An examination of self-efficacy, perceived support, and impact of illness in siblings of children with cancer

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An examination of self-efficacy, perceived support, and impact of illness in siblings of children with cancer

Abstract
Currently, there is a paucity of research dedicated to understanding the experience of siblings of children with cancer. Literature available reveals both positive and negative experiences of these children, leading to mixed outcomes in intervention research. The current project includes a review of the psychological literature and a survey of 20 siblings regarding clinical variables such as self-efficacy, perceived support, and impact of illness and medical knowledge. Independent t test analyses of the data revealed no significant relationships between clinical, demographic, and medical variables, though several approached significance. These findings are discussed in light of study strengths, limitations, and resulting clinical implications.

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ABSTRACT

Currently, there is a paucity of research dedicated to understanding the experience of siblings of children with cancer. Literature available reveals both positive and negative experiences of these children, leading to mixed outcomes in intervention research. The current project includes a review of the psychological literature and a survey of 20 siblings regarding clinical variables such as self-efficacy, perceived support, and impact of illness and medical knowledge. Independent $t$ test analyses of the data revealed no significant relationships between clinical, demographic, and medical variables, though several approached significance. These findings are discussed in light of study strengths, limitations, and resulting clinical implications.

Key words: Siblings of children with cancer, self-efficacy, perceived support
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An Examination of Self-Efficacy, Perceived Support, and Impact of Illness in Siblings of Children with Cancer

According the American Cancer Society (ACA, 2008), cancer is defined as “a group of diseases characterized by uncontrolled growth and spread of abnormal cells” (p. 1). The ACA describes childhood cancers as those beginning before age 15. In their 2008 report, the ACA estimated that 175,300 new cases of childhood cancer occurred in 2008, and approximately 96,400 children died of cancer that same year.

When a child is diagnosed with cancer, the entire family faces new challenges and obstacles. Initial diagnosis, treatment, side-effects of treatment, time in the hospital, remission, and potential relapse cause disruptions for all family members. While parents face financial and emotional difficulties, the sibling of the diagnosed child also struggles to make sense of the diagnosis and its impact on his or her former family life (Alderfer, Labay, & Kazak, 2003; Ballard, 2004; Sharpe & Rossiter, 2002). Moreover, the sibling bears witness to the physical and emotional toll not only of the diagnosed child, but also his/her parents. While initial research focused overwhelmingly on the diagnosed child and his/her parents, research has increasingly turned toward the siblings of these diagnosed children. To date, several studies have investigated the emotional, physical, behavioral, and psychosocial impact a diagnosis of cancer has on the sibling. However, research and therefore findings have been extremely limited as to what these children are experiencing and how best to prevent negative psychological outcomes for these children. As such, the effectiveness of interventions for assisting these siblings has also been limited. As the authors will discuss in the literature review, greater focus has been on siblings of children with chronic illness leaving researchers to extrapolate and generalize findings to siblings of children with cancer. However, several studies and meta-analyses have found that siblings of
children with cancer are, in fact, thriving rather than struggling. The current push for empirically-supported treatments by family advocates is driven by the notion that these children are suffering, leading to a cart-before-the-horse phenomenon in the literature. Available literature has attempted to uncover and understand hypothesized distress, leading to misguided, though well-intentioned, attempts to intervene and fix hypothesized problems without understanding these children’s experiences well. This is not to say that continuing research along the current track cannot be fruitful. A similar progression of literature can continue so long as efforts are made to delineate the salient areas to intervene and target interventions accordingly. Continued effort at understanding these children’s experience is first needed to determine areas of risk and resilience for these children in the context of their familial situation and siblings’ cancer diagnosis. As a result, interventions can be designed to bolster resilience and buffer risks.

Researchers have posited that perhaps there are unidentified variables that are moderating the effects of these interventions and that, by identifying and understanding them, interventions can be tailored for increased effectiveness. The current study aims to look specifically at three of these potential variables: self-efficacy, perceived support, and the impact of illness and medical knowledge. Self-efficacy, or one’s perceived ability to reach one’s goals or cope with negative events, has been posited as a potential protective factor (Bandura, 1997; Beckham, Burker, Lytle, Feldman, & Costakis, 1997; Kaul, 2011; Reivich, 2010). Similarly, perception of support in difficult times and knowledge of medical terms and procedures have also been hypothesized to act as buffers against potential risk factors and are essential for healthy psychological functioning (Ballard, 2004; Hahn, Cella, Bode, & Hanrahan, 2010; Lobato & Kao, 2002; McKernon et al., 2001). Literature on how these variables relate to siblings of children with chronic illness is growing; however, research specifically targeting these variables in siblings of
children with cancer has been extremely limited. As such, they will be analyzed for their potential relationship to demographic and medical variables, such as age, gender, type of cancer diagnosis, and ethnicity. In doing so, the researchers hope to shed light on which variables are affecting these children in order to inform intervention to buffer them from ill effects, such as difficulty adapting to their sibling’s cancer diagnosis.

Prior to outlining the current study, relevant literature is described as the basis for its methodology. Because research is somewhat scant on siblings of cancer patients in particular, the following sections first provide an overview of literature on the wellness, adjustment, and areas of difficulty revealed to date for children whose sibling has received a serious diagnosis for a chronic physical condition. Next, literature on emotional and psychosocial adjustment in siblings of children with cancer is provided and reveals mixed findings regarding areas of struggle. An overview of the literature available regarding intervention is examined for potential risk and resiliency factors. Finally, potential moderating variables related to adjustment are introduced. In particular, research on outcomes as they related to communication, self-efficacy, and support are reviewed. The progression of the current literature review is designed to highlight the most salient areas for targeting intervention and further examination of sibling wellness, which are the foci of the present study.

**Chronic Conditions in the Family: Sibling Reaction and Adjustment**

A meta-analysis conducted by McHale and Gamble (1997) sought to describe and examine the relationships of children with a disabled sibling and their personal adjustment. The authors described the sibling relationship as having both “bright and bleak moments” (p. 132) that can be simultaneously loving and resentful. Looking at negative or problem events, the authors found no significant differences in the total number of problems reported by children
with disabled versus nondisabled siblings. However, differences were found in the type of problem reported by the sibling. For example, children with a disabled sibling reported worrying about their sibling’s emotion and physical well-being whereas children with a healthy sibling reported mutual fights more often. Differences were also found in the way children cope with these events. Children with a disabled sibling reported a greater incidence of direct action, both positive (e.g., playing) and negative (e.g., hitting). To that end, the authors noted that distraction, in contrast with direct action, was an uncommon response for children. Additionally, they found that the child’s relationship satisfaction with the sibling was not correlated with measures of well-being; however, the authors found higher levels of anxiety and depression, and lower levels of self-esteem among children who perceived being treated unfairly by their parent. It is important to note that these themes were found for children with disabled and nondisabled children alike. The authors add that a common theme in the literature is a sense of a double standard for these children. In other words, they perceive having a different set of expectations than does their sibling, leading to general feelings of unfairness. In order to help these children cope with negative emotions and events, the authors suggested that treatments include a forum to express and exchange experiences in order to convey to these children that both positive and negative feelings toward their sibling are common.

Waite-Jones and Madill (2008) also suggested a mixture of positive and negative emotions in their study of healthy siblings of children with juvenile idiopathic arthritis. Eight families participated in semi-structured interviews to gain qualitative descriptions of siblings’ experiences. The authors described using grounded theory to collect and analyze the data in order to generate a reverse-engineered hypothesis. As such, they reported reviewing and revising the interview questions between each participant interview. The siblings, ages 9-24, participated
in a one-time interview lasting anywhere from 10 to 45 minutes. Questions were generally open-ended and interview transcripts were then analyzed for participant response themes. Five overarching themes emerged from the interviews, describing siblings as often 1) comparing themselves to the norm, 2) experiencing social contagion, 3) experiencing emotional contagion, 4) feeling amplified ambivalence, and 5) adjusting socially and emotionally. Waite-Jones and Madill defined social contagion refers to one’s friends’ values and attitudes influencing that person. Similarly, they defined emotional contagion refers to negative emotions from others being integrated by the individual. What is perhaps most salient to the current study is the idea that siblings must often compete with the ill child for parental time and affection and at the same time, they feel concern and affection toward the ill child. All children in this study described what a “good child” ought to be or should say; however, ambivalent feelings were still expressed, though often hid from the parents. Finally, Waite-Jones and Madill noted, as one might expect, that as age increased the siblings appeared better able to accept and cope with the impact of having an ill sibling.

Looking at another chronic health problem, Hollidge (2001) examined the psychological adjustment of siblings of a child with diabetes. In order to assess psychological adjustment, the author collected data from semi-structured interviews and standardized assessments. Assessment measures included the Child Behavioral Checklist (CBCL; Achenbach, 1991), the Piers-Harris Children’s Self-Concept Scale (Piers, 1984), the Reynolds Child Depression Scale (Reynolds, 1989), and the Revised Children’s Manifest Anxiety Scale (Reynolds & Richmond, 1985). The semi-structured interview was comprised of 20 questions focused on the children’s feelings about having a sibling with diabetes, expression of worry, and patterns of communication. Interrater reliability analyses were performed for each question. A total of 28 healthy children
completed the assessments and interview. The participants (15 female and 13 male) ranged in age from 8 to 12 years (M = 10.3 years) and were recruited from a diabetes clinic in Ontario, Canada. Of the 28 children, 20 were older than their siblings with diabetes and eight were younger. Ethnicity was not reported.

Hollidge (2001) found elevated levels of anxiety in the moderate to high range on both the Revised Children’s Manifest Anxiety Scale (Reynolds & Richmond, 1989) and on the anxiety cluster of the Piers-Harris Children’s Self-Concept scale (Piers, 1984). He noted that all other clusters of the Piers-Harris scale (e.g., happiness, physical appearance, and intellectual status) were in the average range. On the Reynolds Child Depression Scale (Reynolds, 1989), the participants exhibited some depressive symptoms, but none fell in the clinical range. Finally, Hollidge found that the children’s scores on the CBCL (Achenbach, 1991) were close to the highly competent level, meaning they did not exhibit behavioral problems. Regarding the interviews, the authors identified emotional themes of responsibility, unhappiness, jealousy, competition, negativity, shame, and guilt, which can be seen in siblings of children with cancer and is reviewed later in the literature review. Among these feelings, a positive relationship was found between degree of responsibility and degree of jealousy, as well as between competition and negative feelings, such as guilt and shame. Approximately half of the participants expressed worry about developing diabetes, and all expressed worry and anxiety about their sibling’s diagnosis. Additionally, 26 of the children reported declining to talk to their parents or friends about their concerns for two reasons: 1) fear that their parents would be angry; and 2) fear that they would increase their parents’ worry. These themes of support and need for medical knowledge will be discussed as they relate specifically to siblings of children with cancer. From analyses with the CBCL, Hollidge found that children who were younger than their sibling with
diabetes had more difficulty than did older siblings. Gender and family size were not found to have any mediating effects on the variables assessed. The author concluded by stating that anxiety appears to be a key factor for these children. However, because a comparison group was not included in the study, the extent of difference between children with healthy siblings and those with diabetic siblings is unknown.

In an effort to synthesize the literature on siblings of children with chronic health conditions, Vermaes, van Susante, and van Bakel (2011) conducted a meta-analysis of 52 studies. They focused on two main areas to investigate: first, which if any demographic variables may moderate sibling outcomes and second, the effects of the ill-child on siblings internalizing problems, externalizing problems, and making positive self-attributes. Internalizing problems include depression and anxiety, which are experienced internal to the individual. Externalizing problems are generally behavioral, such as aggression, and are overtly noticeable. Positive self-attributes refers to giving one’s self credit for successes due to internal or personal characteristics. Of the studies analyzed, the majority were published in the 1990s (41%) and nearly half (48%) used siblings as informants, rather than parents. They noted their study included several chronic health conditions, including anemia, diabetes, seizure, and cancer, to name a few.

Vermaes et al. (2011) found that siblings of diagnosed children were more likely to internalize problems than siblings of healthy children, which may suggest suppression as a coping technique. Gender, birth order, and type of chronic condition were not found to have a significant moderating effect on internalizing or externalizing problems, or making positive self-attributes. The authors noted that they were surprised gender did not have a moderating effect as it is generally hypothesized that girls are more likely to internalize problems and boys to
externalize. In regard to age, the authors found that younger children are less likely to make negative self-attributes than older children. It is important to note that while this finding is consistent with Hollidge’s (2001) study, it is contradictory to the aforementioned Waite-Jones and Madill (2008) finding that in fact older children cope more successfully than their younger counterparts.

They noted specifically that siblings of children with cancer were more likely to experience internalizing and externalizing problems than siblings of healthy children and their rate of making positive self-attributions was lower as well (Vermaes et al., 2011). At the conclusion of their study, the authors observed that improved treatment options and increased attention on siblings has not led to expected decreases in sibling mental health issues. For future research, the authors suggested identifying those siblings who are at a higher risk of experiencing mental health problems and investigating what works in helping siblings cope.

Overall, siblings of children with chronic conditions report a variety of experiences both positive and negative (Vermaes et al., 2011). Across review studies, children reported worrying about their diagnosed sibling’s emotional and physical well-being, as well worrying about their own health. This emerging theme supports the need for increased knowledge of medical conditions and procedures in order to allay anxiety. The importance of support has also been highlighted as a potential buffer against negative outcomes, including internalizing and externalizing problems. Regarding demographic data, it appears that younger children have a more difficult time adjusting than do older children. However, findings have been mixed concerning age when looking specifically at siblings of children with cancer as reviewed below.

Significantly more research has been dedicated to siblings of children with chronic illness than is specific to siblings of children with cancer. For the most part, research does not suggest
any significant or determinable mental health differences between children with healthy siblings and children with ill siblings. A similar trend can be seen when studying siblings of children with cancer: the majority of children seem to be adapting well. However, as reviewed in the following sections, there are some children with siblings diagnosed with cancer who do appear to struggle with emotional and psychological adjustment. These areas of difficulty are reviewed in the following sections.

**Emotional and Psychosocial Adjustment of Siblings of Children with Cancer**

**Role adjustment in the family.** Literature has centered on role adjustment in the family, as well emotional distress, and posttraumatic stress reactions in particular as these tend to have lasting impact on development. Building on her own meta-analysis of qualitative studies, Woodgate (2006) conducted a qualitative study to understand how pediatric oncology and its symptom trajectory are understood and experienced by the diagnosed child, their parents, and their siblings, focusing specifically on understanding the siblings’ perspectives on childhood cancer. The only inclusion criteria were fluency in English and that the sibling was at least five years old or older. Families were included regardless of different cancer diagnoses and different stages of the illness. A total of 30 siblings (15 male and 15 female) between the ages of six and 21 years old participated ($M = 12$). Of the 30, 19 were older than the diagnosed child, 10 were younger, and one was a twin. Twenty-seven of the siblings lived with both of their parents and three lived with only one parent. All siblings were white. The study took place in Western Canada from July 1998 to December 2000.

A total of 48, open-ended interviews were conducted with the siblings, with nine siblings completing more than one interview (Woodgate, 2006). The reason for these additional interviews was not given. The siblings were asked to report on their sibling’s cancer and how it has affected them from first learning of the diagnosis to the time of the interview. The interviews
lasted between 30 to 120 min and were videotaped. All interviews took place in the sibling’s home and were face-to-face.

From the data collected from the individual interviews and the focus group, and consistent with the previous meta-analysis, two categories emerged: loss of a family way of life and loss of self within the family (Woodgate, 2006). For the participants, their sibling’s diagnosis of cancer changed not only how their family related to one another but also their sense of self in the family unit. The author noted that, during the interviews, the siblings repeatedly spoke about their parents’ or sibling’s experiences, despite attempts to have them focus on their own experiences. Within these two over-arching categories, three ways of coping within these categories also emerged. Siblings reported responding to their experience within their family unit by being careful not to do anything that could add to further disruptions in family life. In addition, increased feelings of responsibility were noted across interviews. The author noted that although the sibling was conscientiously trying to lessen the burden on parents, most felt they had not done enough. A second theme of being present also emerged. This theme included being a shoulder to cry on, listening to other family members’ concerns, and comforting and taking care of their ill sibling. Again, they downplayed their role in helping their parents and sibling. The third theme that appeared was enduring sadness. While feelings of jealousy, fear, worry, anger, shame, and guilt were present in several interviews, all siblings, regardless of what stage of treatment their sibling was in, expressed feeling sad. The authors reported that the siblings took care to hide or diminish their feelings so as not to add to familial distress. Interestingly, in their interviews with the parents and diagnosed sibling, the author noted that parents did not realize the extent of the sibling’s sadness.
Because siblings perceive their involvement in their family to be minimal, Woodgate (2006) concluded by stating that future research should focus on helping siblings maintain a sense of being within their families to offset feelings of helplessness.

Cordaro, Veneroni, Massimino, and Clerici (2012) also had questions regarding siblings’ adjustment post-diagnosis and the potential minimization of problems, similar to what Woodgate (2006) observed. In the current study, 30 parents of children with cancer completed the CBCL (Achenbach, 1991) on their healthy child and participated in a semi-structured interview. Demographic information, such as birth order and age and gender of both the ill and healthy child, was also collected. Data from 33 parents of healthy children were also collected for comparison. In order to participate, the healthy siblings had to be between the ages of 4 and 18 years and could not have any disabilities or psychiatric diagnoses. Parents were also excluded if they had any psychiatric conditions. The authors hypothesized that siblings of children with cancer would have greater difficulties than those children in the comparison group. However, the opposite emerged: siblings in the clinical sample scored significantly better both on the overall CBCL score and most subscales. They scored worse on scales related to competencies (school performance, hobbies, extracurricular activities) than they did on scales measuring behavioral problems and internalizing and externalizing problems. Birth order was the only moderating demographic variable that emerged, with siblings older than the diagnosed child in the clinical sample scoring significantly worse than siblings younger than the diagnosed child. No significant differences were found related to sibling gender or age. The authors questioned if their findings truly indicate that siblings of children with cancer are more resilient than siblings of healthy children, if parents in the clinical sample were more distracted and thus assessing their child’s psychosocial functioning was difficult to assess, or if siblings in the clinical sample hid
difficulties from parents in order to not add to parental burden. As such, the authors stressed the importance of collecting data from multiple sources, including the healthy sibling.

**Emotional distress.** Sahler et al. (1994) sought to determine the frequency and intensity of emotional distress and behavioral problems in siblings of children with cancer. A total of 254 siblings and their parents completed a combination of interviews and self-report measures. The parents were asked to report on sibling emotional and behavioral problems both pre- and post-diagnosis. Pre-diagnosis scores were compared to a matched control group, and the researchers found no difference in emotional/behavioral problem frequency or intensity between groups pre-diagnosis. However, the researchers noted an 18% increase in frequency of emotional/behavioral problems post-diagnosis in the sibling group. They hypothesized four levels of adaptation based on (1) presence/absence of problems pre-diagnosis, (2) the prior problem increased, decreased, or did not change, (3) presence/absence of problems arising post-diagnosis, and (4) engagement in or perceived need for mental health services for the sibling. Using data derived from these criteria, they categorized subjects into four levels of adaptation: dysfunctional, Intermediate 1, Intermediate 2, and resilient. Not surprisingly, the researchers found that the major risk factor for development of emotional/behavioral problems post-diagnosis was emotional/behavioral problems pre-diagnosis, which may be critical for identifying risk of poor outcomes. They noted that children’s scores in the resilient group did not differ significantly from those of the control group. Using demographic information in combination with adaptation levels, Sahler et al. found that boys under 11 years old appear to be more vulnerable to problem behavior and girls older than 11 years are more likely to develop emotional distress post-diagnosis.

In order to investigate the prevalence and types of risk factors for psychosocial problems over time in siblings of children with cancer, Houtzager, Grootenhuis, Hoekstra-Weebers, Caron,
and Last (2003) assessed 83 siblings (from 56 families) ranging in age from seven to 18 years old. To be included in the study, the child with cancer had to be diagnosed for the first time within four to eight weeks of the present study. In addition, the sibling of the child with cancer had to be between age seven and 18. Assessments included the Youth Self Report (YSR; Vogels et al., 1998), which measures general emotional and behavioral functioning, the Dutch Children’s AZL/TNO Quality of Life Questionnaire (Vogels et al., 1998), which measures daily functioning, and the State-Trait Anxiety Inventory for Children (STAIC; Spielberger, Gorsuch, & Lushene, 1970). Demographic information was also collected, such as age and gender of the siblings, family socio-economic status, and type of cancer (e.g., solid or brain tumor, or leukemia or lymphoma). Sibling functioning pre-diagnosis was reported on by the parents, as well as physical functioning of the children and any major family life events in the last year (e.g., divorce, birth of a child, moving, changing schools, etc.). These assessments were taken both immediately after the diagnosis of cancer was given (Time 1) and six months after diagnosis (Time 2).

Houtzager et al. (2003) found that nearly half (48%) of siblings experienced a major life event the year prior to their sibling’s diagnosis, suggesting that these children may have had elevated stress levels at the time of participation. Additionally, 52% of parents reported one or more problems in overall functioning, including physical, sleep, or eating problems. The authors found several differences between groups. At Time 1, adolescent female siblings reported significantly more internalizing problems and anxiety. Additionally, more siblings reported “significantly impaired emotional, social, and overall quality of life compared with the normal population” (p. 1427). At Time 2, quality of life was lower for siblings of a child with cancer, but not significantly so, when compared to the healthy comparison group. However, the emotional,
social, and total quality of life scores were significantly lower than the comparison group. The
performed regression analyses showed no significant effects when compared to Time 1 or Time 2. Because none of the target variables predicted changes from Time 1 to Time 2, Houtzager et al. believe that another factor, such as coping, family functioning, and education about the illness, may play an important role.

Similarly, Australian researchers Patterson, Millar, and Visser (2011) sought to determine domains of need of siblings of children with cancer in order to develop a new, more specific instrument. The researchers used a combination of qualitative and quantitative methods to create their measure, the Sibling Cancer Needs Instrument (SCNI; Patterson, Millar, & Visser, 2011), including a focus group, surveys, and telephone interviews in order to determine psychosocial needs of these siblings. A total of four children, ages 14-17, participated in the focus group and were asked about “important, unmet needs” (p. 18) they may have. The participants’ responses were cross-checked with needs identified in the literature and any needs not raised by the participants were introduced by the facilitator. Seven children participated in phone interviews lasting approximately 30 min. Again, any unmet needs from the literature that were not raised by the child were introduced by the researchers. Finally, 26 staff members at a local cancer agency were given a survey in which they were asked to list five needs of siblings of diagnosed children.

The researchers identified 10 conceptual domains, including peer support, information, sibling relationship, expressing and coping with feelings, respite, acknowledgment, involvement in the cancer experience, instrumental support, and access to support services and professional help (Patterson et al., 2011). From these identified domains, a pool of 80 survey items was generated. Using a national organization, CanTeen Australia, the researchers mailed the survey as well as posting a survey link online. Twelve participants completed the online survey and 62
completed pen-and-paper copies. Participants, ages 12-24, were predominantly Australian-born (90%) and female (63%). Using the 80 items generated from the initial study, participants were asked to rank each item on a Likert-type scale from 1=no need to 4=high need. If the participant endorsed a need, they were then asked yes or no if the need had been met. Scores from the SCNI were compared to participant scores on the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) and the Depression, Anxiety, and Stress Scales-21 (DASS-21; Lovibond & Lovibond, 1995) to establish convergent validity.

Patterson, Millar, and Visser (2011) found that 90.1% of participants endorsed at least one need, with an average of 38.8 needs endorsed (SD=27.0). On average, 10.2 needs were rated as unmet per participant. The most frequently endorsed domains of need were peer support, involvement in the cancer experience, and respite. The most frequently endorsed unmet need domains were peer support, acknowledgment, and access to support services. Unsurprisingly, a significant, positive correlation was found between number of unmet needs and total SDQ score, indicating greater psychosocial difficulties. While this instrument fills an assessment gap by looking specifically at the needs of these siblings, its generalizability may be limited due to sample characteristics. More specifically, all were members of a peer support organization, which may have a direct impact on perceived needs. Additionally, the researchers do not indicate which domains, if any, were added to consideration due to the literature review in Study 1.

**Posttraumatic stress and adjustment.** More specifically, Alderfer et al. (2003) looked at posttraumatic stress and long-term adjustment in siblings of children with cancer. A total of 78 siblings participated, with an average age of 14.2 years (SD=2.2). The majority of participants were older than the diagnosed sibling (55.6%), Caucasian (88.0%), and middle class (44.4%). On average, families were 5.3 years post-treatment. For comparison, a preexisting reference sample
of children was used from hospital-based pediatric practices. On average, these children were 13.2 years old, female (54.2%), Caucasian (61%), and lower class (37%). Each group was given the Revised Children’s Manifest Anxiety Scale (RCMAS; Reynolds & Richmond, 1985), Impact of Events Scale-Revised (IES-R; Weiss & Marmar, 1997), Posttraumatic Stress Disorder Reaction Index (PTSD-RI; Pynoos, Frederick, Nader, & Arroyo, 1987), and Assessment of Life Threat and Treatment Intensity Questionnaire (ALTIQ; Stuber et al., 1997).

Alderfer et al. (2003) found that nearly one-third of siblings reported moderate to severe scores on the PTSD-RI and nearly half had mild posttraumatic stress scores. On the IES-R, 38.7% of siblings reported one or more symptoms of re-experiencing, 22.7% endorsed two or more symptoms of arousal, and 21.3% reported three or more symptoms of avoidance. However, the researchers note that despite meeting DSM-IV criteria for PTSD, siblings’ average anxiety score was in the normal range. Using two 2x2 ANOVAs, the researchers found that female siblings and those older than 6 years at diagnosis were more likely to report posttraumatic stress symptoms. Comparatively, children from the reference sample reported less intrusion, avoidance, and posttraumatic stress symptoms. However, the two groups did not differ on total anxiety scores. The researchers argue that general measures of adjustment and measures of distress may not be sensitive enough to capture the complexities of having a sibling diagnosed with cancer. They note that perhaps female siblings are more likely to experience PTSD as females are more likely to take on a caregiver role and such responsibilities and thus exposure to suffering may increase posttraumatic stress symptoms.

Kazak et al. (2004) specifically looked at Posttraumatic Stress Syndrome (PTSS) in survivors, their parents, and siblings in a randomized wait-list control trial testing the Surviving Cancer Competently Intervention Program (SCCIP; Kazak, 1999). The target of this intervention
is the reduction PTSS using cognitive-behavioral and family approaches in four sessions over a single day. The researchers note that they included siblings as an exploratory aim since they were unaware of any research indicating PTSS in siblings at the time of the study. Using an oncology tumor registry, the researchers identified survivors of childhood cancer between the ages of 11 and 19 years. Survivors were excluded from participation based on relapse, mental retardation, non-fluency in English, and residence greater than 150 miles from the hospital in which the study would be conducted. The eligible survivors and their families were mailed informational packets describing the study. Of the 530 families that were identified, 437 were reached by phone and 106 were found to be ineligible based on parent report. Of the 330 eligible families, 150 enrolled in the current study.

Baseline data were collected (Time 1; T1) using a structured clinical interview and questionnaires, including the IES-R, the PTSD-RI, the STAIC, and the RCMAS (Kazak, 2004). Using gender and age to stratify the groups, 76 families were selected to the treatment group and 74 were assigned to the wait-list control group. Given that sibling involvement was exploratory, only one sibling per family was included; 19 were assigned to the treatment group and 24 were assigned to the wait-list control. In order to maximize participation of all family members and accommodate schedules, 32 intervention days were held over 39 months. The structured interview and questionnaires were re-administered at Time 2 (T2) 3 to 5 months post-intervention for the SCCIP group and 8 to 10 months after T1 for the wait-list control group.

The researchers found that PTSS scores of the SCCIP group from T1 to T2 had a greater decrease than those scores of the wait-list control group (Kazak, 2004). However, these scores were not significant pre- and post-intervention. Unfortunately, the researchers do not discuss possible hypotheses as to why sibling scores did not decrease.
Houtzager, Grootenhuis, and Last (1999) conducted a review of literature from 1980 to 1999 on sibling adjustment to childhood cancer. Specifically, they narrowed their search to adaptation and coping in siblings only and excluded studies that focused exclusively on bereavement. The authors noted that the majority of children with cancer before the 1980s died from their disease. This, coupled with little focus on the sibling in research, led the authors to narrow their search to post-1980. Their review is divided into four sections: (1) emotional and social-behavioral adjustment, (2) sibling characteristics and resources, (3) family characteristics and their potential impact on the sibling, and (4) conclusions and directions for future research.

Across the four domains, the researchers noted conflicting reports regarding salient factors for siblings, and sibling and family characteristics (Houtzager et al., 1999). For example, one study (Packman et al., 1997 as cited in Houtzager et al., 1999) reported moderate to severe symptoms of PTSS in siblings, while Fife et al. (1987) reported low, stable levels of anxiety over time. Adding to conflicting findings, the researchers found three studies that reported no differences between sibling and control groups in the prevalence of emotional problems. Similarly regarding depression, one study noted no significant differences between the sibling and control groups (van Dongen-Melman et al., 1995). The researchers concluded that, based on their review of the literature, siblings do not seem to suffer from severe psychopathology. However, they highlight the conflicting nature of the studies reviewed and cite study designs and population characteristics as sources for this conflict. They concluded by encouraging the use of standard measures, a control group or longitudinal design, and more substantial samples to increase power.

Ten years later, Alderfer et al. (2010) also conducted a systematic review of the literature published between 1997 and 2008 and included 65 qualitative, quantitative, and mixed methods
reports. Similarly to Houtzager, Grootenhuis, and Last (1999), Alderfer et al. found that siblings of children with cancer do not experience a greater prevalence of psychiatric disorders than siblings of healthy children. However, they note a subset of these children report PTSS, poor quality of life, and negative emotional states. They also found positive aspects emerging post-diagnosis, including increased sibling maturity and empathy. The authors urge a future research focus on moderating variables and changes to normative development as opposed to psychiatric diagnoses.

Given the noted negative consequences (e.g., sleep problems, increased responsibility, anxiety, posttraumatic stress, etc.), of a subsection of siblings it may be useful for those in positions of support to monitor and focus on bolstering or preventing negative outcomes in emotional, social, and behavioral realms. Interventions already designed to focus on these areas and outcomes of their implementation with these siblings are explored below.

**Interventions for Siblings of Children with Cancer**

Prchal and Landolt (2009) conducted a meta-analysis of psychological interventions for siblings of children with cancer in the hope of outlining the future direction of research. Their initial search resulted in 431 published articles and 18 dissertations on pediatric oncology. Studies that did not focus on psychological interventions and siblings, were not available in full text, and did not use validated measures were excluded from their study, leaving 10 articles and four dissertations. These 14 studies represented 11 different sibling interventions and were published between 1986 and 2005. Only three programs defined time since diagnosis as an inclusion criterion. Seven of the 11 interventions used a group setting, while three used a camp format, and one was designed for individual intervention. Sample sizes varied from 11 to 90 siblings and participant age ranged from six to 20 years. The reviewed studies were then divided into five categories based on specific type of intervention: enhancement of medical knowledge,
coping, family communication, reduction of posttraumatic stress, and providing peer support through recreational activities.

Of the four studies that examined depression as an outcome measure, all found a significant reduction in depressive symptoms among siblings after they received the intervention (Prchal & Landolt, 2009). Significant differences were also found in six of the 10 studies (including one randomized controlled trial, RCT) that looked at anxiety, while four (including two RCTs) found no significant change. Six studies utilized the SPQ (Sahler, Carpenter, & Davis, 1990) and all found significant change in at least one of the measure’s subscales. Sibling self-esteem was assessed in four studies: two with a camp format and two with a group format. Significant differences in self-esteem were found with the camp format, but no significant differences were found in the group format. Two of the studies (one RCT) assessed posttraumatic stress. The RCT resulted in no significant differences, whereas the other study did report differences pre- and post-intervention. Additionally, two studies (both camp format) measured health-related quality of life and both showed significant improvement. In seven of the studies that assessed satisfaction with the intervention, all received positive feedback with a generally high level of satisfaction. Finally, no significant differences were found regarding social adjustment and self-reported behavioral problems. Based on the results of their study, Prchal and Landolt (2009) recommended using manualized interventions in randomized controlled designs. Additionally, relationships between the dependent variables and covariates (e.g., age, gender, ethnicity, diagnosis, time since diagnosis, etc.) should be examined further. Finally, they recommended distinguishing content components of the intervention and evaluating them separately.
Focusing specifically on pediatric oncology, Barrera, Chung, Greenberg, and Fleming (2002) created the Siblings Coping Together program (SCT), a group intervention designed for siblings of children with cancer. A total of 17 participants were divided into three groups to run consecutively over a one year time period. Children were included in the group if (a) they had a sibling who was diagnosed with any type of cancer, (b) at least one parent was concerned about the child’s behaviors or emotions, and (c) being between the ages of six and 18. The authors noted that any child whose sibling died was excluded from the study. The SCT was developed based on a cognitive behavioral model and incorporated such techniques as challenging cognitive distortions, cognitive restructuring, problem solving, and assertiveness training. The protocol consisted of eight weekly sessions of 2 hours each, in a hospital setting. To assess pre- and post-group functioning, both the sibling and one parent completed several measures. The sibling completed the Children’s Depression Inventory (CDI; Kovacs, 1992), the STAIC, the SPQ, and the YSR. The parent completed the CBCL. Both the sibling and the parent completed the Sibling Group Satisfaction Questionnaire (SGSQ; Barrera et al., 2002), which was constructed for this program to assess satisfaction.

The authors reported that while they were able to complete Groups 1 and 3, Group 2 was discontinued due to low attendance (n = 4) and the death of the ill child in two cases (Barrera et al., 2002). In total, 12 siblings completed the protocol. Data from these participants revealed that, at pretest, approximately one third of the siblings had clinical levels of anxiety, while scores of depression and behaviors were within normal limits. The authors found that depression and state anxiety scores were significantly lower at post-intervention than at pre-intervention. The authors noted that behavior scores followed a similar trend, but were not significant. Of the nine siblings and parents that completed the satisfaction survey, all rated the group as very useful or somewhat
useful in reducing their fears surrounding their sibling’s diagnosis. The majority of siblings (n = 8) reported that the group was very helpful in providing education about cancer, helping express feelings, and getting along with other family members. Most (n = 7) parents reported a reduction in their child’s level of anxiety, improvement in behavior, expression of feelings, and reduction of family distress. The authors concluded by encouraging other researchers to conduct groups using the SCT manual in order to empirically validate it following APA guidelines.

Houtzager, Grootenhuis, and Last (2001) evaluated anxiety of siblings of children with cancer before and after a five-session intervention group. The aim of the intervention group was to enhance control strategies, such as information exchange and confidence in caregivers, in order to reduce anxiety. The goal of the study was to answer three questions: whether participation in the group decreased the sibling’s anxiety, whether the amount of anxiety was comparable to normal peers, and which characteristics of the participant and their ill sibling would predict anxiety-reduction. Siblings were recruited from a medical center in Amsterdam. Since the sibling support group was started in 1994, ten groups have been completed. Of those, six groups (n = 38) completed pre- and post-group questionnaires. From these groups, siblings were excluded if they attended the full-dose group more than once, or if they were unable to attend all five sessions. Nine boys and 15 girls (n = 24), ages seven to 18 years old (M = 11.3, SD = 3.13), participated. Diagnoses of the ill child included leukemia, lymphoma, solid tumors, and brain tumors. Thirteen of the children were still in active treatment and time since diagnosis ranged from two months to seven years and five months. Anxiety was assessed using the STAIC and was completed by the sibling. Parents of the sibling completed demographic information, as well as information about the diagnosed child. Predictor variables included diagnosis, time since diagnosis, currently receiving treatment, and survival perspective. Survival perspective was
divided into two categories: first treatment of the child or relapse. Diagnosis was also divided into categories: leukemia and lymphoma, solid tumors, and brain tumors.

Using a paired samples \( t \) test to measure whether anxiety decreased pre- and post-test, Houtzager et al. (2001) found that the mean group anxiety was significantly lower at post-test than at pre-test \( (t = 3.49; \text{df} = 23; p = 0.002) \). However, one participant reported higher anxiety post-group than at pre-group. The authors found that, when comparing participant scores to a Dutch normative sample, anxiety levels for participants were relatively high in comparison both pre- and post-intervention. Specifically, young and adolescent boys experienced drops in anxiety scores that were comparable to the normative sample. Young girls experienced a decrease in anxiety, but were significantly higher than the comparison group post-intervention. For adolescent girls, both pre- and post-test scores were comparable to the comparison group. When looking at information obtained from the parents, the authors found no significant impact of time since diagnosis on reported anxiety scores. However, type of cancer did appear to have an impact on anxiety. Specifically, siblings of children with leukemia or lymphoma experienced greater decreases in anxiety post-group than did siblings of children with a tumor. The variables of gender and currently being in treatment were non-significant. The authors encouraged future researchers to incorporate coping skills in order to reduce anxiety into sibling support groups.

Across the research, several themes have consistently emerged, including a sense of loss; intense emotions such as anger, jealousy, and guilt; role adjustment; perceived support; and medical knowledge. However, specific variables within these domains have varied across studies as to what is salient for these siblings. Since Houtzager et al. (2001) published their review studies have continued to claim certain constructs to be salient for siblings of children with cancer, while others have refuted these constructs in favor of others. For example, Barrera et al.
(2002) and Woodgate (2006) both found depression and sadness to be salient factors, whereas Hollidge (2001) did not. Regarding the construct of adaptation, Madan-Swain, Sexson, Brown, and Ragab (1993) found no group differences in adaptability pre- and post-group. However, Horwitz and Kazak (1990) did report significant differences pre- and post-group. The construct of anxiety as a salient factor is also debated. Several studies have found it to be an important factor (see for example, Barrera et al., 2002; Hollidge, 2001; Houtzager et al., 2001; Houtzager et al. 2003). However, as Prchal and Landolt (2009) found in their meta-analysis, four of ten studies (two RCTs) found that anxiety was not a salient factor.

From these findings, it appears that there a subsection of children who are struggling emotionally and psychologically, while other children do not evidence these issues. And for these children, intervention can be helpful; however, research has yet to determine why some siblings are at risk for developing psychological problems while others are not. Consequently, interventions are helpful for some and do not appear to be for others. As previously mentioned, some researchers have posited that one or several moderating variables may be at play which may strengthen resilience and shield against risk. The following sections examine literature on three of these potential variables: communication, self-efficacy, and perceived support.

**Variables Related to Adjustment in Siblings of Children with Cancer**

**Communication.** Breyer, Kunin, Kalish, and Farkas-Patenaude (1993) examined reactions, stressors, relationships, and behavior of healthy siblings of children with cancer. Both parents and siblings completed a questionnaire geared toward these variables. A total of 73 siblings, ages five to 18 ($M = 10$), were surveyed. Of these, 35 were male and 38 were female. The majority of the participants were White (92%), five were Black, and one was Hispanic. Diagnoses of the ill child included leukemia, lymphoma, musculoskeletal tumors, brain tumors, and other cancers. Most of the ill children (59%) were diagnosed less than a year from the
beginning of the study. The parents, siblings, and diagnosed children were recruited from a cancer institute in Boston where they were attending one of six annual day-long workshops on how to cope with stress. The parent and the healthy sibling were given separate questionnaires, though the two questionnaires shared six of seven questions. Questions included reactions to the sibling’s diagnosis, how often the diagnosis was talked about at home, what the healthy child found helpful in coping, and how relationships have changed since receiving the diagnosis. The question specific to the child asked who they found it most easy to talk to about their sibling’s diagnosis. The question for parents only asked about behavior changes in the well-sibling since the diagnosis.

From the responses to the questionnaires, Breyer et al. (1993) were able to identify three patterns. The first pattern was characterized by communication difficulties and negative behavior changes experienced by the well-sibling. For example, one sibling reported that the illness was rarely spoken about at home and that he did not talk to anyone about his sibling’s diagnosis. In addition, his parents reported an increase in acting out behaviors. The second pattern was characterized by communication difficulties and positive behavior changes. The third pattern to emerge was communication with positive behavior change. The authors found that the majority of parents (59%) reported an increase of negative behavior changes since the diagnosis. Only 10% reported positive behavior changes. When asked about the relationship between the sibling and the diagnosed child, 29% reported a closer relationship and 27% reported a less-close relationship. Similarly, 34% of siblings reported feeling less-close to their sibling and only 8% felt closer. The results indicated that positive changes can come about within the family following a diagnosis of cancer. Finally, the authors stated the future research should narrow
down the important factors in family communication and interactions that allow the family members to do well while still incorporating the diagnosis.

**Self-efficacy.** While suppression and distraction have been briefly mentioned, strong coping skills may also include self-efficacy, or one’s perceived ability to reach one’s goals or cope with negative events (Reivich, 2010). In their study of self-efficacy for children coping with a sibling’s cancer diagnosis, Madan-Swain et al. (1993) examined the effects of individual and familial differences on coping and adaptation. Variables included age and birth order of the sibling, and the age at which the child was diagnosed with cancer. Furthermore, the authors compared siblings of children with leukemia and siblings of children with a tumor. They hypothesized that the sibling group and the nonclinical group would differ in their style of coping, and that individual and familial differences would correlate with sibling adaptation and coping. A total of 32 siblings participated in the study, ranging in age from 5 to 16 years old ($M = 11$ years, $SD = 2$ years). Of the 32 siblings, 13 had a sibling diagnosed with a tumor (7 with a brain tumor and 6 with a solid tumor, respectively) and 19 had a brother or a sister who was diagnosed with acute lymphocytic leukemia (ALL). The siblings were referrals from a major university medical center. The diagnosed group was comprised of 19 children who were classified as mild-to-moderate risk (ALL). They ranged in age from 6 years old to 17 years old ($M \approx 10$ years, $SD = 3$ years), and had had the diagnosis of ALL for a maximum of 2 years. The nonclinical comparison group consisted of 10 children, ages 7 to 17 ($M = 11$ years, $SD = 3$ years). The authors performed analyses of variance and found no significant differences between the groups in terms of age or gender. All three groups reported on their coping strategies using the Kidcope (Spirito et al., 1988), completed the KASTAN-Children’s Attribution Style
Questionnaire (CASQ; Seligman et al., 1984) as a measure adaptation, and reported on his/her family’s functioning using the Children’s Family Environment Scale (C-FES; Pino et al., 1984).

The authors found no differences overall among the three groups on measures of coping, adaptation, and family functioning (Madan-Swain et al., 1993). However, significant differences were found between siblings of children with ALL and siblings of children diagnosed with a tumor. Siblings of tumor patients were found to engage in greater frequencies of wishful thinking than siblings of children diagnosed with ALL. No other significant differences were found between the two sibling groups. Additionally, no interactions were found when analyzing the effect of gender or the effect of the child’s age at diagnosis. Concerning the effect of age on coping, the authors found that as age increased, so did the endorsement of efficacy and frequency of using coping strategies. The authors call for further research examining factors such as depression, isolation, and perceived parent and peer support.

Hamama, Ronen, and Rahav (2008) also examined self-efficacy, as well as duress responses, and coping resources in healthy siblings of children with cancer. Specifically, they investigated role overload as the stress factor, anxiety and psychosomatic symptoms as duress responses, and self-efficacy as a coping resource. They defined *duress* as “a dynamic state of imbalance between oneself and one’s surroundings, when the latter is perceived as placing too many demands on one’s personal well-being” (p. 121). In response to duress, an individual can develop anxiety and psychosomatic symptoms. They defined *role overload* as “an imbalance between the role demands placed on the individual and the resources at the person’s disposal to meet those demands” (p. 122). Hamama et al. identified five burdens of role overload: time burden, developmental burden, physical burden, social burden, and emotional burden. They posited four hypotheses. First, healthy siblings who experience a higher role overload would also
experience a high number of anxiety and psychosomatic complaints. Second, healthy siblings with higher levels of self-control and self-efficacy would have a lower level of role overload. Third, healthy siblings with higher levels of self-control and self-efficacy would have fewer reported duress responses (i.e., anxiety and psychosomatic complaints). Finally, healthy siblings who have higher levels of self-control and self-efficacy will have a lower correlation between role overload and duress responses than will healthy siblings with lower levels of coping resources. A total of 100 Israeli Jewish siblings (53 boys and 47 girls) ranging in age from eight to 19 years old participated. Participants were recruited from pediatric oncology departments at five hospitals over the course of 19 months. Inclusion criteria included having a sibling actively receiving treatment and the ability to speak and understand Hebrew. The five groups of siblings (one from each hospital) were analyzed for differences on parental employment, parental level of education, birth order of the sibling, and number of children in the family. No significant differences were found. The siblings completed the Burden Interview (Zarit & Zarit, 1982) to examine role overload, the State-Trait Anxiety for Children Scale (Spielberger, Edwards, Montouri, & Lushene, 1970), the Frequent Symptoms Scale for psychosomatic complaints (Rahav & Ronen, 1994), the Children’s Self-Control Scale (Rosenbaum & Ronen, 1990), and one question designed to tap into self-efficacy (Bandura, 1997). The parents completed a demographics questionnaire.

Hamama et al. (2008) found a significant, positive correlation between both role overload and anxiety ($r = .23, p < .05$) and role overload and psychosomatic symptoms ($r = .26, p < .01$). Anxiety positively correlated with psychosomatic symptoms. Additionally, self-control was negatively correlated with role overload, and self-control and self-efficacy were linked with lower levels of anxiety and psychosomatic symptoms. No correlation was found between self-
efficacy alone and duress symptoms. Among children 12 years old and older, greater self-control was linked with lower levels of anxiety. The authors listed three limitations for their study: the lack of a matched comparison group, only one question to assess self-efficacy, and the use of self-report measures. For future research, they recommended developing interventions that focus on increasing self-control as a means to reduce role overload and distress symptoms.

**Perceived support.** Support surrounding a sibling’s disease has been examined as a potential moderating variable for siblings of children with cancer and is defined as the perception that one is cared for and is part of a network that provides comfort and assistance (Sloper, 2000). Martinson, Gilliss, Colaizzo, Freeman, and Bossert (1990) conducted a qualitative, preliminary study examining the reactions of family members to having a child diagnosed with cancer. For the purposes of this paper, the authors’ findings related to sibling perceptions will be reported here. A total of 40 families participated; the parents and diagnosed child were interviewed at the time of diagnosis and annually thereafter. During the second year of the study, the researchers reported they decided to include siblings in order to gain a more complete understanding of family life. As such, siblings were interviewed at years 3, 4, and 5. The sample was comprised of Midwestern, middle-class, Christian families; all participants were Caucasian. The siblings were asked six questions related to diagnosis, prognosis/mortality, knowledge, impact of cancer on themselves, worry, and hope for the future. Specifically related to impact of cancer, several children described feeling neglected, displaced, and unimportant. Moreover, three children reported feelings of jealousy, followed by feelings of guilt. When asked about support, two children reported confiding in their mothers, one in their father, and one reported talking only when prompted by other adults. One child denied confiding in anyone, and two declined to answer the question. One child in particular voiced difficulty in confiding to friends given their
limited understanding of cancer. In their analyses of the data, the authors concluded that siblings had conflicting feelings regarding their sibling’s diagnosis, but often did not share these feelings with their parents, friends, or other adults.

Sloper (2000) was also interested in how siblings perceive support and what effect this perception might have on negative outcomes, such as anxiety and depression. Using a qualitative, longitudinal design, subjects were interviewed at two designated time points: 6 and 12 months post-diagnosis. A total of 94 siblings were interviewed at Time 1 and 64 were interviewed at Time 2; the author noted that the lower response rate at Time 2 was generally due to conflicting schedules which did not allow for the interviews to be completed in a timely manner. Interviews were semi-structured and inquired about medical knowledge, initial reaction to their sibling’s diagnosis, impact of diagnosis on family life, relationships, and activities, perceived support, and coping strategies. Subjects were included regardless of their sibling’s type of cancer, length of treatment, or type of treatment. Of those who participated at Time 1, 51% were female and 57% were between 8 and 11 years of age. Only 4% identified as ethnic minorities.

After transcribing and coding the interviews, Sloper (2000) found a number of themes. One of the most prominent that she noted was perceived loss of attention or status, with over half of interviewed siblings expressing sadness, anger, resentment, and guilt toward their parents, the diagnosed sibling, and other adults. However, at Time 2, approximately two-thirds did not feel their parents treated them differently than their diagnosed sibling. The author also noted a general need for more information about cancer in order to alleviate concern about “catching” cancer and their own health. Siblings were also asked about what has been most beneficial in helping them cope with their sibling’s diagnosis. At Time 1, the majority of siblings (80%)
reported that having at least one person to confide in who provided support and comfort. This number decreased slightly at Time 2 to 66% of siblings. The author concluded by emphasizing the importance of medical knowledge and support for these siblings and for families on the whole.

In line with Sloper’s (2000) findings, Wilkins and Woodgate (2005) also identified perceived support and medical knowledge as integral components to sibling adjustment. The authors conducted a systematic review of qualitative research using 27 peer-reviewed studies published after 1979. Of the reviewed studies, number of participants ranged from 1 to 254 and participant age ranged from 5 to 40 years, though the majority was between ages 7 and 18 years. Demographic variables, such as ethnicity and birth order, were not reported. Through their analyses, the authors reported major themes including loss, intense feelings, and unmet needs. The theme of loss included reports of spending less time with parents, losing routine, changing family roles, and losing activities. The authors noted that along with changing roles, researchers also noted sibling gains in maturity, empathy, and independence as byproducts of efforts to decrease parental burden. Regarding the theme of intense feelings, Wilkins and Woodgate identified emotions such as sadness, anxiety, anger, jealousy, and guilt. Finally, the third theme of unmet needs encompassed family communication and medical information. Across the literature, support and knowledge have been identified as critical components to positive adjustment in siblings.

To date, the literature on siblings of children with cancer has been scant. Available research largely indicates little difference between children with healthy siblings and children with siblings diagnosed with cancer. However, there does appear to be a subsection of children who are struggling with emotional and psychosocial difficulties, though research has yet to tease
out why some siblings are at risk for developing psychological problems while others are not. As previously mentioned, some researchers have posited that one or several moderating variables may be at play, bolstering resilience and buffering risk. Based on the reviewed literature, the current study seeks to examine three of these potential moderating variables: self-efficacy, perceived support, and impact of illness and medical knowledge. Several researchers (e.g., Bandura, 1997; Beckham et al., 1997; Hamama et al., 2008; Kaul, 2011; Reivich, 2010), have studied the role of self-efficacy and found it relates positively to psychosocial adjustment particularly with siblings of children with chronic illness. However, it has not been examined in relation to siblings of children of cancer. As such, this variable was included in our analyses. Impact of illness and perceived support have received similar attention as potential crucial components to psychological health (e.g., Ballard, 2004; Hahn et al., 2010; Lobato & Kao, 2002; McKernon et al., 2001). Demographic variables such as age and gender were examined, as well as medical information, including type of diagnosis and current treatment, to establish what, if any, affect these would have on self-efficacy, impact of illness, and perceived support in order to better understand these constructs. Similarly, with our direct variables, results have been mixed as to what demographic variables are salient. By studying direct and demographic variables, we hope to uncover which, if any, of these constructs influence one another in order to add knowledge and direction to interventions geared toward these children. Specifically,

- The authors hypothesized participants’ total scores on measures of self-efficacy and perceived support would be positively correlated (cf. Beckham et al., 1997; Reivich, 2010).
Additionally, based on available literature, the authors hypothesized that scores of self-efficacy would also be positively correlated with a measure of communication (cf. Cohen, 1999; Conway & Meyer, 2008; Dyson, 1998).

Due to the paucity of literature available, additional correlational analyses were exploratory in nature.

The following sections outline the present study, including study design, procedure, and materials. Study results are then reviewed, followed by implications for current practice.

**Method**

**Procedure**

Permission for this project was sought and obtained by the University’s Institutional Review Board for both parent and child participation. Parents were asked to provide demographic information, such as sibling age and gender, as well as medical information, such as type of cancer diagnosis and current involvement in treatment. Parent ethnicity was also recorded. Siblings were asked to complete instruments to assess self-efficacy, perceived support, and impact of illness. Both parent and child participants had the option of completing a paper and pencil survey or online utilizing an electronic survey, SurveyMonkey.

Parents and children were recruited through an ad in the Leukemia and Lymphoma Society (LLS) monthly newsletter, *Candlelighters for Children with Cancer*, flyers, and the LLS listserv. Additionally, paper copies were available at the LLS offices. Child participant inclusion criteria were constructed in an effort to maximize sample size while also matching current gaps in the literature. In order to be included in the study, child participants needed the following characteristics: (1) have a sibling diagnosed with cancer within the 12 months prior to study participation, (2) be between 11 and 18 years old, (3) live in the family home, (4) be able to give
assent and/or informed consent, and (5) read and speak English. Child participants were not excluded on the basis of type of cancer diagnosis of their sibling. Additionally, the child participant’s sibling did not need to be actively involved in treatment for cancer.

If completing the survey online, the child participant’s parent or legal guardian first gave permission for their child to participate and informed consent for their own participation. The parent or guardian then answered demographic and medical questions. All parent participation was complete at this point, unless the parent or child opted to enter an optional drawing at the end of the survey. The child subsequently provided assent, and the parent or guardian was instructed to leave the room in order to protect participant privacy and integrity of responses. The child participant then completed the measures.

**Measures**

Parents answered five questions: (a) what type of cancer has your child been diagnosed with, (b) is the child currently undergoing treatment, (c) how old is the sibling of the diagnosed child, (d) what is the gender of the sibling of the diagnosed child, and (e) what ethnicity do you identify with. While both parents and children participated, our primary participants were the children. As such, only child demographic data was collected.

**Self-efficacy.** In accordance with Bandura’s (1997) recommendation on measuring self-efficacy, one item was given to tap into this construct using a Likert-type scale ranging from 1 *unable to cope* and 10 *coping well*. It read: “To what extent do you feel you are managing to cope with your sibling’s disease?” This item was created to measure self-efficacy as it relates to having a sibling with an illness and is an adaptation of Bandura’s question.

**Perceived social support.** The Multidimensional Scale of Perceived Support (MPS; Zimet, Dahlem, Zimet, & Farley, 1988) is a 12-item self-report measure that assesses
adolescents’ (ages 11-17) involvement in networks through which they can receive aid. Three subscales are imbedded in the measure: Family, Friends, and other Significant Persons. There is no item overlap between subscales. High scores on each of these subscales and the total score are indicative of higher functioning. Zimet et al. (1988) found internal reliability estimates of .88 for total score and .87, .85, and .91 for the subscales Family, Friends, and Significant Persons, respectively. Additionally, test-retest reliability was reported as .85 and construct validity was established ($r = -.25$). The child participant was instructed to rate each item on a 7-point Likert scale ranging from very strongly disagree to very strongly agree. The highest possible score for each subscale is 28 and the highest possible total score is 84. For the purposes of this study, we calculated the three subscale scores and the child participant’s total score.

**Impact of illness and medical knowledge.** Finally, the child participants completed the SPQ (Sahler, Carpenter, & Davis, 1990), a 23-item self-report measure designed to assess several domains of the impact of cancer: Interpersonal Relationships, Intrapersonal Reactions, Communication, and Fear of disease. Low scores on Interpersonal Relationships, Intrapersonal Reactions, and Fear of disease are indicative of higher functioning. In contrast, low scores on Communication are indicative of lower functioning. As such, reverse scoring was used on this subscale. Internal consistency was found to range from 0.65 to 0.85 (Carpenter & Sahler, 1991). Child participants’ scores on the aforementioned subscales as well as total score were calculated.

**Results**

The researchers were interested in determining if significant relationships exist between self-efficacy, scores on the MPS and scores on the SPQ. As a follow-up, scores on these measures were also analyzed to determine if significant relationships existed between demographic and medical information variables. Specifically, subscale scores on the MPS
(Family, Friends, and Significant Persons) and total MPS score, the SPQ subscale scores (Interpersonal, Intrapersonal Reactions, Fear, and Communication) SPQ total score and perceived self-efficacy were analyzed. A total of 21 online surveys were completed; no paper and pencil format surveys were completed. One completed survey was excluded given the child participant’s age (10 years old) fell outside the scope of inclusion criteria. Consequently, 20 surveys were included in our analyses.

**Demographics**

Given the research focus on siblings, only child participant demographic information was collected.

<table>
<thead>
<tr>
<th>Table 1</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Participant Characteristics</strong></td>
</tr>
<tr>
<td>Characteristic</td>
</tr>
<tr>
<td>Age</td>
</tr>
<tr>
<td>11-14</td>
</tr>
<tr>
<td>15-17</td>
</tr>
<tr>
<td>Sibling in Tx</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Type of Diagnosis</td>
</tr>
<tr>
<td>Leukemia</td>
</tr>
<tr>
<td>Lymphoma</td>
</tr>
<tr>
<td>Tumor</td>
</tr>
</tbody>
</table>

The average age of the child participants was 14.5 years with a range of 11 to 17 years (SD=2.31 years). Of those who participated, 80% (n=16) were female and 20% (n=4) were male. The majority of parents (90%, n=18) identified as being of European origin, 10% (n=2) identified as Hispanic origin. No parents identified as African-American, American Indian/
Alaska Native, Asian American/Pacific Islander, or Biracial/Multiracial. With regard to type of cancer of the diagnosed child, 35% (n=7) reported being diagnosed with leukemia, 20% (n=4) with a tumor, 15% (n=3) with ALL, and 15% (n=3) with Non-Hodgkin’s lymphoma, and Hodgkins, Neuroblastoma, and Pre-B All were each endorsed once. The question of diagnosis was open-ended on the survey, leading to varying degrees of specificity by participants. A total of 55% (n=11) reported the diagnosed child was currently in treatment and 45% (n=9) reported the diagnosed child was not currently receiving treatment.

**Analyses**

In order to address current research questions and hypotheses, data were analyzed for possible correlations first between clinical variables, then between demographic and medical variables. Variables were analyzed using Pearson product moment correlations utilizing data collected from 20 completed surveys. The Bonferroni method was used to control for Type I error; a $p$ value of less than .025 was required for significance based on two primary analyses to test hypotheses. In order to explore differences in scores between demographic and medical variables and clinical variables, independent-samples $t$ tests were conducted.

**Clinical variables.** The authors hypothesized that there would be a positive, significant relationship between perceived self-efficacy and total score on the MPS (i.e., the child’s perceived support from family, friends, and significant others). This relationship was not found to be significant. As a follow-up to this analysis, the authors looked specifically at each subscale to determine if any significant relationships emerged. Indeed, a significant positive correlation was found between self-efficacy and scores on the subscale Support Person, $p = .019$ (see Table 2). Relationships between self-efficacy and the other subscales (Family and Friends) were not significant.
Regarding the second hypothesis looking at the relationship between self-efficacy and SPQ subscale Communication, the results of the correlational analysis indicated that the correlation was not significant (see Table 2). As a follow-up, the authors then explored relationships between the other subscales and total score with self-efficacy. No significant relationships were found between self-efficacy and other subscales (Interpersonal Relationships, Intrapersonal Reactions, Fear) or the total SPQ score. Significant relationships were found between MPS subscales Family, Friends, and Support Person and the total MPS score; however, these relationships were not examined as they are expected relationships given that the subscales comprise the total score. Likewise, relationships between subscales on the SPQ with the total SPQ score did not warrant further attention. Finally, significant relationships between MPS and SPQ subscales as there is significant overlap between what the questions measure.
Table 2

Correlational Analyses of Self-Efficacy, Perceived Support, and Impact of Illness

<table>
<thead>
<tr>
<th>Measure</th>
<th>Self-Efficacy</th>
<th>Multidimensional Scale of Perceived Support</th>
<th>The Sibling Perception Questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>1. Self Efficacy</td>
<td></td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>2. Family</td>
<td>.293</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>3. Friends</td>
<td>.350</td>
<td>.401</td>
<td></td>
</tr>
<tr>
<td>4. Support Person</td>
<td>.519*</td>
<td>.569*</td>
<td>.690**</td>
</tr>
<tr>
<td>5. Total</td>
<td>.475</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>6. Interpersonal Relationships</td>
<td>-.466</td>
<td>-.548*</td>
<td>-.441</td>
</tr>
<tr>
<td>7. Intrapersonal Reactions</td>
<td>.208</td>
<td>.085</td>
<td>.035</td>
</tr>
<tr>
<td>8. Communication</td>
<td>.382</td>
<td>.794**</td>
<td>.385</td>
</tr>
<tr>
<td>9. Fear</td>
<td>-.411</td>
<td>-.498*</td>
<td>-.487</td>
</tr>
<tr>
<td>10. Total</td>
<td>-.221</td>
<td>-.206</td>
<td>-.307</td>
</tr>
</tbody>
</table>

*. Correlation is significant at the 0.025 level (2-tailed).

**. Correlation is significant at the 0.005 level (2-tailed).
Demographic and clinical variables. As a follow-up to the initial analyses, an independent samples t test was used to determine if a significant difference could be found between children whose siblings were in treatment and those whose siblings were not. Follow-up analyses were not conducted for other demographic and medical variables as the groups were too heterogeneous in size. No significant differences emerged between those whose siblings were in treatment versus those not in treatment, on measures of self-efficacy, perceived support, and impact of illness and medical knowledge (see Table 3).

Table 3

Impact of treatment involvement on self-efficacy, perceived support, and impact of medical knowledge

<table>
<thead>
<tr>
<th>Measure</th>
<th>In Treatment</th>
<th></th>
<th>Not In Treatment</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Self-Efficacy</td>
<td>4.45</td>
<td>0.820</td>
<td>4.11</td>
<td>0.423</td>
</tr>
<tr>
<td>MSPS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family</td>
<td>19.64</td>
<td>4.105</td>
<td>17.89</td>
<td>1.679</td>
</tr>
<tr>
<td>Friends</td>
<td>22.55</td>
<td>5.317</td>
<td>21.89</td>
<td>0.964</td>
</tr>
<tr>
<td>Significant Person</td>
<td>22.55</td>
<td>6.517</td>
<td>20.89</td>
<td>1.859</td>
</tr>
<tr>
<td>Total</td>
<td>64.73</td>
<td>13.305</td>
<td>60.67</td>
<td>3.969</td>
</tr>
<tr>
<td>SPQ Interpersonal</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationships</td>
<td>17.27</td>
<td>6.635</td>
<td>18.89</td>
<td>2.264</td>
</tr>
<tr>
<td>Intrapersonal Reactions</td>
<td>15.94</td>
<td>4.206</td>
<td>16.00</td>
<td>1.518</td>
</tr>
<tr>
<td>Communication</td>
<td>7.64</td>
<td>4.032</td>
<td>5.44</td>
<td>0.784</td>
</tr>
<tr>
<td>Fear</td>
<td>1.91</td>
<td>2.071</td>
<td>3.56</td>
<td>1.082</td>
</tr>
<tr>
<td>Total</td>
<td>42.73</td>
<td>8.696</td>
<td>43.89</td>
<td>3.208</td>
</tr>
</tbody>
</table>

MSPS – The Multidimensional Scale of Perceived Support
SPQ – The Siblings Perception Questionnaire

Discussion
The current study was conducted to determine factors related to self-efficacy that are salient for siblings of children with cancer in order to further the literature and inform treatment for these children. Currently, very little research has been done to investigate what these children may be experiencing, though various treatment protocols have been created and tested, yielding mixed results. In order to gain understanding about the experiences of these children, the current study built upon research findings looking at chronic illness. Specifically, self-efficacy, perceived support, and the impact of illness and medical knowledge were analyzed. Given the reviewed literature, demographic and medical information were also collected and analyzed for potential relationships to clinical variables. The following paragraphs provide discussion and interpretation of present findings according to the hypotheses tested. In addition, study limitations and suggestions for future research are explored.

The first aim of the current study was to examine the relationship between self-efficacy and perceived support. Significant correlations were not found between self-efficacy and the total score on the Multidimensional Scale of Perceived Support. Exploratory analyses, however, revealed a significant, positive correlation between self-efficacy and the subscale Significant Persons. Significant correlations were not, however, found between self-efficacy and the subscales Family or Friends. The correlation between self-efficacy and perceived support from a support person may point to the importance of relationships with adults outside the family, such as teachers, pastors, coaches, or perhaps a boyfriend or girlfriend in the participant’s life. One explanation for the results in the current research is that siblings do not want to “burden” their parents with their struggles, concerns, or worries. To that end, it may be easier to speak to another adult outside the immediate family unit. As demonstrated in previous research (Hollidge, 2001; McHale and Gamble, 1997; Waite-Jones and Madill, 2008), another possible explanation
for this correlation is that these children may not feel their parent/s have time to listen to and comfort them. Instead, this may lead these children to seek out alternative sources of support. This correlational result, indicating a positive relationship between self-efficacy and perceived support, is commensurate with extant literature on siblings of a child with a chronic illness in that it suggests that a support person is critical for siblings of children with cancer specifically. However, this is the first study to look specifically at types of support persons and as such is the first to suggest that a support person external to the family is positively correlated with self-efficacy. This finding is especially important in informing potential programs and funding for these children. Identifying individuals with whom the child can talk should be a focus of future research. Finally, a third possible explanation for the positive relationship between sibling self-efficacy and his/her perception of support is that as children enter adolescence, it is developmentally appropriate for them to begin to confide in individuals other than their parents. Reliance on others for emotional and psychological support is a normative and healthy part of finding one’s individuality and asserting independence (Kazdin, 1993; Shirk, 2001). As such, it may be valuable to explore building extra-familial adult supportive relationships as a potential intervention or prevention measure for siblings of children with chronic illness including cancer in future studies.

The second aim of the present study was to investigate a possible relationship between self-efficacy and communication, as measured by the Siblings Perception Questionnaire. This measure was designed to assess several domains with respect to the impact of cancer, including interpersonal relationships, intrapersonal reactions, fear of disease, and communication. However, a significant relationship was not found between self-efficacy and the subscale Communication as hypothesized. This is contrary to previous literature which has shown a
significant relationship between these constructs for siblings of children with chronic illness. Building off of the first hypothesis, which revealed the importance of a support person outside of the family unit, this finding may be explained by the nature of the items that load onto this subscale. Specifically, the items on this subscale focus on parents and friends with only one item dedicated to other adults. This finding may lend support to our findings with our first hypothesis: that having at least one support person to confide in other than one’s parents is positively associated with self-efficacy.

Given the paucity of literature available, analyses examining possible relationships between self-efficacy and additional subscales on the SPQ as well as between subscales on the MPS and SPQ were exploratory in nature. None of these correlations were significant for this sample size, which was small.

As a follow-up to these analyses, an independent samples t test was conducted to compare if a participant’s scores on self-efficacy, the MPS, and the SPQ would change based on whether or not the participant’s sibling was in treatment currently. However, no significant differences emerged in this follow-up analysis. Other possible predictive variable groups (i.e., age, type of cancer, gender) were too heterogeneous in their make-up, and so follow-up analyses were not conducted. Demographic characteristics reported by the parent participants in the current study appear similar to demographics in the Portland, Oregon area. Specifically, the sample was largely Caucasian.

**Limitations and Future Directions**

This study sought to build on previous research about what factors may be salient for these children with respect to their self-efficacy. There are several strengths of the current study. A primary strength of the current study was the use of self-report measures rather than relying
strictly on secondary report from adults in the child’s life. Collecting data from a protected population such as these children can be a challenging process; however, first-hand knowledge is invaluable to understanding these children’s experiences. To date, there has been very limited literature devoted to siblings of children with cancer. Even fewer studies have looked at self-efficacy, support, impact of illness, communication, and medical knowledge. The current project examined these variables specifically and in conjunction with demographic and medical variables.

It is important to note that overall, these children appear to be doing well. The mean score on our measure of self-efficacy was 4.25, which suggests that these children have a strong belief in their ability to cope with their sibling’s diagnosis. One possible explanation is that these children are exhibiting adequate functioning while the family is adjusting to a cancer diagnosis. Given the paucity of literature pertaining to self-efficacy and these children, no normative data were available. Replication studies in the future could lead to filling this gap by providing data that could lead to standardization. Without a longitudinal study to examine the long-term effects, it is difficult to say if these children are, in fact, thriving or if negative effects will surface over time.

Through examination of the current study’s findings, the construct of resilience emerged as an important factor, though it was not measured directly. Currently, there is a plethora of research dedicated to resilience in children (e.g., Luthar, Cicchetti, & Becker, 2000; Masten, 2001; Prince-Embury & Courville, 2008; Werner & Smith, 1982). It is possible that current knowledge on general resilience in children could shed light on potential moderating or mediating factors that may buffer siblings of children with cancer from negative consequences. Future research regarding siblings of children with cancer may benefit from incorporating
measures of general resilience to further investigate whether themes of overlap between resilience in children who have siblings with cancer and resilience in children across several other difficult circumstances. In order to measure this construct, the Resiliency Scales for Children and Adolescents (Prince-Embury, 2006) may be useful.

The current study’s lack of significant findings may have been impacted by the small sample size, leading to inadequate power to detect significant effects. In addition, statistics used for exploratory analyses of demographic information were impacted by the lack of variability in participants’ reports. Specifically, the current study’s sample was largely female and of European origin, leading to a sample limited in both size and demographic heterogeneity. Given sample characteristics, application of findings to diverse groups should be made with caution. It may be helpful for future researchers to partner and recruit with an organization such as the Leukemia and Lymphoma Society or the American Cancer Society on a national level to reach a broader audience and thus capture a more diverse sample regarding gender, ethnicity, and type of cancer diagnosis. Through such a partnership, it may be possible for researchers to attend annual events, such as summer camps, to reach siblings who may not otherwise be involved in the organization. Additionally, future researchers may investigate advertising through hospitals or on the internet to increase participation and diversity.

Examining perceived support and self-efficacy in a larger sample would also allow for more sophisticated statistical analyses. The current study used correlational analyses, which do not allow inferences regarding cause and effect processes. Specifically, the research does not reveal if greater self-efficacy leads to seeking out and depending on a significant person for comfort and support, or conversely, if having such an individual leads to higher levels of perceived self-efficacy. Furthermore, due to the correlational nature of the analyses of clinical
variables, it is unknown if a causal relationship exists, to what extent, and if any mediating variables may diminish or enhance the relationship.

In addition, previous literature (cf. Hollidge, 2001) suggested the important role parent coping and stress appraisals have on these children. Exploration of the role of self-efficacy, perceived support, and medical knowledge of parents may provide useful information regarding how children are coping. In doing so, further factors associated with building resistance and buffering against risk maybe uncovered.

Another important limitation of the current study is related to potential selection bias. While both online and paper-pencil versions of the survey were made available, only online surveys were completed. If completing online, participants in the current study were required to have access to the survey via Internet. Thus, it may be inferred that parent and child participants had access to a computer or device with Internet access or transportation to the LLS office where computers were available for use. These parents and children may be inherently different from those who chose not to participate in the current study or did not have access to the survey. Further, those children who are not experiencing negative consequences to their sibling’s diagnosis may not have had sufficient motivation to participate, leading to a truncated sample.

Conclusion

The results of this study provide a preliminary view into specific variables that siblings of children with cancer may be struggling with. Specifically, the presence of a support person, apart from friends and family, was found to correlate positively with self-efficacy. This finding, coupled with literature on chronic illness in general, indicates that having a support person outside the family unit is a valid and important area for future research. If, as some studies suggest, some children are predisposed to seek out such relationships, it will be important for
future researchers to investigate what interventions may be implemented for those children who are inclined to reach out. This finding is especially important in informing potential programs and funding for these children, particularly in identifying individuals with whom the child can talk and strengthening existing relationships. Future research should continue to explore this and other variables in order to gain deeper-level understanding in order to inform treatment. In an effort to aid and support these children, several evidence-based treatments have been developed; however, given the paucity of research, current treatments have yielded mixed results as to what is effective. Replication studies with larger, more diverse samples will be valuable in the pursuit of better understanding of these children. Although many facets of siblings’ experience are unknown, it is clear from the literature that there are positive and negative aspects of the experience of having a sibling diagnosed with cancer. Improved understanding of both potential mediating and moderating variables in order to inform mental health treatment is worthy of ongoing empirical investigation.
References


Appendix A: Informed Consent for Parent and Child Participation

1. Study Title

Salient Factors for Siblings of Children with Cancer (025-13)

2. Study Personnel

<table>
<thead>
<tr>
<th>Name</th>
<th>Erin Murphy, MS</th>
<th>Alyson Williams, PhD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Role</td>
<td>Principal Investigator</td>
<td>Faculty Advisor</td>
</tr>
<tr>
<td>Institution</td>
<td>Pacific University</td>
<td>Pacific University</td>
</tr>
<tr>
<td>Program</td>
<td>School of Professional Psychology</td>
<td>School of Professional Psychology</td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:erincmurphy@pacificu.edu">erincmurphy@pacificu.edu</a></td>
<td>alysonmeasewilliams@yahoocom</td>
</tr>
<tr>
<td>Telephone</td>
<td>(971) 269-8109</td>
<td>(503) 352-2429</td>
</tr>
</tbody>
</table>

3. Study Invitation, Purpose, Location, and Dates

You and your child are invited to participate in a research study about salient factors affecting siblings of children diagnosed with cancer. The project has been approved by the Pacific University IRB and will be completed by July 2013. The study will take place online or by paper copy, and the results of this study will be used to inform supportive services.

4. Participant Characteristics and Exclusionary Criteria

In order to participate, your child must have a sibling who was diagnosed with cancer in the past 12 months. Additionally, your child must be between the ages of 11 and 17, be currently living in the family home, and be fluent in English at a second-grade level. As the parent or guardian, your child must have been diagnosed with cancer in the past 12 months and you must be able to read English at a second-grade level.

You and your child will not be excluded on the basis of type of cancer diagnosis or phase of treatment.

5. Study Materials and Procedures

You and your child may complete the questionnaires through a website called SurveyMonkey or by paper copy available through the Leukemia and Lymphoma Society (LLS).
You may fill out these questionnaires at home, at the LLS office, or on any computer. The questionnaires will take your child approximately 20 minutes to complete. Before beginning the questionnaire, you will read the assent page to your child. If he or she agrees to participate, your child will be instructed check “Yes, I agree and understand assent”. These questionnaires will include questions about your child’s mood, the impact of their sibling’s diagnosis, and your child’s perceived social support. Your child will be asked to answer questions about their family life. In addition, you will be asked to answer questions about demographic information, as well as information about your child who was diagnosed with cancer. These questions include type of cancer, the age and gender of the sibling, and phase of treatment, if any. All information gained by the researchers is confidential. At any time, you and your child can close out of the web page and withdraw from the survey.

The researchers anticipate approximately 40 completed surveys from families agreeing to participate.

### 6. Risks, Risk Reduction Steps, and Clinical Alternatives

#### a. Anticipated Risks and Strategies to Minimize or Avoid Risk

Some of the questions you and your child will be asked are personal, including questions about your child’s mood, family support, and social support. You do not have to answer any particular question that you do not want to answer. Additionally, you may exit the survey at any time. A list of local resources and supports will be available both through the online survey and in paper form. Please do not hesitate to reach out for support.

#### b. Unknown Risks

It is possible that participation in this study may expose to currently unforeseeable risks.

#### c. Advantageous Clinical Alternatives

This study does not involve experimental clinical trials.

### 7. Adverse Event Handling and Reporting Plan

In the event that you become sick, injured, distressed, or otherwise uncomfortable as a result of your involvement in the research study, you may stop your participation immediately. Due to the anonymous nature of the survey, if you withdraw by quitting the survey, your responses may still be used in analyses. If an adverse event occurs, promptly notify the principal investigator or the Pacific University Institutional Review Board. If the investigators become aware of an adverse event, the IRB office will be notified by the next normal business day for minor events (e.g. your child is distressed). There are no foreseen major risks.

If you experience or are directly affected by an adverse event, you will be given the opportunity to withdraw any data collected from you during the study up to submitting your responses to the survey online.
8. **Direct Benefits and/or Payment to Participants**

a. **Benefit(s)**

There is no direct benefit to you as a study participant.

b. **Payment(s) or Reward(s)**

Participants will not be paid for their participation. However, you may choose to enter a drawing for one of five $20 giftcards to Big Al’s fun center.

9. **Promise of Privacy**

Participation in this study is anonymous unless you choose to enter the drawing or receive study results, which means your personally identifying information will then become confidential and separate from yours and your child’s responses on the surveys.

If you choose to provide your name and contact information for the purposes of receiving study results and/or entering the drawing, this information will not be connected with information provided in the survey. If you choose to provide this information, it will be kept confidential and locked on a password protected database only the investigators have access to. For example, demographic and medical information will be collected as part of the survey, but will not be associated with your name, should you choose to provide that for a chance to see study results or enter to win the gift certificate prize for participation.

Your name and your identity will not be used for publication or publicity purposes. Should results of this study be presented or published professionally, all personal identifiers of participants will have already been separated from particular data.

10. **Medical Care and Compensation in the Event of Accidental Injury**

During your participation in this project it is important to understand that you are not a Pacific University clinic patient or client, nor will you be receiving complete mental health care as a result of your participation in this study. If you are injured during your participation in this study and it is not due to negligence by Pacific University, the investigator(s), or any organization associated with the research, you should not expect to receive compensation or medical care from Pacific University, the investigator(s), or any organization associated with the study. If you are injured and it directly is related to your participation in this study as a research subject, please contact the Pacific University Institutional Review Board at 503-352-1478.

11. **Voluntary Nature of the Study**

Your decision whether or not to participate will not affect your current or future relations with Pacific University or the Leukemia and Lymphoma Society. If you decide to participate, you are free to not answer any question or withdraw at any time without prejudice or negative
consequences. Due to the anonymous nature of the survey, if you withdraw by quitting the survey, your responses may still be used in analyses. If you are completing a paper copy and wish to withdraw from the study, you may have your packet shredded at the LLS office or simply do not return the survey to the researchers. Please note that once the survey is turned in to the researchers, you will not be able to withdraw your survey due to the anonymous nature of the study.

12. Contacts and Questions

The investigators will be happy to answer any questions you may have at any time during the course of the study. If you are not satisfied with the answers you receive, please call the Pacific University Institutional Review Board at 503-352-1478 to discuss your questions or concerns further. If you have questions about your rights as a research subject, or if you experience a research-related injury of any kind, please contact the investigator(s) and/or the IRB office. All concerns and questions will be kept in confidence.

13. Statement of Consent for Parent Participation

YES  NO

[__________  __________]
I am 18 years of age or older and the parent/guardian of a) one child with a cancer diagnosis, and b) another child who is the sibling of this child with cancer.

[__________  __________]
I have read and understand the description of my duties as a participant and all my questions have been answered within this document to my satisfaction regarding the study.

[__________  __________]
I understand that I may withdraw CONSENT to PARTICIPATE at any time without consequence.

[__________  __________]
I know that I may keep a copy of this form for my records.
I voluntarily AGREE to participate in this study and understand that I may withdraw at any time without consequence (CONSENT to PARTICIPATE).

14. Statement of Permission for Child Participation

YES  NO

[__________  __________]
I am the legal parent/guardian of the child participant.

[__________  __________]
I have read and understand the description of my child/ward’s participation duties and all questions have been answered to my satisfaction.
I will discuss this research study with my child/ward and explain the procedures that will take place.

I grant permission for my child/ward to participate in this study.

I understand that the investigators also will obtain my child/ward’s independent assent before further activity.

I understand that I may withdraw this permission and/or that my child/ward may withdraw assent at any time without consequence.
Appendix B: Assent

1. Study Title

Salient Factors for Siblings of Children with Cancer

2. Study Information

My name is Erin Murphy and I am a graduate student at Pacific University. I am conducting a research study to help learn about how kids and young adults cope when a sibling has been diagnosed with cancer. I am asking you to be a part of this study because you have a brother or sister who was diagnosed with cancer. I want to tell you a little bit about the study so you can decide if you want to be in the study or not.

If you want to be in this study, you will be asked if you have someone in your life that you can talk to when worried or scared. You will also be asked about your family and friends. There will also be questions about how you feel about your brother or sister’s illness and how much you feel like you can handle your brother or sister being sick. Some questions also ask if you are sad about your sibling’s cancer and if you are afraid you may catch cancer. You don’t have to answer any questions. This study will take place either on the computer or on paper, whichever you choose.

There also are some good things that might happen to you if you participate. We might find out information that will help other kids some day.

Please talk about this study with your parents before you decide if you want to be in it. Even if your parents say you can be in this study, you can still say that you don’t want to. It is okay to say “no” if you don’t want to be in the study. No one will be mad at you. If you change your mind later and want to stop, you can.

You can ask your mom or dad any questions about this study. After all your questions have been answered, you can decide if you want to be in this study or not.

If you want to be in this study, please click “Yes, I’d like to participate”

If you do not want to be in this study, please click, “No, thank you”
Appendix C: Demographic Questionnaire

Demographics

1. What type of cancer was your child diagnosed with?
2. Is your child currently undergoing treatment? Yes/No
3. How old is your child who is the sibling of the diagnosed child?
4. Gender of child who is the sibling of the diagnosed child: F/M
5. What ethnicity do you most identify with? Please circle one.
   African American
   American Indian/Alaska Native
   Asian American/Pacific Islander
   European Origin
   Latino-a/Hispanic
   Biracial/Multiracial
Appendix D: Self-Efficacy Question

To what extent do you feel you can handle your sibling’s disease? Please select one.

1 = I’m not handling it very well.

2

3

4

5 = I’m handling it very well.
Appendix E: Multidimensional Scale of Perceived Support

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the "1" if you Very Strongly Disagree
Circle the "2" if you Strongly Disagree
Circle the "3" if you Mildly Disagree
Circle the "4" if you are Neutral
Circle the "5" if you Mildly Agree
Circle the "6" if you Strongly Agree
Circle the "7" if you Very Strongly Agree

1. There is a special person who is around when I am in need. 1 2 3 4 5 6 7
2. There is a special person with whom I can my joys and sorrows. 1 2 3 4 5 6 7
3. My family really tries to help me. 1 2 3 4 5 6 7
4. I get the emotional help and support I need from my family 1 2 3 4 5 6 7
5. I have a special person who is a real source of comfort to me. 1 2 3 4 5 6 7
6. My friends really try to help me. 1 2 3 4 5 6 7
7. I can count on my friends when things go 1 2 3 4 5 6 7
8. I can talk about my problems with my family. 1 2 3 4 5 6 7
9. I have friends with whom I can share my joys and sorrows. 1 2 3 4 5 6 7
10. There is a special person in my life who cares about my feelings. 1 2 3 4 5 6 7
11. My family is willing to help me make decisions. 1 2 3 4 5 6 7
12. I can talk about my problems with my friends. 1 2 3 4 5 6 7
Appendix F: The Sibling’s Perception Questionnaire

On a Likert scale, please rate each statement:

0= never, 1= some of the time, 2= neutral, 3= most of the time, and 4= always

1. I wish my parents would spend less time with my brother/sister.
   0  1  2  3  4

2. I wish my parents would spend more time with me.
   0  1  2  3  4

3. People are more interested in my brother/sister than me.
   0  1  2  3  4

4. Since my brother/sister was diagnosed, people don’t care how I feel.
   0  1  2  3  4

5. Since my brother/sister was diagnosed my parents ignore me.
   0  1  2  3  4

6. Since my brother/sister was diagnosed I have too much to do in the house.
   0  1  2  3  4

7. I don’t want to bother my parents with my worries.
   0  1  2  3  4

8. I wish I knew someone who understands how I feel.
   0  1  2  3  4

9. Since my brother/sister was diagnosed, we don’t do much as a family.
   0  1  2  3  4

10. I feel sad about my brother/sister’s cancer.
    0  1  2  3  4
On a Likert scale, please rate each statement:

0= never, 1= some of the time, 2= neutral, 3= most of the time, and 4= always

11. I wish there was something I could do about my brother/sister’s cancer.
   0  1  2  3  4

12. I think about my brother/sister’s cancer.
   0  1  2  3  4

13. I wonder why my brother/sister got sick.
   0  1  2  3  4

14. I feel mad about my brother/sister’s cancer.
   0  1  2  3  4

15. I understand why my parents have to spend time with my brother/sister.
   0  1  2  3  4

16. I can forget that my brother/sister has cancer.
   0  1  2  3  4

17. I can talk to my parents about my schoolwork.
   0  1  2  3  4

18. I can talk to my parents about my brother/sister’s cancer.
   0  1  2  3  4

19. I can talk to other adults (like my teachers) about my brother/sister’s cancer.
   0  1  2  3  4

20. I can talk to my friends about my brother/sister’s cancer.
   0  1  2  3  4

21. I worry that I can catch cancer from my brother/sister.
   0  1  2  3  4
22. I am afraid of my brother/sister’s cancer.

0  1  2  3  4

23. My friends worry that they can catch cancer from my brother/sister.

0  1  2  3  4