

**SIBLINGS OF PEDIATRIC CANCER PATIENTS: STRESS AND PSYCHOLOGICAL
OUTCOMES**

by

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Submitted to the Graduate Faculty of
Arts and Sciences in partial fulfillment
of the requirements for the degree of
Masters of Science

University of Pittsburgh

2009

UNIVERSITY OF PITTSBURGH

ARTS AND SCIENCES

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SIBLINGS OF PEDIATRIC CANCER PATIENTS: STRESS AND PSYCHOLOGICAL OUTCOMES

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Each year, 12,500 pediatric cancer cases are diagnosed in the U.S. Although a majority survives these illnesses, challenges associated with prolonged, intensive treatment periods disrupt the entire family system, and effects on siblings are poorly understood. We have employed a developmentally-sensitive, transactional stress framework to study adjustment in 20 adolescent siblings (ages 10-17) of children undergoing cancer treatment. We aimed to (1) determine if contextual threat and treatment intensity are associated with sibling distress, as measured by perceived and posttraumatic stress and symptoms of anxiety and depression; (2) identify factors that may moderate these relationships; (3) understand the nature of sibling stress using qualitative data; and (4) compare adjustment between younger and older adolescent siblings. Qualitative data were collected using a semi-structured interview consisting of open-ended questions and probes about contextual details of the cancer experience. Qualitative findings fell into three broad categories consistent with the transactional theory of stress: (1) uncertainty regarding diagnosis, prognosis, and family changes; (2) loss of normalcy; and (3) cancer as a serious, adult illness. Quantitative analyses revealed positive associations between contextual threat and depression, anxiety, and perceived stress scores; and between treatment intensity and anxiety scores. In terms of potential moderators, older siblings endorsed more symptoms of depression and posttraumatic stress than younger siblings, and siblings younger than the child with cancer endorsed more symptoms of depression and higher levels of perceived and

posttraumatic stress than siblings older than the child with cancer. Overall, results suggest that contextual threat is a promising approach to predicting sibling distress and that sibling adjustment can be conceptualized using a transactional stress framework.

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1.0 INTRODUCTION

Each year, 12,500 children and adolescents are diagnosed with cancer in the United States (Surveillance, Epidemiology, and End Results (SEER), 2007). Although a growing majority survives the illness, childhood cancer causes disruption for all members of the ill child's family. The psychosocial impact of pediatric cancer on sick children and parents is well-researched (Patenaude & Kupst, 2005; Grootenhuis & Last, 1997); however, the impact on siblings is not as well understood (Alderfer & Noll, 2005; Kazak et al., 2003). Although a small body of literature suggests that a subset of siblings experiences enduring adjustment difficulties (for review, see Houtzager et al., 1999 or Williams, 1997), it is difficult to draw firm conclusions due to methodological limitations of the extant literature and related inconsistent findings. To better understand the experiences of child and adolescent siblings of children with cancer, we have utilized a developmentally sensitive, qualitative interview combined with an evaluation of the objective degree of stress associated with the cancer experience. Given considerable evidence that stressful life events can precipitate the development of symptoms of childhood and adolescent psychopathology (Grant et al., 2003), examination of stress among siblings of childhood cancer patients is warranted.

Here, we report on a study of 20 adolescent siblings of children with cancer. In this study, we employ qualitative and quantitative measures to evaluate the contextual threat associated with the cancer and the intensity of each child's treatment, and we examine the relationship between

these factors and measures of sibling distress. We also consider potential moderators of the relationship between cancer-related stress and sibling distress, including sibling age and relative birth order. Finally, the nature of the threat associated with the sibling experience is elucidated through an analysis of qualitative interview data.

In the following sections, we outline the impact of childhood cancer on siblings, conceptualizing the cancer diagnosis of a brother or sister as a major life stressor. To date, the literature examining sibling adjustment to this stressor has been largely atheoretical. Thus, we present the developmental psychopathology model as a theoretical basis for considering sibling adjustment. In addition, we discuss the transactional theory of stress, a well-defined model accounting for individual differences in response to threatening life events. Following these theoretical perspectives, the extant literature on sibling adjustment is considered.

1.1 THE CHANGING NATURE OF PEDIATRIC CANCER RESEARCH

Significant biomedical advances over the past several decades have increased the survival rate for pediatric cancer to over 70% (SEER, 2007). Thus, the focus of research has shifted from examining the experience of dying from cancer to that of living with the burden of chronic illness (Simms et al., 2002). Improvements in prognosis and survival are accompanied by a series of challenges faced by the child with cancer and the family, including prolonged and more intensive treatment periods. Current protocols require primary caregivers to spend extended periods of time in the outpatient clinic or hospital and have the potential to result in chronic disruption of the family system (Alderfer & Kazak, 2006). Siblings may be particularly

vulnerable throughout this period as attention is shifted to the sick child. In addition to being physically absent for long periods, caregivers are coping with a major life stressor which may limit their emotional availability. As a consequence, siblings are frequently placed in the temporary care of extended family members or friends, and many report feeling abandoned (Wilkins & Woodgate, 2005). Already a frightening and confusing time, decreased communication with parents may contribute to feelings of isolation reported by some siblings (Houtzager et al., 1999; Williams, 1997).

Thus, having a brother or sister diagnosed with a chronic illness like cancer may place considerable strain on the family and be a source of stress to siblings. Evidence suggests that life stress contributes to the course of development and maturation among children and adolescents. Indeed, life stress has been associated with increased vulnerability to a range of clinical problems (Moos, 2002). However, the presence of life stress alone is not sufficient to predict the development of psychopathology. Individual developmental trajectories vary markedly, with negative life events predicting outcomes ranging from developmental competence across multiple domains of functioning to the emergence of psychopathology (Masten & Curtis, 2000). Thus, research on siblings of pediatric cancer patients should seek to identify factors that might moderate differences in individual adaptation to the cancer experience.

1.2 DEVELOPMENTAL PSYCHOPATHOLOGY PERSPECTIVE

Developmental psychopathology is a broad approach to studying the dynamic processes underlying pathways of development (Cummings, Davies, & Campbell, 2000). This perspective conceptualizes normal and maladaptive development as multiply determined, resulting from the

transaction of numerous internal and environmental factors. A significant life event, such as having a brother or sister diagnosed with cancer, may have negative or positive consequences depending on additional factors such as family structure and support, developmental stage and coping abilities of the child, level of caregiver distress, and availability of peer support. The negative event is neither necessary nor sufficient to predict present or future maladjustment or competence. Rather, the dynamic interplay of factors over time predicts developmental outcomes. Furthermore, the influence of positive and negative factors is likely to change over time and across development, so that a seemingly taxing situation at one age may not be problematic at another. It is also possible that adjustment difficulties may not be evident at the time of the disruption but emerge at a later stage of development, a phenomenon called the “sleeper effect” (Kendall, 1991). The purpose of the current study is to begin to identify risk and resilience factors that may influence developmental pathways among siblings. We expect that factors impacting siblings’ response to the stressor might include their developmental abilities to appraise the situation as threatening and implement effective coping skills.

1.3 ADOLESCENT SIBLINGS: A DEVELOPMENTAL PERSPECTIVE

Most existing studies of sibling distress examine samples that span a considerable age range and thus lack sensitivity to developmental factors (Murray, 2000a; Murray, 2000b). As a result, examination of variability in the meaning of the illness and its impact on psychosocial functioning as a function of cognitive, emotional, and social development have yet to be examined comprehensively. In the present study, we have gathered pilot data using a semi-structured interview to assess the experiences of younger versus older adolescent siblings of

childhood cancer patients. We have chosen to limit our investigation to adolescence based on evidence that transitions in early and late adolescence are accompanied by changes in vulnerabilities that may parallel the development of psychopathology (Masten, 2004). We acknowledge that this research is underpowered to carry out a systematic analysis of distress as a function of age; however, we hope that the current findings will lay the groundwork to conduct additional developmentally-sensitive studies in the future.

Adolescence may be a particularly difficult time to endure the stress of a family member's cancer diagnosis, as this developmental period is characterized by striving for autonomy, with an associated shift in the focus of relationships from the family to the peer group (Steinberg & Silverberg, 1986). Thus, a family crisis may present the adolescent with a difficult choice. The adolescent may choose to identify with the family and therefore compromise the normal developmental process of individuation that would otherwise occur during this time. Alternately, the adolescent who chooses to maintain their focus on peer relationships may experience guilt about being away from the family during a time of crisis. Indeed, several qualitative investigations have noted that guilt is a common response to the illness experience (e.g. Quinn, 2004). Other qualitative research has identified disruption of social activities as a primary concern for siblings of pediatric cancer patients (Freeman et al., 2000). However, social strain may not be present in all families with pediatric cancer, as some families may be able to rely on wider support networks to lessen disruption to siblings' social lives.

In addition to the social changes that are characteristic of adolescence, more sophisticated cognitive skills also may modulate the impact of the illness experience. As these siblings enter the formal operations stage of cognitive development, they develop the ability to think abstractly and reason beyond the "here and now" (Piaget, 1952). Accordingly, they are able to form a more

nuanced understanding of the meaning and potential consequences of a cancer diagnosis. Their primary appraisal of the event as a threat may increase its perceived stressfulness, which in turn could intensify the strong emotions such as fear and anxiety that are commonly reported by adolescent siblings (e.g., Nolbris & Hellstron, 2005; Quinn, 2004; Sargent et al., 1995; Sidhu et al., 2005).

1.4 TRANSACTIONAL STRESS AND COPING

Although it is widely assumed that having a brother or sister diagnosed with cancer is perceived as stressful by siblings, to date, no research has directly explored this hypothesis. Stress is a ubiquitous phenomenon, yet there remains considerable debate about how it is defined. The most widely accepted definition was proposed by Lazarus and Folkman (1984), whose transactional model suggests that “psychological stress involves a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her wellbeing.” This definition is routinely applied to adult populations, though some caution should be taken with children or adolescents who may lack the cognitive maturity to appraise a situation as threatening or exceeding coping resources. Thus, stressors are likely to differentially impact children and adolescents as a function of cognitive development. In the case of childhood cancer, adolescents are more likely to perceive threat and potential harm as a consequence of their brother’s or sister’s diagnosis and thus are more likely than younger children to perceive stress. At the same time, adolescents may have greater coping resources, which would enable them to deal with the stressor more effectively.

Although no quantitative studies have directly assessed the transactional stress model in siblings, several qualitative investigations have uncovered themes of perceived loss that are consistent with the types of appraisals outlined in Lazarus and Folkman's (1984) model. Appraisals of loss for siblings of children with cancer have been reported in the contexts of loss of attention (Sloper, 2000; Sargent et al., 1995), loss of status within the family (Sloper, 2000; Sargent et al., 1995), loss of routine (Barrera et al., 2002; Sloper, 2000; Freeman et al., 2000), loss of certainty and security (Sloper, 2000), loss of companionship with the ill child (Sloper, 2000; Shapiro & Brack, 1994) and with the parents (Freeman et al., 2000), and family separations and disruptions (Sargent et al., 1995). Similar themes are offered by parents, who report that siblings of children with cancer lose control, normalcy, routine, security, worldview, and an opportunity to experience childhood (Sidhu et al. 2005; Bjork et al., 2005). According to the model, coping resources should moderate whether these appraisals of loss result in heightened emotional distress. In defining coping in youth, most researchers have relied on Lazarus and Folkman's (1984) transactional model of adult stress which defines coping as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person." Compas et al. (2001) adopt a similar approach when defining coping in children and adolescents as "conscious volitional efforts to regulate emotion, cognition, behavior, physiology, and the environment in response to stressful events or circumstances." It is likely that developmental stage will influence not only the cognitive appraisal of threat, but also the perception of the presence and use of coping resources.

1.5 SIBLING DISTRESS

Existing literature provides initial evidence that subgroups of siblings of children with cancer experience distress when symptoms of psychopathology are measured. Indeed, results of a meta-analysis show a modest correlation between having an ill sibling and showing impaired psychological functioning, poorer self-concept, and disrupted peer activities (Sharpe & Rossiter, 2002). To date, the pediatric cancer sibling literature has focused on depression, anxiety, internalizing disorders, and posttraumatic stress reactions. In most cases, studies do not find mean differences in the incidence of clinical syndromes; instead, they compare frequency of symptoms among siblings versus normative data.

The four studies that have included measures of depression consistently show that siblings' mean depression scores fall within the normal range (Barrera et al., 2002; Barrera et al., 2004; Lahteenmaki et al., 2004; Wellisch et al., 2006). However, Barrera et al. (2004) found significant inter-individual variability in levels of depression, suggesting that mean depression scores may obscure the distress experienced by a subset of siblings.

Findings from studies examining anxiety among siblings have been less consistent. Six studies show higher anxiety among siblings of pediatric cancer patients as compared to matched controls or norms (Barrera et al., 2002; Houtzager et al., 2001, 2003, 2004a; Lahteenmaki et al., 2004; Sidhu et al., 2006), while two do not (Barrera et al., 2004; Alderfer et al., 2003). In the study by Lahteenmaki et al. (2004), state and trait anxiety were significantly higher in school-aged siblings of pediatric cancer patients than controls at three months post-diagnosis; however, there were no group differences at the 15-month follow-up. A similar reduction in anxiety over time was reported in a study by Houtzager et al. (2003, 2004b), in which adolescent female siblings endorsed an increase in anxiety symptoms at 1-month post-diagnosis (Houtzager et al.,

2003) but not at 2-years post-diagnosis (Houtzager et al. 2004b). Intervention studies have found pre-intervention anxiety levels to be higher than norms (Houtzager et al., 2001) or in the clinical or at-risk ranges (Barrera et al.; 2002; Sidhu et al., 2006). In contrast, two studies found siblings' anxiety levels to be in the normal range (Alderfer et al., 2003; Barrera et al., 2004). One factor that may account for inconsistent findings is time since diagnosis, which is rarely considered in these studies.

Unlike mixed findings with regard to sibling anxiety, two studies agree on the presence of posttraumatic stress in siblings of childhood cancer patients. In a study by Alderfer et al. (2003), 49% of siblings reported mild posttraumatic stress reactions and 32% had moderate to severe reactions. Posttraumatic stress symptoms were endorsed more often by female siblings who were older than age 6 at the time of diagnosis. Compared to a reference group of children with no chronic illness, siblings of pediatric cancer patients reported more symptoms of intrusion and avoidance. Similar findings are reported by Packman et al. (2004) who found that one third of siblings exhibited moderate to severe posttraumatic stress reactions.

Qualitative studies also show themes of emotional distress, with common symptoms including worry or anxiety (Nolbris & Hellstrom, 2005, Quinn, 2004, Sidhu et al., 2005), loneliness (Bjork et al., 2005, Nolbris & Hellstrom, 2005, Packman et al., 2004, Sidhu et al., 2005), jealousy (Nolbris & Hellstrom, 2005), anger (Nolbris & Hellstrom, 2005), fear (Freeman et al., 2000, Quinn, 2004, Sargent et al., 1995), guilt (Quinn, 2004), and resentment (Quinn, 2004). The age of the sibling may play a role in how these feelings are expressed. For example, Barrera et al. (2002) found that adolescents tended to mask their feelings, while younger children tended to express their feelings more openly, but reported fears of upsetting their parents with cancer-related worries.

In addition to adjustment difficulties, many siblings also show patterns of resilience in the face of the family's pediatric cancer experience (Sidhu et al., 2005). Positive outcomes include enhanced maturity, independence, compassion, and protectiveness of the ill child (Quinn, 2004, Sargent et al., 1995, Sloper, 2000). These positive changes are endorsed more often by adolescents than younger children (Sargent et al., 1995).

1.6 SIBLING DISTRESS: POTENTIAL MODERATORS

One possible explanation for mixed findings in the sibling literature is a failure to consider potential moderators of the cancer experience. Indeed, the developmental psychopathology approach would suggest that the cancer is only one factor influencing whether or not children of a certain age in a certain context show symptoms of maladjustment. Based on the transactional model of stress, a number of factors are likely to moderate the emotional impact of childhood cancer. Primary among these are cognitive appraisal of the potential threat and availability of coping resources such as family support.

Other factors that may moderate the emotional experience of siblings include age and time since diagnosis. Despite samples that span considerable age ranges, few studies have adequate power to examine age as a moderator, and there is no clear relation between age and adjustment problems in siblings of childhood cancer patients (Lahteenmaki et al., 2004; Alderfer et al., 2003; Hamama et al., 2000; Houtzager et al., 2001). One goal of the current study is to use a qualitative grounded theory approach to identify potential moderating factors such as age, gender, relative birth order, and time since diagnosis that may shed light on inconsistencies in the extant literature.

1.7 LIMITATIONS OF THE EXTANT LITERATURE

Existing literature on siblings of children with cancer is limited by methodological shortcomings including small, heterogeneous samples and lack attention to possible mediators and moderators of emotional responses. Many quantitative studies rely on convenience samples and do not include control groups, and most data is collected within the hospital setting, which may be associated with illness or death. Many qualitative studies examine data collected from parents or nurses, rather than from the siblings themselves (e.g., Sidhu et al., 2005; von Essen & Enskar, 2003; Ballard, 2004). Furthermore, the methods used to analyze qualitative data are seldom specified, with designs ambiguously labeled as “descriptive” or “exploratory” (Wilkins & Woodgate, 2005). Although there are exceptions (e.g., Alderfer et al., 2003; Horwitz & Kazak, 1995; Packman et al., 2005), most qualitative and quantitative studies lack a theoretical framework, making interpretation difficult. A goal of the current investigation is to begin to address some of these limitations by (1) taking an inductive, grounded theory approach to analyzing qualitative data, allowing patterns of sibling adjustment to emerge, (2) using quantitative measures to examine siblings’ cancer experience within the context of a widely accepted transactional model of stress, (3) recruiting a more homogeneous sample of siblings, (4) seeking to understand whether developmental factors might impact the experience of distress, and (5) collecting data primarily outside the hospital setting.

1.8 SPECIFIC AIMS

The overarching goal of this study was to add to the small and methodologically limited body of literature about the effects of pediatric cancer on siblings by examining siblings' experiences through both qualitative and quantitative methods. For this purpose, we employed a semi-structured interview assessing siblings' cancer experience. Consistent with the inductive nature of grounded theory (Glaser & Strauss, 1967), a priori hypotheses were not specified with regard to qualitative themes. Rather, provisional hypotheses were formulated, tested, and revised during the course of data collection in order to build a theory that is data-driven rather than limited by the scope of existing theories. In addition to qualitative analyses, several exploratory quantitative analyses were carried out. Here, an objective measure of cancer-related stress was examined in relation to symptoms of depression, anxiety, posttraumatic stress, and perceived stress and possible moderators of these associations were considered. Based on Lazarus and Folkman's (1984) transactional model of stress, we expected that siblings' developmental ability to cognitively appraise the event as threatening would mediate the presence of distress.

Since the existing literature suggests that a subset of siblings shows stress-related difficulties in the years following diagnosis, we aimed to examine factors that may be used to identify vulnerable individuals. Specific hypotheses are as follows:

- (1) The degree of contextual threat endorsed by siblings in a semi-structured stress interview will be positively associated with distress, as measured by perceived stress and symptoms of depression, anxiety, and posttraumatic stress.
- (2) The intensity of the cancer treatment will be positively associated with distress, as measured by perceived stress and symptoms of depression, anxiety, and posttraumatic stress.

(3) The cancer experience will have a different impact on early (ages 10-14) and later (ages 15-17) adolescent siblings. Although this study was underpowered to fully examine developmental effects, it was hypothesized that due to more sophisticated cognitive ability to understand potential consequences of a cancer diagnosis, later adolescents would show more symptoms of distress than early adolescents.

2.0 METHODS

2.1 PARTICIPANTS

Twenty siblings of children with cancer from 15 families were enrolled in this study between October, 2007 and October, 2008 (see Table 1). Inclusion criteria included having a sibling currently on treatment for cancer who was diagnosed at least six months earlier, speaking English fluently, and being between the ages of 10 and 17 (mean = 13.95, sd = 2.28). More than half of the sample was in early adolescence, ages 10-14 (n = 13), with the remainder in later adolescence, ages 15-17 (n = 7). The sample included 12 male and eight female siblings, and time since diagnosis ranged from eight to 33 months (mean = 16.25, sd = 7.91). Thirteen sibling participants were older than the child with cancer and seven were younger. All 20 siblings were Caucasian. Exclusion criteria included death of the sick child, history of cancer or other life-threatening disease in the sibling, and mental retardation in the sibling.

2.2 PROCEDURE

Participants were recruited from two children's hospitals in Pennsylvania: the Children's Hospital of Pittsburgh (CHP) and the Children's Hospital of Philadelphia (CHOP). At both institutions, registries were used to identify children who were currently on treatment for

pediatric cancer and who had been diagnosed at least six months earlier. Siblings between the ages of 10 and 17 were invited to participate in the research study. A letter was sent to parents, explaining the nature of the study and inviting interested families to contact the researcher for more information. In Pittsburgh, eligible participants were also informed about the study by a member of the medical treatment team during clinic visits. In Philadelphia, families received a follow-up telephone call to offer additional information and determine interest in participating. Brief telephone screenings were conducted to ensure eligibility, and appointments for data collection were arranged. Fourteen siblings were interviewed in their homes, three in the hospital library or conference room, and three in the study offices at the University of Pittsburgh. During data collection appointments, siblings participated in a 30- to 60-min qualitative interview and completed a brief battery of psychosocial questionnaires. Outside this appointment, information about diagnosis and treatment was extracted from medical charts of the children with cancer. Sibling participants were compensated with Target gift cards valued at \$25 and entered into a lottery to receive an I-Pod.

2.3 INSTRUMENTS

Qualitative interviews began with open-ended questions about siblings' experiences of having a brother or sister with cancer (e.g., "Tell me what it is like to have a brother or sister who has cancer" and "How have things been different since your brother or sister was diagnosed?"). A series of probes was identified for each open-ended question to aid participants who required prompting. During the course of data collection, interview data were transcribed and analyzed, and provisional hypotheses were developed. As the grounded theory approach to qualitative

research is by nature an iterative process (Glaser & Strauss, 1967), the exact questions asked during the qualitative interview evolved during the course of the study.

Contextual Threat: In addition to open-ended questions, all participants answered targeted questions about the contextual details of the cancer experience. These questions were modeled after semi-structured stress interviews that attempt to ascertain the contextual threat associated with various stressors (e.g. Rudolph & Flynn, 2007; Williamson et al., 2003). After the interview, a team of three members with experience in pediatric psychology rated the degree of contextual threat associated with the cancer experience on a 4-point scale corresponding to (1) little/no effect, (2) some effect, (3) moderate effect, or (4) great effect. The following domains were rated: (1) time since diagnosis, (2) frequency of hospital visits, (3) distance to the hospital, (4) inpatient versus outpatient status, (5) sibling caretaker (e.g., parent, extended family, non-relative, none), (6) frequency of the ill child being sick when they come home from the hospital, (7) changing employment status of parent(s) after diagnosis, (8) presence of illness in other family members, (9) financial impact of the cancer, (10) presence of friends, (11) presence of someone to talk to, (12) other stressful events occurring since the ill child was diagnosed, and (13) other ongoing stressful situations. The ratings for each domain were summed and an average contextual threat score was calculated for each participant. In addition, the team of raters assigned a holistic contextual threat stress score to each participant based on the aggregate of responses (see Appendix).

To determine treatment intensity, researchers with experience in pediatric oncology completed the Intensity of Treatment Rating Scale 2.0 (ITR-2; Werba et al., 2007). This 7-question instrument was developed specifically for pediatric cancer diagnoses, classifying treatment intensity into four groups, from least to most intensive on the basis of treatment

duration, side effects, and recovery time. This measure has high interrater reliability ($r = 0.87$) and content validity ($r = 0.95$; Werba et al., 2007).

Siblings completed a short battery of questionnaires measuring distress, including the following measures:

- Perceived Stress Scale (PSS; Cohen et al., 1983). The PSS is a 10-item self-report instrument that measures the extent to which situations in the participant's life are appraised as being stressful. The internal consistency is considered to be good ($\alpha = 0.85$), and test-retest reliability is high ($r = 0.85$; Cohen et al., 1983). The wording of PSS questions was modified for use with children and adolescents.
- Child Depression Inventory (CDI; Kovacs, 1981). The CDI is a 27-item self-report questionnaire that assesses the frequency and severity of depressive symptoms. It has relatively high levels of internal consistency, test-retest reliability, and predictive validity (Ialongo et al., 2001; Mattison et al., 1990), along with adequate construct (Worchel et al., 1992) and discriminate validity (Carey et al., 1987). This measure has been validated in children and adolescents, ages 7-18.
- Revised Child Manifest Anxiety Scale (RCMAS, Reynolds & Richmond, 1985). The RCMAS is a 37-item self-report measure of child and adolescent anxiety. Internal consistency values are above 0.80 (Gerard & Reynolds, 1999). Test-retest reliability is adequate, with 1-week, 5-week, and 9-month Pearson correlations of 0.88, 0.77, and 0.68, respectively (Wisniewski et al., 1987; Reynolds, 1981). Concurrent validity is strong when compared to the STAIC ($r = 0.88$; Chorpita et al., 1996). This measure has been validated for children and adolescents, ages 6-19.

- Children's Posttraumatic Stress Disorder Reaction Index (PTSD-RI; Pynoos et al., 1987).

The PTSD-RI is a 20-item self-report measure that corresponds to the diagnostic criteria for PTSD. Posttraumatic stress reactions are categorized as mild, moderate, or severe.

The scale has been shown to have good reliability and validity (Pynoos et al., 1993), with internal consistency estimated at $\alpha = .74$ (Alderfer et al., 2003).

2.4 DATA ANALYSIS

Qualitative data were assessed using grounded theory methodology. After transcription, data were analyzed using open coding, which refers to the process of breaking down, examining, comparing, conceptualizing, and categorizing data. During this process, line-by-line codes were assigned to the transcripts, and the codes were generated by the text itself. These open codes were examined according to frequency and patterns, and a set of focused codes were developed. Then, all transcripts were re-analyzed applying the identified focused codes to larger sections of text. This process is termed axial coding and involves putting the data back together and making connections between categories (Strauss & Corbin, 1990). Focused codes were refined throughout the process of axial coding. Provisional hypotheses were formulated on the first 15 interviews and verified on the final five participants.

Next, we examined whether contextual threat and treatment intensity were related to the degree of distress endorsed by siblings. For this purpose, Pearson Product-Moment correlations were calculated between the contextual threat and ITR-2 values and measures of distress. Next, a series of linear regressions were performed to determine whether contextual threat alone, ITR-2 alone, or both in combination predicted scores on the CDI, RCMAS, PTSD-RI, and PSS. Here,

ITR-2 and contextual threat were entered into the first and second steps of models predicting distress. Finally, we examined whether age at assessment, age at diagnosis, gender, birth order relative to the child with cancer (older versus younger) and time since diagnosis moderated associations of contextual threat or treatment intensity with distress. Here, bivariate correlations were conducted to identify potential moderators that were significantly associated with distress, and the identified covariates were entered into the first step of regression equations examining whether contextual threat or ITR-2 accounted for variability in distress. Finally, to evaluate hypothesis 3, a series of one-way ANOVA tests examined whether older and younger adolescents differed on levels of distress. We acknowledge that these analyses are limited by the small sample size which yields limited power to detect significant effects.

3.0 RESULTS

3.1 QUALITATIVE RESULTS

The purpose of qualitative data analysis was to identify stressful aspects of the cancer experience. After focused codes were developed, those consistent with Lazarus and Folkman's (1984) theory of transactional stress were selected for further analysis. Specifically, we selected codes relating to themes of perceived threat or loss and/or aspects of the cancer experience identified as exceeding siblings' perceived ability to cope. Selected codes were confirmed during verification interviews with five sibling participants. Stressors fell into three broad categories (see Table 2): (1) uncertainty about diagnosis, prognosis, and changes within the family; (2) loss of normalcy; and (3) cancer as a serious, adult illness. We also sought to identify common coping techniques and to characterize available coping resources. Finally, tentative hypotheses are offered regarding the role of potential moderating factors such as age, gender, birth order, and time since diagnosis.

3.1.1 Uncertainty

The majority of siblings described considerable uncertainty leading up to and following the cancer diagnosis. Siblings' narratives illustrated that no one knows what is wrong with the ill child initially. They described multiple doctor visits, tests, incorrect diagnoses, hospital stays,

and hypotheses before an accurate diagnosis was “finally” reached. A 16-year-old brother of a teenager with leukemia described it this way:

Last year, around October, he got pretty sick. We didn’t know what was wrong with him. We took him to the hospital. The doctors ran tests. They thought he had mono. Turns out he did. He started to get better, and he came back home for about a week and a half. He started getting sick again. It was a lot worse this time. He wasn’t eating. He didn’t really sleep a lot. He was in a lot of pain. We took him back to the hospital and the doctors ran more tests. They ruled out mono already. About half a week later to a week later, um, we got the news that he had leukemia.

The sense of uncertainty persisted after diagnosis and extended to unknowns regarding prognosis, survival, and family changes. Siblings reported thoughts such as “I wondered what was going to happen,” or “will (s)he ever be okay?” A 14-year-old brother of a girl with leukemia summed up his experience by stating that “the hardest part is just not knowing what’s going to happen next.” Uncertainties were reported to be emotionally and physically taxing for all members of the family.

Ongoing uncertainty was accompanied by a pattern of ups and downs corresponding to the ill child’s health and mood states. With regard to health states, siblings described a roller coaster of hope and disappointment and of nervousness and relief as the ill child’s health vacillated – a common pattern in pediatric cancer. A 16-year-old brother of a teenager with leukemia described his brother’s health as follows:

He was in and out of the hospital for two or three months. Every time he would get out of the hospital he was fine for a day or two, and then he would start getting sick again, and he would have to stay in [the hospital] for a week . . . The doctor said he was starting to get better really fast which was good and then at the start of the year he started getting worse again. My parents didn’t really tell me much but I listened to what they were saying. Every time they would talk they kept saying that his platelets were low. He was in and out of the hospital again . . . He finally started to get better and now he’s going back to Children’s once a month to get chemo.

Siblings indicated that their own emotional state was dependent on the health status of their ill brother or sister. For example, a 14-year-old sister of a child with leukemia stated simply, “When she got better, I was happy. When she got worse, I was sad.” Similarly, a 12-year-old brother of a teenager with rhabdomyosarcoma explained that “on days that she got

really sick, I was worried – really worried – because I didn’t want her to get sick. It just makes me feel bad when she’s sick . . . I got happy when she felt better.”

Similarly, siblings indicated difficulty managing their reactions to the ill child’s wildly fluctuating emotions that result from steroid treatment. They reported that ill children – especially younger ones – were moody, demanding, and prone to outbursts. Siblings also indicated resentment over parents giving in to the ill child without disciplining the acting-out behavior. An 11-year-old sister of a child with Lymphoblastic Lymphoma explained:

He just screams from the steroids. He used to just be a bear . . . he would just throw fits and go crazy, hitting himself. We would actually have to hold him down and give him ravioli before he would actually hurt himself . . . Sometimes he bites [shows interviewer scar on her arm]. In January I was laying on the floor with my winter coat on, and he was throwing this big fit, and he came over and just latched onto my arm.

3.1.2 Loss of Normalcy

One of the most salient themes to emerge from interview data was siblings’ desire to maintain or reestablish a sense of normalcy after the considerable disruption of routines that accompanies childhood cancer. Siblings recalled normalcy before their brother or sister was diagnosed with cancer, and they reported anxiously waiting for their lives to go back to normal after the cancer treatments end and the threat passes.

Siblings indicated that changes in their brother’s or sister’s appearance, such as hair loss or weight gain, symbolized the broader loss of normalcy within the family. Common changes included less time with immediate family members, fewer dinners out or family outings, less attention from parents, and the incorporation of cancer treatment into everyday life. A 12-year-old brother of a child with leukemia explained that he found it difficult to adjust to his family giving his brother medicine everyday. “Medicine is just part of everyday life, you know? Dexamethasone . . . Zophren . . . It’s just like this is normal now.”

One particularly salient aspect of “loss of normalcy” was assuming a parental role within the family system, which involved decreased emotional and physical availability of parents and a concomitant increase in responsibilities such as childcare and chores. Some siblings reported that extra responsibility makes them feel as though they are contributing to their brother or sister's recovery; others resented the additional workload. A 14-year-old brother of a child with leukemia described a transition from being the “backup” caretaker of his seven younger siblings before the diagnosis to it being “a full-time job” afterward:

You know how sometimes when you get older, your parents like you to babysit and stuff? If I go over to my friend's house and help him babysit his brothers and sisters while his parents go out, it's like you just got to make sure they don't swallow anything or do stuff like jump on the couches or stuff like that . . . [Brother with cancer] is not allowed to have vitamins, like any kind of vitamins, cause they have folic acid in them and somehow that interferes with the chemo. Sometimes when my mom takes one of the little ones for like a check up or something like that, I get left babysitting sometimes, and that means I'm in charge of breakfast, bathing them, getting them their vitamins, and getting them out the door to school. So, I've got to make sure that [Brother with cancer] doesn't accidentally take a vitamin from one of the other kids, cause he don't know they're vitamins, he thinks they're candy or something like that. He sees everybody else eating one and so he wants to eat one too . . . he might like throw a fit or something like that. And most often, the only way to handle when he throws a fit is to pretty much just give him whatever he wants because it's not going to stop otherwise.

In addition to increased responsibilities, this 14-year-old sibling also communicated concern about teaching his brother about social norms, explaining “we're teaching him that if he's irritable to us, whatever he asks for, we're going to give him.” Similarly, a 14-year-old sister of a child with neuroblastoma explained that she is concerned about the adjustment of her sister when she starts kindergarten. For some siblings, family changes were more substantial. A 17-year-old sister of a teenager with anaplastic glioma recalled needing to move from her mother's to her father's house when she was 15 to become the primary caretaker of her younger brother and dogs after her older brother was diagnosed.

In addition to changes within the household, some siblings described being bounced among surrogate caretakers during times of active treatment. A 17-year-old sister of a child with rhabdomyosarcoma and optical glioma explained:

[My brother] was inpatient for a month after his surgery, because they had to wait for his incision to heal before they could start chemo. So I was living with my cousin, my friend, my grandparents, my great-grandparents – it was crazy.

Loss of normalcy was also evident in peer and school settings, with siblings citing (1) less time with friends due to concerns about germs, lack of transportation, frequent trips to the hospital or clinic, and increased need to be at home; (2) missing school; and (3) having difficulty concentrating in school or completing homework. A 17-year-old sister of a teenager with anaplastic glioma indicated that she frequently stayed home from school to watch her brother with cancer: “When he takes his Advan or something, like someone has to be here with him so he doesn’t try to drive or something, because it makes him really high.” A 14-year-old sister of a child with neuroblastoma described her reentry into school, “As soon as I walked in, everyone just stared and no one talked. I was just like looking around, like ‘okay.’ I didn’t know what to say, and none of the teachers knew what to do.” Many siblings reported that teachers were lenient about completing assignments and exams on time but that they resented the extra attention and “just wanted to be treated normally.”

In perhaps the most fundamental loss, some siblings indicated a loss of their sense of self as a result of the cancer experience, defining themselves as "the sibling of the child with cancer." This is exemplified through both explicit quotes and more subtle patterns of discussing the situation from the perspective of the child with cancer or parents. A 16-year-old brother of a child with leukemia explained that “it’s selfish to think it’s your problem also. It’s my sister going through everything.” Similarly, a 12-year-old brother of a child with leukemia explained, “I’m not important – I’m just the behind-the-scenes guy.” Siblings indicated that this shift in self-view extended to other patterns of interaction. The majority of siblings said that peers, teachers, extended family members, and family friends frequently asked about the emotional and

physical wellbeing of the child with cancer but seldom asked about the sibling. A 12-year-old sister of a child with meningioma remarked, “It gives people something to talk about with me. Like if there’s an awkward silence, they’ll be like ‘How’s [sister with cancer]’?” Finally, some siblings indicated that they feel responsible for the emotions of their family members or friends. They described not expressing their emotions or struggles to avoid burdening other people.

3.1.3 Cancer = Serious, Adult Illness

Some siblings, especially younger ones, reported initial confusion, not comprehending the seriousness of the diagnosis or understanding why everyone was “making such a big deal.” A 12-year-old sibling explained:

It was just this big word that she had: rhabdomyosarcoma . . . I was confused because I didn’t really know what cancer was, and I thought that most people get through it and it’s not a big deal. But then one time my dad sat me down and explained to me what it actually was, and then I realized that it is a big deal and it’s really bad.

Regardless, nearly all siblings came to associate cancer with a serious, adult illness that could lead to death. The word "cancer" is emotionally charged, and siblings described it as “a huge disease” or “a really big deal.” A 13-year-old sibling of a child with neuroblastoma explained that he “knew it was going to be horrible and nothing good would come out of it.”

With regard to prognosis, most siblings indicated awareness of the possibility of their brother’s or sister’s mortality. A 12-year-old sibling of a child with meningioma explained that “in math class, [she] was learning about percentages, and the topic was the leading most causes of death, and the biggest one was cancer.” Awareness of mortality was reported to be one of the most frightening components of the sibling experience. A 10-year-old brother of a child with

leukemia explained that he “thought [cancer] was something that as soon as you got it you were sure to die.” Similarly, a 16-year-old brother of a medulloblastoma patient shared his thoughts:

You gotta take the best out of life, because my sister could die – literally. I don’t want to say ‘why didn’t I do that with her?’ I want to say ‘I DID do that with her, and I know she died loving it and loving me.’

Not surprisingly, nearly all siblings reported that managing their own strong emotions was challenging. They reported being shocked by the diagnosis and overwhelmed by strong emotions such as sadness, worry, fear, anger, guilt, and helplessness. Other siblings described posttraumatic stress symptoms, comparing themselves to soldiers returning from war. They described having “meltdowns” or “breakdowns” when their brother’s or sister’s health would worsen, and two siblings reported that they had recently been medicated for anxiety. These emotions were intensified by the realization that their brother’s or sister’s life may be in jeopardy and by the changes in their daily routines and responsibilities.

Given their conceptualization of cancer as a serious disease that could lead to death, siblings implied that they lost their sense of security. They explained that cancer “happens to other people's families” and indicated lack of understanding about why it happened, how it happened, and whether or not they could get cancer, too. A 14-year-old brother of a child with leukemia wondered out loud, “I think about why it happened. I just don’t understand why God would do that.” Siblings revealed that their brother’s or sister’s diagnosis abruptly ended their carefree childhood. A 17-year-old sister of a child with rhabdomyosarcoma and optical glioma explained, “I’ve come to realize that there’s always something that could pop up. I could be happy right now, but that doesn’t mean that it’s going to last. I try not to get too happy so I don’t get too let down.”

3.1.4 Coping

Having a brother or sister with cancer was reported to be taxing and/or exceeding siblings' ability to cope. However, many siblings faced this life challenge with courage and resilience. They described a myriad of coping mechanisms, and most siblings indicated that they employed various methods to deal with thoughts and emotions related to cancer and its effects on the family. We classified coping mechanisms into three broad categories according to the work of Connor-Smith and colleagues (2000): primary control engagement coping, secondary control engagement coping, and disengagement coping (Table 3).

Primary control engagement coping refers to volitional efforts to enact control over the environment or one's reactions to the environment. Sibling examples of primary control engagement coping included instrumental or problem-focused coping, emotional disclosure or expression, and information-seeking. Instrumental or problem-focused coping included helping with household responsibilities or participating in cancer-related events or fundraisers. A 12-year-old brother of a child with leukemia explained that helping with housework and childcare allowed his mother to focus on administering the home medication regimen. He recalled an instance of his mother making a mistake with the medication, which resulted in his brother with cancer being taken to the hospital, explaining, "I'd rather him live than die, and this is what we have to do for him to be cured." Similarly, his 14-year-old sibling recalled "helping as much as [he] could – just found work and did it . . . [he] felt like a happier person because [he] was helping, like [he] was an important part of [his] family." With regard to fundraising, a 14-year-old sister of a child with neuroblastoma explained that participating in cancer events "keeps your mind off it and on it at the same time."

Some siblings indicated that emotional disclosure or expression helped them cope with strong emotions and that seeking additional information helped them understand what was happening to their brother or sister. Siblings reported talking about the cancer or writing about it in a journal “made it feel better” or “gave [them] happier thoughts inside.” Other siblings reported feeling better after crying, either alone or with someone else. Several siblings reported that they looked on the internet or in science textbooks for information about cancer, while other siblings indicated that they asked their parents or the medical staff questions. Most siblings indicated that the extra information helped ease their worry; others indicated that inaccurate information increased cancer-related anxieties.

Secondary control engagement coping refers to volitional efforts to fit with or adapt to one’s environment, including positive thinking or cognitive reframing, religion, and acceptance. With regard to positive thinking or cognitive reframing, siblings indicated that changing the way they think about the cancer helped mitigate strong emotions. A 16-year-old brother of a child undergoing bone marrow transplant for leukemia explained that he focuses on his mother’s successful fight against breast cancer, “Mom beat cancer, and so will [brother with cancer].” Some siblings indicated that acceptance of the situation helped them “move on” after the diagnosis. A 14-year-old brother of a child with leukemia revealed that he “accepts [the cancer] as a fact, and that’s pretty much all you can do . . . there’s nothing you can do to change it.” Other siblings said that religion or prayer helps them to accept the situation. For example, a 16-year-old brother of a child with leukemia explained that he “knows that [the cancer] is in God’s hands and that [his] brother will be alright.”

Unlike primary and secondary control engagement coping, disengagement coping refers to a response that is oriented away from the source of stress, such as distraction,

overachievement, or avoidance. The most commonly cited coping method was distraction, exemplified by listening to music, playing video games, or hanging out with friends to temporarily “get their mind off the cancer.” Siblings reported that when they stopped thinking about cancer, their intense worry, sadness, or other strong cancer-related emotions subsided. Similar to distraction, a subset of younger siblings reported that they focus on improving their own performance in school or sports, either to stop thinking about the cancer (disengagement coping) or to reinstate parental attention (primary control engagement coping). With regard to avoidance, several siblings indicated dealing with thoughts or emotions related to the cancer by “trying to think of something else – FAST.” A 17-year-old sister of a teenager with anaplastic glioma explained, “I try to get the thoughts out of my head – sometimes it helped, and sometimes I would just get paranoid that something bad is happening. Sometimes the thoughts just would happen.” Another 17-year-old sister of a child with rhabdomyosarcoma and optical glioma explained:

I am a big fan of denial. Someone would tell me something and I'd act like I had no idea what was going on. I go out just to get away from everything . . . I go out with my friends and come home and act like nothing ever happened. I just want to avoid getting upset.

3.1.5 Social Support

The ability of an individual to cope with a stressor such as a family member’s cancer diagnosis is enhanced by coping resources such as social support, and siblings described both positive and negative changes within their support systems following diagnosis. With regard to immediate family, most siblings reported that parents and ill children were generally less available due to hospital visits and treatment demands but that they experienced increased closeness following the cancer diagnosis. A 13-year-old brother of a child with neuroblastoma explained:

My mom, my dad, my brother, and my sisters would support me and say ‘don’t worry, she’s going to be okay’ if I got really sad about it, and then I would start to feel better. They were the ones who gave me the most support – it felt best to be with them.

Siblings also looked to parents for cues about how to react to the diagnosis. A 14-year-old sister of a child with neuroblastoma recalled observing her mother return home for the first time after learning about the diagnosis, “I thought [my mom] was just going to go on the couch and watch TV, which she never does. But when I saw her go to the laundry room I was like ‘oh, it’s going to be fine.’”

When parents were unavailable, extended family members, particularly grandparents, provided emotional and instrumental support to siblings. An 11-year-old sister of a child with Lymphoblastic Lymphoma explained that her grandmother transported her to and from the hospital and “felt bad for [her] because [brother with cancer] was getting all the attention.” In addition to direct support to siblings, extended family members supported parents, which indirectly influenced siblings. Family friends and fellow church members also supported parents by offering meals, rides, prayers, and companionship.

Siblings reported that support from friends was inconsistent. While friends were a source of distraction to “get their minds off [the cancer]”, most siblings reported reduced contact with friends due to lack of transportation, concern about contamination, or increased time in chores or childcare activities. With regard to offering emotional support, most siblings indicated that their friends “just don’t understand” or “don’t care” after a few days. Other siblings revealed increased popularity as a result of the cancer. A 14-year-old brother of a child with leukemia recalled making new friends when peers would say, “you’re the kid whose brother has cancer,” and a 14-year-old sister of a child with neuroblastoma recalled, “I’ve never had so many people wave and say hi to me. It’s like, ‘I don’t know who this person is, but they’re waving and saying

hi and asking about my sister.” Despite newfound popularity, many siblings indicated refraining from talking about the cancer with friends to avoid upsetting themselves or their friends. Instead, most siblings reported talking to parents, and a subset indicated confiding in professionals such as psychologists or social workers at the hospital, teachers, or counselors.

Finally, some siblings indicated being comforted by feeling part of the larger cancer community. This meant participating in cancer-related events or fundraisers with other families of individuals with cancer, as well as simply meeting others who are battling the disease. An 11-year-old sister of a child with Lymphoblastic Lymphoma recalled being astonished when she met a 38-year-old woman in a retail store who had the same diagnosis as her brother. The few siblings who had the opportunity to meet other siblings of children with cancer indicated that this was valuable. A 14-year-old brother of a child with leukemia remarked, “It was really helpful. You know what they’re going through, too.”

3.1.6 Potential Moderators

During the process of qualitative analysis, attention was given to factors that might impact the sibling experience, such as age, gender, birth order, and time since diagnosis. Although our sample is too small to report conclusions with confidence, we attempted to generate hypotheses for future, larger-scale studies.

With regard to age, the most notable difference between older and younger adolescents was the degree of confusion following diagnosis. Younger adolescents did not comprehend the seriousness of a cancer diagnosis, the reason for extended parental absence and worry, and the increased attention on the ill child. They did not understand how cancer differs from other childhood illnesses that are cured quickly. In general, siblings reported that the cancer experience

got better over time due to improvements in the ill child's health and siblings' improved coping competence. Younger adolescents reported that things got worse before they got better; older adolescents comprehended the serious nature of the diagnosis from the outset and were more likely to report loss of security. In other age-related differences, younger but not older adolescents coped by overachieving in school or sports, and extended family members offered more instrumental support to younger adolescents who had more practical needs than older adolescents. While both younger and older siblings evaluated time with friends to be a helpful distraction, older siblings also reported greater reliance on friends as a source of emotional support.

With regard to birth order, siblings younger than the child with cancer were more likely to discuss loss of security, uncertainty, and seriousness of cancer. In contrast, siblings older than the ill child tended to discuss increased household and childcare responsibilities. Few differences emerged with regard to sibling gender and time since diagnosis.

3.2 QUANTITATIVE RESULTS

3.2.1 Contextual Threat and Treatment Intensity

Bivariate correlations were calculated among contextual threat ratings, treatment intensity, and distress (Table 4). Holistic contextual threat provided an objective indicator of the level of threat associated with the cancer experience as a whole. Using holistic ratings, contextual threat was positively correlated with higher scores on the CDI, RCMAS, and PSS, with a similar trend for PTSD-RI. There was no significant association between holistic contextual threat and scores on

the ITR-2. Average contextual threat scores were obtained by calculating a mean score based on various aspects of contextual stress (e.g., degree of parental separation, distance to the hospital, presence of social support). In contrast to holistic ratings, average contextual threat was not significantly correlated with any of the distress measures. Thus, holistic contextual threat was used in all subsequent analyses. Treatment intensity was positively associated with scores on the CDI and RCMAS, with a similar trend for PTSD-RI; it was not significantly associated with PSS scores.

Next, linear regression analyses were conducted to further examine relationships among contextual threat, treatment intensity, and distress. Initial analyses confirmed the above associations of holistic contextual threat and treatment intensity with distress. Contextual threat predicted scores on the CDI ($R^2 = .43$, $p = .002$), RCMAS ($R^2 = .24$, $p = .03$), and PSS ($R^2 = .47$, $p = .001$), with a trend on analysis of PTSD-RI ($R^2 = .15$, $p = .10$). ITR-2 accounted for significant variance in scores on the CDI ($R^2 = .27$, $p = .02$) and RCMAS ($R^2 = .46$, $p = .001$), with a trend for PTSD-RI scores ($R^2 = .18$, $p = .07$). ITR-2 did not predict PSS. These results suggest that contextual threat and treatment intensity are associated with sibling distress.

Next, we examined whether associations between holistic contextual threat and distress were independent of treatment intensity. For these regressions, treatment intensity was entered in the first step and holistic contextual threat in the second step of models predicting scores on distress measures. Results showed an association between contextual threat and scores on the CDI ($R^2 = .26$; $p = .007$) that was independent of ITR-2; however, treatment intensity retained an independent association with CDI ($R^2 = .27$, $p = .07$), suggesting that treatment intensity and contextual threat contribute independently to levels of sibling depression. Contextual threat also predicted scores on the RCMAS (trend: $R^2 = .08$; $p = .10$) and PSS ($R^2 = .39$; $p = .003$)

independently of treatment intensity, which did not significantly contribute to these outcome measures. When entered together, neither ITR-2 nor contextual threat independently predicted scores on the PTSD-RI. Overall, these results suggest that contextual threat independently accounts for a portion of the variance in depression, anxiety, and perceived stress scores, and treatment intensity independently accounts for a portion of variance in depression only.

3.2.2 Possible Moderators

Point-biserial and Pearson Product-Moment correlations were calculated to determine associations among current age, age at diagnosis, time since diagnosis, relative birth order, gender, contextual threat, treatment intensity, and distress measures (see Table 4). These analyses revealed a positive association of current age with symptoms of depression and posttraumatic stress. A similar and possibly related pattern was observed for age at diagnosis, with older age being associated with more symptoms of depression and greater posttraumatic and perceived stress. Because of the high correlation between current age and age at diagnosis ($r = .95$), only current age was examined as a covariate in subsequent analyses.

With regard to relative birth order, siblings younger than the child with cancer endorsed more symptoms of depression, anxiety, perceived stress, and posttraumatic stress than siblings older than the child with cancer. Siblings who were younger also had brothers or sisters who received more intense treatment protocols. Time since diagnosis and gender were not significantly associated with scores on any distress measures.

Next, a series of regression analyses was carried out to examine associations among holistic contextual threat, treatment intensity, and distress after controlling for the identified covariates: current age and relative birth order. Entering current age and relative birth order into

the first step of the regression model reduced the amount of variance (R^2) accounted for by holistic contextual threat from .43 to .22 for CDI, from .24 to .12 for RCMAS, from .47 to .33 for PSS, and from .15 to .04 for PTSD-RI. Nonetheless, contextual threat remained a significant predictor of CDI ($p = .001$) and PSS ($p = .001$), with a trend for predicting RCMAS ($p = .07$), suggesting that the positive association between holistic contextual threat and distress is largely independent of current age and relative birth order. After considering covariates, contextual threat no longer significantly predicted PTSD-RI scores. When age and relative birth order were entered into models with treatment intensity, R^2 values for ITR-2 decreased from .27 to .003 for CDI, from .46 to .15 for RCMAS, and from .18 to .00 for PTSD-RI, with only the association between treatment intensity and anxiety remaining significant ($p = .04$). Thus, the association of treatment intensity with depression and posttraumatic stress is largely explained by associated variance in current age and relative birth order.

Finally, a series of regression analyses was conducted to determine whether current age, relative birth order, treatment intensity, and contextual threat independently predicted distress. For this purpose, current age was entered in step 1, relative birth order in step 2, treatment intensity in step 3, and contextual threat in step 4 of models predicting distress scores. Results showed that depression scores were predicted by current age ($R^2 = .22$, $p = .04$); relative birth order independently of age (R^2 change = .36, $p = .001$); and contextual threat independently of age and relative birth order (R^2 change = .22, $p = .001$). As expected, there was no independent association of treatment intensity with CDI scores. For anxiety, current age and relative birth order did not significantly contribute to variance in RCMAS scores; however, anxiety scores were predicted by treatment intensity independently of age and relative birth order (R^2 change = .15, $p = .09$), and by contextual threat independently of age, relative birth order, and treatment

intensity (R^2 change = .07, $p = .14$). Perceived stress was predicted by relative birth order independently of current age (R^2 change = .23, $p = .02$), and by contextual threat independently of age, relative birth order, and treatment intensity (R^2 change = .35, $p = .001$); there was no independent association of current age or treatment intensity with PSS scores. Finally, posttraumatic stress scores were predicted by relative birth order independently of current age (R^2 change = .29, $p = .03$), with a trend for being predicted by current age (R^2 change = .19, $p = .11$); posttraumatic stress was not independently associated with contextual threat or ITR-2. Taken together, these results suggest that older age, younger relative birth order, and greater contextual threat are independently associated with more symptoms of depression in siblings. Higher levels of anxiety are predicted independently by greater treatment intensity and more contextual threat. Higher levels of perceived stress are predicted independently by younger relative birth order and greater contextual threat. Finally, current age and relative birth order independently accounted for variability in PTSD symptoms.

3.2.3 Subgroup Analyses: Older vs. Younger Adolescents

Based on the developmental literature and the theoretical model of stress, it was hypothesized that older siblings (current age 15-17 years) would show more distress than younger siblings (10-14 years). Regression analyses supported this age effect, with older current age being associated with more depression and posttraumatic stress independently of contextual threat, treatment intensity, and relative birth order. To further examine age, we employed ANOVA to compare older and younger age groups on measures of distress. Consistent with expectations, results of these analyses showed that older adolescents endorsed more symptoms of depression ($F(1,18) = 9.77$, $p = .006$), anxiety, ($F(1,18) = 4.95$, $p = .04$), and posttraumatic stress ($F(1,18) = 7.81$, $p =$

.01) than younger adolescents, with a similar trend for perceived stress ($F(1,18) = 2.57, p = .13$; see Figure 1). Consistent with regression findings, when relative birth order was entered as a covariate, older adolescents continued to score higher on measures of depression ($F(1,17) = 4.35, p = .05$) and posttraumatic stress ($F(1,17) = 3.24, p = .09$) than younger adolescents, but differences in anxiety and perceived stress were no longer evident.

3.2.4 Clinical Context

Scores on the PTSD-RI revealed that 20% of participants ($n = 4$) showed no posttraumatic stress reaction (score < 12), 50% ($n = 10$) showed mild reactions (score 12 to 24), 20% ($n = 4$) showed moderate reactions (score 25 to 39), and 10% ($n = 2$) showed severe reactions (score >39 ; see Table 5). On the CDI, 15% ($n = 3$) of siblings fell into the clinical range for depression (score ≥ 18). None of the siblings older than the child with cancer fell into the highest quartile of total anxiety scores on the RCMAS, as compared to age- and gender-matched norms, while 43% of siblings younger than the child with cancer fell into the highest quartile, with two siblings falling above the 97th percentile in total anxiety scores. The same pattern is true when broken down by younger- and older adolescent, though aforementioned analyses suggest that birth order may be a better indicator of anxiety.

4.0 DISCUSSION

In this study of 20 adolescent siblings of pediatric cancer patients, qualitative and quantitative methods were employed to examine the sibling experience. Information derived from qualitative interviews fell into three broad categories consistent with the transactional theory of stress (Lazarus & Folkman, 1984). First, siblings indicated uncertainty with regard to diagnosis, prognosis, and family changes, and they described experiencing an emotional “roller coaster” as a result of the ill child’s fluctuating health and mood states. Second, siblings described a general loss of normalcy following the cancer diagnosis, including assuming a parental role. Siblings also indicated a loss of their sense of identity. Third, siblings described cancer as a serious, adult illness and were aware of the risk of mortality. This knowledge was accompanied by strong emotions, including sadness and worry, and a general loss of security. Qualitative themes are consistent with previous research that reports emotional intensity, loss of attention within the family, and loss of normalcy and security (e.g., Freeman et al., 2000; Sargent et al., 1995; Sloper, 2000). Although themes related to loss are relatively common in the qualitative sibling literature, coping is seldom investigated. The current sample of siblings reported coping with cancer-related stressors using a variety of methods, including instrumental coping, distraction, and avoidance. Given that coping among siblings is poorly understood, these data lay the groundwork for future exploration of this complex topic.

In quantitative analyses of relationships among contextual threat, treatment intensity, and subjective measures of distress, results showed positive associations between holistic contextual threat and symptoms of depression, anxiety, and perceived stress, independent of siblings' current age and relative birth order. With regard to treatment intensity, siblings who had brothers or sisters on more intensive regimens endorsed more symptoms of anxiety. Although preliminary, results suggest that contextual threat is a stronger predictor of sibling distress than treatment intensity. While treatment intensity per se has not been investigated in the sibling literature, a subset of studies has found no relationship between cancer diagnosis and sibling adjustment (Houtzager et al., 1999). It is likely that treatment intensity varies by cancer diagnosis; thus, current findings are consistent with prior studies and suggest that factors other than the sick child's diagnosis and treatment influence levels of sibling distress.

Quantitative investigation of contextual threat is novel in the sibling literature and is a promising direction for future study. Holistic contextual threat scores covaried with measures of sibling depression, anxiety, and perceived stress. The holistic approach is employed in other semi-structured stress interviews (Rudolph & Flynn, 2007; Williamson et al., 2003), which also assign threat values based on overall descriptions of the nature and extent of stressors. In contrast, there was no association of average contextual threat, as assessed across a series of stress domains (e.g., distance to the treatment facility, social support, additional stressors), and measures of distress. This suggests that various aspects of contextual threat have synergistic rather than additive effects on sibling stress; in other words, the whole is greater than the sum of its parts.

Also noteworthy is the finding that contextual threat does not predict sibling posttraumatic stress. The PTSD-RI was the only quantitative measure to include questions

specific to the cancer experience, though qualitative reports suggest that siblings view their brother's or sister's cancer as a life threatening experience, with some siblings likening their emotional reactions to those of soldiers returning from war. Thus, siblings' experience of posttraumatic stress may be so ubiquitous that it is unaffected by contextual threat. Indeed, 50% of siblings endorsed mild posttraumatic stress reactions and an additional 30% endorsed moderate or severe reactions. These results are consistent with previous work; Alderfer et al. (2003) found that 49.3% of siblings showed mild posttraumatic stress reactions and 32.0% showed moderate to severe reactions, and that mean PTSD-RI scores were significantly higher than those of a comparison group.

In contrast to findings on posttraumatic stress, most siblings did not fall into the clinical range on measures of depression or anxiety, though scores covaried positively with contextual threat. Although contextual threat has not been assessed in prior sibling samples, semi-structured stress interviews have been used in studies of adolescent depression and anxiety (e.g., Rudolph & Hammen, 1999; Rudolph et al., 2000). The connection between higher contextual threat and symptoms of depression and anxiety may be a broader phenomenon in adolescent developmental psychopathology, and unlike measures of posttraumatic stress, not unique to the experience of siblings of pediatric cancer patients. With regard to perceived stress, it makes sense that siblings who report higher levels of contextual threat also endorse more subjective stress. Given that these reports are completed by the same respondent, the two measures may be confounded. For example, siblings who are more attuned to the stressfulness of the cancer experience may offer more threatening details than siblings who experience less subjective stress. On the other hand, the positive association may represent siblings' accurate perception of stress based on objective levels of threat surrounding the cancer diagnosis. Future research may benefit from gathering

information regarding contextual threat from someone other than the sibling, permitting an examination of whether perceived stress or coping style mediate the connection between contextual threat and sibling distress.

One question that pervades the sibling literature is whether results reflect normal variations in distress or clinically significant elevations. Current findings are consistent with prior research (e.g., Alderfer et al., 2003; Barrera et al., 2002, 2004; Lahteenmaki et al., 2004; Wellisch et al., 2006) which suggests that relatively few siblings show clinically significant levels of depression or anxiety, though many show elevations in posttraumatic stress. Future sibling research may benefit from including measures that reflect variations in normal functioning rather than psychopathology per se, such as perceived and posttraumatic stress, quality of life, and mood states. Indeed, qualitative findings about high levels of sibling stress and negative mood states (e.g., Sloper, 2000) tend not to be reflected in scores on paper-and-pencil symptom questionnaires.

The few existing studies that have considered the role of moderating factors such as age, relative birth order, gender, or time since diagnosis have yielded inconsistent findings. Thus, consistent with the developmental psychopathology perspective, a secondary aim of the current study was to examine potential moderators of sibling distress. Analyses showed that older siblings endorsed more symptoms of depression and posttraumatic stress than younger siblings independent of contextual threat, treatment intensity, and relative birth order. In a clinical context, none of the younger adolescents fell into the highest quartile of anxiety scores compared to age- and gender-matched norms, while 43% of older adolescents scored in the highest quartile, with two siblings falling above the 97th percentile in total anxiety scores. This is consistent with the majority of previous research which reports no *mean* elevation in anxiety (e.g., Alderfer et

al., 2003; Barrera et al., 2004). However, few studies have examined sibling anxiety as a function of age; one exception is the work of Houtzager et al. (2003), which found that older age is associated with higher anxiety. Qualitative analyses also revealed age-related differences, with younger adolescents reporting more confusion, overachievement, and instrumental support from extended family members. In contrast, older adolescents were more likely than their younger counterparts to discuss loss of security and cite friends as a source of emotional support. The finding that older adolescents endorse higher distress than younger adolescents is consistent with the transactional theory of stress (Lazarus & Folkman, 1984), with older adolescents being more cognitively sophisticated and thus having the ability to appraise their situation as more threatening and of greater potential harm.

An interesting finding to emerge from both qualitative and quantitative data was an association between relative birth order and sibling distress. Specifically, when compared to siblings who were older than the child with cancer, siblings younger than the child with cancer were more likely (1) to discuss the seriousness of the cancer diagnosis and related uncertainty and loss of security, and (2) to score higher on quantitative measures of depression and perceived and posttraumatic stress, independent of sibling age, contextual threat, and treatment intensity. Although relative birth order did not independently account for variability in anxiety, an interesting pattern of clinical scores emerged. None of the siblings who were older than the child with cancer fell into the highest quartile of total anxiety scores when compared to age- and gender-matched norms, while 43% of siblings younger than the child with cancer fall into the highest quartile. It is possible that siblings younger than the child with cancer perceive the cancer situation differently. For example, siblings younger than the ill child may perceive their older brother or sister as a stable or protective figure whose illness leads to a fundamental loss of

security, or they may receive differential treatment from parents. Alternately, the tendency of siblings older than the ill child to assume increased responsibility at home may be an active coping mechanism and give them a defined role in helping the family handle the challenges of childhood cancer. Examination of relative birth order is novel in the pediatric cancer sibling literature and warrants further investigation.

Overall, quantitative and qualitative results are not only consistent but also complimentary. We conceptualized cancer as a stressor that may or may not lead to feelings of distress in siblings depending on their cognitive appraisal of the event as threatening. Analysis of qualitative data allowed us to identify themes related to threat, loss, and aspects of the cancer that exceed perceived coping ability. According to Lazarus and Folkman's (1984) theory of transactional stress, these themes should predict subjective experiences of distress. Consistent with this model, siblings who reported greater contextual threat showed higher scores on measures of distress. Moreover, older adolescents who are developmentally more likely to appraise the situation as threatening than younger adolescents showed the highest levels of distress. Although the current study was not designed to identify mediators, results suggest that cognitive appraisals of threat may be one pathway linking the cancer experience to distress among siblings. Taken together, the qualitative and quantitative data provide substantive support for conceptualizing the sibling experience according to the transactional theory of stress.

4.1 STRENGTHS AND LIMITATIONS

Unlike the majority of previous work that is largely atheoretical, the present study applies the developmental psychopathology and transactional stress models (Cummings et al., 2000; Lazarus

& Folkman, 1984) to the examination of siblings of pediatric cancer patients. We aimed to provide a more systematic, theoretically grounded report that contributes to current understanding and informs future work. Indeed, this report integrates qualitative and quantitative findings to present a more comprehensive description of the sibling experience. Methodological strengths include recruitment of a more homogeneous sample than much of the extant literature, with the inclusion of only adolescent siblings of children who are at least 6-mos. post diagnosis and on active treatment. Furthermore, 85% of data were collected outside the hospital setting, thereby separating the measurement of distress from the location that has been associated with illness; our intention was to obtain a more realistic, less inflated picture of general distress within this population.

The most basic limitation of this study is its cross-sectional design, which limits our ability to identify patterns that develop over time or make causal claims about relationships among variables. Because we did not include comparisons with a control group, it is not clear to what extent our findings represent a departure from normative developmental processes. Furthermore, this study was underpowered to explore statistical significance in most quantitative analyses, and, due to the small sample size, it is possible that significant outcomes are spurious. However, the consistency of observed associations across different measures of distress suggests that this is not the case.

Although this study employs a more homogeneous sample than prior research, the span of ages (10 to 17) is considerable. In addition, specifying that the ill child must have been on active treatment for at least 6-mos. systematically eliminates siblings of children with briefer treatments, and the sample was comprised of all Caucasian families, thus limiting generalizability of findings. Furthermore, the current sample may not be representative of the

“typical” pediatric cancer family. Families that agreed to participate may have less emotional impairment, better prognosis, or less intensive treatment. Alternately, they may be more impaired by the cancer experience and therefore view psychosocial sibling research as more pertinent. Finally, the lack of information about socio-economic status of participating families limits our ability to situate the sample within the population of families of children with cancer.

There are also limitations with regard to qualitative analysis. Data were analyzed by a single researcher and were not verified by a second coder, nor were findings confirmed in focus groups with siblings. Also, the grounded theory methodology specifies that data collection should proceed until theoretical saturation occurs, rather than stopping at a predetermined sample size. Although findings about stress appear to be robust, questions remain about the differential implementation and goals of various coping methods.

In addition to methodological limitations, theoretical considerations regarding the lack of consensus in the field about how to define stress and coping in child and adolescent populations limits construct validity. There is also question about whether symptoms of distress as measured in this study are indicative of increased risk for psychopathology or reflect normal variability. Finally, we acknowledge that the constructs examined in this study are only a few of the factors that influence the course of sibling development, and we do not quantitatively measure outcomes associated with positive adjustment to the cancer experience. Overall, however, findings represent a step toward understanding pathways that may lead to competence or maladjustment in siblings of children with cancer.

4.2 FUTURE RESEARCH

Given the early stage of the field of sibling research, there are many avenues for future study. Quantitative outcomes should be replicated and extended to include groups not represented in the current study, including bereaved siblings, bone marrow donors, and siblings of children with less intensive treatment regimens. Future research should continue to integrate qualitative and quantitative findings to allow for a comprehensive understanding of siblings' experiences to emerge. In particular, the field would benefit from prospective studies of sibling coping to better understand (1) differences according to age and process of adjustment; (2) changing coping goals over time; and (3) relationships between coping strategies and distress. Findings from qualitative work may be strengthened by the addition of a quantitative coping measure.

Overall, research would benefit from the adoption of a developmentally-sensitive view of sibling adjustment. Larger samples would allow for subgroup analyses of siblings of different ages, and longitudinal designs would elucidate adaptation over time. For example, siblings may react to the cancer differently when the crisis has passed, when they progress through developmental milestones, when they have a more sophisticated cognitive capacity to assign meaning to the event, or when they have children of their own. Thus, future work could also assess adult siblings of pediatric cancer patients who may provide qualitative accounts of their post-diagnosis trajectory and lay the groundwork for longitudinal work.

Finally, consistent with a developmental psychopathology approach, future research should continue to identify and investigate effects of moderators such as age, relative birth order, contextual threat, and treatment intensity. Other possible moderators might include preexisting sibling psychopathology, presence of additional siblings, family function, IQ, parental mental health, and religious beliefs.

APPENDIX

EXAMPLES OF INFORMATION IN CONTEXTUAL THREAT RATINGS

S01: Holistic contextual threat = 1

S01 is a 16-year-old male who is the youngest of three children. He has two older brothers, ages 18 and 21. At the time of the interview, S01 had just begun his junior year of high school where he participated in several sports (baseball, football, basketball, and wrestling). S01 transferred to public school from private school at the beginning of his freshman year.

S01's older brother (age 18) was diagnosed with ALL one year ago. Currently, his brother goes to the hospital once per month for chemo. S01 reported that the hospital is 15-20 min away. He said that his mom goes to the hospital with his brother and sometimes stays overnight (~25-30% of the time). During these times, his dad generally was home. However, S01 reported that he often made dinner for himself and got himself ready for the next day.

S01's dad is retired, and his mom is still working. He reported that the family was impacted financially to some degree, but that "at the time, my dad would just spend the money so we wouldn't have to worry about it." He indicated that the family does not go out as often because his brother with cancer cannot go in order to avoid infection risk.

With regard to social support, S01 indicated that he became closer to his best friends after the cancer diagnosis. At the time of interview, he had been dating his girlfriend for 1-wk. He indicated that he can talk to his friends, parents, or counselors at school. He lives at home with his mom, dad, and brother w/ cancer; his oldest brother lives at college.

He reported that another source of stress in his life is thinking about college.

S20: Holistic contextual threat = 4

S20 is a 17-year-old female with an older brother (age 18, with anaplastic glioma), and a younger brother (age 15). Her older brother was diagnosed with cancer 23-months prior to the interview. S20 reported that her brother was inpatient for 12 consecutive weeks when first diagnosed; at the time of interview, she reported that her brother goes to the hospital every other week to receive experimental chemo, MRIs, and check-ups. The family lives approximately an hour and a half from the treatment facility, and S20's mother generally accompanies the ill child to appointments. When they need to stay overnight, S20 and her younger brother generally stay home with their father. S20 reported that her brother often throws up from the chemo when he comes home from the hospital.

When her brother was diagnosed, their mother quit her job as an operating room tech. She remained unemployed for nearly 2-years before returning to work a few weeks prior to the interview. Their father works at a warehouse. Although the cancer otherwise would have had a considerable financial impact, S20 reported that charity organizations have donated gas, Christmas gifts, and food.

S20 reported that she has two friends and that she has recently lost some friends because of "too much drama." She reported that she gets stressed by rumors at school and by peers trying

to fight with her. She indicated there is “sometimes” someone available for her to talk to. At the time of the interview, S20 reported that she was on homebound after a recent psychiatric hospital visit due to her “breaking down” and threatening to run away.

S20’s parents divorced about 13-years ago. She lives at home with her father and two brothers, and her mom visits occasionally. Her grandfather is a truck driver and occasionally lives at their house when he is not on a job. When her brother was first diagnosed, S20 reported that she was forced to move from her mother’s to her father’s house in order to take care of her younger brother (then age 13) and dogs while their parents were at the hospital, sometimes for several days in a row without another adult present. S20’s father is blind, which means that S20 and her younger brother assume many household responsibilities. Their household is characterized as conflictual, with frequent fighting among family members.

TABLES

Table 1: Participant Demographic Data

Subject	Gender	Age	Relative Birth Order (relative to child w/ cancer)	Primary Cancer Diagnosis	Time Since Dx (mos.)
S01	Male	16	Younger	Leukemia (ALL)	12
S02	Male	14	Older	Leukemia (ALL)	21
S03	Male	12	Older	Leukemia (ALL)	21
S04	Male	17	Older	Leukemia (ALL)	33
S05	Male	14	Older	Leukemia (ALL)	33
S06	Male	17	Younger	Meduloblastoma	8
S07	Female	12	Older	Meningioma	11
S08	Female	14	Older	Leukemia (ALL)	8
S09	Female	14	Older	Leukemia (ALL)	8
S10	Male	12	Younger	Rhabdomyosarcoma	9
S11	Female	11	Older	Lymphoblastic Lymphoma	9
S12	Female	14	Older	Neuroblastoma	16
S13	Male	13	Older	Neuroblastoma	16
S14	Male	10	Older	Leukemia (ALL)	12
S15	Male	16	Younger	Leukemia (ALL)	8
S16	Female	10	Younger	Leukemia (ALL)	19
S17	Female	17	Older	Rhabdomyosarcoma	13
S18	Male	14	Older	Leukemia (ALL)	22
S19	Male	15	Younger	High-Grade Glioma	23
S20	Female	17	Younger	High-Grade Glioma	23

Table 2: Qualitative Codes: Stress

Uncertainty	
Uncertainty	Siblings describe considerable uncertainty surrounding the diagnosis. The family does not know what is wrong with the child, and there are multiple doctor visits, tests, incorrect diagnoses, and hypotheses. Uncertainty persists after diagnosis and extends to prognosis, survival, and changes within the family.
Dealing with the "roller coaster" of ill child's health and mood states	Siblings describe a series of ups and downs. They report difficulty managing their reactions to the ill child's fluctuating emotions, which are salient as a result of the steroids and put the family on edge. Siblings report ill children to be moody and demanding, and they report that parents often give in and seldom discipline the ill child. Siblings also describe a roller coaster of hope and disappointments, or of nervousness and relief, when the ill child's health vacillates between improvement and decline.
Loss of Normalcy	
Desire to maintain or re-establish sense of normalcy	Siblings indicate a desire to maintain or reestablish a sense of normalcy, with the implication that life is distinctly NOT normal when you have a brother or sister with cancer. They talk about "normalcy" before their brother or sister was diagnosed with cancer and report looking forward to their lives going back to normal after treatments end.
Assuming parental role	Some siblings report changes in their relationship with parents, including feeling isolated from parents, getting less attention from them, or being the object of parents' increased irritability. Many siblings report considerable increases in household responsibilities after diagnosis, including caring for younger children or having more chores around the house.
Loss of own identity	Some siblings indicate that they lose their sense of self as a result of the cancer experience and that they begin to define themselves as "the sibling of the child with cancer." Many show difficulty discussing the cancer from their own perspective, instead focusing on the difficulty of the child with cancer and parents. They report that others ask about how the child with cancer is doing but neglect to ask how the healthy sibling is handling the situation.
Cancer = Serious Adult Illness	
Cancer = serious adult illness	Siblings indicate that the word "cancer" is emotionally charged, with past experience with cancer generally in the context of adults. They indicate that the disease is serious with intense treatment, and that it may involve death.
Confusion	A subset of siblings indicate a period of confusion after the diagnosis. They explain that initially they did not realize the seriousness of the diagnosis, the reason for extended parental absence and worry, and the increase in attention given to the ill child.
Awareness of mortality	Many siblings indicate that they believe their brother or sister could die from the cancer. This idea is reported to be one of the most difficult and frightening aspects of dealing with their brother's or sister's cancer diagnosis.
Managing strong emotions	Siblings report being shocked by the cancer diagnosis and overwhelmed by strong emotions such as sadness, worry, fear, anger, guilt, and helplessness.
Disrupted sense of security	Siblings indicate that cancer "happens to other people's families" and wonder why it happened to theirs. They indicate a fundamental loss of security, and many siblings report that they are waiting for the next bad thing to happen.

Table 3: Qualitative Codes: Coping

Primary Control Engagement Coping	
Instrumental / Problem-Focused Coping	Siblings report feeling better by actively doing something to improve their situation, despite few opportunities to help directly. They report increasing their contribution to household and childcare activities to alleviate parental stress and participating in cancer-related events and fundraisers.
Emotional disclosure & expression	Siblings indicate that they deal with strong emotions by talking about cancer or crying, either alone or with a parent, grandparent, or other person. Some siblings report that writing in a journal is helpful.
Information-Seeking	A subset of siblings report attempting to find information about the cancer diagnosis and prognosis on the internet, in textbooks, and by asking questions to parents or doctors. Most report this to be helpful, though some indicate that false information led to increased anxiety.
Secondary Control Engagement Coping	
Positive thinking	Some siblings report that it is imperative for them to focus on the positive and remain optimistic about their brother's or sister's battle with cancer, which helps them deal with strong emotions.
Acceptance	Some siblings indicate that they cope with the cancer by accepting it as fact and acknowledging that there is nothing they are able to do to change the situation. They report that this allows them to move on and avoid becoming stuck.
Religion	A subset of siblings report that they turned to religion to help them cope. This includes increased attendance at church and increased prayer, as well as the emotional and instrumental support of fellow church members.
Disengagement Coping	
Avoidance	Some siblings report that they cope with the cancer by simply trying not to think or talk about it. This is expressed explicitly (e.g., "I just tried not to think about it") as well as implicitly in terms of avoiding the topic of cancer or their reaction to cancer within the interview itself.
Distraction	Nearly all siblings report active attempts to distract themselves from thoughts and feelings related to cancer. Frequently cited methods of distraction include listening to music, playing video games, using the computer, watching TV, and spending time with friends.
Overachievement	Some younger siblings indicate that they focus their attention on succeeding in academic, musical, sports, and leadership pursuits, either to stop thinking about the cancer or to attract positive parental attention. In the latter case, this could be conceptualized as primary control engagement coping.

Table 4: Correlations Among Contextual Threat, Treatment Intensity, Distress Measures, and Possible Moderators

	Age	AgeDx	Gender	BrthOrd	TimeDx	ITR-2	CtxtAvg	CtxtWh	CDI	RCMAS	PSS	PTSDRI
Age	1.00	0.95**	-0.12	0.17	0.19	0.17	0.03	0.23	.46*	0.30	0.36	0.44*
AgeDx	0.95**	1.00	-0.02	0.16	-0.11	0.19	0.01	0.25	.43*	0.33	.41†	.47*
Gender	-0.12	-0.02	1.00	-0.09	-0.30	-0.07	-0.19	0.00	0.10	0.25	0.20	0.01
BrthOrd	0.17	0.16	-0.09	1.00	-0.05	.69**	0.00	0.21	.67**	.57**	.51*	.61**
TimeDx	0.19	-0.11	-0.30	-0.05	1.00	-0.14	0.02	-0.07	0.12	-0.15	-0.11	-0.01
ITR	0.17	0.19	-0.07	.69**	-0.14	1.00	0.13	0.32	.52*	.68**	0.32	.42†
CtxtAvg	0.03	0.01	-0.19	0.00	0.02	0.13	1.00	.79**	.39†	0.27	0.34	0.27
CnxtWh	0.23	0.25	0.00	0.21	-0.07	0.32	.79**	1.00	.65**	.49*	.69**	.38†
CDI	.46*	.43*	0.10	.67**	0.12	.52*	.39†	.65**	1.00	.76**	.83**	.76**
RCMAS	0.30	0.33	0.25	.57**	-0.15	.68**	0.27	.49*	.76**	1.00	.66**	.71**
PSS	0.36	.41†	0.20	.51*	-0.11	0.32	0.34	.69**	.83**	.66**	1.00	.72**
PTSDRI	0.44*	.47*	0.01	.61**	-0.01	.42†	0.27	.38†	.76**	.71**	.72**	1.00

Abbreviations: AgeDx (Age at Diagnosis), BthOrd (Relative Birth Order), TimeDx (Time since Diagnosis), ITR-2 (Treatment Intensity), CnxtAvg (Average Contextual Threat); CnxtWh (Holistic Contextual Threat), CDI (Depression), PhysAnx (Physical Anxiety), SocAnx (Social Anxiety), RCMAS (Total Anxiety), PSS (Perceived Stress), PTSDRI (Posttraumatic Stress)

Table 5: Descriptive Statistics for Distress Measures

	<u>Minimum</u>	<u>Maximum</u>	<u>Mean</u>	<u>Std. Deviation</u>
Depression (CDI)	0	31	7.1	8.8
Anxiety (RCMAS)	0	26	8.6	7.4
Perceived Stress (PSS)	4	31	12.4	6
Posttraumatic Stress (PTSD-RI)	7	53	22.6	2.6
Treatment Intensity (ITR-2)	2	4	2.6	0.6
Average Contextual Threat	1.7	2.8	2.1	0.3

FIGURES

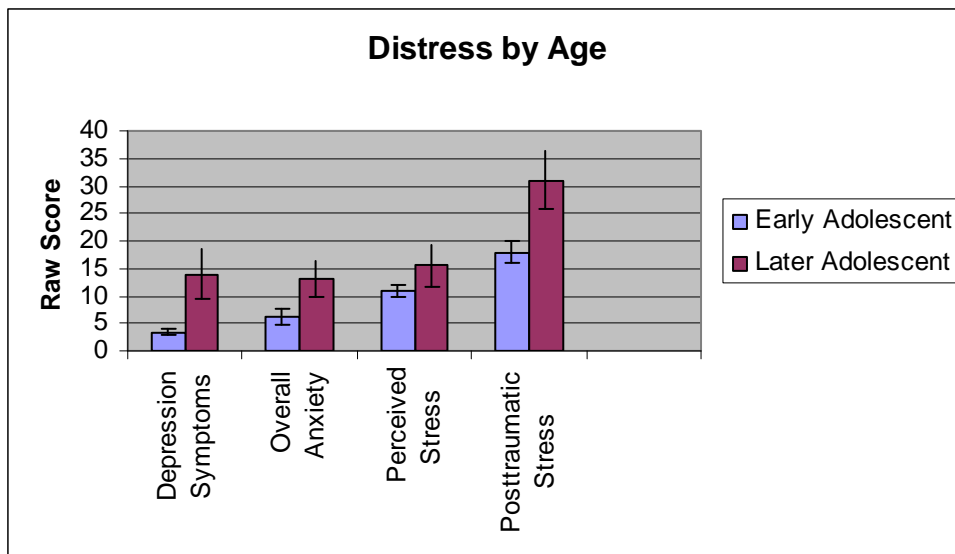


Figure 1: Sibling Distress by Age

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