 1 2 3 4 5 Very Much
Having to take medications or undergo treatments.	0 Never 1 Only once 2 About once a month 3 About once a week 4 About Several times a week 5 Every day	0 No Control 1 2 3 4 5 Complete Control	0 No Impact at all 1 2 3 4 5 Very High Impact	0 Not at all 1 2 3 4 5 Very Much

How much do you think this stressor is related to your chronic illness?						How typical is this stressor to adolescence?					
0	1	2	3	4	5	0	1	2	3	4	5
Not						Not					
related					Very	typical					Very
					related						typical
0	1	2	3	4	5	0	1	2	3	4	5
Not						Not					
related					Very	typical					Very
					related						typical
0	1	2	3	4	5	0	1	2	3	4	5
Not						Not					
related					Very	typical					Very
					related						typical

Note: The two scales above are found on the reverse side of the Personal Stressor List for self-generated stressors as well as standard stressors. Ratings on these scales are obtained for all stressors.

Appendix K
RAND-36-Item Health Survey 1.0

This survey was developed at Rand as part of the Medical Outcomes Study. Reproduced by permission.

Health Status Questionnaire

1. In general, would you say your health is:

(circle one number)

Excellent 1
 Very good 2
 Good 3
 Fair 4
 Poor 5

2. Compared to one year ago, how would you rate your health in general now?

(circle one number)

Much better now than one year ago 1
 Somewhat better now than one year ago 2
 About the same 3
 Somewhat worse now than one year ago 4
 Much worse now than one year ago 5

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(circle one number on each line)

	Yes, limited a lot	Yes, limited a little	No, not limited at all
3. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
4. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
5. Lifting or carrying groceries	1	2	3
6. Climbing several flights of stairs	1	2	3
7. Climbing one flight of stairs	1	2	3
8. Bending, kneeling, or stooping	1	2	3
9. Walking more than a mile	1	2	3
10. Walking several blocks	1	2	3
11. Walking one block	1	2	3
12. Bathing or dressing yourself	1	2	3

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(circle one number on each line)

	Yes	No
13. Cut down the amount of time you spent on work or other activities	1	2
14. Accomplished less than you would like	1	2
15. Were limited in the kind of work or other activities	1	2
16. Had difficulty performing the work or other activities (for example, it took extra effort)	1	2

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(circle one number on each line)

	Yes	No
17. Cut down the amount of time you spent on work or other activities	1	2
18. Accomplished less than you would like	1	2
19. Didn't do work or other activities as carefully as usual	1	2
20. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?		

(circle one number)

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

21. How much bodily pain have you had during the past 4 weeks?

(circle one number)

None	1
Very mild	2
Mild	3
Moderate	4
Severe	5
Very severe	6

22. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

(circle one number)

Not at all 1
 A little bit 2
 Moderately 3
 Quite a bit 4
 Extremely 5

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks ...

(circle one number on each line)

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
23. Did you feel full of pep or energy	1	2	3	4	5	6
24. Have you been a very nervous person?	1	2	3	4	5	6
25. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
26. Have you felt calm and peaceful?	1	2	3	4	5	6
27. Did you have a lot of energy?	1	2	3	4	5	6
28. Have you felt down- hearted and blue?	1	2	3	4	5	6
29. Did you feel worn out? ..	1	2	3	4	5	6
30. Have you been a happy person?	1	2	3	4	5	6
31. Did you feel tired?	1	2	3	4	5	6
32. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?						

(circle one number)

All of the time 1
 Most of the time 2
 Some of the time 3
 A little of the time 4
 None of the time 5

How TRUE or FALSE is each of the following statements for you?

(circle one number on each line)

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
33. I seem to get sick a little easier than other people . . .	1	2	3	4	5
34. I am as healthy as anybody I know	1	2	3	4	5
35. I expect my health to get worse	1	2	3	4	5
36. My health is excellent	1	2	3	4	5

Please answer YES or NO for each question by circling "1" or "2" on each line.

	Yes	No
37.* In the past year, have you had 2 weeks or more during which you felt sad, blue, or depressed; or when you lost all interest or pleasure in things that you usually cared about or enjoyed?	1	2
38.* Have you had 2 years or more in your life when you were depressed or sad most days, event if you felt okay sometimes?	1	2
39.* Have you felt depressed or sad much of the time in the past year?	1	2

*Note that questions 37-39 are not part of the RAND-36-Item Health Survey

Appendix L
Sociodemographic Questionnaire
(To be completed by parent)

Adolescent's surname: _____

First Name: _____

Date of Birth: _____ Age: _____ Sex: _____

Present grade level: _____

Type of school program **(please check one)**:

1. _____ Regular program
2. _____ Regular program with tutor
3. _____ Special program for learning disabilities
4. _____ Special program for students with behavioural and emotional problems or developmental problems
5. _____ Other (please specify): _____

Father's Age: _____

Highest level of education attained by Father: _____

Occupation of Father: _____

Mother's Age: _____

Highest level of education attained by Mother: _____

Occupation of Mother: _____

Combined family income (per year) : _____

Marital status of parents **(please circle one)** :

Married Divorced Separated Common-law One-parent Single

Other (please specify): _____

Please specify the place of residence of your adolescent (parents' home, father's, mother's, other) : _____

Who lives in this residence with the adolescent? _____

Is your adolescent adopted? No ____ Yes ____ (if yes at what age?) _____

Completed by: _____ Date: _____

Relation to adolescent _____

Appendix M
Medical Questionnaire
(*To be completed by parent*)

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Adolescent's Surname: _____

First Name: _____

Name of Family Doctor:

Diagnosis (please be as precise as possible) : _____

Age of adolescent when diagnosed: _____

Please specify below the major treatments required for your adolescent's condition. For example, dietary, medications, procedures (*e.g., lumbar punctures*) :

On average, how many days of school does your adolescent miss in a year? _____

If applicable, please list below any problems your adolescent has encountered or is presently experiencing (medical or psychological problems, learning difficulties):

Has your adolescent ever participated in therapy of a psychiatric or psychological nature (including individual, group, or family therapy)?

No __ Yes __ If yes, please specify the type of intervention, the date and its duration:

Completed by: _____ Date:

Relation to adolescent: _____

Appendix N

Categories Derived from The Personal Stressor List

Health Concerns – Poor/declining health; Fears surrounding blood sugar regulation; Frustration related to having a chronic illness (why me?); Pain; fear of dying from illness, PMS, migraines, Sleep deficit; Fatigue

Restrictions due to illness –Dietary; Cannot consume alcohol; Medication regimen interferes with activities, Restricted from sports; Cannot sleep over at friends

Physical limitations due to illness –Tires easily from activities /Reduced physical endurance; Cannot keep up; Impaired athletic ability (illness-related); Lack of accessibility to places due to illness; Sexual activity limited

Clinic/hospital visits & Medications/treatment – Hospitalization; Appointments; Meeting clinic staff/new doctor; Undergoing procedures; Remembering to take medications; Compliance with treatment; Needles/medication in front of others; Treatment side effects

Body image/sexual maturation– Starting menstruation; Weight control; Physical appearance/stature; Acne; Identity issues; Sexual curiosity; Self-image as individual with chronic illness

Mental health/emotional well-being – Depression; Loneliness; Lack of motivation Mood swings; Anxiety; Anger/temper flare ups; Nightmares; Self-esteem, Assertiveness issues,

Relationship with parents- Pressure from parents; Rules; Punishments; Disagreements; Nagging or reminding illness-related or other; Parents unaware of adolescent's feelings about illness; Parental concern; Concern for parents

Relationship with siblings–Fighting; Teasing; Taking possessions; Competition/rivalry; Concern for siblings; Lack of contact with siblings; Babysitting siblings

Relationship with other family members (or not specified)– Concerns/problems with aunts/uncles/cousins/grandparents; Situations at home; Family responsibilities

Relationship with other adolescents- Maintaining a social life; No friends near home; Friend moved; Losing /hurt by friend; Concern of/for friend; Peer pressure; Fighting; Teased/rejection due to illness or otherwise; Feeling different from peers/Having to explain illness; People not believing has an illness

Relationship with boy/girlfriend/dating –Also included lack of relationship;
Finding a boyfriend/girlfriend

School – Homework; Grades; Relationship with teacher/explaining illness to teacher;
Dislike school; Incidents at school; Late for class; Attendance/skipping class; Quit
school/expelled/suspended; Graduation

Sports & Extracurricular activities -Competition; Team tryouts; Problems with
teammates/bandmembers; Time consuming; Injuries

Money/finance –Finding part time job; Stressful job; too many hours at work; Losing
job due to illness; Not enough money; Cannot afford desired items

Discontinuity/change/-divorce/separation; new living arrangements/siblings leave
home/grandparent moves in/moving; changing schools

Independence/responsibilities – Decision-making; Privacy; Fear of/greater/lack of
responsibilities; Greater responsibility for health care/ Lack of confidence in new
roles; Fear of lack of independence due to illness; Achievement oriented

Concerns about the future (other than health) – Fears about getting
married/having children; Future career; University; Spiritual concerns

Daily hassles – Household chores; Sharing family computer, Taking the bus, Getting
up in the morning; Being late; Interruptions; Losing things/Breaking things; Too
much to do/missing some desired activities/time management

Other –Alcohol/drugs/problems with the law; Death of pet/giving pet away;
Pregnancy; Item stolen; Car accident; Failing driver's test; Boredom