

EMOTIONAL AND BEHAVIORAL FUNCTIONING OF SIBLINGS OF PEDIATRIC
CANCER PATIENTS: DISCORDANCE BETWEEN PARENT AND SELF-REPORT AND
ASSOCIATIONS WITH FAMILY FUNCTIONING

By

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Pediatric cancer is a life-altering disease which can profoundly impact the psychological functioning of the children it affects. However, pediatric cancer not only affects the ill-child but the entire family system. Research examining the psychological functioning and adjustment of parents of pediatric cancer patients has been widely disseminated; however studies assessing the emotional and behavioral functioning of the non-ill siblings have only recently started to appear. Research that has been conducted in this area suggests that oncology siblings can exhibit some emotional and behavioral difficulties in response to the ill-child's diagnosis and resultant changes in family dynamics. Additionally, despite preliminary research suggesting that children with different types of cancer (i.e., tumors versus leukemia) have different emotional and behavioral outcomes, not enough is known to guide treatment guidelines as programs for these children and their families begin to be developed. This project used standardized clinical measures to evaluate the psychological functioning of 35 healthy siblings of oncology patients recruited from a pediatric hospital. Additionally, we examined other factors that may affect sibling functioning, including psychological

functioning of the parent and ill-child, and perceptions of broader family functioning. This study recruited 20 families from an outpatient clinic to act as a primary care comparison group. Results suggest that overall, patients, mothers, and siblings are doing well at the individual level. However, siblings are endorsing more difficulties in the family unit and more psychological problems than reported by their mothers. The results of this study further highlight the importance of assessing the psychological functioning of the whole family unit when working with a child diagnosed with cancer. Finally, the current study design provides a framework for future studies investigating the complex set of factors that may affect functioning of individual family members.

CHAPTER 1 INTRODUCTION

Childhood cancer is a devastating disease that greatly impacts the lives of the patients affected. However, cancer not only affects the patients, but it can significantly affect the quality of life and psychosocial functioning of the surrounding family members as well. Extensive research has been conducted examining the psychological functioning of ill-children and their parents (Alderfer, Long, Lown, et al., 2010; Prchal and Landolt, 2009). However, recent attention has also been given to the emotional and behavioral functioning of siblings of children with cancer (i.e., Alderfer, Labay, & Kazak, 2003; Labay & Walco, 2004; Houtzager, Oort, Hoekstra-Weebers, et al., 2004a). These siblings not only have to face uncertainty regarding their siblings' health status, but their lives are often disrupted by the constant changes in routine, reduced parental involvement or emotional availability, reduced social support and access to friends, and increased responsibilities or assumption of new roles within the family (Prchal et al, 2009; Guite, Lobato, Shalon, et al., 2007). Given all these changes, it is not surprising that these children may experience some emotional or behavioral distress; however, research has only started to unearth which factors contribute to the expression of psychological symptoms in these children.

The present study sought to add to the developing research for siblings of pediatric cancer patients. As children are not immune to the influence of the family members that surround them, it is important to have a framework in mind that includes the influence that other family members and environmental factors may have on the emotional and behavioral functioning of the siblings. One component includes individual factors such as: demographic characteristics, health status, and pre-illness functioning

and coping, which may vary for each family member. Another component may include family characteristics such as communication, role and routine changes, emotional availability and responsiveness, and available resources such as socioeconomic status and social support. While each of these factors is important to acknowledge individually, the interaction of these factors may greatly impact the functioning of the individual sibling as well. This paper did not seek to propose a model of the sibling's emotional and behavioral functioning, but rather recognize that there are several factors external to the child that may influence their emotional and behavioral functioning. Thus, significant emphasis is placed on the patients' and parent's psychological functioning and the adjustment of the family unit in our discussion of the healthy siblings. Furthermore, while this project sought to address significant gaps in the literature, the ultimate goal lies in providing further evidence for the implementation of psychological services for this vulnerable population.

Family Environment

When we are examining the psychological adjustment of siblings in response to a cancer diagnosis and treatment, it is important to note that children function within a family context, and thus there may be factors that contribute to or buffer the development of emotional and behavioral symptoms. The idea that family functioning could play a key role in shaping a child's behavior has prompted several researchers to empirically analyze the effect of family functioning on siblings psychological functioning (Alderfer et al., 2010). A review of studies in this area found 28 articles assessing the family unit; however, it should be noted that while there has been an emphasis in the literature on including family factors in research, 19 of these studies provided solely qualitative information. Thus, an area of needed development is to provide quantitative

accounts of the family context in which siblings exist. The overall findings from this meta-analysis (Alderfer et al., 2010) suggest that siblings perceive that they are receiving less attention and spending less time with their parents, which may be an accurate assessment, as the majority of parents across studies expressed that they have difficulty attending to the needs of both of their children (Alderfer et al., 2010). Other important factors that were noted to change after receiving a cancer diagnosis were disruptions of routines, increasing responsibilities for the sibling, and difficulty depending on their family for the support they are accustomed to.

The quantitative studies that do exist provide us with important information and are guiding new research in the field. In a study examining siblings' perceptions of family functioning, results showed that family harmony was viewed as a problem by children dealing with their sibling's brain tumor diagnosis (Freeman, O'Dell, & Meola, 2003). Usually siblings receive most information regarding the health status of their sibling from the family unit; however, the siblings are usually the family members who are often overlooked (Lobato & Kao, 2002). Research by a team at Brown University noted that children often benefit from receiving developmentally-appropriate information about their siblings illness. More specifically, children who participated in a clinical program designed to increase sibling knowledge and connectedness, displayed significantly fewer behavioral symptoms on the Child Behavior Checklist, per parent report, post-treatment (Lobato et al., 2002). These results suggest that the family environment, including family connectedness and communication, can have a significant and positive impact on the siblings' emotional and behavioral functioning. However, this is not a universal finding. Labay and Walco (2004) found that siblings who endorsed positive

relationships with family members had higher levels of maladjustment and decreased social skills. They hypothesized that these children are actually at higher risk for maladjustment because the stress of the medical outcomes and procedures are increased because of the close relationship.

Another study that points to the importance of functioning of the family unit in predicting maladjustment in siblings is a study of 99 siblings of pediatric cancer patients by Sloper and While (1996). They indicated that 24 of the 99 siblings had levels of behavioral problems in the borderline or clinical range 6 months after diagnosis of cancer. The authors suggested that while the majority of the siblings did not have clinically significant emotional or behavioral symptoms, factors that contributed to clinical levels in 24 children included the family's method of coping with illness and how the siblings perceived changes in relationships and communication with others (Sloper et al., 1996). These findings suggest that while the majority of children do not exhibit clinical levels of symptoms, there may be certain familial factors that place them at risk for maladjustment.

A limitation of this research is that the majority of researchers do not use control groups; therefore the reader cannot ascertain whether findings are specific to families dealing with cancer or to families in general (Alderfer, 2010). Thus, this study seeks to quantitatively assess family functioning in the domains of communication, roles, conflict, emotional availability and responsiveness, in pediatric oncology and a primary care groups.

Patient Factors

When working with siblings of pediatric cancer patients, it is important to note that individual characteristics of the ill-child, such as health status and treatments, can

impact the functioning of the healthy sibling. Fortunately, the world of pediatric cancer treatment and research is vastly changing. Within the last couple decades researchers and clinicians have made substantial strides to improve treatments targeting pediatric patients, and to that end, have had amazing success at increasing 5-year survivorship outcomes (Patenaude & Kupst, 2005). Due to these changes in survivorship, research has emerged addressing psychological functioning in addition to the children's medical outcomes.

Pediatric oncology patients experience significant life stressors associated with painful and scary medical procedures, uncertainty about their diagnoses, separation from family and friends, and in some cases, physical changes associated with their condition or medical treatments. One might expect significant difficulty adjusting and the possibility of maladaptive psychological symptoms due to these changes in the children's lives; however, many research studies suggest that these children do not experience substantial psychological impairment during (Eiser, Hill, & Vance, 2000; Kazak, Rourke, Alderfer, Pai, Reilly, & Meadows, 2007) or after completing treatment (Patenaude et al., 2005). In a meta-analysis completed by Eiser et al., (2000), the majority of research studies reported that pediatric cancer patients did not exhibit significantly more global symptoms than population norms. In fact, one study reported that these patients exhibited significantly less symptoms than population norms (Elkin, Phipps, Mulhern, & Fairclough, 1997 as cited in Eiser et al, 2000). Given the fact that the majority of children do not express clinical levels of psychological distress, it has led many researchers to examine factors that contribute to the development of psychological symptoms in some children.

One of the most influential individual factors affecting functioning of pediatric patients is type of diagnosis. According to the Children's Oncology Group (COG), there are three main types of pediatric cancer diagnoses: leukemias (cancers of the blood), lymphomas (cancers of the immune system), and solid tumors, which can be further separated into brain and Central Nervous System (CNS) tumors and other solid tumors (Children's Oncology Group, 2011). Each type of cancer has its own prognosis, treatment course, and associated symptomatology. Due to these differences, it could be expected that children with different oncological diagnoses would exhibit various physical and psychological outcomes. In a study utilizing data from the national research project, the Childhood Cancer Survivor Study, data showed that survivors who were diagnosed with leukemia, CNS tumors, and neuroblastomas were more likely to exhibit problems with depression/anxiety and antisocial behaviors than children with other types of cancer (Schultz, Ness, Whitton, et al., 2007). Furthermore, children with CNS tumors were more likely to exhibit difficulties with social competence. Given the research above, it may be particularly important for health care workers treating these children to closely monitor any changes in or deterioration of mental health status.

Considering that each pediatric cancer diagnosis comes with its own unique treatment regimen, another important individual factor to consider is type of oncological treatment. Most researchers in the field agree that children with cancers with central nervous system (CNS) involvement have an increased risk for short (Moore, Challinor, Pasvogel, et al., 2003) and long-term psychological sequelae (Hill, Kornblith, Jones, et al., 2003). In a study of patients who were currently undergoing or had recently completed treatment for acute lymphoblastic leukemia with CNS involvement, results

showed elevated scores in the domains of somatization, depression, anxiety, and withdrawal (Moore et al., 2003). In addition to these internalizing symptoms, these authors also reported higher levels of attention and learning problems. The authors also postulated that children who experience academic or cognitive difficulties in response to their treatments might also be at higher risk for behavioral symptoms. These results suggest that children diagnosed with ALL with CNS involvement, who have subsequently received intrathecal chemotherapy and/or intracranial radiation, may have additional emotional and cognitive symptoms than children without CNS involvement.

Finally treatment status may act as an individual factor that may play a role in the patient psychological functioning. Pediatric cancer treatment, unlike many other chronic disorders, goes through several stages with various side effects and stressors on the individual patient and the family. Some research suggests that children who have been recently diagnosed with cancer exhibit more psychological symptoms than a comparison group (Sawyer, Antoniou, Toogood, et al., 2000). However, in that same study, parents rated their children comparably to the community sample one year into treatment and then at subsequent yearly follow-ups. In a different study of children with acute lymphoblastic leukemia, researchers found differences in physical and psychological functioning 6 weeks and 1 year after diagnosis (Moore et al., 2003). The authors found that individual treatment factors, such as treatment intensity and medical complications, were predictive of decreased motor and emotional functioning. Results from this study show that treatment intensity is not significantly correlated with health related quality of life one year post diagnosis compared to 6 weeks; however, complications associated with oncological treatment continue to be correlated with

emotional functioning. Their results also suggest that children with acute lymphoblastic leukemia may have more physical and emotional complaints due to the intense treatments they received during their first phase of chemotherapy (Moore et al., 2003). Putting these results together, it suggests that health care workers not only need to acknowledge the type of cancer, but also the treatment phase in working with these families.

Sibling Factors

Individual patient factors as mentioned above can influence not only the psychological functioning of the patient, but the surrounding family members as well. If we continue to emphasize the involvement of various factors contributing to the emotional and behavioral functioning of siblings, it is also important to acknowledge individual sibling factors that may contribute to their emotional and behavioral functioning such as: demographics, health status, treatments for their sibling, and pre and post-diagnosis coping. Earlier research in the area of pediatric psycho-oncology suggested that healthy siblings of pediatric cancer patients are at higher risk for psychological maladjustment (Cohen, Friedrich, Jaworski, Copeland, & Pendergrass, 1994 provide references). However, recent studies suggest that while siblings may exhibit some emotional and behavioral changes in response to the ill-child's diagnosis and resultant treatment, their symptoms are usually not clinically significant at the group level (Alderfer et al., 2010). However, some researchers report that the percentage of siblings whose scores fall within the sub-clinical or clinical ranges is higher than normative groups (Houtzager, Grootenhuis, Caron, et al., 2004b). A similar question to the one proposed in the oncology group arises: if the majority of siblings do not

experience serious psychological maladjustment, what factors are implicated for the minority of siblings that do experience significant psychological difficulties?

Emotional Functioning

Often when a child is diagnosed with cancer, they are thrust into a world of changes: frequent medical appointments and painful procedures, significant time away from home and school, and large disruptions to their daily routine. However, what is often overlooked is that siblings have significant changes to their lives as well (Alderfer et al., 2010). Not only do these children have to worry about the uncertainty of their brother or sister's illness (individual factors), they often have limited contact with one or both of their parents and the daily structure that they are accustomed to (family factors). Possibly due to these changes, siblings often have significant difficulty adjusting and these difficulties may present as emotional symptoms. Common emotional symptoms found within this population include depression, anxiety, and post-traumatic stress symptoms (Alderfer et al., 2010).

Recent research in the area of pediatric psychology suggests that anxiety is a common symptom after learning about a siblings' cancer diagnosis (Houtzager, Grootenhuis, & Last, 2001). In fact, a clinical psychology group in the Netherlands received frequent consults about siblings of pediatric cancer patients to the point where they created a support group to enhance sibling knowledge about the disease and to foster peer support in order to decrease anxiety (Houtzager et al., 2001). A study examining the effectiveness of their program found that 18 out of 24 siblings initially had anxiety scores above the 80th percentile on the State Trait Anxiety Inventory before starting the group. Additionally, siblings' levels of anxiety were significantly higher than age-based norms. The exception to this finding was in the sub-group of adolescent

females where anxiety was comparable to the normative sample before and after treatment. At the end of the treatment, the young males and the adolescent boys exhibited normative levels of symptoms; however, the younger females continued to endorse higher levels of anxiety than age-based norms. The same research team reported that anxiety appeared to be associated with various individual factors such as age, number of days in the hospital, types of control strategies used, and other family factors (Houtzager et al., 2004a). Overall, anxiety decreased as days in the hospital and the child's sense of optimism increased. Families who rated themselves as more cohesive reported higher levels of anxiety, which supports the idea that individual and family factors may interact. Findings by Houtzager et al. (2004a) may suggest that being closer to family could actually serve as a risk factor of anxiety possibly due to more time spent with the ill-child or more exposure to ill-child's treatment.

Going beyond generalized anxiety, one of the most recent areas of research for siblings of pediatric cancer patients is post-traumatic stress. Alderfer, Labay, and Kazak (2003) reported that approximately 49% of siblings in their sample experienced mild post-traumatic stress reactions years after diagnosis. More concerning results showed that 32% of siblings experienced moderate to severe levels of post-traumatic stress reactions. Results also showed that girls and siblings older than six were more likely to endorse post-traumatic stress symptoms. Alderfer and colleagues (2003) postulated that these children are at particular risk because they may take on caregiving roles and are exposed to more of the medical procedures and familial distress. This also provides an example of how an individual factor (age of sibling) can interact with family factors

(caregiving changes), highlighting that different age groups may experience different psychological symptoms possibly in part to their roles played within the family unit.

Given the stressful nature of having a sibling with cancer, it would not be surprising to see significant depressive symptoms, in addition to anxiety, in these children. However, in a recent meta-analysis of psychological functioning in siblings of children with cancer, the majority of studies showed that siblings show comparable or lower levels of depressive symptoms than community controls (Alderfer et al., 2010). Interestingly, compared to the findings for anxiety symptoms, there was not a trend for a higher percentage of children falling within the sub-clinical or clinical ranges, at the group level, than the normative controls. In line with the question asked above, what factors then are contributing to the expression of anxiety in these children, but not depression? This study sought to add to the research examining which individual and family factors are associated with the presence of psychological symptoms in these children.

Behavioral Functioning

While emotional symptoms are frequently discussed within the sibling literature, there is less research examining behavioral symptoms. It is not unfounded that these children would exhibit acting out behaviors given the dramatic changes in their lives and the significant decrease in daily routines, structure, and at times, lack of parental involvement or supervision. In a large-scale study of siblings of cancer patients, researchers showed that the sibling group had significantly higher scores on the Externalizing scale, including aggression and conduct problems, of the Child Behavior Checklist compared to age-based norms (Cohen et al., 1994). While this was an important finding, what was more concerning was that a significantly larger proportion of

siblings had scores one or two standard deviations above the mean compared to the normative group. Results indicated that the extent of externalizing behaviors was predicted by the individual factors of sibling age at time of diagnosis and age at the initiation of the study, as parents were more likely to endorse externalizing symptoms in their younger children than older children. However, these results are not universal, as other studies have shown decreased rates of aggression, substance use, and anti-social behavior in pediatric cancer survivors in comparison to their peers (Verrill, Schafer, Vannatta, and Noll, 2000). The strength of the Cohen et al. study lies in their examination of factors that would make children more prone to developing externalizing symptoms, but there are likely other factors, which this study aimed to examine, that play a role in the development of increased emotional and behavioral problems.

Differences Between Different Cancer Groups

While it is important to examine the emotional and behavioral symptoms in siblings in general, it is also important to acknowledge that psychological functioning may also be associated with the type of cancer the ill-child has. There are many types of pediatric cancer diagnoses that are associated with a vast array of prognoses, treatments, and physical outcomes that may subsequently affect families in different ways (Sidhu, Passmore, & Baker, 2006). In a large study examining outcomes for siblings of pediatric cancer patients, siblings were found to have significantly higher levels of psychological distress than siblings of non-ill children (Cadman, Boyle, & Offord, 1988). Siblings of cancer patients may have particular difficulties with psychological adjustment given the physical (Sidhu et al., 2006) and cognitive impacts of the disease (Freeman et al., 2003), intensive treatments, and variable prognoses (Sidhu et al., 2006). The next section will discuss the differences that have been found between cancer groups.

While there has been an increase in studies examining the emotional and behavioral functioning of pediatric cancer patients and their siblings, little research has examined possible differences across different oncological diagnoses. Research that has been done in this area suggests that children diagnosed with leukemia and lymphomas exhibit different psychological symptoms than children with solid or brain tumors, and respond differently to psychological treatment (Houtzager et al., 2001). As described in a previous section, researchers examined the effect of a group therapy treatment on levels of anxiety in siblings of pediatric cancer patients. Results showed that siblings showed greater levels of anxiety before starting the treatment; however, after participating in a group program designed to increase the siblings' knowledge of their ill-child's disease and treatment, the siblings' level of anxiety significantly decreased. An interesting finding from this research suggests that siblings of children with brain tumors did not benefit from the treatment at the same levels as siblings of leukemia and lymphoma patients. The Surveillance Epidemiology and End Results suggest that the 5-year survival rates (ages 0-19) for brain and other central nervous system cancers is 75.2% and 68.8% for neuroblastomas, compared to 84.0% for children with acute lymphoblastic leukemia (Ries, Melbert, Krapcho, et al., 2007). Given that the survival rates for brain and solid tumors are lower than for leukemia, siblings of these patients may have more difficulty adjusting to their sibling's diagnosis and treatment and subsequent anxiety related to their prognosis (Houtzager et al., 2001). Future research should aim to examine differences between cancer groups in order to ascertain whether some groups are at particularly high risk for maladjustment, thus providing evidence for appropriate assessment.

Informant Factors

Most studies examining the psychological functioning of children with cancer and their siblings have heavily relied upon parent-report of the child's emotions and behavior, as opposed to the child's self-report (Guite, Lobato, Kao, et al., 2004). In some instances parent-report of emotional and behavioral symptoms may be necessary, such as when the child is too young or unable, due to medical factors, to complete their own ratings (Eiser and Morse, 2001). However, if the child is old enough to provide their own account of their functioning, they may provide clinically useful information that the parent may not have provided. Furthermore, it is conceivable that report of a child's functioning may differ depending on who the informant was as well as the nature of psychological functioning of the informants themselves, thus producing a "parent-child discrepancy" in the reported functioning of the child.

Reviews of parent-child discrepancy literature indicate that parents of ill-children usually endorse more negative outcomes than the patients rate themselves (Eiser et al., 2001). However, in a study of siblings of children with cancer, siblings endorsed more internalizing, externalizing, and overall problems than their parents on the Child Behavior Checklist, 1 month following their siblings' diagnosis and interestingly, 2 years post-diagnosis (Houtzager et al., 2005). In the same study, siblings also reported lower quality of life than their parents. The authors hypothesized that the parents may have been less likely to see emotional problems in the siblings because they may be spending significant time attending to the ill-child. Additionally, they noted that parents of children with cancer are frequently out of the home attending to the ill-child and thus may not be spending significant amounts of time with the siblings, which could reduce their ability to see emotional disturbances should they exist.

The psychological state of the parent is also an important individual factor to consider when utilizing parental proxy report of a child functioning. Research suggests that parents who endorse problems with their own psychological functioning are more likely to endorse psychological symptoms in their child (Cohen et al., 1994). The nature of this relationship is unclear, but could be reflective of a reporting bias (e.g., depressed parents may perceive their child's functioning more negatively) or a relational effect where children of depressed parents may actually have more mood or behavior problems because of the influence of their parent's mood on them). An example of this is illustrated in a study examining predictors of sibling maladjustment (Cohen et al., 1994). This study examined the various factors that predict psychological symptoms in siblings of children with cancer at various points in their treatment protocols. Results suggest that mothers who endorsed significant depressive symptoms were more likely to endorse higher scores on the Child Behavior Checklist and lower scores on a measure of social competence. This has large implications when working with these families clinically as children may be less likely to engage in treatment if they do not feel as distressed as their parents think they are (Davidson, 2005). This also suggests that individual factors of different family members may interact to affect the emotional and behavioral functioning of the sibling.

Child's age is also an important individual factor when comparing parent and child ratings. As children's age increases the likelihood of similarities between parent and child report tends to increase, likely given the maturing child's ability to express their needs and emotional state (Eiser et al., 2001). As discussed previously in this review, Houtzager et al. (2004b) found that siblings endorse significantly more emotional

symptoms two years post diagnosis than their parents. In the discussion of these findings, the authors suggest that the younger children may exhibit maladjustment in terms of their social relationships instead of in emotional symptoms because they are more dependent on their family members for coordinating social visits than teenagers. They also suggest that the younger children's physical symptoms may be an external expression of stress, anxiety, or a method of gaining their parents attention since they do not yet have the verbal skills to communicate their feelings. This idea would also support the finding that parents and children agree more on behavioral symptoms, those that they can externally observe, than emotional symptoms.

Parent-child relationships can be greatly affected by a cancer diagnosis (Zeltzer, Dolgin, Sahler, et. al., 1996). Parents can become less communicative and can spend significantly less time with the non-ill child. Conversely, family factors such as parent-child communication may improve between the ill-child and the parent given their increased time with one another and the need for clear communication in order to properly treat the child (Eiser et al, 2001). An area of needed research is to determine whether there are differences between parent-child report with the ill-child and parent, sibling and parent, and controls in which there is no illness within the family unit.

In summary, the research discussed above shows that when working with families living with cancer, it is important to assess not only the patient, but also the surrounding family unit. More importantly, while most studies use parental proxies to assess patient and sibling functioning, it seems imperative that mental health professionals receive information from the patient and the parent. However with the addition of multiple informants, you also have the increased time of scoring and interpretation. This

provides justification for the use of broadband screening measures in order to screen for more serious psychopathology than giving each family member multiple measures to assess different domains of functioning. This last factor will be discussed in the section below.

Measurement Factors

Pediatric patients and their families have often received services through referrals from their medical teams through a traditional consultation approach. However, several problems arise with this model of psychological intervention; 1) many families are not referred until they have significant problems and 2) many families who are not experiencing significant psychopathology or significant distress, but have sub-clinical symptoms or are having difficulty adjusting, may be missed. The present trend in psycho-oncology research is veering away from focusing on major psychopathology to a more preventative and universal model of psychological care (Kazak et al., 2007). As Kazak et al. (2007) noted, the majority of patients and families reasonably have some minor adjustment difficulties, but overall most families do not exhibit major psychopathology. Using their knowledge from 20 years of research in pediatric psycho-oncology, they have implemented a model of care that emphasizes screening for all, but intervention for only those who need it, recognizing that that majority of families do not require in-depth clinical services (Pediatric Psychosocial Preventative Health Model [PPPHM] for more information, Kazak et al., 2007). A strength of their program lies in their ability to identify families that need the most aid and provide needed services. However, as the reader can gather from the research summarized above, the majority of psychological research in this field has focused on specific areas of functioning, such as anxiety, depression, and post-traumatic stress disorder, or disease-specific

measures, as opposed to more broadband measures of functioning. While individually each measure may not take much time to complete, if these families are asked to complete several measures in order to tap into multiple areas of emotional and behavioral functioning, they could be spending hours completing these measures. Since most families will not experience clinically significant symptoms, and it is time intensive to complete several measures, it seems appropriate to have families complete broadband questionnaires that evaluate various domains of psychological functioning at one time (Wolfe-Christensen, Mullins, Stinnett, Carpentier, & Fedele, 2009).

The Child Behavior Checklist (CBCL; Achenbach, 1991a, b) is often used in clinical settings as a broadband measure of emotional and behavioral functioning in children with cancer (Wolfe-Christensen et al., 2009 provides listing of studies that have utilized CBCL). The CBCL is a useful tool in examining several domains of psychological functioning; however, Perrin, Stein, & Drotar (1991) note that there are some problems with using this measure within an oncology population (Perrin, Stein, & Drotar (1991) as cited in Wolfe-Christensen et al., 2009). First, there are concerns that pediatric oncology patients may have higher scores on the internalizing composite scale due to endorsement of somatic items associated with their illness and treatment. Second, the CBCL is less sensitive to sub-clinical levels of symptoms. Third, the CBCL may not provide accurate social competence scores given the scales that make up the composite. In response to these concerns, Wolfe-Christensen et al. (2009) proposed the use of the newer broadband measure, the Behavior Assessment System for Children, 2nd Edition (BASC-2; Reynolds & Kamphaus).

The BASC-2 is a widely used measure of emotional, behavioral, and adaptive functioning (Reynolds et al., 2004), which includes both parent and self-report forms. In contrast to the popular CBCL, Wolfe-Christensen et al. (2009) suggested that the BASC-2 has several advantages over the CBCL including individual subscales for emotional symptoms, a wide range of T scores that allows participants to score below 50, scales to assess validity of participant responses, and normative scores for various diagnostic groups (Wolfe-Christensen et al., 2009). While the BASC-2 has been extensively used in children with clinical disorders such as Attention-Deficit/Hyperactivity Disorder (ADHD) and learning disorders, there is limited research examining the use of the BASC-2 in children with medical diagnoses. In order to address this gap in the literature, Wolfe-Christensen and colleagues (2009) initiated a study to compare scores of pediatric oncology patients to a healthy control sample. Using a discriminate function analysis, the authors found that the BASC-2 was able to distinguish between the two groups in terms of emotional and cognitive complaints. While their results provided evidence for the use of the BASC-2 as a good screening tool in the pediatric cancer population, they had 2 limitations that should be addressed: (1) their sample failed to find differences between different subtypes of cancer (i.e., leukemia/lymphoma, solid tumors, and brain tumors) and (2) they only included parent-report versions of the questionnaire. Future research should seek to assess whether there are differences between oncological groups (leukemia vs. brain tumor) in a different sample of participants and should include child self-report versions of the forms.

Limitations of the Existing Literature and Goals of the Current Study

Despite the vast research in the area of psychosocial functioning of families with a child with pediatric cancer, there are several limitations that should be addressed. One of the consistent limitations throughout the literature is the lack of appropriate control groups in studies examining children's adjustment to their siblings' cancer diagnosis. This study sought to expand on the literature in this area and provide a primary care group of children with non-ill siblings in order to assess whether many of the relationships cited in the literature (i.e., discordance between parent and child report, increased maladjustment with non-cohesive family units) are consistent for families in general or whether they are specific to the cancer population. Additionally, the present study adds to the current literature base by providing quantitative reports of family functioning as rated by both the parent and the children.

While there is still some disagreement about whether siblings exhibit negative psychological outcomes in response to living with a brother or sister diagnosed with cancer, there appears to be consistent evidence that parents and children endorse different psychological symptoms, and that in order to provide the most comprehensive assessment of the siblings' functioning researchers have to obtain information from the siblings themselves in addition to parent-report. This study sought to advance the literature in this area by providing a comprehensive assessment of the child's broadband emotional and behavioral functioning and the functioning of the family based not only on the parents' perspective, but also on the siblings' report as well. While many studies have examined the psychological functioning of siblings, this study went one step further by assessing what aspects of family functioning affect the psychological adjustment of the siblings.

Study Objectives and Hypotheses

This study adds to the literature by examining the emotional and behavioral functioning of pediatric patients, their siblings, and their parents. Additionally, this study attempts to add to the literature in the field differentiating the psychological symptoms that present between different family members. A recent addition to the literature, and one in which this study aims to incorporate, is the inclusion of individual (patient, sibling, and parent) and family factors that are associated with children's psychological functioning. A final contribution of the present study collects similar information from a primary care group of siblings to assess whether the proposed findings are specific to siblings in the oncology population or whether siblings from healthy populations exhibit similar patterns. Study aims and hypotheses are as follows:

Aim 1: Describe Psychological Functioning of Families with a Child with Cancer

The preliminary goal of this project was to describe an often overlooked aspect of the psychological functioning of families living with a child with cancer: the psychological functioning of siblings. As noted in the literature, the patient is not the only family member at risk for experiencing emotional and behavioral disturbance, siblings and parents are also at risk for psychological maladjustment. In order to study sibling and parent wellbeing in a pediatric cancer population, research should include measures to assess siblings' and mothers' psychological functioning as well as the patient's. However, as noted in the review of the literature, parents and their children may have differing opinions about their functioning. Thus, the current study incorporates both the parent perspective and the sibling's self-report of their psychological functioning.

Sub Aim 1. Describe psychological functioning of children in families living with a child with cancer, including the child with cancer and siblings.

Hypothesis 1.1.1: It is not anticipated that siblings of oncology patients (from here on will be called “oncology siblings”) will exhibit clinically significant symptoms at the group level, but a larger percentage of them will fall in the at-risk or clinical ranges compared to a primary care comparison group (from here on will be called “primary care siblings”). It is not expected oncology siblings will endorse significantly higher scores than the normative sample. This was tested for parent-report and self-report versions of the measure.

Hypothesis 1.1.2: We do not expect pediatric oncology patients (from here on will be called “oncology patients”) as a group to have clinically elevated scores on a broadband psychological measure. It is hypothesized however, that the percentage of children falling into the at-risk or clinical range will be significant higher than a primary care comparison group (from here on will be called “primary care patients”). It is anticipated that oncology patients will not endorse significantly higher scores than the normative sample. This hypothesis was tested for parent-report and self-report versions of the measure.

Sub Aim 2. Explore psychological functioning of mothers of children with cancer.

Hypothesis 1.2.1: Given the small expected sample sizes, exploratory analyses will be conducted to compare groups. Mothers (from here on will be called “oncology mothers”) as a group will have significantly higher levels of self-reported psychological symptoms than mothers of children without cancer (from here on will be called “primary care mothers”).

Aim 2: Describe Differences Between Parent and Child Report

The second goal of this project was to assess how families living with a cancer diagnosis perceive the siblings’ psychological functioning and family adjustment. As

alluded to in Aim 1, siblings and parents often see the siblings' emotional and behavioral functioning and family adjustment differently and one goal of this project was to provide further support to the literature citing these differences. Thus, the current study incorporates both the mother's perspective and the sibling's self-report of their psychological functioning. For example, clinicians could incorporate questions about the sibling's functioning when asking questions about the family's adjustment. Additionally, researchers may choose to avoid using parent-proxy methods alone if it is determined that this lone perspective does not provide the most accurate assessment of the child's psychological functioning.

Sub Aim 1. Describe differences in ratings of the oncology sibling's psychological functioning based on parent and sibling self-report. Given the small expected sample sizes, traditional analyses comparing group means may not find statistical differences that may exist. Thus, other methods of comparisons will also be employed (methods section).

Hypothesis 2.1.1: Oncology mothers and siblings will not have a high level of agreement in their endorsement of externalizing symptoms. Mothers will endorse significantly more externalizing symptoms (i.e., hyperactive, aggressive behavior) than their non-ill child (sibling).

Hypothesis 2.1.2: Oncology mothers and siblings will not have a high level of agreement in their endorsement of emotional symptoms. Mothers will endorse significantly more emotional symptoms (i.e., depressive and anxious symptoms) than their non-ill child (sibling).

Hypothesis 2.1.3: Oncology mothers and siblings will not have a high level of agreement in their endorsement of adaptive symptoms. Mothers will report that the siblings have significantly lower adaptive skills (i.e., activities of daily living, social skills, and functional communication) than the siblings will report themselves.

Sub Aim 2. Describe differences in ratings of family functioning based on mother and sibling self-report in the oncology group. Similar to psychological functioning, we will employ various methods of comparison as traditional analyses comparing group means may not find statistical differences.

Hypothesis 2.2.1: Oncology mothers and siblings will not have a high level of agreement in their endorsement of family functioning. Mothers will describe significantly better family functioning than will the sibling in the family.

Hypothesis 2.2.2: Oncology mothers and patients will not have a high level of agreement in their endorsement of family functioning. Oncology mothers will describe significantly better family functioning than will patients in the family.

Hypothesis 2.2.3: Oncology mothers will report worse family functioning than mothers in the primary care group.

Aim 3: Differences Between Cancer Diagnoses

The third goal of this project addressed another under-researched area within the pediatric cancer literature: the differences in psychological functioning between different types of cancer groups. Research cited earlier in the review has shown that siblings of cancer patients often exhibit different emotional and behavioral symptoms based on the diagnosis of their sibling. For example, some research has shown that siblings of brain and solid tumor patients exhibit significantly more anxiety than siblings of lymphoma and leukemia patients (Houtzager et al., 2001). Over the past decade, significant

improvements have been made in treatments for pediatric cancer patients, subsequently increasing 5-year survivorship rates. However, there are still significant differences in prognoses and survivorship rates between different cancer groups. Despite substantial improvements in medical outcomes, little research has been conducted examining how siblings function in light of various diagnoses. Thus the third aim of this study addressed that deficit. For the purposes of this study, pediatric oncology patients will be divided into four subgroups: leukemias, lymphomas, sarcomas/solid tumors, and brain/central nervous system tumors (CNS) (based on standards utilized in the literature).

Hypothesis 3.1: Siblings of sarcomas/solid tumors and brain/CNS tumor patients will have significantly higher levels of emotional and externalizing behavior symptoms and worse adaptive skills than siblings of leukemia and lymphoma patients. These differences will be described qualitatively as we do not expect a large enough sample to conduct statistical comparisons.

Aim 4: Factors Associated with Psychological Functioning (Exploratory)

The final aim of this project was to examine various factors that are associated with psychological symptoms in siblings of children with cancer. While information regarding the psychological functioning of siblings is interesting and informative, research shows that the majority of siblings, as a group, do not exhibit clinical levels of symptoms (Alderfer et al., 2010). However, at the individual level, a larger percentage of siblings fall in the sub-clinical or clinical ranges on behavioral measures. Therefore, future research in this area will specifically need to account for factors that are associated with the development of these symptoms in siblings with clinically significant levels.

Hypothesis 4.1: Individual and family factors such as demographic characteristics, health status, and family functioning will be correlated with emotional and behavior functioning in oncology siblings.

CHAPTER 2 METHODS

Participants

This study was reviewed and approved by the University of Florida Institutional Review Board. A total of 55 families provided consent and completed study measures. Participants were recruited from two academic medical center clinics in rural Florida: a pediatric oncology clinic ($n = 35$) and a primary care clinic ($n = 20$). Families were seen at the clinics for either a routine medical appointment or an inpatient hospital stay. All participants were identified by the respective medical teams and subsequently approached by a member of the research team to review and obtain informed consent from the mother. Assent was obtained from children who were 8 or older (the minimum age required to complete the measures). All families were advised that refusal to participate in the study would not impact their medical care nor would their medical teams see their individual responses.

Pediatric participants included 2 groups: a pediatric oncology group and a primary care group. Children in both groups met the following inclusion criteria: (1) between the ages of 2 and 17 and (2) able to independently complete study measures if old enough to complete study measures (over the age of 8 for the Behavior Assessment System for Children-2nd Edition and 12 for the Family Assessment Device). Only mothers were asked to participate in the study given their previous precedence in the literature and greater likelihood of being at the routine appointments. Mothers were required to: (1) be over the age of 18, (2) live in the home with the oncology patient and at least one sibling, and (3) able to independently complete study measures. Families were required to have at least one other sibling living in the home who was: (1) between the ages of 2

and 17, (2) able independently complete study measures, and (3) living in the home with the patient and the mother at the time of the assessment. If there was more than one sibling living in the home, the sibling closest in age to the patient was included in the study. Additionally, oncology patients met these additional criteria: (1) diagnosed with of any form of cancer (e.g., leukemia, brain tumor), (2) completed at least 8 weeks of active treatment, or (3) if in remission, were no more than one year beyond completion of active treatment. Children and their mothers were excluded if the mother reported any of the following: (1) being legally blind in both eyes, (2) being legally deaf in both ears, or (3) diagnosed with mental retardation. Additionally, the study excluded patients who: (1) were diagnosed with another severe medical illness (as determined by the medical staff) and/or (2) had a history of bone marrow transplantation. In order to reduce the risk of confounding factors, siblings were excluded from the study if mothers reported that they were diagnosed with a serious chronic medical or psychiatric illness (e.g., sickle cell anemia, HIV, etc.). Children in both groups were not excluded for mild medical diagnoses (e.g., allergies) unless they had severe/serious complications (e.g., frequent hospitalizations, emergency room visits).

Emotional and behavioral symptoms can occur in both healthy children (Centers for Disease Control (CDC), Simpson, Bloom, Cohen, Blumberg, 2005) and those diagnosed with cancer (Moore et al., 2003) thus in order to maintain generalizability to both groups, children with mild to moderate psychiatric disorders (e.g., depression, ADHD; as determined by the medical and research team) were not excluded in either the oncology or primary care groups. Potential limitations of including these participants

are discussed in the discussion. Patients and siblings with severe psychiatric disorders (e.g., schizophrenia, autism) were excluded.

Procedure

General Procedures

Parents and children completed appropriate measures during their routine appointment or inpatient stay. Special emphasis was placed on the families not discussing the measures with one another. Mothers completed the same measure for multiple children, thus they were encouraged to think clearly about which child they were completing the measure for and to try to not to let other children's behavior affect their ratings. Siblings who were not present during the appointment or inpatient stay completed appropriate measures over the phone after orally assenting to study procedures. Participants were given \$5.00 compensation for their participation in the study.

Measures

A review of each measure, the utility of the measure for this particular line of research, and a comment on the psychometric strength of the measure is presented below. A summary of measures completed by each participant is presented in Table 2-1.

Demographic and medical information

Basic medical and demographic information was collected from both the oncology and primary care group.

Medical history. Medical information was collected from a review of the patient's medical records. The chart review extracted information regarding the patient's

diagnosis, types and lengths of treatments received, disease progression, history of hospitalizations, and dates and types of applicable surgeries or procedures.

Demographic questionnaire. Mothers completed a demographic questionnaire requesting information about their family structure, their children's medical history, children's history of psychological/psychiatric services, and current emotional and behavioral concerns.

Emotional and behavioral functioning of children

The Behavior Assessment System for Children, Second Edition (BASC-2: Reynolds & Kamphaus, 2004) was used as the primary measure of emotional and behavioral functioning of the oncology and primary care children. The BASC-2 is a multi-dimensional psychological questionnaire that evaluates various aspects of children's psychological and behavioral functioning. There are distinct versions of the BASC-2 that allow for parent-report, teacher-report, or child self-report ratings of functioning in the identified child. For the current study, the parent-report and child self-report versions of the BASC-2 were utilized.

Ratings on the parent-report versions of the BASC-2 produce composite scores for measured Externalizing Problems (e.g., aggression, hyperactivity and conduct problems), Internalizing Problems (e.g., anxiety, depression, and somatization), Behavioral Symptoms (e.g., atypicality, withdrawal), and Adaptive Skills (e.g., adaptability, leadership, activities of daily living, functional communication, and social skills). Standardized scores are also produced for the individual scales within each composite index, as indicated in parentheses in the preceding sentence. There are different parent-report versions of the BASC-2 for 3 distinct age groups: 2 – 5 years old, 6 – 11 years old, and 12 – 21 years old. Mothers completed the appropriate

questionnaires based on the age of their children, one for the patient and another one for the sibling. Age norm-referenced standardized scores for each of the primary scales and their composite score domains were generated using norms from the published software for each group (i.e., parent-report, patient-report, sibling-report) (Reynolds & Kamphaus, 2004). BASC-2 scales have a mean of 50 and a standard deviation of 10. T-scores are considered at-risk between 60-69 (30-39 for the Adaptive Skills) while scores above 70 are considered clinically significant (≤ 29 for Adaptive Skills). Within a normative sample, the Parent Rating Scales (BASC-2: PRS) have test-retest reliability scores that range from .78 to .92 across age groups for the composite scales. Internal consistency scores ranged from .85 to .95.

Children (within the oncology and primary care groups) of appropriate age completed the self-report version of the BASC-2. Youth Self-report Profiles (BASC-2: SRP) are available for ages 8-11, 12-21, and 18-25 (the 18-25 form was not utilized for the current study) with composite scales measuring School Problems, Internalizing Problems, Inattention/Hyperactivity, Emotional Symptoms, and Personal Adjustment. Test-retest reliability scores for the self-report profiles composite scores range from .74 to .89 in a normative sample. Internal consistency scores for the composite scales range from .74 to .84. In our sample of oncology mothers, Cronbach's alpha was .882 patients and .882 for the siblings on the PRS-P; .883 for patients and .873 for siblings on the PRS-C, and .512 for the patients and .791 on the PRS-A. In our sample of primary care mothers, Cronbach's alpha was .842 patients and .867 for the siblings on the PRS-P; .812 for patients and .946 for siblings on the PRS-C, and .871 for the patients and .934 on the PRS-A. In our sample of oncology children, Cronbach's alpha

for the self-report forms was .459 for patients and .529 for siblings on the SRP-C, and .672 for the patients and .824 for the siblings on the SRP-A. In our sample of primary care children, Cronbach's alpha was .886 for patients and .554 for siblings on SRP-C, and .908 for patients and .651 for siblings on the SRP-A.

A safety assurance plan was put in place to review the parents' and children's responses on items assessing suicidal and/or homicidal thoughts or actions to ensure that appropriate measures were taken to ensure safety and provide any necessary treatment referrals.

Maternal psychological functioning

The Brief Symptom Inventory (BSI; Derogatis, 1993) was used as a brief assessment of psychological symptoms in oncology and primary care mothers. The BSI is a 53-item scale designed to quickly assess symptoms of psychological distress. The items comprise 9 symptom subscales of Somatization, Obsessive-Compulsive behavior, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation, and Psychoticism. There are also three global scales: Global Severity Index (GSI), Positive Symptom Distress Index (PSDI), and Positive Symptom Total (PST). Gender norm-referenced standardized scores for each of the scales were generated using norms from the published manual for each group (i.e., oncology and primary care groups). Internal consistency ratings have been reported for the various scales from .71 to .85 (Derogatis & Melisaratos, 1983). Test-retest reliability scores have been shown for the global indices to range from .80-.90. Cronbach's alpha for the oncology sample was .960 and .957 for the primary care group. A safety assurance plan was put in place to review the mother's responses on items assessing suicidal and/or homicidal thoughts to ensure that appropriate measures were taken to ensure safety.

Family functioning

Mothers and children (12 years and older) completed the McMaster's Family Assessment Device (FAD: Epstein, Baldwin, & Bishop, 1983) to assess perceived current functioning of the family unit. The FAD is a 60-item measure assessing the global functioning of family units. Furthermore, the FAD assesses specific components of family functioning such as Problem Solving, Communication, Roles, Affective Responsiveness, Affective Involvement, and Behavioral Control. The FAD has been found to have internal reliability scores ranging from .57 to .86 and all scales had internal reliabilities within the adequate range, with the subscale of Roles only producing marginal reliability (Miller, Epstein, Bishop, et al., 1985). Cronbach's alphas for the oncology group were as follows: .928 for mothers, .865 for siblings, and .863 for the patients. Cronbach's alphas for the primary care group were as follows: .894 for the mothers and .810 for the patients. There were only 4 primary care siblings, making the group too small for assessment of measurement reliability.

Table 2-1. Summary of measures completed by study participants

Oncology Patient	Oncology Group		Primary Care Patient	Primary Care Group	
	Oncology Sibling	Oncology Mother		Primary Care Sibling	Primary Care Mother
Self-Report BASC-2	Self-Report BASC-2	Parent-Report BASC-2 (for patient & sibling)	Self-Report BASC-2	Self-Report BASC-2	Parent-Report BASC-2 (for patient & sibling)
FAD	FAD	FAD BSI Demographic Questionnaire	FAD	FAD	FAD BSI Demographic Questionnaire

Note: BASC-2 = Behavior Assessment System for Children, FAD = Family Assessment Device, BSI = Brief Symptom Inventory.

Statistical Analyses

The Statistical Package for the Social Sciences 20.0 (SPSS) was used to conduct statistical analyses. Descriptive statistics, including means and standard deviations, were calculated for each group. Statistics are provided for the entire sample and by group. Separate scores are provided for the parent, sibling, and patient report on measures completed by both groups. Total and subscale scores are provided for the BSI. For the BASC-2, the mean scores are provided for each of the subscales. Percentages of individuals above the at-risk (T-scores of 60-69) and clinically significant (T-scores ≥ 70) cutoff scores were calculated for each group. For the FAD, the General Functioning score as well as the scores for the 6 behavioral subscales (Problem Solving, Communication, Roles, Affective Responsiveness, Affective Involvement, and Behavior Control) are provided. Each FAD Scale has its' own clinical cutoff score indicative of poorer functioning. Clinical cutoff scores are provided in the Tables 3-15 through 3-17.

Aim 1

To examine sub aim 1, independent samples *t* tests were used to compare the oncology patients and siblings to primary care children in behavioral symptomatology as rated on the BASC-2. Separate *t* tests were conducted for the self-report and parent-report measures. To examine sub aim 2, independent samples *t* tests were used to compare means of the oncology mothers and primary care mothers, assuming equal variances. Welsh *t* tests were also conducted to compare the oncology sample to the normative population.

Aim 2

To examine hypotheses 2.1.1 through 2.1.3 and 2.2.1 and 2.2.2, various methods of comparison were conducted to compare mother and child scores. First, independent samples *t* tests were used to compare the oncology mothers and children across scales on the BASC-2. Second, discrepancy scores were calculated to measure the level of agreement between mothers and their children using a model proposed by Garber et al. (1998) and utilized by Guite et al. (2004). Using this model, the children's scores of perceived psychological and perceived family functioning were subtracted from the mothers' scores to create a discrepancy score, with higher scores indicating more discrepancy. Standard deviations of the group as a whole were then calculated for each scale of the BASC-2 and FAD. The dyad discrepancy scores were then compared to the standard deviation for each scale. According to model used by Guite et al. (2004), dyads were considered discordant if the calculated discrepancy scores were more than half of the standard deviation above zero. Third, Pearson product-moment correlations were calculated to measure the relationship between mother and child report.

Aim 3

As we did not have a large enough sample to examine differences between diagnostic groups (i.e., leukemia versus brain tumor), differences between groups were described qualitatively. Percentages of children falling in the at-risk or clinically significant ranges were calculated by groups for both mother and sibling report.

Aim 4

Our sample did not allow for testing of a model that predicts psychological functioning. However, correlations between oncology siblings' self-report BASC-2 and the FAD scores were conducted to in order to examine factors that may impact the

sibling's perception of their individual functioning and the functioning of their family unit as a whole. Pearson product-moment correlations were run for normal variables while Spearman correlations were run non-normal variables. For the purposes of the exploratory analyses, large correlations were considered to be scores greater or equal to .5. Significant correlations are described below. Given that the focus of this project is on individual and family functioning, analyses examining relationships with teachers or school functioning were not conducted.

CHAPTER 3 RESULTS

A total of 55 families (oncology group, $n = 35$; primary care group, $n = 20$) were included in the present study. Demographic characteristics of study participants are presented in Table 3-1.

In the oncology group, 48 eligible families were approached and informed about the study. Thirty-eight provided informed consent (92.1%) and subsequently completed study measures. Of the 35 participating families in the oncology group, 22 oncology patients and 22 siblings completed at least one of the self-report measures. Fewer oncology patients and siblings completed measures than mothers as children had to be at least 8 years old to complete at least one of the study measures. The oncology patients ranged in age from 2 to 17 years (Mean age = 8.9) and 57.1% were male. The diagnoses of the oncology patients included leukemias (62.8%), lymphomas (8.6%), brain/CNS tumors (11.4), and solid tumors/sarcomas (17.1%). The mean length of time since 1st diagnosis was 12.38 months ($SD = 12.10$) and the majority of oncology patients were receiving treatment at the time of this study (85.7%). Medical characteristics of the oncology group are presented in Table 3-2.

In the primary care group, 30 eligible families were approached and informed about the study. Twenty-three provided informed consent and 20 (87%) completed study measures. Patients in the primary care group ranged in age from 2 to 17 with a mean age of 8.9 and were 45% male. Of the 20 families in the primary care group, 12 patients and 6 siblings completed at least one of the self-report measures.

Socio-economic status (SES) was calculated for each group using the Hollingshead Four Factor Index of Social Status (Hollingshead, 1975), which generates

a score using information regarding parental educational and occupational status.

Approximately 38% of our oncology group and 35% of the primary care group reported household incomes of over \$50,000. The Hollingshead score for the primary care group was higher ($M = 41.75$, $SD = 17.95$) than the oncology group ($M = 36.03$, $SD = 12.58$), but this difference was not statistically different, $t(53) = 1.39$, $p = .172$, suggesting that the two groups are comparable in terms of socioeconomic status.

Chi-square tests and independent sample t tests were used to compare the oncology and primary care groups across the other demographic variables. The two groups were similar on the variables of sibling gender, $\chi^2(1) = 2.31$, $p = .128$, patient gender, $\chi^2(1) = .753$, $p = .386$, patient age, $t(53) = .072$, $p = .942$, and mothers' age, $t(53) = 1.01$, $p = .318$. Groups were statistically different in terms of sibling age, $t(53) = 2.95$, $p = .005$, with the mean of the oncology group approximately three and a half years older than the primary care group.

Psychological Functioning of Siblings of Pediatric Cancer Patients

Aim 1 sought to examine the psychological functioning of families with a child with cancer (i.e., siblings, patients, and mothers). The following section will describe the psychological functioning of the siblings of pediatric cancer patients in comparison to the primary care group and a normative sample. In order to address Aim 2, differences in perception between mothers and children, findings are discussed in terms of mother and sibling self-report.

Mother Report

At the group level, mothers did not report at-risk or clinically significant emotional or behavioral problems for the siblings in the oncology or primary care groups (Tables 3-3 and 3-4). Examination of ratings at the individual level revealed that a subset of

mothers endorsed at-risk or clinically significant levels of emotional or behavioral problems across the two sibling groups (Table 3-5). The oncology mothers endorsed at-risk or clinically significant concerns in Externalizing Problems (20.0%), Hyperactivity (20%), Aggression (22.9%), Conduct Problems (8.6%), Internalizing Problems (17.1%), Anxiety (8.6%), Depression (22.9%), Somatization (11.4%), Behavioral Symptoms (17.1%), Atypicality (5.7%), Withdrawal (11.4%), Attention Problems (25.7%), Adaptive Problems (11.4%), Adaptability (20%), Social Skills (28.6%), Leadership (14.8%), Activities of Daily Living (14.3%), and Functional Communication (17.1%). The primary care mothers endorsed at-risk or clinically significant concerns in Externalizing Problems (10%), Hyperactivity (15%), Conduct Problems (14.3%), Internalizing Problems (10%), Anxiety (20%), Somatization (15%), Atypicality (15%), Attention Problems (15%), Adaptability (15%), Social Skills (10%), Leadership (14.3%), Activities of Daily Living (25%), and Functional Communication (20%).

Comparison of oncology and primary care siblings based on mother's report

Independent samples *t* tests and Mann-Whitney tests were used to compare the oncology and primary care groups across the BASC-2 scales (Table 3-5). Overall, ratings made by mothers in the oncology group produced slightly higher scores (indicative of worse psychological functioning, albeit within normal limits in terms of group means) than mothers of primary care siblings across most scales of the BASC-2 with the exception of Anxiety, Atypicality, Adaptive Problems, Adaptability, and Social Skills. However, the only statistically significant difference between the two groups was found on the Depression scale, where oncology mothers reported more depressive symptoms in oncology siblings than primary care mothers ($t(52) = 2.18, p = .034$).

Comparison of oncology siblings to normative sample based on mother's report

Welsh *t* tests were also conducted to compare the oncology mother's ratings to the Behavior Assessment System for Children-2nd Edition (BASC-2) normative sample (Table 3-5). Overall, mothers are endorsing slightly lower scores across most scales on the BASC-2 (indicative of better psychological functioning) for oncology siblings. Nevertheless, there were no significant differences on any scale of the BASC-2 between the study sample and the BASC-2 normative samples.

Self-Report

As was indicated by their mother's report, oncology siblings themselves did not produce clinically elevated scores on the BASC-2 at the group level (Table 3-3). However, within the group, a subset of oncology siblings did endorse at-risk or clinically significant emotional or behavioral concerns (Table 3-6) on the BASC-2 in the following domains: School Problems (5.3%), Attitude to School (21.1%), Attitude to Teachers (15.8%), Sensation Seeking (10.5%), Internalizing Problems (5.3%), Atypicality (5.3%), Locus of Control (10.5%), Anxiety (10.5%), Depression (5.3%), Somatization (10.5%), Inattention (15.8%), Attention Problems (21.1%), Hyperactivity (21.1%), Personal Adjustment (5.3%), Interpersonal Relations (5.3%), and Self-Reliance (10.5%).

Primary care siblings endorsed at-risk concerns at the group level in Attention Problems ($M = 60.0$, $SD = 9.92$) and Inattention/Hyperactivity ($M = 60.33$, $SD = 11.98$). At the individual level, a subset of primary care siblings endorsed at-risk or clinically significant concerns in School Problems (33.3%), Attitude to Teachers (16.7%), Sensation Seeking (25%), Internalizing Problems (16.7%), Social Stress (16.7%), Anxiety (16.7%), Depression (16.7%), Somatization (25%), Inattention (21.1%), Attention Problems (50%), Hyperactivity (33.3%), Self-Esteem (16.7%), and Emotional

Symptoms (16.7%) (Table 3-7). These proportions should be interpreted with caution in light of the very small sample size ($N = 6$) which may not be an accurate representation of the broader population.

Fisher's exact tests were conducted to compare proportions of elevated scores between the oncology and primary care groups; however, there were no statistically significant differences between groups.

Comparison of siblings in different cancer groups

Aim 3 sought to examine differences between different cancer groups (i.e., leukemia versus brain tumor). The following section discussed differences in sibling self-report between cancer groups.

Leukemias. Tables 3-8 and 3-9 show the proportion of children in the oncology group falling into the at-risk and clinically significant ranges (as rated by mothers and siblings), broken down by diagnosis. In the Leukemia group, a subset of mothers endorsed at-risk or clinically significant concerns in Hyperactivity (9.1%), Internalizing Problems (9.1%), Depression (13.6%), Somatization (13.6%), Behavioral Symptoms (9.1%), Atypicality (22.7%), Withdrawal (18.2%), Attention Problems (22.7%), Adaptability (9.1%), Social Skills (13.6%), and Functional Communication (18.2%).

Similar to their mothers, a subset of siblings in this group endorsed at-risk or clinically significant levels of concerns across scales of the BASC-2. Elevations were found in the following scales: Attitude to School (30%), Attitude to Teachers (30%), Internalizing Problems (10%), Locus of Control (20%), Anxiety (10%), Depression (10%), Inattention/Hyperactivity (30%), Attention Problems (40%), Hyperactivity (40%), Personal Adjustment (30%), and Self-Reliance (10%). Overall, these results suggest that mothers and siblings of leukemia patients perceive that the siblings are doing

relatively well in terms of emotional, behavioral, and adaptive functioning, but there are a subset of participants perceiving some psychological difficulties.

Lymphomas. More mothers in the lymphoma group endorsed at-risk and clinically significant levels of problems. At-risk and clinically significant concerns were found for Externalizing Problems (66.7%), Hyperactivity (33.3%), Aggression (100%), Internalizing Problems (66.7%), Anxiety (66.7%), Depression (100%), Somatization (33.3%), Behavioral Symptoms (66.7%), Attention Problems (33.3%), Adaptive Problems (33.3%), Adaptability (66.7%), Social Skills (66.7%), Leadership.(33.3%), Activities of Daily Living (33.3%) and Functional Communication (33.3%).

There were only 2 siblings that were old enough to complete the BASC-2 measure, so the following results should be interpreted with caution. Half of the siblings in this group endorsed at-risk concerns in Atypicality, Somatization, Personal Adjustment, and Interpersonal Relations. Interestingly, siblings in this group did not endorse any clinically significant problems on any scale of the BASC-2.

Solid tumors. Similar to the Lymphoma group, mothers in the solid tumor group are endorsing higher percentages of at-risk and clinically significant symptoms compared to the leukemia group. A subset of mother endorsed at-risk or clinically significant concerns in the following BASC-2 domains: Externalizing Problems (50%), Hyperactivity (50%), Aggression (50%), Conduct Problems (33.3%), Internalizing Problems (16.7%), Depression (16.7%), Behavioral Symptoms (33.3%), Attention Problems (16.7%), Adaptive Problems (16.7%), Adaptability (33.3%), Social Skills (50%), Leadership.(16.7%), Activities of Daily Living (16.7%) and Functional Communication (16.7%).

Overall, siblings of solid tumor patients endorsed good functioning across BASC-2 scales. Twenty percent of siblings endorsed at-risk or clinically significant levels in School Problems, Attitude to School, Attitude to Teachers, Sensation Seeking, and Self-Reliance.

Brain tumors. Mothers in the brain tumor group also endorsed higher percentages of at-risk and clinically significant concerns compared to the leukemia group; however, there were only 4 children in this group, so these results should be interpreted with caution. A subset of mothers endorsed at-risk or clinically significant concerns in the following BASC-2 domains: Externalizing Problems (25%), Hyperactivity (25%), Aggression (25%), Internalizing Problems (25%), Depression (25%), Behavioral Symptoms (25%), Attention Problems (50%), Adaptive Problems (25%), Adaptability (50%), Social Skills (50%), Leadership (66.7%), and Activities of Daily Living (50%). These results suggest that a small portion of mothers in our sample perceived significant difficulties in emotional, behavioral, and adaptive functioning in their non-ill children.

Finally, there were only two siblings old enough to complete the BASC-2 measure; however, these children endorsed good functioning across areas of the BASC-2. One child endorsed clinically significant concerns in Attitude to Teachers and Anxiety. There were only two children in this group; however, these children suggest that children in our sample are endorsing good emotional, behavioral, and adaptive functioning.

Comparison of oncology and primary care siblings based on self-report

Independent samples *t* tests and Mann-Whitney tests were used to compare oncology and primary care siblings. Overall, primary care siblings endorsed lower

scores (indicative of better functioning, albeit within normal limits) on most scales of the BASC-2 except for Self-Esteem. Significant differences were found in School Problems, $t(32) = -2.56, p = .025$, Attitude to School, $U = 74.0, p = .036$, Attitude to Teachers, $t(32) = -2.68, p = .020$, and Somatization, $t(32) = 3.65, p = .002$.

Comparison of oncology siblings to normative sample based on self-report

Oncology siblings' scores were compared to the BASC-2 normative sample and they endorsed better emotional, behavioral, and adaptive functioning across all scales of the BASC-2 except Depression (Table 3-4). Significant differences were found for the following scales: Internalizing Problems, $t(19) = 3.05, p = 0.01$, Emotional Symptoms, $t(19) = 3.42, p = 0.00$, Personal Adjustment, $t(19) = 3.45, p = 0.00$, Atypicality, $t(19) = 3.16, p = 0.01$, Social Stress, $t(19) = 4.88, p = 0.00$, Sense of Inadequacy, $t(18) = 2.33, p = 0.03$, Interpersonal Relations, $t(19) = 3.75, p = 0.00$, and Self-Esteem, $t(19) = 8.26, p = 0.00$.

Comparison Between Mother and Sibling Report

Analyses were conducted to compare the perceptions of oncology mothers and the siblings using independent samples t tests. The following scales are represented across parent- report and sibling-report versions of the BASC-2 forms, and thus could be compared in this study: Internalizing Problems, Anxiety, Depression, Somatization, Hyperactivity, Atypicality, and Attention Problems. Oncology mothers rated the oncology siblings as having more psychological symptoms than the siblings' self-ratings indicated, with the exception of Anxiety, but none of the comparisons were statistically significant. However, 50% or more of the mother-sibling dyads were classified as discordant across all areas of the BASC-2 (Table 3-3). The majority of Pearson product-moment correlations between mother and sibling report for the BASC-2 scales fell within

the small range with the exception of Anxiety ($r = .328$, moderate) and Attention Problems ($r = .406$, moderate). None of the Pearson correlations were statistically significant. The intraclass correlation results followed a similar pattern with all correlations classified as small with the exception of Anxiety ($r = .323$, moderate) and Attention Problems ($r = .405$, moderate). None of these correlations were statistically significant.

Psychological Functioning of Pediatric Oncology Patients

The following section continues to address Aim 1 by describing the psychological functioning of pediatric cancer patients from the perspective of the mothers and the patients themselves. The current study sample is also compared to the primary care group and the normative sample. Additionally, this following section also addresses Aim 2 as it describes differences between mother and patient report.

Mother Report

Overall, oncology mothers did not endorse any at-risk or clinically significant behaviors at the group level for the oncology patients (Table 3-3) as rated by the BASC-2. In terms of the percentage of mothers endorsing at-risk or clinically significant levels of symptoms (Table 3-10), the following scales had a small proportion of mothers endorsing at-risk or clinically significant concerns: Externalizing Problems (5.7%), Hyperactivity (8.6%), Aggression (5.7%), Internalizing Problems (17.1%), Anxiety (14.3%), Depression (20%), Somatization (40%), Behavioral Symptoms (5.7%), Atypicality (5.7%), Withdrawal (8.6%), Attention Problems (14.3%), Adaptive Problems (11.4%), Adaptability (8.6%), Activities of Daily Living (14.3%), and Functional Communication (14.3%).

Similarly, primary care mothers did not endorse any clinically significant emotional, behavioral, or adaptive difficulties for the primary care patients at the group level (Table 3-5). Comparable to above, a subset of mothers endorsed at-risk or clinically significant concerns in the following BASC-2 domains: Externalizing Problems (15%), Hyperactivity (15%), Aggression (25%), Conduct Problems (23.1%), Anxiety (10%), Depression (10%), Somatization (20%), Behavioral Symptoms (10%), Atypicality (10%), Withdrawal (20%), Attention Problems (25%), Adaptability (15%), Social Skills (15%), Leadership (15.4%), Activities of Daily Living (20%) and Functional Communication (10%) (Table 3-10).

Comparison of oncology and primary care patients based on mother report

Independent sample *t* tests and Mann-Whitney tests were used to compare emotional, behavioral, adaptive functioning in the two groups. The only significant difference between groups was in Somatization, $t(53) = 2.44$, $p = .018$, where oncology mothers endorsed significant more symptoms (e.g., “complains of pain”, “has headaches”) than primary care mothers.

Comparison of oncology patients to the normative sample based on mother report

Welsh *t* tests were also conducted to compare scores produced by oncology mother’s ratings to the published BASC-2 normative sample (Table 3-11). Overall, oncology mothers endorsed better emotional, behavioral, and adaptive functioning in the oncology patients on every scale on the BASC-2 except for Internalizing problems, Adaptive Skills, Somatization, and Activities of Daily Living. However, significant differences were only found in Externalizing Problems, $t(34) = 3.03$, $p = 0.005$, Behavioral Symptoms, $t(34) = 2.77$, $p = 0.009$, Aggression, $t(34) = 2.94$, $p = 0.006$,

Conduct Problems, $t(28) = 2.78$, $p = 0.01$, Somatization, $t(34) = 3.16$, $p = 0.00$, Atypicality, $t(34) = 2.33$, $p = 0.03$, and Social Skills, $t(34) = 3.16$, $p = 0.00$.

Self-Report

In general, neither oncology patients nor primary care patients endorsed any emotional or behavioral concerns at the group level (Tables 3-3 and 3-5). Similar to their mothers, a small proportion of patients endorsed at-risk or clinically significant concerns in the following BASC-2 domains (Table 3-12): Sensation Seeking (13.6%), Anxiety (13.6%), Somatization (36.4%), Sense of Inadequacy (9.1%), Inattention/Hyperactivity (9.1%), Attention Problems (9.1%), Hyperactivity (27.2%), Relations with Parents (9.1%), Interpersonal Relations (9.1%), and Self-Reliance (9.1%).

Primary care patients had larger proportions of participants endorsing at-risk or clinically significant concerns on the BASC-2 (Table 3-12), such as School Problems (33.3%), Attitude to Teachers (33.3%), Attitude to Teachers (25%), Sensation Seeking (28.6%), Internalizing Problems (16.7%), Locus of Control (16.7%), Social Stress (25%), Anxiety (16.7%), Depression (25%), Sense of Inadequacy (16.7%), Inattention/Hyperactivity (16.7%), Attention Problems (50%), Hyperactivity (8.3%), Personal Adjustment (16.7%), Self-Esteem (8.3%), and Self-Reliance (25%).

Comparison of oncology and primary care patients based on self-report

Independent samples t tests and Mann-Whitney tests were used to compare the groups across the BASC-2 scales (Table 3-11). Overall, there were no significant differences between the oncology and primary care patients with the exception of the school scales and Somatization. Oncology patients endorsed significantly more symptoms of Somatization than primary care patients, $t(17) = 2.85$, $p = .011$.

Interesting, primary care patients endorsed significantly more difficulty with the school

scales: School Problems, $t(32) = 2.32, p = .026$; Attitude to School, $t(32) = 2.42, p = .021$; and Attitude to Teachers, $t(32) = 3.46, p = .001$.

Comparison of oncology patients and normative sample based on self-report

Oncology patient's scores were compared to the BASC-2 normative sample (Table 3-11) and results showed that they endorsed better emotional, behavior, and adaptive functioning with the exception of Inattention/Hyperactivity, Sensation Seeking, Anxiety, Somatization, and Hyperactivity. Significant differences were found for the following scales of the BASC-2: School Problems, $t(21) = 4.06, p = 0.00$, Personal Adjustment, $t(21) = 2.85, p = 0.01$, Attitude to School, $t(21) = 2.66, p = 0.02$, Attitude to Teachers, $t(21) = 6.05, p = 0.00$, Atypicality, $t(21) = 2.28, p = 0.03$, Depression, $t(21) = 2.91, p = 0.01$, Somatization, $t(12) = 2.66, p = 0.02$, Relations with Parents, $t(21) = 2.13, p = 0.05$, Interpersonal Relations, $t(21) = 2.31, p = 0.03$, and Self-Reliance, $t(21) = 2.24, p = 0.04$.

Comparison between Mother and Patient Report

In order to test for differences in perception between oncology mothers and patients, Independent samples t tests were used to compare group means on the following scales: Internalizing Problems, Anxiety, Depression, Somatization, Hyperactivity, Atypicality, and Attention Problems. Mothers endorsed worse functioning in Internalizing Problems, Depression, Atypicality, and Attention Problems; yet, there were no significant differences between the groups. Even though there were no significant differences between groups, 50% or more of all the mother-patient dyads were qualified as discordant across all scales of the BASC-2 (Table 3-3). Pearson product-moment correlations between mother and patient report for the BASC-2 scales ranged from small (.185, Hyperactivity) to large (.707, Somatization). Three correlations

were statistically significant: Internalizing Problems, $r = .484$, $p = .011$, Depression, $r = .602$, $p = .002$, and Somatization, $r = .707$, $p = .003$. Similar results were found with intraclass correlation coefficients with the correlations ranging from small (.185, Hyperactivity) to large (.690, Somatization). Three of these correlations were also statistically significant: Internalizing Problems, $r = .406$, $p = .027$, Depression, $r = .530$, $p = .005$, and Somatization, $r = .690$, $p = .003$.

Psychological Functioning of the Mothers

Aim 1 also had the goal of describing the psychological functioning of mothers. Additionally, we proposed that the oncology mothers in our sample would have worse psychological functioning than the primary care group and a normative sample. The following section addresses these aims.

On the whole, oncology mothers did not endorse significant psychological distress at the group level as measured by the Brief Symptom Inventory (BSI) (Table 3-13). In order to have a significant BSI score the participant either had to have an elevated Global Severity score or two elevated subscale scores. Only 8 (22.9%) oncology mothers had elevated Global Severity scores and 13 (37.1%) had two or more elevated scales (Table 3-14). Similar to the oncology group, primary care mothers did not endorse significant psychological distress at the group level. Only 1 (5%) mother had an elevated Global Severity score and 2 (10%) had two or more elevated scales. See Table 3-14 for the proportions of mothers reporting poor functioning across other scales of the BSI.

Overall, oncology mothers endorsed more psychological distress than primary care mothers across all subscales; however, none of the scales were elevated at the group level. Mann-Whitney tests were used to compare symptom subscales between

groups (Table 3-13). There was a significant difference in Global Severity between the patient ($M = 53.26$, $SD = 11.34$) and primary care ($M = 45.30$, $SD = 9.93$) groups, ($U = 209.5$, $p = .042$). Oncology mothers endorsed significantly more distress than primary care mothers in the following subscales: Obsessive-Compulsive ($U = 206.5$, $p = .011$), Interpersonal Sensitivity ($U = 235.5$, $p = .037$), Anxiety ($U = 219.0$, $p = .020$), Hostility ($U = 193.5$, $p = .005$), and Paranoid Ideation ($U = 238.0$, $p = .041$), and Positive Symptom Total ($U = 216.5$, $p = .019$). No significant differences were found for Somatization, Depression, Phobic Anxiety, Psychoticism, or Positive Symptom Distress. Fisher's exact tests were also computed to compare the proportion of mothers endorsing clinical symptoms in the oncology and primary care groups. None of these comparisons were statistically significant.

Family Functioning

In addition to describing the individual family members' functioning, a goal of Aim 2 was to describe the functioning of the family unit as a whole. The following section will describe perceived family functioning from the sibling, patient, and mother perspective. Additionally, this section will compare this group to the primary care group.

Oncology Group

Perceived family functioning of oncology mothers

Both oncology and primary care mothers endorsed good family functioning and none of the Family Assessment Device (FAD) scales were elevated at the group level (Tables 3-15 and 3-16). A little less than a quarter of oncology mothers endorsed difficulties in General Functioning (22.9%). Mothers in this group endorsed the most difficulties in the area of Roles (40%). Only 5% of mothers in the primary care group endorsed clinical impairments in General Functioning (Table 3-18).

Perceived family functioning of oncology siblings

Oncology and primary care siblings endorsed clinical impairments in family functioning across domains. Oncology siblings as a group reported impairment in Communication, Affective Responsiveness, and Affective Involvement. Table 3-18 provides percentages of participants who endorsed at risk or clinically significant concerns across all scales. Fifty percent of the oncology siblings endorsed clinically significant levels in General Functioning ($n = 6$). Additionally, at least a quarter or more of the siblings endorsed clinically significant levels of symptoms across all other domains: Problem-Solving (33.3%), Communication (58.3%), Roles (41.7%), Affective Responsiveness (41.7%), Affective Involvement (50%), and Behavior Control (25%).

Perceived family functioning of oncology patients

When examining the oncology patient's report of family functioning, they reported clinically significant concerns in Affective Involvement at the group level (Table 3-16). Large percentages of participants endorsed clinically significant levels across domains. Fifty percent of the oncology patients endorsed clinically significant levels in General Functioning (50%). Additionally, there were several other subscales in which over a quarter of the participants endorsed clinical levels: Problem-Solving (25%), Communication (25%), Roles (41.7%), Affective Responsiveness (41.7%), and Behavior Control (25%). Over half of the oncology patients endorsed clinically significant levels in Affective Involvement (58.3%).

Comparison between oncology mothers and siblings perception of family functioning

Tables 3-15 and 3-16 present the means, standard deviations, and percentages of discordant pairs between oncology mothers and their children across scales on the

FAD. Independent samples *t* tests were conducted to compare differences in their perceptions of family functioning between the oncology mothers and their children. In general, oncology siblings perceived their family as having more impairment than their mothers perceived (Table 3-15). There were significant differences in Communication, $t(45) = -2.47, p = .017$, Affective Responsiveness, $t(45) = -3.08, p = .004$, Affective Involvement, $t(45) = -2.56, p = .014$, and General Functioning, $t(45) = -2.1, p = .041$. Pearson product-moment correlations ranged between small for Behavior Control ($r = -.167$) and moderate for Affective Responsiveness ($r = .438$). None of the Pearson correlations were statistically significant. The intraclass correlation results showed the same pattern with correlations ranging from small for Behavior Control ($r = -.167$) and moderate for Affective Responsiveness ($r = .402$). None of these correlations were statistically significant. Using the discrepancy model, results show that 50% or more of all mother-patient dyads were classified as discordant on all scales of the FAD. Interestingly, 100% of mother sibling-dyads were discordant on the Behavior Control scale.

Comparison between oncology mothers and patients perception of family functioning

There were no significant differences between oncology mothers and patients. The majority of Pearson product-moment correlations between mother and patient report for the FAD scales fell within the small range with the exception of Problem-Solving ($r = .491$, moderate) and Roles ($r = .380$, moderate). None of the Pearson correlations were statistically significant. The intraclass correlation results showed the same pattern with all correlations classified as small with the exception of Problem-Solving ($r = .408$, moderate) and Roles ($r = .353$, moderate). None of these correlations

were statistically significant. Using the discrepancy model, results show that 50% or more of all mother-patient dyads were classified as discordant on all scales of the FAD.

Primary Care Group

Perceived family functioning of primary care mothers

Overall, primary care mothers endorsed positive family functioning. At the group level, there were no clinically elevated scores (Table 3-17). Percentages of mothers who endorsed at-risk or clinically significant concerns were calculated and there was only one mother in this group who endorsed clinically significant levels in the General Functioning domain (5%). Across all other subscales of the FAD, few mothers endorsed clinical levels of symptoms (Table 3-18).

Perceived family functioning of primary care siblings

Primary care siblings also endorsed clinical impairments in several areas of family functioning (Table 3-18). The following scales were elevated at the group level for the primary care siblings: Problem Solving, Communication, Roles, Affective Involvement, Behavior Control, and General Functioning. The majority of children in this group endorsed clinically significant levels in General Functioning (75%). Primary care siblings also endorsed significant impairments in Problem-Solving (25%), Communication (50%), Roles (50%), Affective Responsiveness (50%), and Affective Involvement (75%). All of the children in this group endorsed clinically significant symptoms in the domain of Behavior Control (100%).

Perceived family functioning of primary care patients

Primary care patients endorsed clinically elevated scores at the group level in Affective Responsiveness and Affective Involvement. Over fifty percent of the children endorsed clinically significant levels in General Functioning (57.1%) (Table 3-18).

Children in this group endorsed significant impairments in Communication (71.4%), Roles (42.9%), Affective Responsiveness (57.1%), and Affective Involvement (71.4%).

Comparison of oncology and primary care mothers report of perceived family functioning

Independent samples *t* tests were used to compare mother reports of family functioning in the oncology and primary care groups (Table 3-19). There was a significant difference in General Functioning for the oncology ($M = 1.62$, $SD = 0.45$) and primary care ($M = 1.34$, $SD = 0.32$) groups; $t(53) = 2.1$, $p = .041$. Oncology mothers endorsed worse family functioning across all scales; however, significant differences were only found in the scales of Problem-Solving, $t(53) = 2.10$, $p = .041$, Communication, $t(53) = 2.34$, $p = .023$, and Roles, $t(53) = 2.11$, $p = .040$. These results suggest that oncology mothers are seeing more deficits in family functioning than primary care mothers.

Exploratory Analyses

The final aim of the current study (Aim 4) was to examine various factors that are associated with psychological symptoms in siblings of children with cancer. The following section will examine the relationships between individual and family functioning in addition to relationships between medical variables and sibling functioning.

Relationships between Sibling Psychological Functioning and Family Functioning

In order to examine factors that may impact the oncology sibling's perception of their individual functioning and the functioning of their family unit as a whole, correlations between their self-report BASC-2 and the FAD scores were conducted. Pearson product-moment correlations were run for normal variables while Spearman

correlations were run non-normal variables. For the purposes of the exploratory analyses, large correlations were considered to be scores greater or equal to .5. Significant correlations are described below. Given that the focus of this project is on individual and family functioning, analyses examining relationships with teachers or school functioning were not conducted.

Analyses revealed a few significant correlations between the oncology siblings' self-report of psychological functioning and their perception of family functioning. Oncology siblings reported a significant positive relationship between Personal Adjustment and Communication, $r = .613$, $p = .023$. Improvements in family Behavior Control were associated with better Personal Adjustment scores, $r = -.524$, $p = .049$. Siblings who endorsed higher scores on Affective Involvement also endorsed more symptoms of Hyperactivity, $r = .568$, $p = .034$. Additionally, siblings who endorsed more Self-Reliance also tended to endorse poor family communication, $r = .767$, $p = .003$. Worse Relations with Parents scores were associated with worse family Roles, $r = -.532$, $p = .046$. Siblings who endorsed worse Interpersonal Relations also endorsed worse family Behavior Control, $r = -.627$, $p = .019$. Finally, there was a significant positive relationship between the sibling variable of Locus of Control and Affective Responsiveness, $r = .639$, $p = .01$; Affective Involvement, $r = .755$, $p = .004$, and General Functioning, $r = .596$, $p = .026$.

Relationships between Medical Variables and Siblings Psychological Functioning

In order to examine the relationship between key medical variables and the oncology siblings' psychological functioning, Spearman correlations were conducted using medical variables and both the BASC-2 composite scores. Both the sibling self-reports and the mother reports were used. The medical variables used were: type of

diagnosis (e.g., leukemia or brain tumor), high or low risk diagnosis (as determined by the medical team), months from diagnosis to study enrollment, total days admitted to the inpatient unit (over whole course of treatment), and finally, miles to hospital from family's home.

No significant correlations were found between the mothers' BASC-2 scores and type of diagnosis, high or low risk diagnosis, number of inpatient days, or miles from the family's home to the hospital. There was a moderate, negative correlation between months since diagnosis and Behavior Symptoms, $r = -.382$, $p = .024$ where fewer months from diagnosis was associated with higher BASC-2 scores. Similarly, there were no significant correlations between type of diagnosis, high or low risk diagnosis, months since diagnosis, or number of inpatient days and siblings' BASC-2 scores. Large positive correlations were found between miles from the family's home and the hospital and siblings' report of Inattention/Hyperactivity, $r = .639$, $p = .002$ and siblings' report of School Problems, $r = .583$, $p = .009$.

Table 3-1. Demographic characteristics of participants in the oncology and primary care groups

Characteristic	Oncology Families (N = 35)	Primary Care Families (N = 20)	Comparison Statistic	p-value
Sibling				
Sibling Age ¹	9.46 (4.17)	6.00 (4.23)	2.95 (t test)	.005**
Sibling Sex (male)	45.7 (16)	25 (5)	2.31 (chi-square)	.128
Sibling Race (Caucasian)	54.3 (19)	50.0 (10)	5.59 (chi-square)	.348
Hispanic	5.7 (2)	0.0 (0)	-	-
African American	31.4 (11)	30.0 (6)	-	-
Asian/PI	0.0 (0)	10.0 (2)	-	-
Biracial	5.7 (2)	10.0 (2)	-	-
Other	2.9 (1)	0.0 (0)	-	-
Patient				
Patient Age ¹	8.9 (4.54)	8.9 (4.70)	0.072 (t test)	.943
Patient Sex	57.1 (20)	45.0 (9)	7.53 (chi-square)	.386
Patient Race (Caucasian)	60.0 (21)	50.0 (10)	5.09 (chi-square)	.405
Hispanic	2.9 (1)	0.0 (0)	-	-
African American	28.5 (10)	30.0 (6)	-	-
Asian/PI	0.0 (0)	10.0 (2)	-	-
Biracial	5.7 (2)	10.0 (2)	-	-
Other	2.9 (1)	0.0 (0)	-	-
Mother Age	36.0 (7.4)	34.0 (6.7)	1.01 (t test)	.318

Note: Data in this table are presented as % (n) unless otherwise noted. ¹Data presented as group mean (standard deviation). **Statistically significant at p < .01.

Table 3-2. Medical characteristics of oncology group

Characteristic	<i>n</i>	%
Diagnosis		
Leukemia	22	62.9
Lymphoma	3	8.6
Solid Tumor	6	17.1
Brain Tumor	4	11.4
Treatment Risk		
High	20	57.1
Low	15	42.9
Treatment Status		
In treatment	30	85.7
Relapse	2	5.7
Recently off treatment	3	8.6
Intervention Status		
Chemotherapy	35	100
Radiation	8	22.9
Surgery ¹	35	100

¹Note: All patients had surgery to place either a port and/or central line.

Table 3-3. Psychological functioning of oncology patients and their siblings across informant type

BASC-2 Scales	Patients			Siblings		
	Mother Report (n = 35)	Self-Report (n = 22)	% of Discordant Mother-Patient Pairs ¹	Mother Report (n = 35)	Self-Report (n = 20)	% of Discordant Mother-Sibling Pairs ¹
Behavioral Symptoms	46.97 (6.41)	-	-	49.14 (9.6)	-	-
Withdrawal	47.31 (9.00)	-	-	48.17 (8.82)	-	-
Atypicality	47.46 (6.38)	47.09 (5.94)	90%	46.06 (7.26)	45.05 (6.93)	50%
Attention Problems	48.69 (8.39)	48.14 (7.67)	77.3%	52.26 (10.80)	48.85 (11.56)	80%
Adaptive Problems	52.8 (8.61)	-	-	50.97 (11.38)	-	-
Adaptability	52.91 (9.13)	-	-	49.91 (11.44)	-	-
Social Skills	54.49 (8.36)	-	-	49.46 (12.0)	-	-
Leadership ²	51.31 (16.0)	-	-	53.46 (11.55)	-	-
Activities of Daily Living	49.88 (9.95)	-	-	50.77 (11.55)	-	-
Functional Communication	51.49 (9.06)	-	-	51.86 (11.12)	-	-
Externalizing Problems	46.71 (6.37)	-	-	50.34 (11.84)	-	-
Aggression	46.57 (6.84)	-	-	49.43 (11.97)	-	-
Conduct Problems ²	43.1 (13.33)	-	-	51.11 (9.5)	-	-
Hyperactivity	48.26 (8.23)	55.5 (8.89)	63.6%	50.80 (11.28)	49.70 (11.29)	80%
Internalizing Problems	51.83 (10.52)	48.59 (6.64)	59.1%	47.60 (10.53)	45.4 (6.7)	85%
Anxiety	48.31 (11.08)	50.45 (8.60)	77.3%	46.77 (10.37)	47.3 (9.19)	70%
Depression	49.77 (9.51)	46.05 (6.32)	50%	49.83 (10.40)	47.2 (6.17)	75%
Somatization	55.69 (10.63)	58.62 (11.67)	76.9%	47.54 (9.57)	47.5 (8.42)	75%
Locus of Control	-	47.86 (8.10)	-	-	47.55 (7.81)	-
Social Stress	-	48.5 (6.10)	-	-	44.0 (5.44)	-
Sense of Inadequacy	-	47.71 (7.92)	-	-	45.84 (7.76)	-
School Problems	-	44.73 (6.04)	-	-	44.80 (11.30)	-
Attitude to School	-	45.36 (8.14)	-	-	47.35 (11.74)	-
Attitude to Teachers	-	43.32 (5.12)	-	-	45.45 (12.12)	-
Sensation Seeking	-	51.0 (11.22)	-	-	47.0 (11.23)	-
Inattention/Hyperactivity	-	51.14 (8.16)	-	-	49.35 (11.29)	-
Emotional Symptoms	-	47.27 (6.91)	-	-	45.0 (6.5)	-

(continued)

Table 3-3 (cont.). Psychological functioning of oncology patients and their siblings across informant type

BASC-2 Scales	Mother Report (<i>n</i> = 35)	Patients Self-Report (<i>N</i> = 22)	% of Discordant Mother-Patient Pairs ¹	Mother Report (<i>n</i> = 35)	Siblings Self-Report (<i>n</i> = 20)	% of Discordant Mother-Sibling Pairs ¹
Personal Adjustment	-	54.18 (6.84)	-	-	55.25 (6.77)	-
Relations with Parents	-	53.36 (7.37)	-	-	53.2 (7.37)	-
Interpersonal Relations	-	53.41 (6.89)	-	-	54.9 (5.80)	-
Self-Esteem	-	52.18 (9.36)	-	-	57.5 (3.99)	-
Self-Reliance	-	53.68 (7.65)	-	-	50.2 (9.4)	-

Note: Data are presented as group means (standard deviation) unless noted otherwise. At-risk scores = T-scores between 60-69 (30-39 for Adaptive Scales) and Clinically Significant scores = T-scores \geq 70 (\leq 20 for Adaptive Scales). ¹See page 40 for description of discrepancy calculation. ²*n* = 26 (patients) and *n* = 27 (siblings) in Oncology group as some scales were not applicable due to participants age.

Table 3-4. Comparison of primary care siblings and a normative sample across informant type

BASC-2 Scales	Mother Report of Siblings						Self Report of Siblings					
	Primary Care (n = 35)			Published Normative Sample			Primary Care (n = 35)			Published Normative Sample		
	t test/U	p-value	Cohen's d	t test	p-value	Cohen's d	t test	p-value	Cohen's d	t test	p-value	Cohen's d
Behavioral Symptoms	1.31	.198	0.36	.528	.602	0.18	-	-	-	-	-	-
Withdrawal	0.826	.412	0.23	1.22	.23	0.42	-	-	-	-	-	-
Atypicality	294.5	.408	0.45	3.19	.031*	0.11	122.5	.731	0.29	3.18	.005**	1.5
Attention Problems	-0.415	.680	-0.13	1.22	.232	0.42	-1.43	.172	-0.51	0.444	.662	0.20
Adaptive Problems	-0.236	.814	-0.07	.503	.618	0.17	-	-	-	-	-	-
Adaptability	0.474	.503	0.13	.046	.963	0.02	-	-	-	-	-	-
Social Skills	-1.75	.86	-0.49	.279	.782	0.10	-	-	-	-	-	-
Leadership ¹	0.03	.976	0.01	1.58	.126	0.68	-	-	-	-	-	-
Activities of Daily Living	0.322	.749	0.09	.393	.697	0.13	-	-	-	-	-	-
Functional Communication	0.121	.232	0.03	.987	.331	0.34	-	-	-	-	-	-
Externalizing Problems	265.0	.078	-0.03	.169	.866	0.06	-	-	-	-	-	-
Aggression	1.08	.287	0.30	.281	.780	0.10	-	-	-	-	-	-
Conduct Problems ¹	0.956	.346	0.34	.616	.543	0.23	-	-	-	-	-	-
Hyperactivity	1.06	.295	0.29	.418	.678	0.14	97.0	.206	0.03	0.120	.906	0.06
Internalizing Problems	0.749	.457	0.21	1.34	.188	0.46	127.0	.857	0.54	3.05	.007**	1.4
Anxiety	-0.904	.370	-0.25	1.84	.075	0.63	0.037	.971	0.01	1.31	.206	0.60
Depression	2.18	.034*	0.60	.096	.924	0.03	-1.52	.138	-0.54	2.01	.058	0.92
Somatization*	279.0	.274	0.25	1.52	.139	0.52	3.65	.002**	1.72	1.03	.327	0.48
Locus of Control	-	-	-	-	-	-	-1.29	.205	-0.46	1.4	.179	0.64
Social Stress	-	-	-	-	-	-	-0.754	.464	-0.27	4.88	.000**	2.2
Sense of Inadequacy	-	-	-	-	-	-	-1.03	.313	-0.36	2.33	.032*	1.1
School Problems	-	-	-	-	-	-	-2.53	.025*	-0.89	2.00	.060	0.91
Attitude to School	-	-	-	-	-	-	74.0	.036*	0.24	1.01	.326	0.46
Attitude to Teachers	-	-	-	-	-	-	-2.68	.020*	-0.95	1.68	.110	0.77
Sensation Seeking*	-	-	-	-	-	-	-0.698	.495	-0.34	0.924	.375	0.43
Inattention/Hyperactivity	-	-	-	-	-	-	-0.277	.783	-0.10	0.257	.800	0.11
Emotional Symptoms	-	-	-	-	-	-	1.1	.276	0.39	3.42	.003**	1.6

(continued)

Table 3-4. (cont.). Comparison of primary care siblings and a normative sample across informant type

BASC-2 Scales	Mother Report of Siblings						Self Report of Siblings					
	Primary Care (<i>n</i> = 35)			Published Normative Sample			Primary Care (<i>n</i> = 35)			Published Normative Sample		
	<i>t test/U</i>	<i>p</i> -value	Cohen's <i>d</i>	<i>t test</i>	<i>p</i> -value	Cohen's <i>d</i>	<i>t test</i>	<i>p</i> -value	Cohen's <i>d</i>	<i>t test</i>	<i>p</i> -value	Cohen's <i>d</i>
Personal Adjustment	-	-	-	-	-	-	1.13	.268	0.40	3.45	.003**	1.6
Relations with Parents	-	-	-	-	-	-	0.325	.747	0.11	1.93	0.069	0.88
Interpersonal Relations	-	-	-	-	-	-	101.0	.259	-0.69	3.75	0.001**	1.7
Self-Esteem	-	-	-	-	-	-	101.5	.269	-0.99	8.26	0.000**	3.8
Self-Reliance	-	-	-	-	-	-	0.941	.354	0.33	.095	0.925	0.04

Note: * Statistically significant at $p < .05$. **Statistically significant at $p < .01$. ¹*n* = 27 in oncology group and *n* = 7 in primary care group as some scales were not applicable due to participants age.

Table 3-5. Psychological functioning of primary care children across informant type

BASC-2 Scales	Patients		Siblings	
	Mother Report (n = 20)	Self-Report (n = 12)	Mother Report (n = 20)	Self-Report (n = 6)
Behavioral Symptoms	48.65 (8.56)	-	47.95 (9.01)	-
Withdrawal	50.25 (9.89)	-	45.7 (7.89)	-
Atypicality	48.0 (6.83)	48.75 (10.81)	47.95 (9.01)	47.0 (6.0)
Attention Problems	50.35 (12.63)	54.00 (13.0)	50.3 (10.12)	60.0 (9.92)
Adaptive Problems	52.4 (10.21)	-	51.35 (8.95)	-
Adaptability	49.35 (9.45)	-	50.85 (9.55)	-
Social Skills	52.55 (12.23)	-	54.75 (9.57)	-
Leadership ¹	54.62 (10.94)	-	53.14 (12.8)	-
Activities of Daily Living	52.95 (10.73)	-	49.5 (8.99)	-
Functional Communication	50.85 (8.66)	-	48.0 (8.85)	-
Externalizing Problems	49.2 (8.4)	-	46.2 (9.06)	-
Aggression	48.35 (10.75)	-	45.85 (9.33)	-
Conduct Problems ¹	49.62 (8.31)	-	47.14 (10.25)	-
Hyperactivity	51.2 (7.82)	49.9 (9.99)	47.9 (9.48)	58.33 (14.0)
Internalizing Problems	46.8 (7.88)	50.25 (9.55)	45.05 (11.12)	46.83 (9.13)
Anxiety	46.8 (10.0)	50.33 (10.33)	48.75 (10.86)	49.17 (11.02)
Depression	47.0 (8.12)	50.08 (9.1)	43.6 (8.42)	46.83 (3.6)
Somatization	48.35 (10.87)	45.43 (4.24)	45.9 (11.7)	47.75 (9.5)
Locus of Control	-	51.75 (8.88)	-	47.83 (5.95)
Social Stress	-	51.58 (13.44)	-	46.83 (11.29)
Sense of Inadequacy	-	50.75 (8.61)	-	46.83 (3.6)
School Problems	-	56.17 (15.04)	-	50.83 (10.17)
Attitude to School	-	54.33 (13.53)	-	49.0 (6.26)
Attitude to Teachers	-	56.42 (16.53)	-	50.33 (9.14)
Sensation Seeking	-	54.43 (8.46)	-	55.00 (12.33)
Inattention/Hyperactivity	-	52.08 (11.68)	-	60.33 (11.98)
Emotional Symptoms	-	50.58 (10.53)	-	46.67 (10.29)

(continued)

Table 3-5 (cont.). Psychological functioning of primary care children across informant type

BASC-2 Scales	Patients		Siblings	
	Mother Report (<i>n</i> = 20)	Self-Report (<i>n</i> = 12)	Mother Report (<i>n</i> = 20)	Self-Report (<i>n</i> = 12)
Personal Adjustment	-	51.00 (9.51)	-	55.67 (6.5)
Relations with Parents	-	52.5 (7.48)	-	53.5 (6.32)
Interpersonal Relations	-	50.00 (12.18)	-	58.17 (3.71)
Self-Esteem	-	50.17 (10.61)	-	53.5 (10.56)
Self-Reliance	-	50.5 (12.17)	-	52.33 (5.32)

Note: Data are presented as group means (standard deviation) unless noted otherwise. At-risk scores = T-scores between 60-69 (30-39 for Adaptive Scales) and Clinically Significant scores = T-scores ≥ 70 (≤ 20 for Adaptive Scales). ¹*n* = 13 (patients) and *n* = 7 (siblings) in primary care group as some scales were not applicable due to participants age.

Table 3-6. Proportion of oncology and primary care siblings with mothers reporting psychological problems

BASC-2 Scale	Oncology (<i>n</i> = 35)	Comparison (<i>n</i> = 20)	Fisher's Exact Test <i>p</i> -value	Cramer's Phi
Externalizing Problems	20.0 (7)	10.0 (2)	0.462	.130
Hyperactivity	20.0 (7)	15.0 (3)	0.731	.062
Aggression	22.9 (8)	5.0 (1)	0.133	.232
Conduct Problems ¹	11.1 (3)	14.3 (1)	1.0	.066
Internalizing Problems	17.1 (6)	10.0 (2)	0.696	.097
Anxiety	8.6 (3)	20.0 (4)	0.242	.165
Depression	22.9 (8)	5.0 (1)	0.133	.232
Somatization	11.4 (4)	15.0 (3)	0.696	.052
Behavioral Symptoms	17.1 (6)	5.0 (1)	0.402	.175
Atypicality	5.7 (2)	15.0 (3)	0.342	.155
Withdrawal	11.4 (4)	5.0 (1)	0.643	.108
Attention Problems	25.7 (9)	15.0 (3)	0.503	.125
Adaptive Problems	11.4 (4)	0.0 (0)	0.285	.216
Adaptability	20.0 (7)	15.0 (3)	0.731	.062
Social Skills	28.6 (10)	10.0 (2)	0.176	.062
Leadership ¹	14.8 (4)	14.3 (1)	1.0	.108
Activities of Daily Living	14.3(5)	25.0 (5)	0.469	.134
Functional Communication	17.1 (6)	20.0 (4)	1.0	.036

Note: Values are presented as percentage of children falling in the at-risk/clinically significant range (*n*). At-risk scores = T-scores between 60-69 (30-39 for Adaptive Scales) and Clinically Significant scores = T-scores ≥ 70 (≤ 20 for Adaptive Scales). ¹*n* = 27 for the Oncology group and *n* = 7 for Primary Care group as some scales were not applicable due to participants age.

Table 3-7. Proportion of oncology and primary care siblings with self-reported psychological problems

BASC-2 Scale	Oncology (<i>n</i> = 19)	Primary Care (<i>n</i> = 6)
School Problems	5.3 (1)	33.3 (2)
Attitude to School	21.1 (4)	0.0 (0)
Attitude to Teachers	15.8 (3)	16.7 (1)
Sensation Seeking ¹	10.5 (2)	25.0 (1)
Internalizing	5.3 (1)	16.7 (1)
Atypicality	5.3 (1)	0.0 (0)
Locus of Control	10.5 (2)	0.0 (0)
Social Stress	0.0 (0)	16.7 (1)
Anxiety	10.5 (2)	16.7 (1)
Depression	5.3 (1)	16.7 (1)
Somatization ¹	10.5 (2)	25.0 (1)
Sense of Inadequacy	0.0 (0)	0.0 (0)
Inattention	15.8 (3)	21.1(4)
Attention Problems	21.1 (4)	50.0 (3)
Hyperactivity	21.1 (4)	33.3 (2)
Personal Adjustment	5.3 (1)	0.0 (0)
Relations with Parents	0.0 (0)	0.0 (0)
Interpersonal Relations	5.3 (1)	0.0 (0)
Self-Esteem	0.0 (0)	16.7 (1)
Self-Reliance	10.5 (2)	0.0 (0)
Emotional Symptoms	0.0 (0)	16.7 (1)

Note: Values are presented as percentage of children falling in the at-risk/clinically significant range (*n*). At-risk scores = T-scores between 60-69 (30-39 for Adaptive Scales) and Clinically Significant scores = T-scores ≥ 70 (≤ 20 for Adaptive Scales). ¹*n* = 12 for the oncology group and *n* = 4 for primary care group as some scales were not applicable due to participants age.

Table 3-8. Proportion of oncology siblings with mothers reporting psychological problems in cancer and tumor groups

BASC-2 Scale	Leukemias (n = 22)	Lymphomas (n = 3)	Solid Tumors (n = 6)	Brain Tumors (n = 4)
Externalizing Problems	4.5 (1)	66.7 (2)	50.0 (3)	25.0 (1)
Hyperactivity	9.1 (2)	33.3 (1)	50.0 (3)	25.0 (1)
Aggression	4.5 (1)	100.0 (3)	50.0 (3)	25.0 (1)
Conduct Problems ¹	0.0 (0)	0.0 (0)	33.3 (2)	0.0 (0)
Internalizing Problems	9.1 (2)	66.7 (2)	16.7 (1)	25.0 (1)
Anxiety	4.5 (1)	66.7 (2)	0.0 (0)	0.0 (0)
Depression	13.6 (3)	100.0 (3)	16.7 (1)	25.0 (1)
Somatization	13.6 (3)	33.3 (1)	0.0 (0)	0.0 (0)
Behavioral Symptoms	9.1 (2)	66.7 (2)	33.3 (2)	25.0 (1)
Atypicality	22.7 (5)	0.0 (0)	0.0 (0)	0.0 (0)
Withdrawal	18.2 (4)	0.0 (0)	0.0 (0)	0.0 (0)
Attention Problems	22.7 (5)	33.3 (1)	16.7 (1)	50.0 (2)
Adaptive Problems	4.5 (1)	33.3 (1)	16.7 (1)	25.0 (1)
Adaptability	9.1 (2)	66.7 (2)	33.3 (2)	50.0 (2)
Social Skills	13.6 (3)	66.7 (2)	50.0 (3)	50.0 (2)
Leadership ¹	0.0 (0)	33.3 (1)	16.7 (1)	66.7 (2)
Activities of Daily Living	4.5 (1)	33.3 (1)	16.7 (1)	50.0 (2)
Functional Communication	18.2 (4)	33.3 (1)	16.7 (1)	0.0 (0)

Note: Values are presented as % (n). At-risk scores = T-scores between 60-69 (30-39 for Adaptive Scales) and Clinically Significant scores = T-scores ≥ 70 (≤20 for Adaptive Scales). ¹These scales were not applicable due to participants' age.

Table 3-9. Proportion of oncology siblings reporting psychological problems in cancer and tumor groups

BASC-2 Scale	Leukemias (n = 22)	Lymphomas (n = 3)	Solid Tumors (n = 6)	Brain tumors (n = 4)
School Problems	0.0 (0)	0.0 (0)	20.0 (1)	0.0 (0)
Attitude to School	30.0(3)	0.0 (0)	20.0 (1)	0.0 (0)
Attitude to Teachers	10.0 (1)	0.0 (0)	20.0 (1)	50.0 (1)
Sensation Seeking ¹	0.0 (0)	0.0 (0)	20.0 (1)	0.0 (0)
Internalizing	10.0 (1)	0.0 (0)	0.0 (0)	0.0 (0)
Atypicality	0.0 (0)	50.0 (1)	0.0 (0)	0.0 (0)
Locus of Control	20.0 (2)	0.0 (0)	0.0 (0)	0.0 (0)
Social Stress	0.0 (0)	0.0 (0)	0.0 (0)	0.0 (0)
Anxiety	10.0 (1)	0.0 (0)	0.0 (0)	50.0 (1)
Depression	10.0 (1)	0.0 (0)	0.0 (0)	0.0 (0)
Somatization ¹	0.0 (0)	50.0 (1)	0.0 (0)	0.0 (0)
Sense of Inadequacy	0.0 (0)	0.0 (0)	0.0 (0)	0.0 (0)
Inattention/Hyperactivity	30.0 (3)	0.0 (0)	0.0 (0)	0.0 (0)
Attention Problems	40.0 (4)	0.0 (0)	0.0 (0)	0.0 (0)
Hyperactivity	40.0 (4)	0.0 (0)	0.0 (0)	0.0 (0)
Personal Adjustment	30.0 (3)	50.0 (1)	0.0 (0)	0.0 (0)
Relations with Parents	0.0 (0)	0.0 (0)	0.0 (0)	0.0 (0)
Interpersonal Relations	0.0 (0)	50.0 (1)	0.0 (0)	0.0 (0)
Self-Esteem	0.0 (0)	0.0 (0)	0.0 (0)	0.0 (0)
Self-Reliance	10.0 (1)	0.0 (0)	20.0 (1)	0.0 (0)
Emotional Symptoms	0.0 (0)	0.0 (0)	0.0 (0)	0.0 (0)

Note: Values are presented as % (n). At-risk scores = T-scores between 60-69 (30-39 for Adaptive Scales) and Clinically Significant scores = T-scores ≥ 70 (≤ 20 for Adaptive Scales). ¹Some scales were not applicable due to participants' age.

Table 3-10. Proportion of oncology and primary care patients with mothers reporting psychological problems

BASC-2 Scale	Oncology (<i>n</i> = 35)	Primary Care (<i>n</i> = 20)	Fisher's Exact Test <i>p</i> -value	Cramer's Phi
Externalizing Problems	5.7 (2)	15.0 (3)	.342	.155
Hyperactivity	8.6 (3)	15.0 (3)	.657	.099
Aggression	5.7 (2)	25.0 (5)	.086	.278
Conduct Problems ¹	0.0 (0)	23.1 (3)	.031*	.408
Internalizing Problems	17.1 (6)	5.0 (1)	.402	.175
Anxiety	14.3 (5)	10.0 (2)	1.0	.062
Depression	20.0 (7)	10.0 (2)	1.0	.130
Somatization	40.0 (14)	20.0 (4)	.149	.318
Behavioral Symptoms	5.7 (2)	10.0 (2)	.616	.079
Atypicality	5.7 (2)	10.0 (2)	.616	.079
Withdrawal	8.6 (3)	20.0 (4)	.242	.165
Attention Problems	14.3 (5)	25.0 (5)	.469	.134
Adaptive Problems	11.4 (4)	5.0 (1)	.643	.108
Adaptability	8.6 (3)	15.0 (3)	.657	.099
Social Skills	2.9 (1)	15.0 (3)	.131	.287
Leadership ¹	0.0 (0)	15.4 (2)	.105	.329
Activities of Daily Living	14.3 (5)	20.0 (4)	.709	.074
Functional Communication	14.3 (5)	10.0 (2)	1.0	.062

Note: Values are presented as %(*n*). At-risk scores = T-scores between 60-69 (30-39 for Adaptive Scales) and Clinically Significant scores = T-scores ≥ 70 (≤ 20 for Adaptive Scales). ¹*n* = 26 for the Oncology group and *n* = 13 for Primary Care group as some scales were not applicable due to participants age. *Statistically significant at $p < .05$.

Table 3-11. Comparisons of oncology patients to primary care and normative samples

	Mother Report of Patients						Self Report of Patients					
	Primary Care (n = 35)			Published Normative Sample			Primary Care (n = 35)			Published Normative Sample		
	<i>t test/U</i>	<i>p</i> -value	Cohen's <i>d</i>	<i>t test</i>	<i>p</i> -value	Cohen's <i>d</i>	<i>t test</i>	<i>p</i> -value	Cohen's <i>d</i>	<i>t test</i>	<i>p</i> -value	Cohen's <i>d</i>
BASC-2 Scales												
Behavioral Symptoms	-1.24	.221	-0.34	2.77	.009**	0.95	-	-	-	-	-	-
Withdrawal	-1.12	.267	-0.31	1.76	.087	0.60	-	-	-	-	-	-
Atypicality	331.0	.745	-0.08	2.33	.025*	0.80	0.581	.565	0.21	2.28	.033*	0.78
Attention Problems	-0.587	.560	-0.16	0.919	.365	0.31	1.66	.107	0.59	1.13	.271	0.39
Adaptive Problems	0.155	.877	0.04	1.91	.064	0.66	-	-	-	-	-	-
Adaptability	1.38	.175	0.38	1.88	.069	0.64	-	-	-	-	-	-
Social Skills	0.629	.534	0.17	3.16	.003**	1.1	-	-	-	-	-	-
Leadership ¹	179.0	.796	0.24	0.448	.663	0.44	-	-	-	-	-	-
Activities of Daily Living	-1.07	.290	-0.29	0.652	.948	0.22	-	-	-	-	-	-
Functional Communication	0.254	.800	0.07	0.969	.339	0.33	-	-	-	-	-	-
Externalizing Problems	-0.124	.221	-0.03	3.03	.005**	1.0	-	-	-	-	-	-
Aggression	-0.667	.510	-0.18	2.94	.006**	1.0	-	-	-	-	-	-
Conduct Problems ¹	145.0	0.23	0.59	3.78	.009**	1.3	-	-	-	-	-	-
Hyperactivity	-1.30	.200	-0.36	1.24	.222	0.42	1.40	.170	0.49	1.31	.271	0.45
Internalizing Problems	1.86	.126	0.51	1.03	.312	0.35	0.596	.555	0.21	0.998	.334	0.34
Anxiety	0.505	.616	0.14	0.899	.375	0.31	0.036	.971	0.01	0.244	.809	0.08
Depression	285.0	.254	-0.31	0.143	.888	0.05	1.52	.139	0.54	2.91	.008**	1.0
Somatization ¹	2.44	.018	0.67	3.16	.003**	1.08	2.85	.011*	1.0	2.66	.021*	1.4
Locus of Control	-	-	-	-	-	-	1.29	.205	0.46	1.23	.231	0.41
Social Stress	-	-	-	-	-	-	0.923	.363	0.33	1.14	.266	0.39
Sense of Inadequacy	-	-	-	-	-	-	1.04	.307	0.37	1.32	.202	0.46
School Problems	-	-	-	-	-	-	2.33	.026*	0.82	4.06	.000**	1.4
Attitude to School	-	-	-	-	-	-	2.42	.021*	0.86	2.66	.015*	0.91
Attitude to Teachers	-	-	-	-	-	-	3.46	.001**	1.2	6.05	.000**	2.1
Sensation Seeking ¹	-	-	-	-	-	-	0.698	.495	0.25	0.031	.764	0.01

(continued)

Table 3-11 (cont.). Comparisons of oncology patients to primary care and normative samples

BASC-2 Scales	Mother Report of Patients						Self Report of Patients					
	Primary Care (n = 35)			Published Normative Sample			Primary Care (n = 35)			Published Normative Sample		
	<i>t test/U</i>	<i>p</i> -value	Cohen's <i>d</i>	<i>t test</i>	<i>p</i> -value	Cohen's <i>d</i>	<i>t test</i>	<i>p</i> -value	Cohen's <i>d</i>	<i>t test</i>	<i>p</i> -value	Cohen's <i>d</i>
Inattention/Hyperactivity	-	-	-	-	-	-	0.275	.784	0.10	0.652	.521	0.35
Emotional Symptoms	-	-	-	-	-	-	1.15	.277	0.41	1.84	.08	0.18
Personal Adjustment	-	-	-	-	-	-	1.13	.268	0.40	2.85	.01	0.98
Relations with Parents	-	-	-	-	-	-	0.324	.748	0.11	2.13	.046*	0.73
Interpersonal Relations	-	-	-	-	-	-	1.05	.302	0.37	2.31	.031*	0.79
Self-Esteem	-	-	-	-	-	-	0.571	.571	0.20	1.09	.289	0.37
Self-Reliance	-	-	-	-	-	-	0.094	.356	0.03	2.24	.036*	0.77

Note: * Statistically significant at $p < .05$. **Statistically significant at $p < .01$. ¹These scales were not applicable due to participants' age.

Table 3-12. Proportion of oncology and primary care patients reporting psychological problems

BASC-2 Scale	Oncology (<i>n</i> = 22)	Primary Care (<i>n</i> = 12)
School Problems	0.0 (0)	33.3 (4)
Attitude to School	4.5 (1)	33.3 (4)
Attitude to Teachers	0.0 (0)	25.0 (3)
Sensation Seeking ¹	13.6 (3)	28.6 (2)
Internalizing	4.5 (1)	16.7 (2)
Atypicality	0.0 (0)	16.7 (2)
Locus of Control	4.5 (1)	16.7 (2)
Social Stress	0.0 (0)	25.0 (3)
Anxiety	13.6 (3)	16.7 (2)
Depression	4.5 (1)	25.0 (3)
Somatization ¹	36.4 (8)	0.0 (0)
Sense of Inadequacy	9.1 (2)	16.7 (2)
Inattention/Hyperactivity	9.1 (2)	16.7 (2)
Attention Problems	9.1 (2)	50.0 (6)
Hyperactivity	27.2 (6)	8.3 (1)
Personal Adjustment	0.0 (0)	16.7 (2)
Relations with Parents	9.1 (2)	0.0 (0)
Interpersonal Relations	9.1 (2)	0.0 (0)
Self-Esteem	4.5 (1)	8.3 (1)
Self-Reliance	9.1 (2)	25.0 (3)
Emotional Symptoms	4.1 (1)	25.0 (3)

Note: Values are presented as percentage of children in at-risk/clinically significant range (*n*). At-risk scores = T-scores between 60-69 (30-39 for Adaptive Scales) and Clinically Significant scores = T-scores ≥ 70 (≤ 20 for Adaptive Scales). ¹*n* = 12 for the Oncology group and *n* = 7 for Primary Care group as some scales were not applicable due to participants age.

Table 3-13. Psychological functioning of mothers

BSI Scale	Oncology (<i>n</i> = 35)	Primary Care (<i>n</i> = 20)	Mann-Whitney Statistic	<i>p</i> -value
Somatization	51.34 (10.09)	50.25 (8.91)	338.0	.830
Obsessive-Compulsive	55.17 (11.00)	47.25 (8.76)	206.5	.011**
Interpersonal Sensitivity	51.97 (10.24)	46.5 (8.27)	235.5	.037*
Depression	51.6 (10.57)	46.1 (7.18)	246.5	.052
Anxiety	52.71 (11.40)	45.4 (9.37)	219.0	.020*
Hostility	53.57 (9.50)	46.2 (7.80)	193.5	.005**
Phobic Anxiety	51.66 (8.44)	49.9 (7.43)	321.0	.57
Paranoid Ideation	52.71 (8.05)	48.55 (9.10)	238.0	.041*
Psychoticism	53.23 (10.47)	51.55 (7.72)	339.0	.828
Global Severity Index	53.26 (11.34)	45.3 (9.93)	209.5	.014*
Positive Symptom Distress Index	52.46 (12.55)	49.40 (7.88)	286.0	.258
Positive Symptom Total	52.0 (10.81)	44.85 (11.74)	216.5	.019

Note: BSI = Brief Symptom Inventory. Data presented as mean (SD). Clinical cutoff score for classification as reporting poor functioning = Global Severity Index T-score > 63 or two subscales with T-scores > 63. Cutoff refers to a value indicative of clinical significance. Values higher than the cutoff indicate clinically significant problems. *Statistically significant at $p < .05$. **Statistically significant at $p < .01$.

Table 3-14. Proportion of mothers reporting poor functioning

BSI Scale	Oncology (<i>n</i> = 35)	Primary Care (<i>n</i> = 20)	Fisher's Exact Test <i>p</i> -value	Cramer's Phi
Somatization	17.1 (6)	10.0 (2)	.696	.097
Obsessive-Compulsive	22.9 (8)	5.0 (1)	.133	.232
Interpersonal Sensitivity	17.1 (6)	10.0 (2)	.696	.097
Depression	20.0 (7)	5.0 (1)	.234	.205
Anxiety	22.9 (8)	5.0 (1)	.133	.232
Hostility	11.4 (4)	0.0 (0)	.285	.212
Phobic Anxiety	17.1 (6)	10.0 (2)	.696	.097
Paranoid Ideation	14.3 (5)	10.0 (2)	1.0	.062
Psychoticism	20.0 (7)	5.0 (1)	.234	.205
Global Severity Index	22.9 (8)	5.0 (1)	.133	.232
Positive Symptom Distress Index	28.6 (10)	10.0 (2)	.176	.216
Positive Symptom Total	17.1 (6)	10.0 (2)	.696	.097

Note: BSI = Brief Symptom Inventory. Values are presented as percentage of mothers with scores in the clinical range (*n*). Clinical cutoff score for classification as reporting poor functioning = Global Severity Index T-score > 63 or two subscales with T-scores > 63. Cutoff refers to a value indicative of clinical significance. Values higher than the cutoff indicate clinically significant problems.

Table 3-15. Family functioning reported by oncology siblings and mothers

FAD Scale	Cutoff Score	Mothers (<i>n</i> = 35)	Siblings (<i>n</i> = 11)	<i>t</i> test	<i>p</i> -value	% of Discordant Mother-Sibling Dyads ¹
Problem-Solving	2.2	1.91 (0.46)	2.11 (0.34)	-1.46	.151	63.6
Communication	2.2	1.93 (0.38)	2.23 (0.35) ²	-2.47	.017*	54.5
Roles	2.3	2.17 (0.40)	2.21 (0.27)	-0.485	.630	54.5
Affective Responsiveness	2.2	1.75 (0.45)	2.20 (0.31) ²	-3.08	.004**	54.5
Affective Involvement	2.1	1.85 (0.50)	2.20 (0.52) ²	-2.56	.014*	90.9
Behavioral Control	1.9	1.56 (0.33)	1.71 (0.35)	-1.8	.079	100.0
General Functioning	2.0	1.62 (0.45)	1.89 (0.33)	-2.1	.041*	72.7

Note: FAD = Family Assessment Device. Data presented as mean (SD). ¹See page 40 for description of discrepancy calculation. Cutoff refers to a value indicative of clinical significance. Values higher than the cutoff indicate clinically significant problems. ²Above clinical cutoff (each scale has a different cutoff score). *Statistically significant at *p* < .05. **Statistically significant at *p* < .01.

Table 3-16. Family functioning reported by oncology patients and mothers

FAD Scale	Cutoff Score	Mothers (n = 35)	Patients (n = 11)	t test	p-value	% of Discordant Mother-Patient Dyads ¹
Problem-Solving	2.2	1.91 (0.46)	1.91 (0.30)	0.017	.987	63.6
Communication	2.2	1.93 (0.38)	2.04 (0.27)	-0.894	.376	90.0
Roles	2.3	2.17 (0.40)	2.13 (0.29)	0.350	.738	72.7
Affective Responsiveness	2.2	1.75 (0.45)	1.97 (0.45)	-1.45	.156	63.6
Affective Involvement	2.1	1.85 (0.50)	2.19 (0.58) ²	-1.89	.066	72.7
Behavioral Control	1.9	1.56 (0.33)	1.64 (0.46)	-0.594	.556	90.0
General Functioning	2.0	1.62 (0.45)	1.75 (0.32)	-0.922	.361	45.5

Note: FAD = Family Assessment Device. Data presented as mean (SD). ¹See page 40 for description of discrepancy calculation. Cutoff refers to a value indicative of clinical significance. Values higher than the cutoff indicate clinically significant problems. ²Above clinical cutoff (each scale has a different cutoff score) and indicative of poor family functioning.

Table 3-17. Family functioning reported by primary care group family members

FAD Scale	Cutoff Score	Mothers (n = 20)	Siblings (n = 4)	Patient (n = 7)
Problem-Solving	2.2	1.65 (0.43)	2.21 (0.32) ¹	1.91 (0.44)
Communication	2.2	1.68 (0.36)	2.3 (0.31) ¹	2.17 (0.43)
Roles	2.3	1.93 (0.43)	2.3 (0.27) ¹	2.12 (0.51)
Affective Responsiveness	2.2	1.57 (0.44)	2.13 (0.44)	2.26 (0.38) ¹
Affective Involvement	2.1	1.79 (0.49)	2.36 (0.56) ¹	2.33 (0.43) ¹
Behavioral Control	1.9	1.47 (0.36)	2.25 (0.29) ¹	1.6 (0.33)
General Functioning	2.0	1.34 (0.32)	2.02 (0.32) ¹	1.89 (0.38)

Note: FAD = Family Assessment Device. Data presented as mean (SD). Cutoff refers to a value indicative of clinical significance. Values higher than the cutoff indicate clinically significant problems. Cutoff refers to a value indicative of clinical significance. Values higher than the cutoff indicate clinically significant problems. ¹Above clinical cutoff and indicative of poor functioning.

Table 3-18. Proportion of family members reporting poor family functioning

FAD Scale	Oncology Group			Primary Care Group		
	Parent (n = 35)	Patient (n = 12)	Sibling (n = 12)	Parent (n = 20)	Patient (n = 7)	Sibling (n = 4)
Problem-Solving	20.0 (7)	25.0 (3)	33.3 (4)	10.0 (2)	0.0 (0)	25.0 (1)
Communication	22.9 (8)	25.0 (3)	58.3 (7)	10.0 (2)	71.4 (5)	50.0 (2)
Roles	40.0 (14)	41.7 (5)	41.7 (5)	15.0 (3)	42.9 (3)	50.0 (2)
Affective Responsiveness	14.3 (5)	41.7 (5)	41.7 (5)	5.0 (1)	57.1 (4)	50.0 (2)
Affective Involvement	22.9 (8)	58.3 (7)	50 (6)	20.0 (4)	71.4 (5)	75.0 (3)
Behavioral Control	14.3 (5)	25.0 (3)	25 (3)	5.0 (1)	0.0 (0)	100.0 (4)
General Functioning	22.9 (8)	50.0 (6)	50 (6)	5.0 (1)	57.1 (4)	75.0 (3)

Note: FAD = Family Assessment Device. Values are presented as percentage of participants falling in clinically significant range (n).

Table 3-19. Comparison of mothers perceived family functioning between oncology and primary care groups

FAD Scale	Cutoff Score	Oncology	Control	<i>t test</i>	<i>p-value</i>
Problem-Solving	2.2	1.91 (0.46)	1.65 (0.43)	2.10	.041*
Communication	2.2	1.93 (0.38)	1.68 (0.36)	2.34	.023*
Roles	2.3	2.17 (0.40)	1.93 (0.43)	2.11	.04*
Affective Responsiveness	2.2	1.75 (0.45)	1.57 (0.44)	1.45	.154
Affective Involvement	2.1	1.85 (0.50)	1.79 (0.49)	0.488	.627
Behavioral Control	1.9	1.56 (0.33)	1.47 (0.36)	1.01	.318
General Functioning	2.0	1.62 (0.45)	1.34 (0.32)	2.21	.041*

Note: Data presented as group means (standard deviation). *Statistically significant at $p < .05$. Cutoff refers to a value indicative of clinical significance. Values higher than the cutoff indicate clinically significant problems.

CHAPTER 4 DISCUSSION

Pediatric cancer is a life-threatening disease that can have a significant psychological impact on patients and their family members. Extensive research has been conducted examining the psychological functioning of the patient and their parents (Alderfer, Long, Lown, et al., 2010; Prchal and Landolt, 2009). Recent research has begun to explore the emotional and behavioral functioning of the siblings and factors that may impact their adjustment to the patients' diagnosis and treatment (i.e., Alderfer, Labay, & Kazak, 2003; Labay & Walco, 2004; Houtzager, Oort, Hoekstra-Weebers, et al., 2004a); however, there have been some methodological problems with past research.

The present study sought to examine the functioning of oncology siblings within an environmental framework that incorporates the functioning of patients, mothers, and families as a whole. By examining the siblings' psychological functioning within this framework we hoped to begin to unearth factors that may contribute to their emotional, behavioral, and adaptive functioning. A better understanding of contributing factors might allow for identification of siblings at risk for developing psychological problems, as well as help inform future intervention research. The current study adds to the existing literature by using a broadband measure approach to psychological assessment in this population, examining findings at both the group and individual level, utilizing multi-informant methods which include child report, and incorporating assessment of broader family functioning.

Psychological Functioning of Siblings of Pediatric Cancer Patients

Utility of Evaluating Findings at Group and Individual Levels

Overall (at the group level), siblings and mothers in the oncology group endorsed good emotional, behavioral, and adaptive functioning. However, examination of the data revealed a subset of individuals experiencing psychological problems. Traditionally, prior research has assessed psychological functioning in these families solely by examining group means. However, as our results show, restricting examination of the data in this manner excludes important information. The current study adds to the literature by highlighting the importance of calculating the proportion of children who fall in the at-risk or clinically significant range on psychological measures. We are not the first to use this method to identify subsets of individuals experiencing problems. Martin et al. (2012) used this approach when examining the social-emotional functioning of children diagnosed with Neurofibromatosis Type 1 and Plexiform Neurofibromas. These researchers found similar results to the current study: While the children did not have elevated scores at the group level, a substantial proportion of children had scores suggestive of at-risk or clinically significant social-emotional problems. The authors suggest that a subset of children experiencing significant social-emotional problems is not accounted for by solely examining group means. While the methods employed in the current study allowed us to identify a subset of individuals experiencing psychological problems, normative data is not available to determine if the rates of problems are higher in families of children with cancer than a general population. For example, the Behavior Assessment System for Children-2nd Edition (BASC-2) manual does not report the percentage of children falling in the at-risk or clinically significant ranges within the normative reference sample (Martin et al, 2012). Thus, it is difficult to

compare the proportion of children falling into at-risk or clinical ranges in our sample to the expected proportions in a normative population. Future research should explore the percentages of children falling into the at-risk or clinical ranges for both normative and pediatric populations.

When considering the methods challenge presented above, we attempted to find applicable ways to compare our sample to children in the United States (U.S.) as a whole. According to the most recent (2009) national report from the Federal Interagency Forum on Child and Family Statistics, approximately 5.3% of children (ages 4-17) in the United States have serious emotional or behavioral difficulties as rated by their parents (Federal Interagency Forum on Child and Family Statistics, 2011). Thus, in order to compare our sample to the U.S. population as a whole, we compared the proportion of children (siblings and patients) falling in the at-risk or clinically significant range on the BASC-2, to the comparison proportion in the U.S. population (Figures 4.1 through 4.4). In other words, observed rates that were higher than 5.3% were considered to represent higher rates of problems than would be occurring in the general national population of children. Using this reference point, we found that a large proportion of siblings and patients fell in the at-risk or clinically significant ranges across scales on the BASC-2 in both self-report and parent-report conditions. Thus, while our groups may be reporting good psychological functioning at the group level, the proportion of children experiencing psychological problems appears higher in families of children with cancer than in the broader US population. It is this subset of children who may benefit from further assessment or intervention. As suggested by Martin et al. (2012), and as

supported by our results, future studies should aim to examine factors associated with poor psychosocial outcomes for this subgroup of children.

Comparison of oncology and primary care siblings

When comparing the psychological functioning of siblings in the oncology and primary care groups, we found that oncology mothers reported observing more psychological symptoms in these children across nearly all of the measures, although the group means indicated generally good reported functioning. However, oncology mothers did report observing significantly higher symptoms of depressed mood in the siblings than were reported in the primary care group. This finding is consistent with prior studies that have noted that depression is a common symptom of poor adjustment for siblings of cancer patients (Alderfer, 2010). It will be important for future researchers to examine potential factors that lead to the development or maintenance of depressive symptomatology in the siblings of children with cancer, including longitudinal studies that can assess the siblings' depressive symptoms over time.

It should also be mentioned that a large proportion (50%) siblings in our primary care group endorsed at-risk or clinically significant levels of behaviors indicative of attention problems. The fairly high rate of reported attention problems in our primary care group was unexpected and raises questions regarding the representativeness of our primary care group sample. Though we purposefully did not exclude children in either group who had pre-existing psychological conditions (in an effort to have study samples representative of their broader population cohort), we did not expect to find attention problems reported in half of the children in our primary care group. Though reported attentional problems alone do not indicate presence of an attentional disorder (such as Attention-Deficit/Hyperactivity Disorder; ADHD), clinically significant levels of

attentional problems reported on the BASC-2 are not expected to occur in children who do not have psychiatric or neurological diagnoses. Thus, it is important to consider whether the rate of observed attention problems in our primary care group is similar to what we might expect in the general population.

According to Centers for Disease Control data from 2008-2010, approximately 9.4% of children ages 5-17 in the United States have been diagnosed with Attention Deficit Disorder or Attention-Deficit/Hyperactivity Disorder (based off of parent report) (National Center for Health Statistics, 2011). Our sample has a much higher proportion (50%) of children endorsing attention problems and thus our comparison sample may not be representative of American children as a whole. One hypothesis for the increased rate of attention problems in our control population is that mothers with inattentive children may be more likely to agree to participate in a project examining psychological functioning. However, the number of families who declined to participate or failed to complete all study measures was quite small ($n = 10$) and assuming their inclusion and lack of reported attention problems would only bring the proportion of reported problems down to 30% (still higher than the estimated 9.4% of children in the general population with clinically significant attention problems). It is also possible that this particular sample was not representative of the primary care clinic as a whole, and that a larger sample would have included more children with normative levels of attention problems. Regardless, it is unlikely that this issue with our primary care group accounts for the psychological problems found in the cancer group. Rather, it is possible that additional group differences in psychological functioning may be identified with a more representative primary care group.

Utility of multi-informant assessment methods

Our results suggest that oncology mothers described worse sibling functioning than the siblings themselves; however, none of the comparisons across informant type (mother versus child) were statistically different. However, an interesting finding showed that over 50% of mother-child dyads (both siblings and patients) were found to be discordant across the psychological scales on the BASC-2. This supports research that suggests that mothers and children do not always perceive the child's psychological functioning the same way (Achenbach, McConaughy, & Howell, 1987). However, the percentage of discordant pairs is very high across scales (up to 90%), which may suggest that the method used to define discordant pairs may be particularly sensitive to minor (and perhaps less meaningful) differences between dyads. Future researchers should determine whether a higher cutoff point (i.e., making discrepancy score less than one standard deviation instead of half a deviation) may be more appropriate in defining discordant pairs. Nevertheless, results from the present study provide further evidence for the importance of gathering information on sibling functioning from both the parents and siblings themselves when assessing emotional, behavioral, and adaptive functioning.

Comparison of oncology group to published questionnaire normative sample

The present study also examined the proportion of mothers who reported observing psychological problems in their children (siblings), and our results support our initial hypothesis that a larger proportion of oncology mothers endorsed at-risk or clinically significant levels of psychological symptoms than the normative sample across many of the domains measured. However, when we statistically compared the observed proportions for the two groups, there were no significant differences in the rates of

mother-reported sibling psychological problems. While at first glance it appears as if oncology mothers are not endorsing statistically different functioning than normative controls, further examination of the effect sizes show a different picture. For example, oncology mothers rated siblings as having more symptoms of anxiety, physical complaints, and unusual behaviors than are present in the published parent-report normative sample data, but these differences were not statistically significant. However, the magnitude of the group differences indicated medium to large effect sizes. Thus, it is likely that with a larger study sample, these observed group differences would be statistically significant and more clearly reflect higher rates of mother-reported psychological problems in siblings of children with cancer. Future studies should aim to include larger samples (at least 88 study participants for a medium effect) to increase the likelihood of finding statistically significant differences should they exist.

Similar attention should also be placed on the sibling's self-report. Independent samples *t* tests and Mann-Whitney tests found some statistically significant differences between the oncology siblings and their primary care and normative comparison groups. Examination of the associated effect sizes of these comparisons reveals that the majority of the comparisons produce medium or large effects sizes. This suggests that a larger study sample may result in even greater levels of statistical significance of differences between groups. This replicates prior research suggesting overall good psychological functioning in siblings of pediatric cancer patients. However, current results also highlight the need for additional research and clinical focus on a subgroup of siblings who do appear to be experiencing psychological problems.

Psychological Functioning of Pediatric Oncology Patients and Comparison to Primary Care Group and Normative Controls

Supporting our initial hypothesis, mothers and patients did not endorse clinically significant levels of emotional, behavioral, or adaptive symptoms on the BASC-2. In fact, oncology mothers endorsed better functioning across most scales of the BASC-2, with effect sizes ranging from .22 to 1.3. Despite our small sample, we were able to detect better psychological functioning across many scales of the BASC-2.

One area in which oncology mothers and patients endorsed significantly more symptoms than the BASC-2 normative sample was in Somatization. The Somatization scale on the BASC-2 is intended to be a measure of psychological distress expressed in a physical manner (Reynolds & Kamphaus, 2004). For example, a healthy child experiencing anxiety may complain of frequent headaches or stomach aches without a medical etiology for their pain. While this may be an effective means of measuring psychological distress in a healthy population, the same may not hold true for a medical population. Pediatric oncology patients may experience physical pain and side effects from their diagnosis and treatment (i.e., pain, nausea). The higher levels of physical complaints in our population may result more from medical side effects from their treatment as opposed to true psychological distress. Results from the current study suggest that this scale may not appropriate for use in a pediatric oncology population or should be interpreted with caution.

Interestingly, primary care patients endorsed significantly more difficulty adjusting to the school setting. The school scales on the BASC-2 are intended to measure a child's overall adjustment to the school environment (Reynolds & Kamphaus, 2004). According to the BASC-2 manual, higher scores on the school composite may "indicate

a pervasive pattern of dissatisfaction with schooling, school personnel, and the structure of the educational process.” It should be noted that approximately 60% of children in the oncology group were not enrolled in a traditional school setting at the time of the study, while only 25% of the primary care group were not enrolled in school. If oncology patients were enrolled in a hospital homebound or home school program, they were encouraged to answer school questions in relation to that program. It is possible that children who were not enrolled in school had lower scores on these scales due to the fact that these items are not applicable to home school or hospital homebound settings (e.g., “My school feels good to me”, “My teachers want too much”). For some of these children, their parents are also filling two roles, parent and teacher, and it may be difficult for these children to be objective about their parent in the teacher role. For pediatric patients not enrolled in non-traditional settings, it may be more appropriate for clinicians to ask patient-centered questions that directly relate to their individual experience (e.g., “I don’t liking thinking about my hospital homebound work”, “I feel like I’m missing out by not being in school”, “My parent is able to only think about school when doing school-related tasks”). These limitations should be considered when choosing psychometric measures for future research in pediatric oncology populations.

Psychological Functioning of the Mothers

Overall, oncology mothers as a group endorsed good personal psychological functioning. Previous research has suggested that mothers of pediatric cancer patients may experience increased psychological distress (Vrijmoet-Wiersma, VanKlink, Kolk, et al., 2008). Contrary to our hypothesis, our sample of mothers did not endorse clinical levels of symptoms at the group level. Our measure of psychological distress, the Brief Symptom Inventory (BSI), has been shown to be a valid measure of psychological

distress in cancer populations (Derogatis, 1993). One hypothesis for why mothers in our sample failed to show any psychological distress is that the BSI is not a reliable measure for our sample. However, the Cronbach's alpha score of .960 calculated from the current study data set suggests good internal consistency of this measure in our oncology group. Thus, we have to consider the possibility that there is something unique about our sample population that leads to better outcomes than have been previously reported. Given that our sample is reporting good psychological functioning, it is possible that they may not be representative of the broader population of oncology mothers.

Additionally, research has suggested that mothers who endorse their own psychological problems are more likely to endorse problems in their children (Cohen et al., 1994). We must take this into consideration when examining the mothers' perception of their children. Oncology mothers at the group level did not endorse clinically elevated scores for the patients or siblings. Mothers in our sample may have been less likely to report psychological problems in their children because they have a positive perception of their own functioning.

Supporting our initial hypothesis, oncology mothers endorsed worse functioning than primary care mothers across several areas of the BSI. We propose that oncology mothers in our sample endorsed more symptoms (albeit not clinically significant levels) of obsessive-compulsive behavior, paranoia, and anxiety because much of their child's treatment and functioning is out of their control, so they attempt to manage other factors in their environment to regain some control. Nevertheless, the majority of mothers in our sample are doing well, with only a few mothers endorsing poor functioning.

Family Functioning of Oncology Families

Even though oncology siblings are endorsing emotional and behavioral functioning within normal limits, one area in which they perceived significant difficulties is family functioning. Perhaps the most interesting findings from the present study stem from the family functioning data. Oncology siblings perceived particular difficulties in family communication, involvement and interaction, and emotional investment. Oncology siblings perceive that their families' use "indirect and vague" communication (Miller, et al., 1985). Additionally, siblings reported problems on the emotional scales which are intended to measure family members' ability to "respond to a range of situations with appropriate quantity and quality of emotion" and "the degree to which family members are involved and interested in the activities of other family members" (Miller, et al., 1985). Mothers and patients often spend a considerable amount of time together due to the child's frequent medical appointments and/or inpatient stays, transportation back and forth from medical visits, and the important caregiving tasks at home. While this may lead to better communication, emotional expression, and understanding between the mothers and patients, siblings do not always get the opportunity to spend as much time with their mothers, which may in fact impede effective communication and impact relationships. As seen in the discrepancy between mothers and siblings in our sample, mothers may be in a difficult position to see this impact on their child because they may not see the day-to-day influence of their changing roles or presence within the family unit.

Additionally, our results support previous research that suggests that individual functioning is correlated with family functioning. Siblings perceive that their own personal adjustment is closely related to the family's communication skills and

behavioral control (e.g., limit setting and boundaries) within the home. Additionally, siblings perceive themselves as being more self-reliant as the family's communication decreases and more in control as the family's emotional expression and recognition, investment in others, and overall functioning decreases. Children also perceive worse relations with their parents as family roles deteriorate, and perceive worse interpersonal relationships as the family's behavior control decreases. While these results cannot imply a causal relationship, they do suggest that the functioning of the family as a whole may impact the siblings' perceived functioning. These results suggest that children may become more independent as they perceive changes in their routines, family relationships, and structure. Thus it is imperative that clinicians assess the sibling's perception of family functioning in addition to their individual emotional and behavioral functioning, as they may be experiencing difficulties that are not perceived by their parents.

There are some limitations to our assessment of family functioning. Our measure of family functioning could only be completed by children 12 or older, thus our results did not include the report of younger children who may perceive differences in family functioning. Future research should seek to develop measures of perceive family functioning that can be completed by younger children. Finally, as many correlations were conducted on this data, we cannot rule out the possibility of Type 1 error. Future researchers could consider utilizing a smaller p value to reduce the likelihood of Type 1 error and recruiting a larger sample of comparison children.

Limitations and Future Directions

There are several limitations to the present study that should be addressed. lymphoblastic leukemia (ALL) is the most commonly diagnosed cancer in childhood

(Children's Oncology Group, 2012). Given the higher prevalence of ALL in the oncology population, it only stands to reason that more patients with ALL would be eligible for the study. In fact, 62% of the participants recruited at the clinic (62%) were diagnosed with ALL. We were able to recruit smaller groups of patients diagnosed with lymphomas, solid tumors, or brain tumors. The small sample sizes recruited in each of these groups prevented us from conducting meaningful comparisons between groups (i.e., brain tumors, lymphomas). However, in reviewing our results, we felt it would be informative to combine the leukemia and lymphoma groups and the brain and solid tumor groups (given that they have similar treatments and risk profiles), and then examine whether there are differences between those groups (Tables 4-1 and 4-2). Results show that there were no statistically significant differences between the leukemia/lymphoma group and the brain/solid tumor group. However, our results are likely more representative of children diagnosed with leukemia and their families as opposed to children and families with other diagnoses. Our results suggest that the percentage of patients and siblings falling into the at-risk or clinically significant ranges differs between diagnoses; however, future studies should seek to recruit larger sample sizes that include children with various diagnoses in order to detect possible differences between diagnoses at the group level. Additionally, we did not include patients who had undergone bone marrow transplants. Bone marrow transplantation requires that patients stay in the hospital for several weeks to months at a time which present may present with unique challenges. Thus future studies should examine similar constructs with this population to patients and families to assess whether they have similar outcomes.

There were several factors that restricted study recruitment that are important to consider when designing future studies, as small sample size clearly affected statistical power of the current study analyses. Potential participants were primarily approached in two ways: at an outpatient appointment (for both groups) or during an inpatient stay (for the oncology group). While the majority of families were open and willing to participate in the study, many families recruited in an outpatient setting were not willing to stay past their appointment time to complete study measures. This was particular true for families in the primary care group. Also, many families were interested in taking study measures home to complete. We chose to not allow families to complete study measures at home as we were concerned about the potential effect of families members discussing their answers with each other and possibility that the forms would not be returned. However, future studies should consider this possibility to potentially increase study participation. Furthermore, some children came accompanied to their appointments by fathers, grandparents, or other guardians, so while they met all other inclusion criteria, they were not eligible to participate without a mother present. Finally, we only were able to recruit from one university-affiliated hospital pediatric oncology clinic, which clearly limited our available sample for recruitment. Future research teams should consider the possibility of collaboration with other medical centers to approach more potential participants, which may also increase the likelihood of enrolling participants to more varied diagnoses.

The present study used a cross-sectional design which does not allow us examine how these children function over time. The structure of the current study did not allow us to make comparisons between families who had recently started cancer treatment

versus families who had been undergoing treatment for a number of years. Our sample included a range of patients who started treatment two months prior to study participation to oncology patients who had been in treatment for 39 months. The literature is inconsistent regarding whether families experiencing more distress long-term or immediately after diagnosis. Future research should continue to address this discrepancy and which factors lead to positive or improved functioning over time.

The current study screened for serious mental health disorders (i.e., autism, schizophrenia), and while they were not specifically targeted, participants diagnosed with mild psychiatric conditions (i.e., depression) were eligible and recruited for the study. One must take into consideration that parents and children diagnosed with these disorders may have been more likely to endorse maladaptive symptoms on the BASC-2 and/or BSI. Thus we cannot definitely know whether the endorsed symptoms are a function of their adjustment to the cancer diagnosis or their underlying pre-existing psychiatric condition. However, this effect is likely minimized in our group comparison since more serious psychiatric conditions were excluded and participants with “mild” psychiatric conditions were included in both the cancer and primary care groups.

The BASC-2 parent-report form has three different questionnaire versions, from which an age-appropriate version is selected for use. Since children in our sample ranged in age from 2 to 17 years, all three BASC-2 versions had to be used in this study. As suggested by Wolfe-Christensen et al. (2009), the BASC-2 scales are supposed to measure the same constructs across the three age group versions; however, given the inherent differences and developmental expectations for children at different ages, there may be some variation between forms. Additionally, while there are both parent and

self-report versions of the BASC-2, there are a limited number of psychological symptom scales that are found on both the parent and child report versions. Thus, we were not able to make informant comparison across all scales. Additionally, as noted on the parent report forms, it is possible that constructs being measured (e.g., anxiety) are somewhat different between parent and self-report versions (i.e., questions assessing symptoms of anxiety are not worded exactly the same on parent and self-report forms).

The significant age difference between our patient and primary care groups is a potential limitation that warrants discussion. The mean age for our community group was approximately 3 years younger than our oncology group. We used age-referenced scores, so this method should control for differences based solely on age. However, because we use age-references scores, we may not have observed any age effects unique to a cancer population. Nevertheless, some of our findings may have been due to differences between the age groups and not cancer specifically.

Strengths and Conclusions

The current study adds to the literature in several important ways. First, our results provide further evidence that both pediatric oncology patients and their siblings as a group are doing well. However, the current study also suggests that a subgroup of both patients and their siblings are experiencing at-risk or clinically significant emotional and behavioral problems. This is an important methodological finding that suggests that research reliant on examination of group means may fail to detect a subset of children who are experiencing significant difficulties. This speaks to the importance of a universal screening approach in clinical settings which would allow mental health professionals in oncology settings to quickly and efficiently identify the small number of children experiencing emotional and behavioral difficulties without having to do a full

psychological evaluation with each family when the majority of families are likely doing well.

Second, the current study highlights the importance of including both parent and self-reports measures when working with these families. Our results show that both patients and siblings endorsed better emotional and behavioral functioning than what was reported by their mothers. Although these differences were not statistically significant at the group level, using a model utilized by Guite, 2004 we found that the majority of mother-child dyads were significantly discordant in their report of emotional, behavioral, adaptive, and family functioning. Although it is difficult to know whether one report may be more 'accurate' than another, it suggests that both reports are important to consider in the assessment process and in targeting interventions. Furthermore, children who perceive fewer problems than their mother may be less likely to participate in or benefit from psychological intervention (Yeh and Weisz, 2001 as cited in Davidson, 2005). This also speaks to the importance of communication between family members, which leads to the final important aspect of the current study design.

This study adds to the literature by providing additional quantitative measures of siblings' report of the broader family functioning. Much of the previous work in this area has included qualitative reports and the current study sought to include a quantitative measure collected from both the sibling and the mother, such that informant differences could be explored. One of the most interesting findings from the current study is the discrepancy between cancer sibling and mother report of family functioning, with siblings perceiving significantly more impairments in family functioning. This may be an area of potential intervention for mental health professionals working with these families.

While siblings may not need individual psychological intervention, they may benefit from interventions targeting problems within the family system and allowing for a setting in which siblings can discuss the impact of their siblings' diagnosis and treatment on their own life and family interactions.

In conclusion, findings support existing literature describing generally good psychological functioning of pediatric oncology patients and their siblings. However, the study design allowed for detection of otherwise "missed" subgroups of children experiencing psychological problems and highlights the utility of multiple informants and broader assessment of family functioning. It also speaks to the need for additional research examining other factors that may impact individual functioning, differences between different cancer groups, and the importance of primary care groups, and larger samples pediatric oncology populations to have adequately powered studies to examine these questions within a family system framework.

Table 4-1. Proportion of oncology siblings with mothers reporting psychological problems in cancer and tumor groups

BASC-2 Scale	Non-Solid (n = 25)	Solid Tumors (n = 10)	Fisher's Exact Test p-value	Cramer's Phi
Externalizing Problems	12.0 (3)	40.0 (4)	.155	-.316
Hyperactivity	12.0 (3)	40.0 (4)	.155	-.316
Aggression	16.0 (4)	40.0 (4)	.186	-.258
Conduct Problems ¹	0.0 (0)	20.0 (2)	.103	-.400
Internalizing Problems	16.0 (4)	20.0 (2)	1.0	-.048
Anxiety	12.0 (3)	0.0 (0)	.542	.194
Depression	24.0 (6)	20.0 (2)	1.0	.043
Somatization	16.0 (4)	0.0 (0)	.186	-.258
Behavioral Symptoms	16.0 (4)	30.0 (3)	1.0	.077
Atypicality	20.0 (5)	0.0 (0)	.292	.258
Withdrawal	16.0 (4)	0.0 (0)	.186	-.258
Attention Problems	24.0 (6)	30.0 (3)	.694	-.062
Adaptive Problems	8.0 (2)	20.0 (2)	.561	-.170
Adaptability	16.0 (4)	40.0 (4)	.186	-.258
Social Skills	20.0 (5)	50.0 (5)	.107	-.300
Leadership ¹	4.0 (1)	30.0 (3)	.093	-.369
Activities of Daily Living	8.0 (2)	30.0 (3)	.128	-.284
Functional Communication	20.0 (5)	10.0 (1)	.649	.120

Note: Values are presented as % (n). At-risk scores = T-scores between 60-69 (30-39 for Adaptive Scales) and Clinically Significant scores = T-scores \geq 70 (\leq 20 for Adaptive Scales). ¹These scales were not applicable due to participants' age.

Table 4-2. Proportion of oncology siblings reporting psychological problems in cancer and tumor groups

BASC-2 Scale	Non-Solid (<i>n</i> = 13)	Brain tumors (<i>n</i> = 7)
School Problems	0.0 (0)	14.3 (1)
Attitude to School	23.1 (3)	14.3 (1)
Attitude to Teachers	7.7 (1)	28.6 (2)
Sensation Seeking ¹	0.0 (0)	20.0 (1)
Internalizing	7.7 (1)	0.0 (0)
Atypicality	7.7 (1)	0.0 (0)
Locus of Control	15.4 (2)	0.0 (0)
Social Stress	0.0 (0)	0.0 (0)
Anxiety	7.7 (1)	14.3 (1)
Depression	7.7 (1)	0.0 (0)
Somatization ¹	14.3 (1)	0.0 (0)
Sense of Inadequacy	0.0 (0)	0.0 (0)
Inattention/Hyperactivity	23.1 (3)	0.0 (0)
Attention Problems	30.8 (4)	0.0 (0)
Hyperactivity	30.8 (4)	0.0 (0)
Personal Adjustment	30.8 (4)	0.0 (0)
Relations with Parents	0.0 (0)	0.0 (0)
Interpersonal Relations	7.7 (1)	0.0 (0)
Self-Esteem	0.0 (0)	0.0 (0)
Self-Reliance	7.7 (1)	14.3 (1)
Emotional Symptoms	0.0 (0)	0.0 (0)

Note: Values are presented as % (*n*). At-risk scores = T-scores between 60-69 (30-39 for Adaptive Scales) and Clinically Significant scores = T-scores ≥ 70 (≤ 20 for Adaptive Scales). ¹These scales were not applicable due to participants' age.

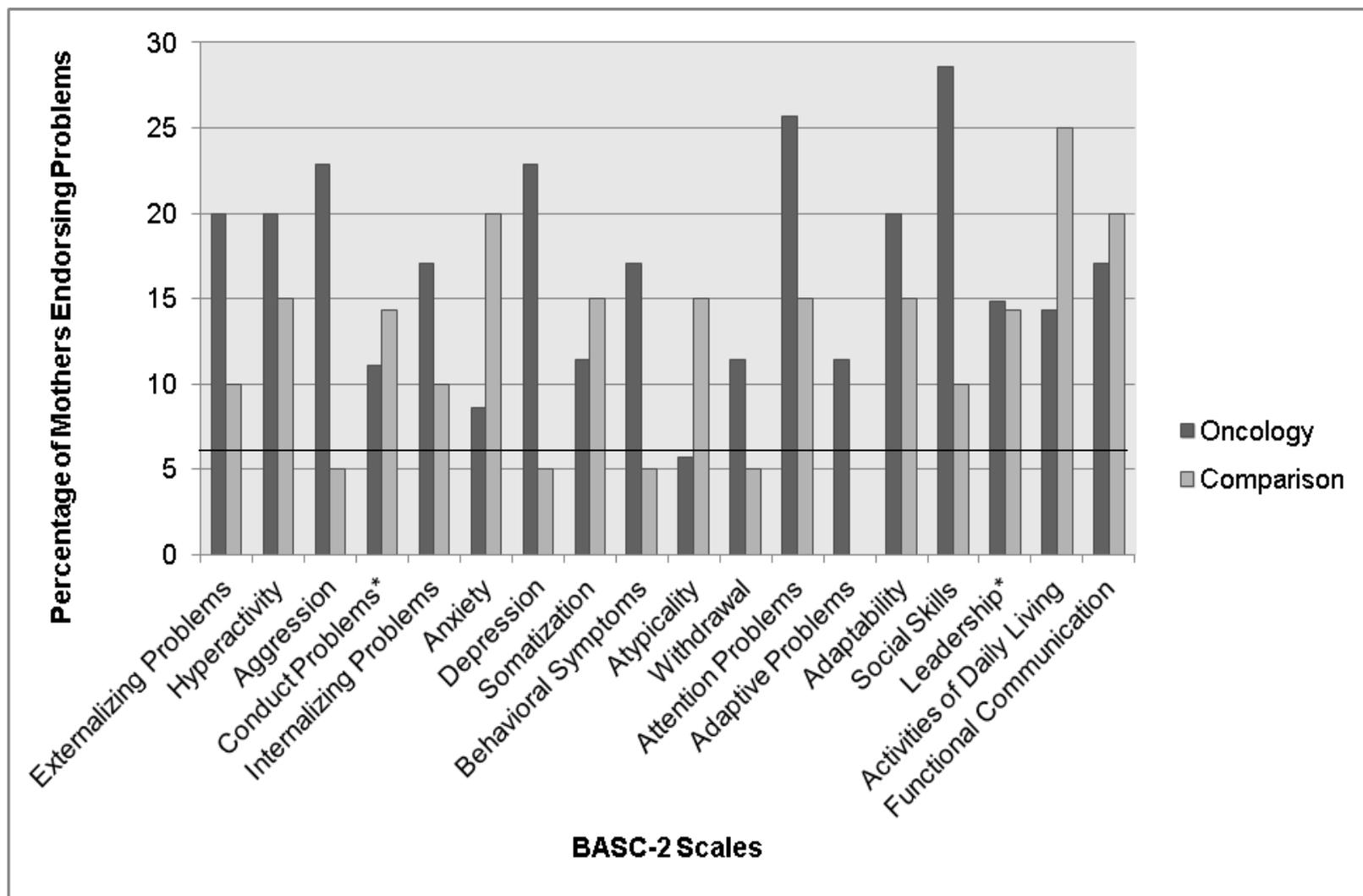


Figure 4-1. Proportion of siblings with mothers reporting psychological problems. ¹n = 27 for siblings.

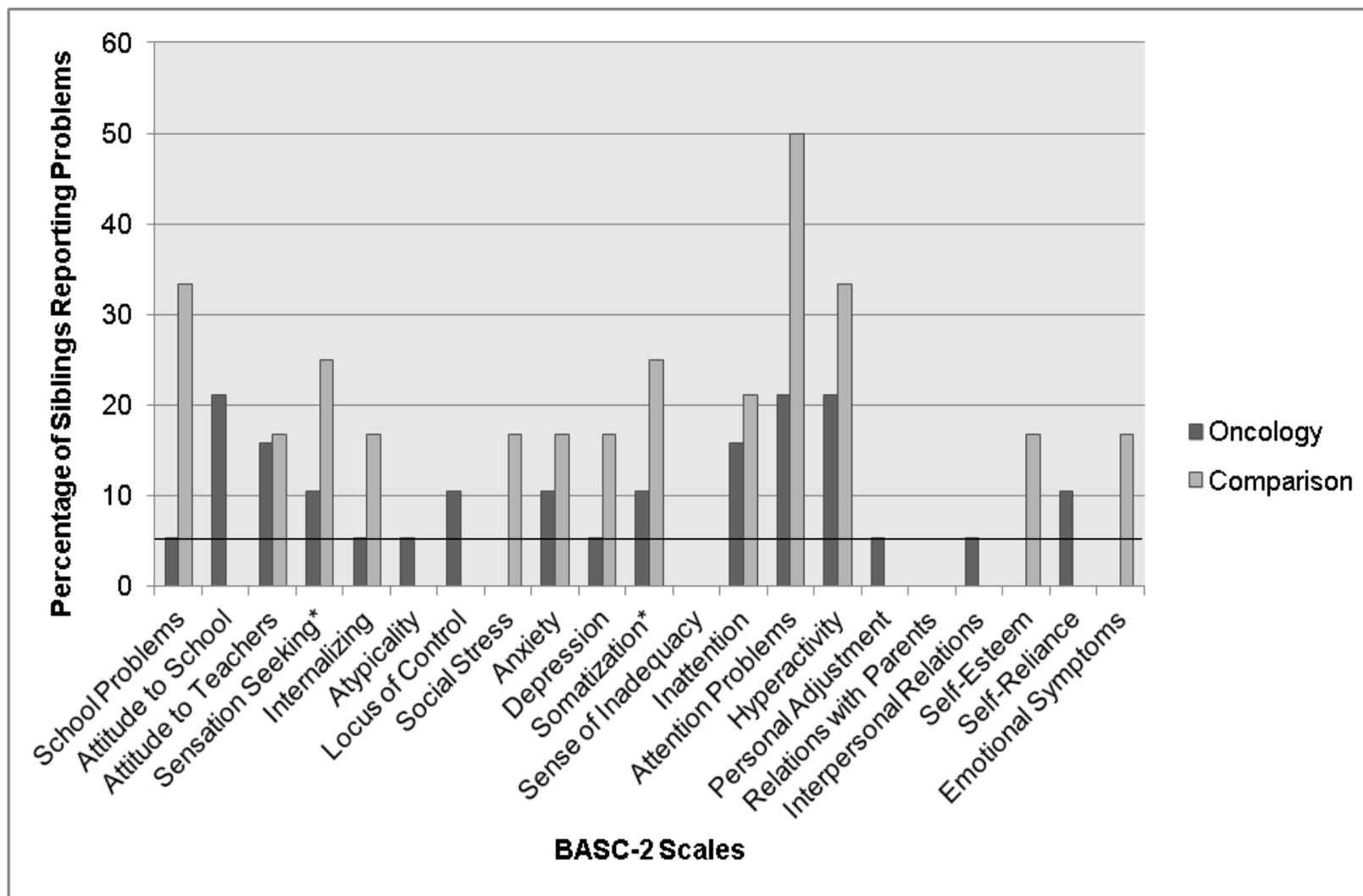


Figure 4-2. Proportion of oncology siblings reporting psychological problems. ¹*n* = 7 for siblings.

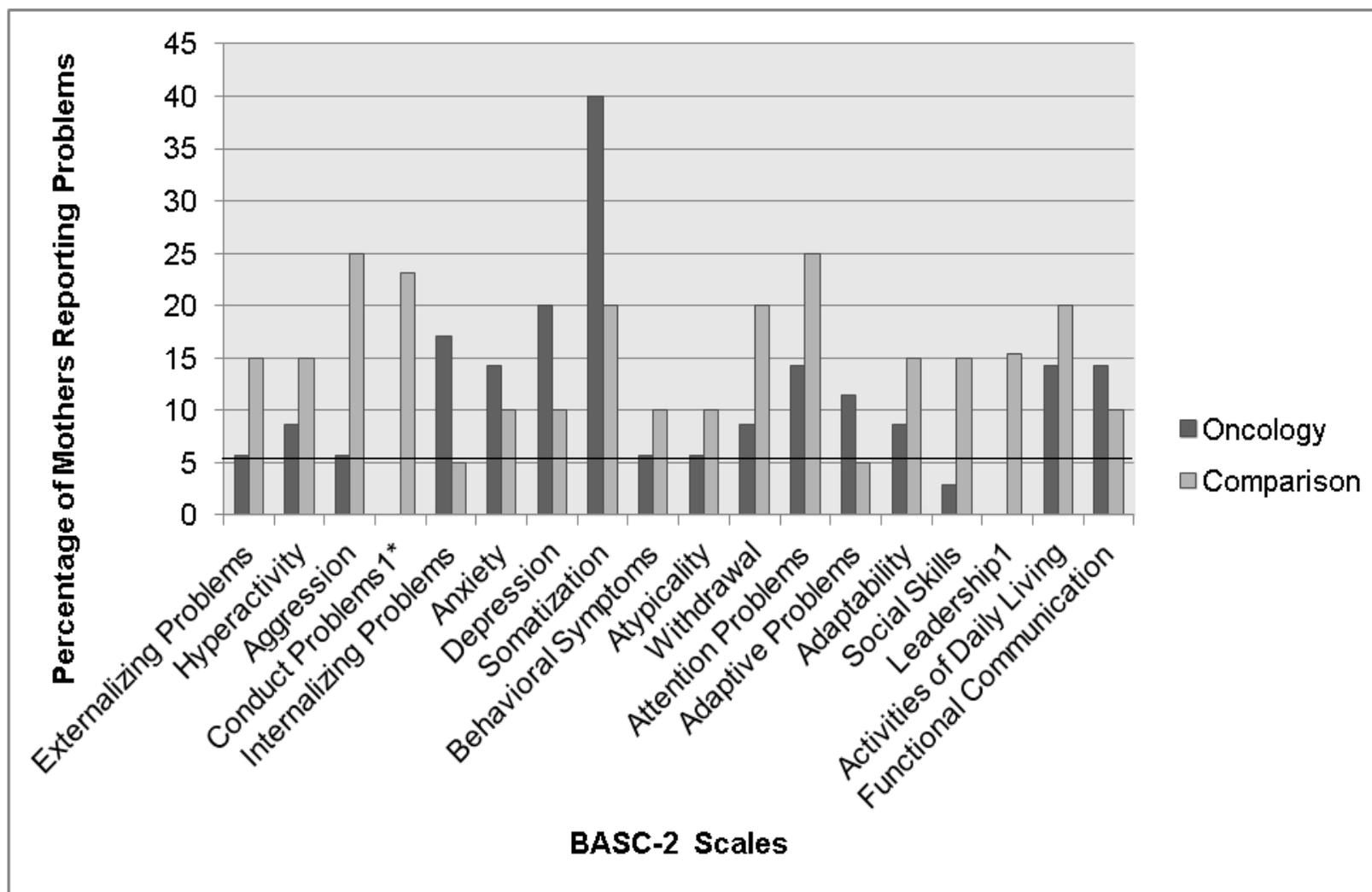


Figure 4-3. Proportion of oncology patients with mothers reporting psychological problems. ¹*n* = 26. *Chi-Square test is statistically significant.

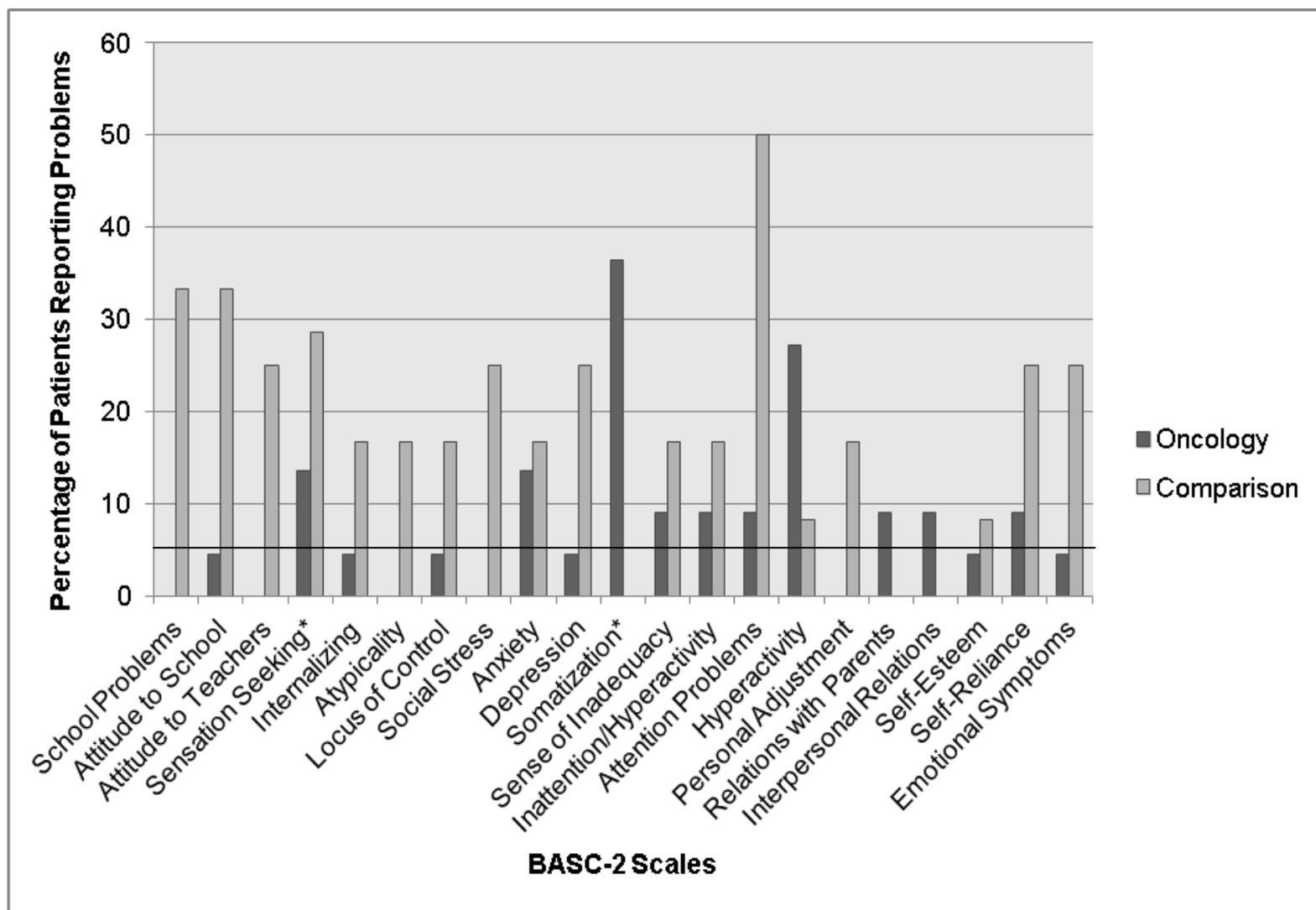


Figure 4-4. Proportion of oncology patients reporting psychological problems. ¹n = 13.

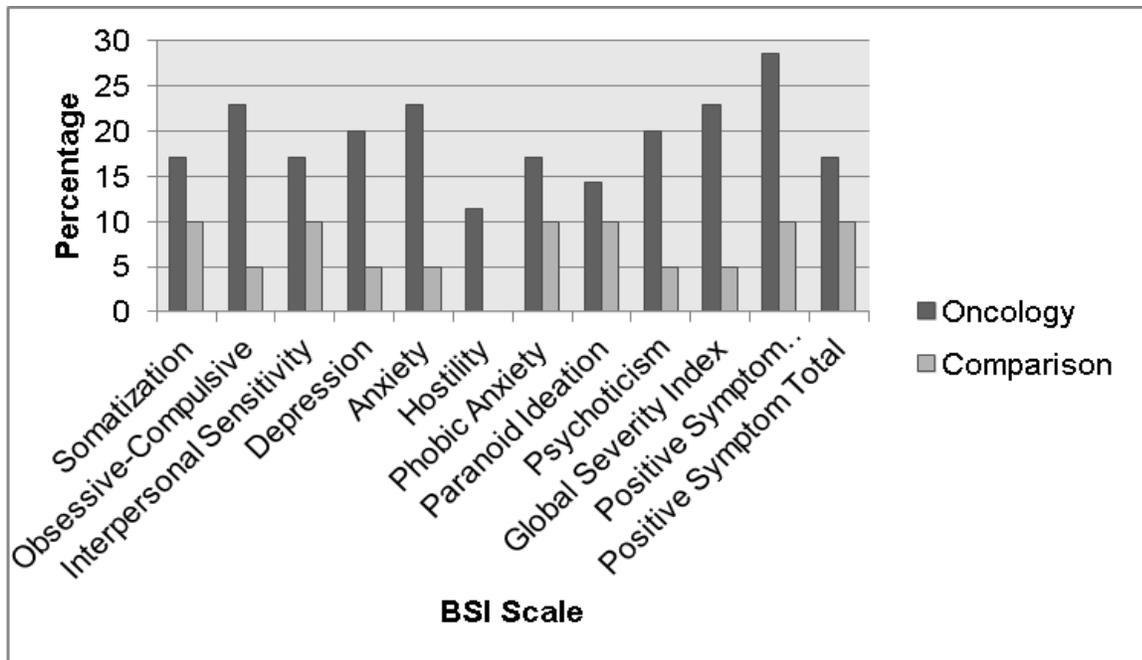


Figure 4-5. Proportion of oncology mothers reporting psychological problems.

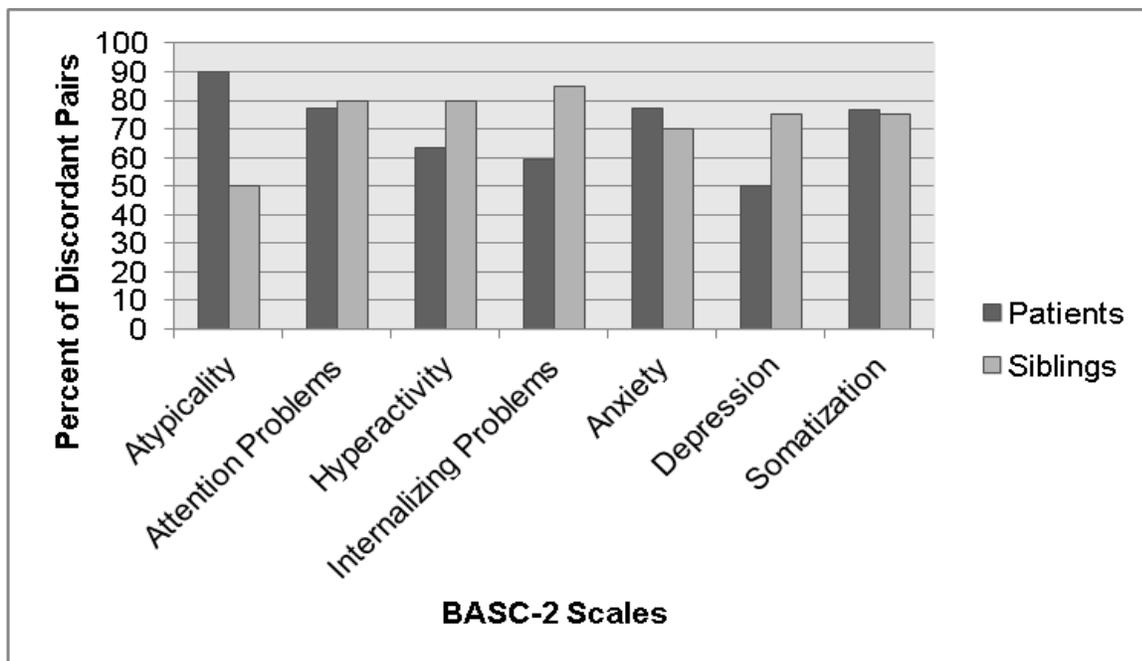


Figure 4-6. Proportion of discordant pairs in the oncology group on the Behavior Assessment System for Children-2nd Edition.

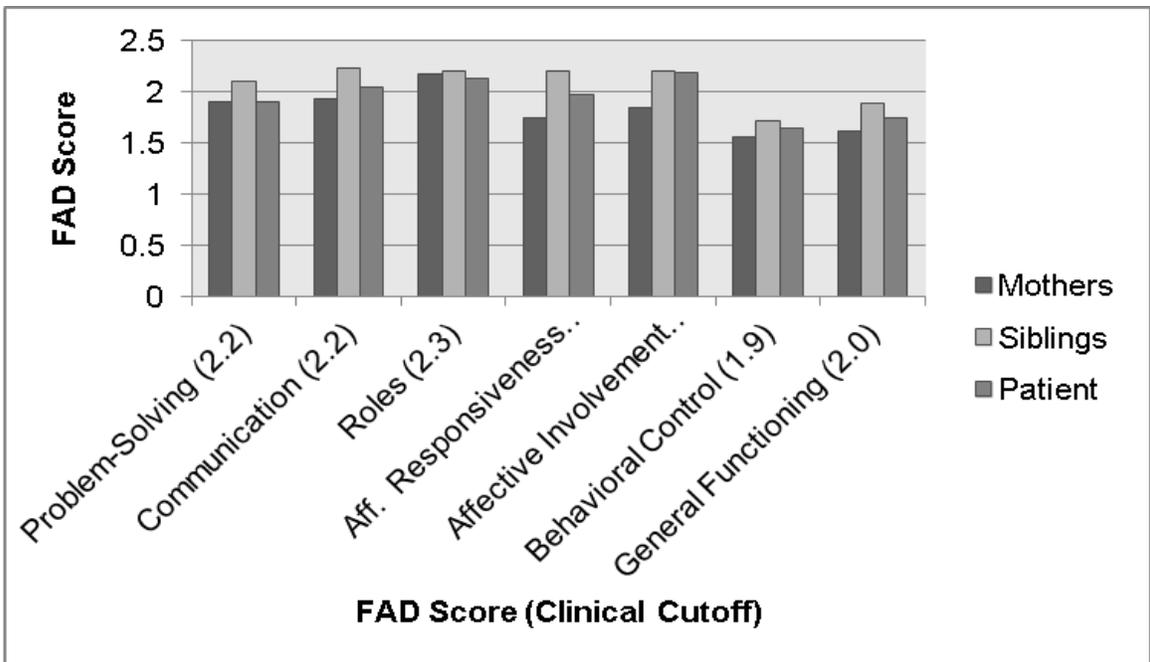


Figure 4-7. Scores for perceived family functioning in the oncology group.

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BIOGRAPHICAL SKETCH

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